Evaluation of MS Specialist Nurses

A Review

and

Development of the Role

Research Context and Synopsis of Part I:
Report on the National Survey of Multiple Sclerosis (MS)
Specialist Nurses in the UK

Part II:
Case Study of a New Multiple Sclerosis (MS) Specialist
Nurse Service in West Berkshire, England

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This two part study involved many people throughout its two year duration. Part I of the Report on the National Survey of Multiple Sclerosis (MS) Specialist Nurses was completed in January 2001. The MS Specialist and Neurology Nurses and the expert “Delphi” group are acknowledged at the beginning of that report, as are the MS Research Trust and South Bank University. Part II of the report on the Case Study of a new MS Specialist Nurse Service was completed in June 2001. We would now like to extend our thanks to all the people who took part. They included people with MS and some of their carers and a range of professional “stakeholders”. We thank them all for the wealth of experience which they contributed to the research and the time that they so generously gave.

Special thanks to the members of the “Stakeholder” Steering Group for their advice and ideas in helping to support the research and develop the MS Specialist Nurse Service. In particular thanks to Chris Jones, Nicola Russell, and others at the MS Research Trust for their help, co-operation and support throughout the study. We should also like to express our appreciation to the Berkshire MS Therapy Centre, which hosted our Steering Group meetings throughout the two years of the project.

Research assistance to the project was provided by Jackie Farrow (Senior Lecturer), Karen Giles (Principal Lecturer), Ben Gray (Research Fellow), Maria Lorentzon (Honorary Senior Research Fellow) Kathryn Robinson (Research Fellow) and research advice by Ann Taket, Professor of Primary Care, all at the Faculty of Health, South Bank University. Many thanks also to Jo Gill at South Bank University who provided administrative support to the project throughout its two year duration and Zara Adams also of South Bank University and Enid Tubbs of the University of Surrey for their help in producing this report.
INTRODUCTION TO THE REPORT

This report describes a project, which was set up to review and evaluate the UK MS Specialist Nurse’s role and to identify evidence of Specialist Nurses' contribution to MS care from a variety of perspectives. The project had two discrete elements. One element was to undertake a national postal survey of all MS Specialist Nurses who could be identified in the United Kingdom (UK); the second element was a developmental case study to evaluate a newly established MS Specialist Nursing service in West Berkshire.

The report is organised in seven sections to reflect these two discrete but complementary elements. Section 1 is an Executive Summary incorporating both elements of the project. Section 2 gives the background to the project. Section 3 outlines the project aims and research timetable. Section 4 is a selective literature review referred to in other sections of the report. Section 5 is a summary of Part I of the report, which is the UK National Survey of MS Specialist Nurses. Part I is presented in a companion document which describes in full the survey methods, findings, conclusions and recommendations. Section 6 presents Part II of the report and describes the methods, findings, conclusions and recommendations of the Developmental Case Study to evaluate a new MS Specialist Nurse Service in West Berkshire. Section 7 is the bibliography for all sections of the report. A final section contains the appendices to Part II.
1. EXECUTIVE SUMMARY

1.1 Background

♦ The project was commissioned by the MS Research (Charitable) Trust and jointly funded with South Bank University.

♦ The purpose of the project was to review and describe the UK MS Specialist Nurse’s role and to identify evidence of Specialist Nurses’ contribution to MS care from a variety of perspectives.

♦ An estimated 85,000 people in the United Kingdom (UK) have multiple sclerosis (MS), with a further 2,500 being diagnosed each year. It is the most common cause of acquired disability in young adults and is characterised by variation and uncertainty. Managing uncertainty is acknowledged to present major challenges in living with chronic illness (Cohen, 1993).

♦ The needs of people with MS are often left un-met by current NHS services (Robinson and Hunter 1998, Nodder et al 2000).

♦ The need for knowledgeable “Link-workers”, in most cases Specialist Nurses has frequently been identified in the literature (British Society of Rehabilitation Medicine 1993) but few in-depth studies of specific UK Specialist Nurse groups are available. These roles need careful evaluation (Humphris 1994a, 1999).

♦ In the literature, stress is placed on the importance of patient information, the need for patient advocates and knowledgeable link workers, who are easily accessible, quick to respond and in some cases make home visits. It is suggested that from the patient's point of view, the MS Specialist Nurse is well placed to take on this role (Kirker and Young 1995, Wahlquist 1984, Winters et al 1989).
1.2 Project outline and aims

The two clear elements of the project consisted of:

- A national survey (postal questionnaire) of all MS Specialist Nurses, or nurses spending the larger proportion of their time specifically on MS care.

  Aim: To make the role of UK MS Specialist Nurses explicit and suggest recommendations for the development, support and educational requirement of these posts through an exploration of nurses’ perceptions of the current role.

- A multiple methods, developmental case-study based around the service of a newly appointed MS Specialist Nurse in West Berkshire.

  Aim: To develop and demonstrate the effectiveness of an MS Nursing Service, based on the needs of the local MS population and other associated stakeholders, using a variety of methods.

1.3 Methods

1.3.1 UK National Survey

The objectives of the survey were:

- To explore the professional profiles of MS Specialist Nurses in the UK.
- To identify how MS Specialist Nurses are employed and managed.
- To investigate the educational backgrounds and needs of MS Specialist Nurses.
- To determine what support systems are available/needed by MS Specialist Nurses.
To identify how MS Specialist Nurses work with others and what contribution they make to the care of people with MS.

To determine what MS Specialist Nurses say about the clinical effectiveness and job satisfaction of such roles.

1.3.2 Developmental case study

The main elements of the case-study were:

- Twenty-four semi-structured interviews with two sets of 12 people with MS, spanning the four disease phases outlined by the MS Society Standards of Healthcare, exploring their experiences and perceptions of service need before and after the availability of a local MS Specialist Nurse. A number of carers also participated.

- Nine semi-structured interviews and attendance at a Primary Care Group Clinical Forum (involving 22 participants) to consult associated professional “stakeholders”. The Forum included General Practitioners (GPs), district nurses, a pharmacist, a neurologist, a consultant in neuro-rehabilitation and the MS Specialist Nurse.

- Development and auditing of two structure, process, outcome style Standards, based on priorities agreed by the local “stakeholder” Steering Group related to (i) diagnosis and (ii) the education of formal (paid) carers.

- A comparative, retrospective review of MS hospital admissions through analysis of medical records.

- A reflective diary maintained by the MS Specialist Nurse.

- A detailed two week diary of MS Specialist Nurse activity.

- A period of service development, using an action research approach involving the researcher and the MS Specialist Nurse, influenced by perceptions of need identified from the data, and ratified by the Steering Group.
Active involvement in project planning and prioritisation by the local “stakeholders” Steering Group.

1.3.3 Data Analysis

- Qualitative and quantitative data analysis techniques were used for the national survey and the case study depending on the different methods used.
- Statistical data were analysed using the Minitab statistical package.

1.3.4 Ethics

- University ethics committee approval was obtained for the survey and Local Authority Research ethics committee for the case study. The project was regulated by the Data Protection Act and registered with the University data protection officer.

1.4 Findings: UK National survey

- The response rate was 61.4%. In the main, MS Specialist Nurses in this sample were very experienced nurses (mean length of time since qualification was 13.5 years), with an expressed commitment to empowering people with MS and their families to regain a feeling of control in living with the disease. Interventions were summarised as addressing five main patient problems:
  - getting care or accessing services,
  - finding information,
  - the need for psychological care, support and counselling,
  - symptom management,
  - problems associated with a general lack of awareness of MS.
In positive terms:

- MS Specialist Nurses provided support from the time of diagnosis and throughout the illness trajectory.
- They formed a direct two-way link between the community and neurologists/the acute care team.
- MS Specialist Nurses helped ward staff co-ordinate complex hospital discharges.
- They often supported patients in their management of beta interferon treatment.
- They were actively involved in local educational initiatives, seeing teaching as one of the most important aspects of their role.
- The opportunity to practice more holistically as a nurse was highly valued.

However the role was identified as:

- very complex, isolating and exhausting, with no boundaries and with a significant risk of “burn out”.
- often having unrealistic caseloads, and lack of support, specifically Clinical Supervision.
- In addition there were considerable discrepancies in the grading of some MS Specialist Nurse posts.

Although generally satisfied with the effectiveness of nursing care possible in the role, and with the job itself, MS Specialist Nurses were aware of improvements to the way in which such roles are set up which could make it less frustrating and more sustainable for newcomers to the speciality.
1.5 Findings: Developmental case-study

1.5.1 Patient interviews

♦ The respondents displayed similar characteristics in terms of gender ratio, age range and age at onset of symptoms to the ‘typical’ profile of people with MS (Robinson et al 2000).

♦ The majority of the respondents had received their diagnosis from local neurologists.

♦ The diagnosis, the time leading up to and following it, were for most a very difficult time, arousing strong emotions, including fear, anger, shock/devastation, abandonment/isolation and occasionally relief. This was the case in three patients who had suspected they were suffering from a brain tumour rather than MS.

♦ Possible explanations for some of these findings include:
  • that differing patient and professional perspectives co-exist (Robinson, 1990),
  • that there was frustration on the part of patients with the knowledge base of professionals,
  • that the timing for patients taking in information was not always right,
  • that there was sometimes not enough contact with other people with similar MS problems around the time of diagnosis,
  • that more holistic support was not available to address non-medical issues.

♦ Those who had had contact with the MS Nursing Service at or around the time of diagnosis, had found it to be very helpful in terms of both support and information given.

♦ Comparative data suggested the concept of “abandonment by the healthcare system” which was a prominent feature before
the establishment of an MS Specialist Nurse, was mitigated following her appointment.

- Further comparative data implied there was a growing awareness, contact with and access to the MS Specialist Nurse describing her as:
  - an ongoing source of support and information for people and their carers at subsequent phases of the disease and not just at diagnosis,
  - an emotional resource for spouses or partners and other family members,
  - adviser to and educator of non-specialists such as GPs, hospital and community nurses and home care assistants,
  - a “lynchpin” and link with other professionals, who was well placed to act as an overall service co-ordinator,
  - requiring a team to assist her to manage the increasing demands of her role.

- GPs and hospital doctors featured as sources of help throughout the disease trajectory, although mixed experiences were reported.

- The key role of specialist physiotherapists in treatment was emphasised.

- Occupational therapists were said to be “very helpful” and supported daily living activities by advising on and arranging equipment and home adaptations.

- Social Service departments were described as key to “the wellbeing of MS patients” by providing home care and mobility assistance inside and outside the home.

- The availability of disabled friendly transport and easy access to public places was viewed as currently restricted but an essential source of help.

- Education for people with MS, the general public and their lay carers was viewed as very important.
The role played by spouses or partners both at the time of diagnosis and later in terms of continued care and support, in some cases over many years, could not be overestimated.

More general support for family carers was seen to be required.

Easier access for patients to specialist treatment (e.g. beta interferon) and care, was said to be needed.

1.5.2 Stakeholder interviews

Consultations with stakeholders in the local management of MS and in the MS Specialist Nurse's service were very positive about the potential to make a difference in MS care. Perspectives focused mainly on:

- Patterns of care for people with MS e.g.:
  - quality of contact between organisations;
  - communication and liaison between professions;
  - economic and financial difficulties;
  - organisational change;
  - psychological problems and the vulnerability of professionals, in terms of their own lack of knowledge and skills working with some people with chronic illness;
  - appropriate supervision, support and education of professionals;
  - the ways in which MS Specialist Nurses augmented care,
  - problems with the delivery of health and social services.

- The employment of an MS Specialist Nurse was said to increase the emphasis on holistic care and chronic disease management.
- The MS Specialist Nurse was seen as an expert in palliative care.
- The MS Specialist Nurse was seen as the natural 'key worker' (e.g. in relations with Primary Care Groups/Trusts).
- The MS Specialist Nurse was seen to be in a position to cascade information about MS to professionals, carers and families of people with MS.
- Stakeholders gave key service recommendations on ways forward in developing MS care and supporting the delivery of MS nursing services.

1.5.3 Development and audit of two local standards

The Steering Group decided on two priority standards that should be formally audited from a variety of perspectives.

- Audit of standard of management at and after diagnosis:

  Three sets of evidence were scrutinised:
  - medical records,
  - nursing records,
  - patient satisfaction questionnaires.

Each set of evidence is summarised below.

- A sample of nine sets of medical records on each occasion:
  - The intervals between receipt of GP referral and first appointment with the neurologist were identical in 2000 and 2001 and in both cases over half the sample (5/9) had appointments with the neurologist within 1-4 weeks of GP referral. No patient waited longer than 12 weeks for an initial appointment.
  - In the first sample 66.6% completed investigations and were told their diagnosis within eight weeks of the initial consultation. This increased to 88.8% in the second sample. All patients in the first sample and all but one in the second received their diagnosis from a Consultant Neurologist as per MS Society and local standards.
A sample of nine sets of nursing records on each occasion:

- In 2000, 33.3% of patients had contact with the MS Specialist Nurse within seven days of diagnosis, as identified by the standard. In contrast, none of the second sample had contact with the MS Specialist Nurse within the first seven days after diagnosis, but this was replaced by more consistent contact (77.8%) within one month of diagnosis.
- Overall, written records suggested the pattern of the MS Specialist Nurse's service to newly diagnosed patients changed over the audit period, probably to accommodate the demands of a developing caseload.

Satisfaction questionnaires sent to two groups of 20 randomly selected newly diagnosed patients:

- Twenty nine patients were invited to attend “Getting to Grips with MS” courses during 1999, and this increased by over a third to 39 in 2000.
- Almost two thirds of patients (61.5%) in the first sample felt the explanation of MS from the doctor at the time of diagnosis was too brief. This improved in the second sample, but just over half (53.8%) still felt that explanations were too brief. Those who felt it was about right increased from 38.5% to 46.2% in the second sample.
  - The feeling of abandonment by the healthcare system was an obvious feature of the first set of comments, but less marked in the second.
- Overall, there was evidence of service improvement from the three perspectives studied. Patients' comments gave a clear indication of the valuable role that many of them felt the MS Specialist Nurse had played in giving information and support around the time of diagnosis.
Audit of MS Specialist Nurse’s involvement in educating formal carers:

Two sets of evidence were scrutinised:
- Evaluation forms from a carers’ educational programme.
- Questionnaires from hospital nursing staff.

The MS Specialist Nurse and County Council Training Officer responded to carers’ requests and jointly planned a programme to meet group needs. This was well evaluated with 30 respondents rating it as excellent (score 5) and 19 rated it as good (4). Only one rated it average (3).

Comments indicated that community carers had a greater understanding of the effects of MS on the individual and family as suggested by qualitative comments.

Hospital nurses did not receive, but would have liked formal training in the care of people with MS but also considered that the MS Specialist Nurse’s advice/support positively affected their care delivery.

Responses to the Registered Nurse Questionnaire, indicated they would contact her when a patient with MS was admitted, especially as they were now aware of how she could help. They viewed the MS Specialist Nurse’s role as advising not only the patients but also themselves.

1.5.4 Review of hospital medical records

Differences in the pattern of MS patient admission were identified between the 12 month period directly before employment of an MS Specialist Nurse, compared with a 12 month period commencing after the MS Specialist Nurse had been established for six months.
Reduction in the rate of emergency rather than elective hospital admissions, a reduction in length of stay and a shift away from predominantly acute general medical ward admissions towards rehabilitation, neurology or Young Disabled Unit care was found.

In addition to likely qualitative benefits for patients and their families, these changes showed considerable cost benefits to the Trust.

A simple calculation of reduced cost, as indicated by a comparison of bed occupancy between the two years amounted to £104,329.65.

Although it is acknowledged that other hidden cost factors may be involved, when the cost of employing an MS Specialist Nurse for one year was offset against this sum, a total saving of £64,611.45 remained.

It is proposed that the establishment and active involvement of an MS Specialist Nurse, providing a focus of expertise, leadership and a combination of direct and indirect intervention may have contributed to the observed differences in patient admission patterns in the two sample years.

1.5.5  MS Specialist Nurse’s Reflective diary

Recordings of the MS Specialist Nurse’s audio diary were used to identify a series of critical incidents in which she had played a key role.

The incidents covered a range of complex psychosocial and physical interventions with clearly identified outcomes.

Some of these outcomes included delaying the hospitalisation of a severely disabled patient so that she could stay home longer with her children, resolving problems of incontinence and constipation, reducing the risk of aspiration pneumonia and arranging respite care.
1.5.6 Detailed diary of MS Specialist Nurse activity

The diary provided a useful “snapshot” of the relative frequency of various interventions.

- The MS Specialist Nurse kept a two week detailed diary, recording her activities in terms of the people she contacted, the venues and timings involved.
- In the breakdown of activities, psychosocial interventions (32) were most common followed by physical (19), social (16) and information giving/education (8). In terms of activities, the most common was telephone work, followed by patient contact in clinic, home or ward and patient related meetings/discussions.
- Teaching/preparation, contact with relatives and administration were the next most frequent cluster of categories with activities associated with own professional development being recorded once during the two week period.
- The MS Specialist Nurse recorded a number of outcomes from her interventions during the first week which involved negotiation and liaison with a variety of agencies on behalf of patients or carers. These outcomes resulted in initiation or a change of treatment to control symptoms, the obtaining of information or benefits for patients and/or their families.

1.5.7 Service Development

- The stakeholder Steering Group formed an important reference point and focus for discussion regarding the MS Specialist Nurse's service, and the wider picture for people with MS in West Berkshire.
- Meeting at two monthly intervals throughout the project, this was a well supported, mutually beneficial opportunity to pool experience and ideas, promoting effective care for people with MS, providing a strong local drive for the project and enhancing
group members' understanding of the local systems and dilemmas in MS care.

- Arising from common issues in qualitative interview data from patients and stakeholders, the Steering Group decided on two priority standards (see section 1.5.3 above) that should be formally audited from a variety of perspectives during the project.

- Through use of a detailed structure/process/outcome approach it was possible to identify and develop strategies to close gaps in service provision and to demonstrate positive outcomes following MS Specialist Nurse activity.

- These tools were recommended for use as part of routine clinical audit and to serve as a template for the development of other standards beyond the time span of the project.

- The period of service development gave further time for the MS Specialist Nurse to establish her service and make an impact on local MS care.

1.6. Conclusion

- This multi-faceted study has attempted to explore the developing role of MS Specialist Nurses, using a variety of methods and perspectives, paying particular attention to the views of service users and the post-holders themselves.

- Joint evidence from the case study and survey suggests that the service offered by MS Specialist Nurses attempts to address the needs that have frequently been highlighted as unmet by previous NHS services. These include the lack of information, fragmentation and lack of continuity in services, poor understanding of the disease among professionals and lack of psychological support, particularly around the time of diagnosis.
People with MS experienced strong emotions around the time of diagnosis including abandonment/isolation; shock/devastation, fear and frustration with the perceived lack of professional knowledge. They wanted professionals to understand that MS is a unique experience for each individual requiring an individualised response. Support for partners and family was also seen as vital.

Patients and neurologists had differing expectations of how the process of diagnosis and subsequent support should be managed. GPs played a role throughout the illness trajectory but with variable effect, depending on their level of expertise and interest.

The MS Specialist Nurse provided a bridge between patient and professionals both at the time of diagnosis and in the longer term management of MS. The documentation of critical incidents demonstrated the impact she could have on patient outcomes. Stakeholders experienced the employment of the MS Specialist Nurse as increasing the emphasis on holistic care, chronic disease management and improving liaison between the primary and secondary care sector.

There is additional evidence that employment of an MS Specialist Nurse can have a significant effect on patterns of MS patient management in hospital, with cost saving implications.

The study has also highlighted some important issues surrounding the effective management, support, educational and developmental needs of MS Specialist Nurses, given their role as relatively independent practitioners, working in a job which is very complex, isolating and exhausting, with no boundaries and with a significant risk of “burn out”. Added frustrations relate to the disease itself, where there are no clear answers or total resolution of symptoms.
The research design demonstrates one approach to exploring and evaluating the complexity of specialist nursing intervention and has highlighted some issues which are responsive to MS Specialist Nursing involvement. It has also provided a potential framework and tools for auditing the service as part of clinical practice, beyond the span of the project.

The value of systematically involving users or “stakeholders” in reviewing, planning, developing and evaluating services has also been demonstrated. This was shown to be a mutually beneficial activity which enhanced care planning and the research process.

1.7 Recommendations and the way forward

Specific to MS Specialist Nurses:

1. At the time of diagnosis, support systems such as MS Specialist Nursing services should be put in place to bridge the gap between patient and physician expectation and to meet a variety of medical and non-medical needs in the longer term management of MS.

2. Consideration of the number of MS Specialist Nurses required nationally so that all people with MS have the potential to access these services, and to ensure that MS Specialist Nurses have manageable workloads.

3. Ensure parity of access to the MS Specialist Nurse in both the public and private sector.

4. National and local clarification of the scope and responsibilities of the role for the benefit of the potential post-holder, managers, other nurses and the multi-disciplinary team.

5. Within the new NHS pay system, recognition of the demanding nature of the role and the development of skills and experience from novice to expert MS Specialist Nurse, through clearly
identified competencies. This should also extend to include some posts at Consultant Nurse level.

6. Longer term contracts where possible to allow for forward planning, capitalising on MS Specialist Nurses’ skills in leading service developments and enhancing job satisfaction.

7. Management recognition of the need for mentoring and supervision systems in place to support MS Specialist Nurses and prevent burnout in their demanding role.

8. Networking opportunities for support, professional development and to encourage innovation.

9. Recognition that MS Specialist Nurse roles should be seen in relation to local Trust/organisational business planning strategies to maximise effectiveness and enhance visibility. A core set of MS Specialist Nurse audit data to be developed and routinely collected locally to best represent the impact and effectiveness of the role.

10. Availability of recognised courses and study days in preparation for the role and as continuing education, covering, for example, specialist clinical MS issues, working with acute and community “systems” and internal politics, autonomous nursing practice and information technology/administration/time management skills.

11. Close liaison, joint visits and meetings between the MS Specialist Nurse, the Primary Care Trusts and members of the primary care team, in particular GPs and district nurses.

12. A 24 hour telephone line to extend the MS Specialist Nursing service.

13. Where possible, the MS Specialist Nurse to extend her educational role to the public as well as lay carers of people with MS.

14. Ensure mechanisms to support patients and their partners to attend “Getting to Grips with MS”, “Taking Control” or other similar courses for the newly diagnosed.
15. Ongoing joint planning and monitoring of educational programmes between the MS Specialist Nurse, Social Services and the hospital sector so that MS Specialist Nurses play a key role in the education of non-specialist practitioners.

16. Mechanisms for service development and joint working to be set up across a range of stakeholders as exemplified by the Steering Group members who met on a regular basis throughout the span of the project.

♦ More general recommendations:

17. Understanding and appreciation on the part of professionals that MS is a unique experience for each individual, requiring an individualised response.

18. Encouragement of patients to bring personal support with them at the time of diagnosis.

19. Appreciation by neurologists that patients are in a period of transition when they are first given a diagnosis of MS and to consider routine follow-up appointments.

20. Appropriate timing and availability of good quality information by service providers to patients to allow them to play an active role in their care.

21. Availability of information packs about MS on hospital wards, nursing homes, social services and private care agencies.

22. Training of non-Specialist Nurses and home carers on a routine basis to meet the needs of people with MS at different stages of the illness trajectory e.g. in the provision of respite care.

23. More respite care for people with MS and their families.

24. Greater support and help for the carers of people with MS, such as that provided by the specialist voluntary sector.

25. Set up record systems to improve information exchange between patients, professionals, the public, private and voluntary sector.
An estimated 85,000 people in the United Kingdom (UK) have multiple sclerosis (MS), with a further 2,500 being diagnosed each year. Epidemiological studies suggest a rate of approximately 100 cases of MS per 100,000 of the UK population, with higher numbers in the north of Scotland (Robinson et al 2000). MS is the most common cause of acquired disability in young adults and is characterised by variation and uncertainty. The needs of people with MS are still often left un-met by current NHS services (Robinson and Hunter 1996, Nodder et al 2000). Following diagnosis they can be left to fend for themselves with no official source of counselling and with identification of and access to resources being very variable (McLellan et al 1989). Often it is only when severe and persistent disability occurs that contact with hospital services is renewed, although surprisingly large numbers of moderate to severely disabled people manage with little or no help (Freeman and Thompson 1999).

Managing uncertainty is acknowledged to present major challenges in living with chronic illness (Cohen, 1993). Multiple sites of neurological damage and unpredictable variations over time mean that patients need to discuss the significance of symptoms and proposed courses of action quite frequently. The UK has relatively few neurologists per head of population and only a proportion of these have a special interest in MS. Various studies have shown that patients often value the opportunity to discuss these unpredictable variations and symptoms quickly and informally with a specialist nurse rather than waiting for hospital appointments (Kirker and Young, 1995). This is one factor which has contributed to the development of specialist MS Nurses in the UK.
The number of specialist Multiple Sclerosis (MS) Nurses has grown dramatically over the last few years, but little is known about their current working practices and effectiveness. The requirement for patient education surrounding issues of beta interferon management, and the need for a knowledgeable link-worker, in most cases a specialist nurse, has led to the proliferation of these roles (British Society of Rehabilitation Medicine 1993, Campion 1997). Some posts are part or wholly funded by the NHS or local MS Society branches while some, such as Innovex Nurses (Schering MS Partnership Programme) involve partnerships between a commercial company and the NHS. Others have been initiated by neurologists, some are nursing led or research oriented posts attached to University departments. Further more, the MS Society has provided some NHS Trusts with matched funding to set up MS Nurse posts in an attempt to encourage a coherent national framework for development over the next three years through the MS Nurse Fund initiative.

Few in-depth studies of specific UK Specialist Nurse groups are available but such roles need careful evaluation (Humphris 1994a, 1999). In the MS literature, stress is placed on the importance of patient information, the need for patient advocates and knowledgeable link workers, who are easily accessible, quick to respond and in some cases make home visits. It is widely suggested that from the patient's point of view, the MS Specialist Nurse is well placed to take on this role (Kirker and Young 1995, Wahlquist 1984, Winters et al 1989). However, the current situation remains unclear in terms of which models of specialist nursing care are successful in meeting the needs of people with MS and which models of support and preparation allow nurses to function effectively in these specialist roles.

This project, commissioned by the MS Research (Charitable) Trust and jointly funded by South Bank University was designed to address some
of these issues. The purpose of the project was to review and describe the UK MS Specialist Nurse’s role and to identify evidence of Specialist Nurses’ contribution to MS care from a variety of perspectives. The project had two discrete elements. One element was to undertake a national postal survey of all MS Specialist Nurses who could be identified in the United Kingdom (UK); the second element was a developmental case study to evaluate a newly established MS Specialist Nursing service in West Berkshire.
3. PROJECT OUTLINE AND AIMS

As stated, the two elements of the project consisted of:

A national survey (postal questionnaire) of all MS Specialist Nurses, or nurses spending the larger proportion of their time specifically on MS care.

Aim: To make the role of UK MS Specialist Nurses explicit and suggest recommendations for the development, support and educational requirement of these posts through an exploration of nurses’ perceptions of the current role.

A multiple methods, developmental case-study based around the service of a newly appointed MS Specialist Nurse in West Berkshire.

Aim: To develop and demonstrate the effectiveness of an MS Nursing service, based on the needs of the local MS population and other associated stakeholders, using a variety of methods.

In order to meet the overall aim of the evaluation i.e. to develop guidelines for practice and the establishment of MS Specialist Nurse Posts, related aims included:

- to determine the current working patterns and practices of different MS Specialist Nurses across the UK,
- to investigate the infrastructures required to support and maintain efficient and effective specialist MS Nursing services,
- to determine the areas of service intervention which enable the MS Specialist Nurse to target key problems effectively from patient and other stakeholders’ perspectives,
➢ to explore practical quantitative and qualitative outcome measures/indicators which have been found to be useful in establishing and monitoring the effectiveness of MS Nursing posts,
➢ to identify the areas which MS Specialist Nurse education programmes should cover in order to provide adequate preparation to work in these roles.

Research Timetable

The research took place over a two year, four month period (Feb 1999-June 2001) and was divided into five distinct phases:

**Phase One: Months 1-4 (February -May 1999) Background and development**

Ongoing review of literature and development of interview schedules, as well as consultation with a specially convened MS Specialist Nurses’ Delphi Group to design the survey questionnaire. Ethics approval from the local Health Authority and South Bank University Ethics committees was obtained. A range of “stakeholders” was approached and invited to become members of a Steering Group. At the end of this period the Steering Group met to agree terms of reference, review progress and advise on the direction of the next phase of the case study.

**Phase Two: Months 5-9 (June-October 1999) Data collection and analysis I**

First set of interviews with people with MS and associated stakeholders. Analysis of these interviews occurred concurrently. The Steering Group continued to meet at two monthly intervals.

**Phase Three: Months 10-15 (November 1999-April 2000) Development of the MS Specialist Nurse role**

This phase commenced with a Steering Group meeting. The aim was for the researcher to report back the findings of the initial data and the
group to examine the role of the MS Specialist Nurse in the context of local need. Aims and objectives for service development were agreed. Two standards were identified as priorities. These were i) management at diagnosis and ii) education of formal carers. The MS Specialist Nurse and researcher developed a set of standards (structure, process, outcome) to audit the service in these areas. A baseline audit was conducted and the MS Specialist Nurse implemented agreed service developments aiming to meet these standards. A feedback report was presented to the Steering Group. An MS Specialist Nurse activity diary was also completed over a two week period.

Following pilot work, the national questionnaire to MS Specialist Nurse was sent out and detailed analysis of the survey data commenced.

**Phase Four: Months 16-20 (May -September 2000). Data collection and analysis II**

A repeat audit of standards took place. Quantitative outcome data to contribute to service evaluation was collected by the researcher and an assistant from a retrospective sample of hospital medical records. These consisted of data concerning hospital admissions. Comparisons were made between a period prior to the availability of the MS Specialist Nurse and the situation after approximately two years in post. Further stakeholder interviews were completed. Retrospective analysis of the MS Specialist Nurse’s reflective diary was undertaken. This phase culminated in a meeting of the Steering Group where the comparative findings from all available aspects of the evaluation were reviewed.
Phase Five: Months 21-29 (October 2000-June 2001) Completion of the research

A second set of patient interviews were conducted to gather more perspectives and to investigate if outcomes could be detected following the development of the MS Specialist Nurse role. Writing the final report of Part I and work on the development of guidelines for MS Specialist Nurse roles took place. Qualitative data analysis for these interviews was completed. The Steering Group reviewed the standards for the MS Specialist Nurse role and considered the need for further development in an ongoing Audit Cycle. Another brief feedback report was sent to all those people with MS taking part in the evaluation. The major part of the work for the development of guidelines for MS Specialist Nurse roles took place through a joint collaboration between a working party developing the UK Multiple Sclerosis Specialist Nurse Association (UKMSSNA), the Royal College of Nursing and the MS Research Trust. The researcher and one member of the study steering committee were members of the group contributing to this work.

April 2001: National launch of these guidelines in the document Specialist nursing in MS - the way forward: the key elements for developing MS Specialist Nurse services in the UK

February - June 2001: Complete case study Part II was integrated with Part I (the survey) and the final report and an Executive Summary (August 2001) were prepared.

September 2001: local launch of MS Specialist Nurse Case Study findings at the Berkshire MS Therapy Centre.
4. **SELECTIVE LITERATURE REVIEW**

This brief selective literature review is designed to illustrate the current level of debate and provide context for the role and practice of Multiple Sclerosis Nurses. The review centres on literature to support the development of guidelines for practice and establishment of this specialist nursing function.

*Main themes for exploration in the review are:*

1. Roles of MS and other specialist nurses.
2. The structure of MS services and multi-disciplinary team-work.
3. Patient and carer views about MS services, and expressed needs for future provision.
4. Audit and effectiveness of specialist nurse services.
5. Educational provision for MS and other specialist nurses.
6. Professional and personal support for specialist nurses.

**4.1 Roles of MS and other specialist nurses**

Although the number of MS Specialist Nurses has grown dramatically and their effectiveness is strongly supported in anecdotal literature, little is actually known about their effectiveness and current working practices. Achieving the most appropriate and effective use of resources has become a common concern in the NHS and Nurse Specialists need to be able to demonstrate how they make a difference and articulate what they do (Humphris, 1999).

Although the concept of a specialist in clinical nursing was first developed in 1940s America, the role was slow to develop in the UK (Bousfield, 1997). Initial posts in the 1960s were predominantly administrative, but the Royal College of Nursing was instrumental in lobbying for a complementary career structure for clinical nurses to help improve standards of care (Royal College of Nursing, 1981). The
role began to develop in the 1980s and quickly extended across a wide range of practice areas, with practitioners having a variety of levels of preparation. This has resulted in a diverse group of individuals, roles and titles (Humphris, 1994).

There is some consensus in the literature about the characteristics of specialist nursing. These include a firm base as a specialist in nursing practice based on research and graduate level educational preparation (Humphris, 1994b), a point which has continued to be emphasised as necessary for specialist practitioners by the UKCC (1991) and the Department of Health (1999b). Although the exact nature of Specialist Nurses' sub-roles has been debated, the framework presented by Humphris (1994a) provides a useful view of six components of specialist nursing practice. These include acting as a facilitator of learning, provider of care, a nursing care consultant; a promoter of research based practice and enquiry, a collaborator and a promoter of quality care.

The development of Specialist Nursing practice is strongly supported by the UK Government, with the clinical career ladder now being extended to include the new role of Consultant Nurse (DoH 1999b, NHSE 1999). However, there is an acknowledged need to clarify the contribution of specialist nursing in what has become a complex, diverse and expanding area of practice.

In the current health care climate there is an acknowledged need for nurse specialists to be able to measure and articulate how they make a difference (Humphris, 1999). While there is pressure to demonstrate consumer orientated cost-effective care,

“…nursing leaders in both the workload measurement field and those studying the nature of nursing increasingly
recognise that much of the practice of nursing remains hidden.” (McWilliam et al 1994).

Further research is needed to make the hidden work of nursing more explicit.

McGee and Castledine (1999) estimated the current number of specialist nurses in the UK to be quite high (n=3191) and to cover a wide range of practice fields (n=125). In the field of MS care, specialist nurses have developed rapidly, particularly over the last five years. This has been stimulated by the need to support and monitor patients treated with beta interferon (Campion, 1997) and growing recognition of the need for a knowledgeable link worker to provide assessment, support, information and co-ordination of care (British Soc. of Rehabilitation Med., 1993, Thompson et al 1997a). From one MS Specialist Nurse in 1990 (Kirker and Young, 1995), there may now be up to 90 posts in the UK but without research, little is known about MS Specialist Nurses as a group. At a time when MS is under scrutiny, the unknown extent of nurses' contribution to care is an important missing part of the equation when developing government recommendations for overall MS management strategies in the UK.

While descriptive data regarding MS Specialist Nurse roles are important in themselves, it is useful in some cases to make comparisons between MS Specialist Nurses and other Nurse Specialists so that these can be seen in context. Few in-depth studies of specific UK specialist nurse groups were available, but one, a PhD thesis by Tait (1996) studied issues associated with the role of Breast Care Specialist Nurses comparable to the work of MS Specialist Nurses. Although covering a different patient group and carried out approximately six years previously, similarities appeared to exist such as nurses' relationship with acute and community care, managing prognostic
uncertainty and that of specialist nursing practice as a concept. Comparisons between specific aspects are drawn more closely in Part I of the study concerning the survey of UK MS Nurses.

The tendency for varied job titles which do not necessarily indicate real differences between roles or educational preparation has been highlighted in the USA as well as the UK (McGee and Castledine, 1999; p. 84). McGee and Castledine conclude that trying to address these distinctions is not particularly illuminating and Hamric (1998) suggests using the term “advanced practice” as an umbrella term for those who comply with certain core competencies, regardless of their job titles.

The importance of the manager's relationship to the Clinical Nurse Specialist (CNS) was identified by nurses in McCaffrey's study of CNS longevity in the role (1997). In McCaffrey's study, as highly motivated, self-directed experts in their field, CNSs felt entitled to some latitude in defining their objectives and cited relationships characterised by a blend of independence and support, along with guidance and clinical freedom as necessary to the effective development and sustenance of the role. Such influences need further investigation.

Expected and actual educational preparation for specialist nursing roles is another area of concern when considering guidelines for practice and development of the role. In Tait's study (1996) a breast care clinical course was stated as a requirement in the job description and that qualifications in oncology nursing, counselling and teaching would be advantageous. Only 48% of existing Breast Care Nurses had breast care courses, 7% had oncology nursing and 38% had teaching qualifications. However 47% had counselling qualifications and 27% were qualified community nurses.
The importance of considerable clinical experience prior to becoming a specialist nurse is illustrated by Glen and Waddington's (1998) case study of role transition experiences for two staff nurses taking up Clinical Nurse Specialist positions. These nurses demonstrated high levels of frustration and stress, often related to the idea of autonomy, implementing change, hidden agendas, politics and conflicting role expectations on making the transition from staff nurse roles.

Autonomy is closely linked to perceived status and recognition of specialist skills and knowledge by other professionals. This can be difficult to measure directly but an indication of nurses' autonomy and status may be gained from the degree of independence they demonstrate in some of their work patterns or achievements. For example, these might include their ability to make direct personal referrals to other relatively high status professional groups, rather than to make suggestions for such referrals through a medical practitioner. It may also include the authority to hold their own clinics, as opposed to assisting in clinics led by other professionals, or the extent of their involvement as a leader of service developments. These form three of the Chief Nursing Officer's ten Key Roles for Nurses in the NHS Plan (DH, 2000).

The ability to choose colleagues with whom to carry out the job is an aspect of autonomous practice and job discretion (Glen and Waddington, 1998). Although Soar (1994) points out that no individual is totally free to practice autonomously, there are differences in the degree of autonomy afforded various disciplines within the bounds of the law, social and professional codes. Historically nursing has had low levels of autonomy and a culture which dictates that they follow orders (Bousfield, 1997). Castledine expressed concerns that the specialist nurse would be seen as a “mini doctor” or medical assistant (1995). However, the potential to practice more autonomously is a
commonly reported factor in motivating Nurse Specialists (Bousfield, 1997; Glen and Waddington, 1998; Tait, 1996) where they can “see the fruits of their labour” (McCaffrey Boyle, 1997). Despite this, there is evidence that Nurse Specialists do not always feel able to exercise sufficient autonomy in their role (Bousfield, 1997, Glen and Waddington, 1998), suggesting that this is an area in need of further investigation.

The debate about autonomous professional practice begs the question as to whether single professional autonomy in the modern health service is possible or even desirable. This issue also relates to multidisciplinary team work and the general structure of services referred to in the next section.

4.2 The structure of MS services and multi-disciplinary team-work

The crucial importance of support at the time of diagnosis has been well documented in other conditions (Mills and Sullivan, 1999, p.76) as well as in MS (British Soc. of Rehabilitation Medicine, 1993,p. 20; p.48). It is suggested that introduction to the potential service offered by an MS Specialist Nurse at this early stage represents an ideal opportunity, not only to provide immediate support and reassurance, but to register as an ongoing contact for future reference. It may also increase the opportunity for health promotion by routinely bringing nurses into contact with relatively well individuals at a stage when they can be encouraged to maintain their own health (Johnson, 1997). All of these common components of the service provided by MS Specialist Nurses have been specifically recommended as an essential part of best practice in MS management (Multiple Sclerosis Society./MS Research Trust, 1999).

The advent of beta interferon as the first treatment to influence the course of the disease both raised the profile of MS and led to a
significant need for patient education and support. The international experience that specialist nurses have an essential role in establishing and successfully maintaining patients on injectable interferon therapy is outlined by Meyer et al (1998). Indirect support for nurse involvement also comes from Mohr et al (1999) who found adherence to beta interferon was related to more empathic clinics which promoted less formal medical relationships with patients. Attention to patients’ concerns, emotional status and expectations of trial participation were related to better adherence. Patients have been shown to perceive nurses as providing a more accessible, relaxed style than doctors (Kirker and Young, 1995) and might therefore be expected to positively influence adherence to beta interferon therapy through nurse-led clinics.

Nurse-led MS clinics have been advocated by several authors, in some cases held concurrently with neurologists' clinics so that urgent medical queries can be addressed (Wilson, 1998). Wahlquist (1994) describes neuroscience nursing practice in an outpatient setting as “a highly satisfying endeavour”, offering unique opportunities to practice holistically. Her evaluation of the impact of a nurse-led MS clinic demonstrated measurable outcomes in terms of reduced morbidity and a reduction in hospital stay.

One study of the cost of MS suggested 33 days per year as the average bed occupancy for a person with secondary progressive MS who requires hospitalisation (Holmes et al 1995) Other studies have shown hospital admission to be reduced through MS Specialist Nurse intervention (Campion, 1996; Wahlquist, 1984).

Difficulty identifying and accessing appropriate Social Services input is a factor recurrently highlighted as a problem, both for the disabled generally (DoH 1998b), and in surveys of MS patients in particular
(Freeman and Thompson, 1997). MS Specialist Nurses may make a contribution by helping people with MS through some of the bureaucracy surrounding social care. The Government's commitment to developing skilled, competent care staff may also lead Social Service managers to involve more MS Specialist Nurses in specialist education for some of their staff in the future (DoH, 1998b) as people with MS form a significant part of the community care caseload.

Concerns about friction and role misunderstanding within and between professions have frequently been expressed. Friction between District and Specialist Nurses was studied by Griffiths, (1994). The study concluded that District Nurses' apparent resistance to Specialist Nurses' input was more related to District Nurses' frustration with their own role in terms of time and caseloads, than to serious disagreement or dissatisfaction with Specialist Nurses per se. Griffiths (1994) mentions the accepted courtesy rule of contacting the District Nurse before home visiting. In Tait's study of Breast Care Nurses, two thirds made home visits but there was little routine liaison with District Nurses despite their stated aim of providing a seamless hospital/community service (1996).

The situation regarding role conflict is less clear in the case of MS specialist nurses. It may be that, as Winters et al (1989) points out, the complexity of disablement and multiple sites of neurological damage mean that the need for interdisciplinary teamwork is obvious in MS, and there is a mutual respect for and reliance on the contributions of each member of the team. There may be less perceived role confusion between the MS Specialist Nurse and therapists than between the MS Specialist Nurse and other nurses, perhaps leading to more satisfaction with the relationship. Winters et al (1989) describes the unique contribution of a nurse-led multi-disciplinary MS clinic in moving away from a fragmented, symptom specific clinic model to a holistic,
co-ordinated approach. More research would be needed to verify these ideas.

Given GP's important roles as “gatekeeper” and referrer to other appropriate services, and recurrent reports of GPs tending to have limited understanding of the special needs of people with MS (Multiple Sclerosis Society, 1997), it would be encouraging to see MS Specialist Nurses targeting GPs with educational initiatives. In their successful evaluation of an MS Liaison Nurse, Kirker and Young (1995) were able to show that, among other things, the MS Specialist Nurse did increase GPs' knowledge of the management of MS.

Lines of communication and reporting can be an issue for specialist nurses. When working in a multi-professional environment, in relative isolation from day-to-day nursing management, it can sometimes be difficult to recognise professional or ethical issues which have a particular nursing dimension (Marsden, 1995). In the absence of clear lines of professional nursing accountability or routine systems of nurse communication, it is possible that some nurses will fail to recognise and explore issues with wider nursing implications and may be deprived of senior nursing advice and back-up at a stage where issues can easily be resolved. Nurses in McCaffrey Boyle's (1997) exploration of Clinical Nurse Specialist longevity identified the value of Directors of Nursing as “power brokers” for the advanced practice role. The need for nurses in relatively isolated roles to be linked with nurse management has to be balanced with the benefits of working with multi-disciplinary peers. The importance of working in a wider multidisciplinary team which fosters the growth of Nurse Specialists has been identified as an additional contributory factor to longevity in the role (McCaffrey Boyle, 1997).
It seems that, by developing specialist roles, MS Specialist Nurses may be capable of implementing significant change in an organisation. More consistent recognition at a management level of MS Specialist Nurses’ experience and aptitude in planning service developments may make better use of their specialist skills on behalf of patients and the organisation, and is endorsed in the NHS Plan by the Chief Nursing Officer (DH 2000).

4.3 Patient and carer views about current MS services and expressed needs for future provision

Sounding out patient opinions about health services has become increasingly prominent in government rhetoric from both major parties in the past two decades. Apart from a degree of ‘spin’ in discussions about ‘patients as customers’, some useful developments have taken place and paternalism is gradually reducing within the NHS.

Kirker et al’s study (1995) identified how much easier patients found it to talk to the MS Liaison Nurse in their own homes rather than in a clinic where they felt they had “come to see the doctor”. Wilson (Wilson, 1998) describes how home visits can enrich the care provided by MS Specialist Nurses and is popular with patients, although acknowledges the time limitations this can impose, and on the basis of audit results, advocates a mixture of visits and clinics.

The clear identification of the patient advocate/knowledgeable link-worker role to help patients find their way through the fragmented and bureaucratic health-care system corresponds well with numerous MS patient survey results and recommendations (British Soc. of Rehab. Med, 1993, Freeman et al 1999; DH, 1999b; Thompson et al 1997a). This suggests that by acting as patient advocates, MS Specialist Nurses are addressing a clearly identified need in this patient group, and in particular providing a voice to prioritise access to acute services from
the community. Other evaluations have also found patient satisfaction with this aspect of care (Kirker and Young, 1995; Sylph, 1996).

McWilliams and Wong (1994) describe the role of “compensating for the characteristics of bureaucracy” (providing ‘insider’ organisational knowledge to co-ordinate disjointed systems and ‘trouble-shooting’ pathways through the system) as a particular strength of nursing, and one which is essential if patients are to experience optimum care.

A natural response to uncertainty is to seek information. MS, with its' variations and complexity generates strongly held beliefs and differing opinions and can result either in an absence of information or an overload of conflicting ideas (Roberts, 2000; Sheridan, 1997). The important, far reaching functions of information regarding health is highlighted by Mills and Sullivan (1999). They identify six uses of information - gaining control, reducing anxiety, increasing compliance, creating realistic expectations, promoting self-care and participation, and feelings of safety and security. According to Coulter et al (1999) patients cannot express informed preferences unless they are given sufficient and appropriate information. If MS Specialist Nurses are an effective source of up-to-date, easy to access, accurate information, they are likely to make a significant contribution to empowering people to live successfully with their MS.

It is widely reported that MS has profound effects on personal relationships within the family, as well as on the individual. Helping spouses to cope with the 'chronic sorrow', which often afflicts both patients and their carers, is discussed by Hainsworth (1995). Gulick (1995) conducted research on coping strategies among carers of people with multiple sclerosis, pointing to the physical, social and emotional disabilities commonly affecting people with this condition which lead to dependence on carers. The latter need to develop problem-solving strategies, e.g. through various self-help organisations. Patients are
often aware of the pressure put on family members, especially if the palliative care stage of the condition has been reached, as demonstrated in research by Hunt (1991). Davis et al (1996) also discuss pressures put on carers of patients at the end-stage of chronic or acute disease, noting the prevalence female relatives performing this role.

The need for someone outside the family who can listen and counsel without being judgmental has been frequently identified (Freeman et al 1997; Multiple Sclerosis Society 1997; Mohr, 1999) and was found to be highly valued by patients (Sylph, 1996). This aspect of care concurs with Miller (1993) who highlighted an important aspect of the nurses' role in chronic illness as to support empowering behaviours and foster the patient's insight into ways of maintaining control. The concept of empowerment has been defined as:

“A social process of recognising, promoting and enhancing people's abilities to meet their own needs, solve their own problems and mobilise the necessary resources in order to feel in control of their own lives.” (Gibson, 1991)

Patients' appreciation of being able to consult with an MS Specialist Nurse quickly, when problems arise, rather than having to wait for a hospital appointment, has already been noted in a previous section (Kirker and Young, 1995).

4.4 **Audit and effectiveness of specialist nurse services**

As previously noted, little is known about the measurable effectiveness of MS Specialist Nurses. This project is designed to provide some data to explore this issue, and to describe what these nurses actually do (Humphris, 1999).
Humphris (1999) states that all professionals have a responsibility to measure in some way the impact of their skills and knowledge in relation to the needs of those for whom they provide a service. The need to put the Clinical Nurse specialist role on a concrete business as well as a clinical footing is also endorsed by Smart (1994) to ensure that it remains a key feature of all provider units' service mixes.

There is widespread encouragement in the literature (Hammerton and Hartley, 1999; Humphris, 1999; Smart, 1994; Wilson-Barnett and Beech, 1994) for specialist nurses' job descriptions to require the post-holder to audit the effectiveness of their service.

The provision of audit advice and support in NHS and jointly funded posts appears to need further clarification and development. This could increase the profile of specialist nursing data within the organisation and facilitate its incorporation into annual reports and business planning processes (Goodman, 1987), thus increasing the visibility of specialist nurses' contributions. Furthermore, Integrated Care Pathways are being promoted as useful audit and service development tools in the literature (Humphris, 1994; Rossiter et al, 1998) and may have important implications for MS Specialist Nurses in demonstrating the effectiveness of their service. At the present time, the formal teaching of carers, nurses, other professionals and voluntary groups does not appear to be valued as audit data. Given that education is described by Humphris and Soar as “probably the most influential role in making a difference to individuals' health-related behaviour”(1994), this situation clearly needs to be reviewed.

Audit of services and general measurement of nurse effectiveness will be able to identify key areas where educational input needs to be made in programmes for MS and other specialist nurses. This topic is discussed further in the next section.
4.5 Educational provision for MS and other specialist nurses

A minimum level of education has been outlined by the Department of Health (1999) for Clinical Nurse Specialists. In the Department of Health's (1999) career framework, the range which includes Clinical Nurse Specialists states that:

“Typically people here will have been educated and trained to first or masters degree level, hold professional registration and in many cases additional specialist-specific professional qualifications.” (18, p.35)

This contrasts with data collected in the early 1990s regarding Breast Care Nurses (Tait, 1996). While 21% of Breast Care Nurses had diploma level qualifications, only 9% had degrees and 3% had master's degrees at the time of the study. Since that time, considerable progress has been made.

The national human resources strategy, Working Together (DH, 1998a), and the introduction of clinical governance both emphasise the importance of continuing professional development (CPD) and lifelong learning in the NHS. It is recommended that all individuals have a Personal Development Plan, linked to performance appraisal.

In Tait's work (1996) the breast care course was stated as a requirement in the job description and that qualifications in oncology nursing, counselling and teaching would be advantageous. However, only 48% of existing Breast Care Nurses had breast care courses, 7% had oncology nursing and 38% had teaching qualifications, although 47% did have counselling qualifications and 27% were qualified community nurses. Personal Development Plans, as well as the design and content of
courses and study days, are important in order for specialist nurses to maximise their potential and reduce some of the role frustrations often experienced (Glenn and Waddington, 1998).

However, opportunities to learn directly from clinical incidents is also an important component of professional development and is now advocated through access to regular Clinical Supervision for all nurses (UKCC, 1996). Butterworth et al (1997) identified issues typically covered by clinical supervision. These include organisational or management issues, reflections on clinical casework, professional development, educational support, confidence building, interpersonal problems and personal matters.

4.6 Professional and personal support for specialist nurses.

Various authors identify the crucial issue of support to facilitate specialist nurses in sustaining their complex and demanding role (Bousfield 1997, Glen and Waddington 1998, Marsden 1995, McCaffrey Boyle 1997).

The UKCC has stated that, while supervision is not to be made a statutory requirement for nurses, every practitioner should have access to it (UKCC, 1996). It has been variously described as:

“… an exchange between practising professionals to assist the development of professional skills”.

(Butterworth and Faugier, 1992, p.12)

“A practice-focused professional relationship involving a practitioner reflecting on practice, guided by a skilled supervisor.” (UKCC, 1996, p.4)
For the purposes of this study, Clinical Supervision was defined broadly as:

“time set aside, with a facilitator, to reflect on incidents and issues at work, with the aim of improving your practice”. (UKCC, 1996, p.4).

There is little literature specifying the ideal frequency of Clinical Supervision, although Cowe and Wilkes (1998) found sessions of three hours every six weeks to be a useful compromise between the demands of busy practice and the need for continuity for a group of Clinical Nurse Specialists setting up group supervision.

Butterworth (1995) identifies five potential models of Clinical Supervision. These include: one-to-one encounters with an expert nurse, one-to-one meetings with members of another discipline, one-to-one contact with a peer of similar standing, a group who work together i.e. team supervision, or a group whose members do not work together i.e. network supervision. However, there is general agreement in the literature that selection of a supervisor and the maintenance of confidentiality is a key issue. Clinical Supervision runs the risk of being used as a management tool with disciplinary connotations where supervisors also fulfil the role of manager (Lyth, 2000) with the resulting concern that the scope and quality of Clinical Supervision sessions could be compromised.

Clinical Supervision is not necessarily easily available. Tait (1996) found among Breast Care Nurses in the early 1990’s that 52% had no regular professional casework supervision. In some cases such support had to be financed by the individual rather than the employer. Tait states that: “Managers or clinicians were rarely supportive of these services, yet there was very positive feedback about the value of
supervision/support sessions from 76% of nurses who had them, several volunteering the information that they could not have survived their jobs without such help” (p 186). Berg et al (1994) point to reduction in stress and increased creativity as a result of clinical supervision.

The demands placed on MS Nurses in helping patients and families live with complex, unpredictable disabilities and their subsequent effects on relationships, work, family roles and emotional status suggests the need for robust systems of professional and personal support in these roles.

4.7 Discussion

Current research based and policy related literature suggests a number of areas concerning multiple sclerosis care, which need further exploration. Gaps have been identified, chiefly concerning the exact role and preparation of the MS Specialist Nurse, including provision for their educational and professional development. More research is also needed regarding the relationships between specialist MS Specialist Nurses, other nursing peers involved in the service and interactions within the multidisciplinary team.

Service based issues, such as the 'post-code lottery' regarding availability of beta interferon clearly need to be dealt with by government (Rous et al 1996; Thompson, 1999; Forbes, Raeburn et al 1999). Balancing the availability of specialist nurses throughout the UK in relation to disease prevalence, is also an important issue requiring investigation and action. Little specific discussion about this topic was found in the published literature, although contributors to the edited volume by Castledine and McGee (1998) touch on this. More focused data are beginning to emerge from a study related to Parkinson's Disease Nurses, which has UK wide coverage (Hurwitz et al 1999).
The impact of providing specialist PD nurses in areas of varying socio-demographic profiles provides information about aspects such as the effects of social deprivation on disease progression and general quality of life for people with Parkinson's Disease.

The specific role definition of MS Specialist Nurses and the education needed to prepare them for this function is central to this study. This review of relevant literature indicates lack of research in this area. Current government guidance indicates masters degree level education as an appropriate preparation for the Specialist Nurse's role (DH, 1999b). Academic education does, of course, need to be built upon extensive clinical experience in the field.

The issue of professional autonomy usually features prominently in any discussion about specialist practice. While it is important for professionals to have sufficient power to make clinical decisions about their work, it is essential to remember that no profession within a multidisciplinary team has, or should have, total monopoly over clinical decision making. The main point is to ensure an effective balance between the expertise of all members of the team to achieve maximum benefit for patients (While and Barriball, 1999; Rowe et al 1996). Development of integrated care pathways is becoming recognised as a central tool for effective team work (Wilson, 1998; Overill, 1998).

More research is needed in the area of patient satisfaction with nurses who are acting in what might be described as 'extended roles'. Strong patient satisfaction has been registered in research concerning the input of nurse practitioners within GP surgeries. High satisfaction levels are expressed with the fact that nurses give more time to patients than GPs (Venning et al 2000; Kinnersley et al 2000) Venning et al based their research on 1,716 primary care patients and Kinnersley et al
conducted their study on a sample of 1,368 patients. It is clearly important to identify whether nurses provide any distinct patient benefit compared to doctors, except in terms of spending more time with patients. This relates to all specialist nursing roles. An interesting comparison can be made with nurse practitioners in US primary care. Mundinger et al (2000) compared patient satisfaction with primary care physicians and nurse practitioners, based on a sample of 3,397 adult patients. In this study no difference in patient satisfaction ratings between doctors and nurses was recorded. Chapple et al (2000) investigated patient perceptions about boundaries between nurses and doctors in nurse-led services within many clinical areas, in which nurses were often viewed as 'mini-doctors'. This is clearly not the aim of specialist nurses in the UK, who generally see themselves as providing a distinct service which is not merely 'diluted medicine'.

More focused research is needed both concerning the interface between specialist nurses and patients, and between all MS professionals and family members/friends, who act as informal carers. Moreover, it seems clear that effective methods of monitoring are absolutely essential in order to provide effective services, in which specialist nurses in the future will have a crucial role.

4.8 **Summary**

- Provision of resources for patients, including specialist nursing, needs to be concentrated in areas of greatest clinical need, with an end to the 'post-code lottery'.

- Appropriate balance between community based and hospital based services needs to be achieved. Some evidence points to specialist MS Nurses' potential to provide a link between the two areas, preventing some unnecessary hospital admissions, providing support within peoples' homes and acting as a central source of
information and advocacy for people with MS, but more research is required to support this.

- The role and current practice of MS Specialist Nurses needs to be explored and made more explicit, at a time when all professionals are expected to demonstrate the effectiveness of their input and when the overall issue of MS management is under close scrutiny. The issue of professional autonomy forms part of this debate.

- Development of guide-lines for education, practice and professional support related to MS Specialist Nurses is needed.

- Interaction between MS Specialist Nurses and other nurses needs to be explored further, as does the relationship between MS Specialist Nurses and other professionals in the multidisciplinary team. This includes the impact MS Nurses have on the knowledge and practice of other professionals through role modelling, teaching and information giving.

- Audit tools in the areas of MS nursing need to be developed and up-dated in order to demonstrate effective service provision and identify areas for further development. Such audit tools need to reflect the views of patients and carers as users of the service.
5. Part 1: NATIONAL SURVEY OF MS SPECIALIST NURSES IN THE UK

Summary of Methods and Findings (See accompanying volume Part I report for full details)

5.1 Summary of Methods
An anonymous postal questionnaire was devised with the help of an MS Specialist Nurse expert group and experienced statistician. Following a pilot, the refined questionnaire was circulated to all 96 specialist nurses working exclusively with, or providing extensive care for people with MS who could be identified from the most up to date MS Research Trust Nurse Forum database.

5.2 Objectives:
- To explore the professional profiles of MS Specialist Nurses in the UK.
- To identify how MS Specialist Nurses are employed and managed.
- To investigate the educational backgrounds and needs of MS Specialist Nurses.
- To determine what support systems are available/needed by MS Specialist Nurses.
- To identify how MS Specialist Nurses work with others and what contribution they make to the care of people with MS.
- To determine what MS Specialist Nurses say about the clinical effectiveness and job satisfaction of such roles.

5.3 Analysis
With the help of an experienced statistician, data were analysed using the Minitab software package, with additional qualitative information added where appropriate.
An initial descriptive analysis identified percentages related to the number of respondents for each question or calculated the mean and median values, with 95% confidence intervals for the mean. Where results related to a particularly low number of responses, this was indicated in the report.

Cross-tabulation was then used to look for relationships between some variables. The chi-square test was used to assess the statistical significance of any relationships from these contingency tables.

5.4 Summary of Main Findings
In total 59 questionnaires were returned, giving a response rate of 61.4%. All 59 questionnaires contained useable data. In the main, MS Specialists in this sample were very experienced nurses (mean length of time in post was 13.5 years), with an expressed commitment to empowering people with MS and their families to regain a feeling of control in living with the disease. Interventions took a variety of forms, but were summarised as addressing five main patient problems:

- getting care or accessing services,
- finding information,
- the need for psychological care, support and counselling,
- symptom management,
- problems associated with a general lack of awareness of MS.

MS Specialist Nurses provided information and ongoing emotional support from the time of diagnosis and multi-disciplinary coordination of care and advocacy on behalf of patients and carers. They formed a direct two-way link between the community (i.e. primary care, social services and the voluntary sector) and neurologists and the acute care team. Having a base in the acute sector together with the
collaboration of an interested neurologist was found to be important factors in facilitating the role.

MS Specialist Nurses helped ward staff co-ordinate complex hospital discharges, often supporting patients in their management of beta interferon treatment and were actively involved in local educational initiatives, seeing teaching as one of the most important aspects of their role. The opportunity to practice more holistically as a nurse was highly valued.

However, the role was identified as very complex, isolating and exhausting, with no boundaries and with a significant risk of “burn out”. The difficulties associated with the role included unrealistic caseloads, and lack of support, specifically Clinical Supervision in addition to some of the frustrations related to the MS disease trajectory, where there were no clear answers or total resolution of symptoms. In addition there were considerable discrepancies in the grading of some MS Specialist Nurse posts, with important implications for defining the scope of the role and support required.

MS Specialist Nurses were generally satisfied with the effectiveness of nursing care possible in the role, and with the job itself, but they were also aware of improvements which could be made to the way in which such posts are set up. Improvements such as clinical supervision, long-term contracts and appropriate grading were among the improvements considered necessary to make the role less frustrating and more sustainable for newcomers to the speciality.
6. Part II: CASE STUDY OF A NEW MS SPECIALIST NURSE SERVICE IN WEST BERKSHIRE

6.1 Introduction
The second element of the project was a developmental case study to evaluate a newly established MS Specialist Nursing service in West Berkshire.

6.1.1 Rationale for choosing a case study
The approach to evaluation selected for the study was that advocated by Stufflebeam and Shrinkfield (1985) who state:

“"The most important purpose of evaluation is not to prove but to improve… We cannot be sure that our goals are worthy unless we can match them to the needs of the people they are intended to serve.ˮ (p. 151)

Evaluation research can encompass a variety of research approaches. Although within the health service it has tended to be of a quantitative nature, comparing differences between two or more groups (Prior 1989), Smith and Cantley (1985) argue that experimental approaches to evaluation research are limited as they fail to acknowledge that service goals are complex and cannot be defined as comprising a single objective reality. They propose that in these situations “pluralistic evaluation” should replace traditional methods. This approach acknowledges that “success” may have a variety of different definitions and a triangulation of different methods is recognised as being of prime importance. Central to a pluralistic evaluation strategy is the identification of all those who are “stakeholders” in the service under review. The views and opinions of these “stakeholders” are
sought and acknowledged in order to demonstrate ways in which a service is or is not successful, and why.

As the focus of the second element of the project was the evaluation of the service provided by an MS Specialist Nurse in a specific, local context, it was decided to use a case study design. A case may be simple or complex (Stake 1994) but it is a functioning, specific “bounded system” with working parts. Such a system has a unique structure and history and, operating within a number of contexts it can be usefully viewed from different perspectives. Concentration on the single case, while acknowledging the complexity of factors involved, has the potential to produce rich, context specific data which in turn informs the practical development of the local service, as well as providing insights into issues which may have a wider application in other MS Specialist Nurses’ roles.

6.1.2 The case study context

The case study focused on a new MS Specialist Nurse post established in West Berkshire in 1998. The local context in which the case study was situated, is described below. The population of West Berkshire is 500,000 and is served by the Royal Berkshire and Battle NHS Hospital Trust. The hospital has two consultant neurologists who spend two thirds of their time in Reading and the other third at the Regional Neurological Centre at the Radcliffe Infirmary in Oxford. The Trust also has a full time consultant in neuro-rehabilitation. As the prevalence of MS is 1/700, there are likely to be approximately 700 patients in the district with the condition. The diagnostic phase is currently managed by the consultant neurologists. When chronic disability begins to ensue, patients are seen by the consultant in neuro-rehabilitation. Prior to the appointment of the MS Specialist Nurse, there were gaps in the provision of support for people with MS at various stages of the disease trajectory. General practitioners partly
filled some of these gaps. Many of them only had on average two to three people with MS on their lists, which implies a relatively low level of knowledge and expertise in this condition.

With the introduction of new therapies such as beta interferon there is a clear need for patients to be supported in the community to ensure treatment is being used effectively. It was decided therefore to appoint an MS Specialist Nurse to act as a point of contact working jointly with members of the multidisciplinary team to ensure a seamless service between primary, secondary and social care. Funding for this post was provided for two years from three separate sources: the local Multiple Sclerosis Society, the NHS Trust and the drug company, Biogen. During the course of the research it was hoped to provide evidence that would help to make the case for the MS Specialist Nurse post to become permanent. This was achieved at the midpoint of the project with funding being identified from the NHS Trust's budget.

6.1.3 Case study aim and design
The aim of the case-study was to evaluate, develop and demonstrate the effectiveness of an MS Nursing service in response to the needs of the local MS population and other associated stakeholders, including lay and professional carers. Data were collected and analysed using a variety of qualitative and quantitative research methods. The case study demonstrates how an action research approach can incorporate multiple methods and various viewpoints to produce a comprehensive evaluation, which can then be used with stakeholders to develop an MS Specialist Nurse service in one locality.

The service development phase of the case study began during the middle period of the evaluation (November 1999-July 2000). The development of the service was conducted using an action research approach (Webb 1990; Holter and Schwarz-Barcott 1993; Hart and
Bond 1995; Sparrow 1997), involving not only the dialogue between the researcher and the MS Specialist Nurse but also the “stakeholder” Steering Group members during their two monthly meetings. Practical developments were identified and agreed in response to perceptions of need derived from the patient and stakeholder interviews. Following implementation, the developments were then audited using two structure-process-outcome style standards, designed to reveal gaps in the service required. Modifications were then introduced on the basis of the findings.

In addition, a retrospective review of medical records was undertaken to identify measurable outcomes of effectiveness in relation to MS patients, during two twelve month periods, one year prior to and six months following the appointment of the MS Specialist Nurse.

The project was organised into five phases (see below) and in the spirit of the cyclical nature of action research, progression from one phase to the next depended on feedback between each phase to inform ongoing developments and evaluation (see flow diagram).

6.1.4 Phases of the case-study (as outlined in Diagram 1)

1. Gathering baseline data from people with MS and identification of other stakeholders in the local service using semi-structured interviews. These data included both the reflections of the MS Specialist Nurse on coping with, and in the case of other professional stakeholders, managing MS in the West Berkshire area with a view to identifying suggestions for further service developments.

2. Analysis of the baseline data and the development of an action plan, audit strategy and review of indicators of effectiveness in the local context. Two structure/process/outcome standards were specially designed for the purposes of audit in relation to
Schematic diagram of case-study method

- Patients → Stakeholder Interviews → Professionals
- Consultation with local Steering Group to prioritise issues
  - Identify quantitative outcome measures: hospital admissions
  - Develop/audit 2 standards:
    1. Care at diagnosis
    2. Education of formal carers
- Period of MS Nurse service development
  - MS Nurse reflective diary
  - Retrospective review of all available medical records (n = 70) of MS admissions for 2 x12 month periods
- Pre MS Nurse → Post MS Nurse
  - 2 week MS Nurse activity analysis
  - Comparison and production of final evaluation report in consultation with local Steering Group → Re-audit 2 standards:
management at diagnosis and the education of paid hospital and community carers. A retrospective review of hospital medical records was undertaken to identify indicators of effectiveness. Plans were fed back to participating stakeholders during Steering Group meetings and in written reports to patient interviewees.

3. A period of service development, informed by users’ views (both patients and professionals) geared towards meeting the specially designed standards.

4. Evaluation of goal achievement and audit of the service using the same standards and indicators of effectiveness as outlined in (2) above. Further exploration of current views on coping and managing MS as experienced by stakeholders following this period of service development.

5. Consideration of insights gained from the local case-study in order to inform proposed national guidelines.

6.1.5 *Steering Group membership*

The Steering Group members were recruited from the following key stakeholders: people with MS, Neurology and Rehabilitation Consultants, Local MS Society Branch, Business and Nursing Managers from the local Hospital Trust, a local GP, Social Services, District Nursing, Community Occupational Therapy, formal and informal carers, the local MS Therapy Centre, the Multiple Sclerosis (Research) Charitable Trust, the researchers (South Bank University), another experienced researcher in the field of MS from Brunel University and the MS Specialist Nurse.

In the event the actual members of the Steering Group comprised people with MS, Neurology and Rehabilitation Consultants, the Local MS Society Branch Chair, a Business Manager from the local Hospital Trust, a Social Services representative, the Priority Care Manager, a district nurse, a community occupational therapist, an informal carer, the manager of the local MS Therapy Centre, the Multiple Sclerosis (Research) Charitable Trust, the researchers, an experienced researcher in the field of MS and the MS Specialist Nurse.
Ten meetings were held throughout the duration of the project and a core group of members consistently attended. This ensured that the project had continuity, support and representation from a broad range of stakeholders. Where there were gaps (e.g. no GP or physiotherapist) the researchers accessed these groups during the stakeholder interviews.

6.1.6 Role of Steering Group in service development
Following each phase of data collection and analysis, as outlined in the flow diagram, the Steering Group discussed the initial findings with the aim of identifying and agreeing priority areas for service development and confirming the validity and reliability of the research approach. Their involvement throughout the study was crucial to keep the research well grounded and informed of developments within the local area.

6.1.7 Role of MS Specialist Nurse as key stakeholder in service development
Given the senior nature of the MS Specialist Nurse role and level of professional development, the process of consultation was sensitive to the needs of the post holder in order to allow her some autonomy in deciding the direction and extent of the change process. It was important to ensure that the aim of the evaluation was not to criticise the work of the MS Specialist Nurse but to help her decide how to organise her work so that she was able to provide a service that met the needs of people with MS and their carers. In addition therefore, the MS Specialist Nurse kept a detailed diary of activities over a two week period complemented by a reflective diary of critical incidents to record ways in which she perceived she had influenced both the processes and outcomes of care.

6.1.8 Validity and reliability issues
As outlined above, the case study design used a variety of data sources and research methods. Such a design maximises the opportunities to enhance the accuracy and validity of the data. During data collection, a number of measures were taken to ensure rigour. Data collecting methods were developed and put under the scrutiny of the Steering Group which assisted in their validation. A
variety of sources were accessed in order to ensure that interview accounts could be checked against documentary evidence and statistical information. The data collection, analysis and interpretation were further validated by reference to the literature.

Furthermore the extensive experience of the research team in either the topic area, qualitative research and/or statistics, further strengthened the reliability and validity of the data.

The strategy of using a variety of data sources, methods and researchers in one research study is known as 'triangulation' which offers an in-depth understanding of the topic under study and a 'negotiated reality' of the research setting (Denzin 1989).

6.1.9 Ethical considerations
People who agreed to be interviewed as part of the case study were given full information about the project aims and objectives and the opportunity to agree or decline to participate. They were also entitled to withdraw from the study at any time without explanation. A form to obtain written consent was available. Any recorded material including signed consent forms, interview tapes and manuscripts were kept in a safe place under lock and key. The data were registered with the Data Protection Officer at South Bank University. Ethics committee approval was sought and obtained from the West Berkshire Health Authority Ethics Committee for the case study. The identification of those participating in the study was confidential to the researcher and other members of the University research team who were involved in data collection and analysis.

6.2 Overview of Case study components
The samples, methods of selection and recruitment, data collection, analysis and findings which represent each component of the case study, are described in detail in six sections:
6.2.1 Patient Interviews

In-depth interviews were conducted with people with MS and in some instances their carers, in order to explore their experiences and perceptions of service need before and after the availability of a local MS Specialist Nurse. This element of the case-study required a qualitative approach (Pope and Mays, 1995) to investigate the meaning people attached to their experiences, and consequently involved a relatively small sample.

Semi-structured face to face and telephone interviews were conducted with two sets of 12 people with MS (24 in total), spanning the four disease phases/levels of disability (i.e. newly diagnosed; minimal impairment; moderate disability; severe disability) as outlined by the MS Society Standards of Healthcare (Freeman, Johnson, Rollinson and Thompson, 1997).

6.2.1.1 Sample selection and recruitment

The patients were selected following randomized, stratified sampling from the database of MS patients held in the neurology department (274 in 1999 and 296...
in 2000). Given the unpredictability of the disease process, it was decided two separate groups of MS patients should be approached six months after the appointment of the MS Specialist Nurse and one year later (i.e. 18 months after the MS Specialist Nurse had been in post). By approaching two separate patient groups rather than following up the same twelve patients one year later it was possible to ensure the sample contained MS patients at defined phases of the disease process, including those who had been newly diagnosed. It was also envisaged that by interviewing the two groups one year apart, it would be possible to gain a perspective on ways the MS Specialist Nurse had made a difference to the provision of services for people with MS in the intervening period.

The consultant neurologists wrote to twenty of their patients before each round of interviews, inviting them to take part in the study (see Appendix 1). It was assumed that in this way 12 respondents in each round would be assured. This assumption proved correct. The patients were sent a detailed information sheet and a reply slip which they returned if they were willing to take part in the study (Appendix 2). In the first round of interviews there were more volunteers than the 12 required and so the final sample was chosen at random. In the recruitment of the sample for the second round of interviews, exactly 12 people volunteered from each of the defined disease phases.

The three interviewers rang the willing respondents and gave further explanations about the study and confirmed their agreement to participate. An appointment was then made for the interview to be conducted in the person’s home or at a convenient time by telephone. The lead research fellow conducted the first set of face to face interviews, with a second research fellow undertaking ten of the telephone interviews and the project leader undertaking one telephone and one face to face interview in the second round (Appendix 3).
6.2.1.2 Method

In the first round of interviews, the researcher travelled to the patient's home to conduct the interview. In the second round patients were given the choice of face to face or telephone interviews. All but one chose to be interviewed by telephone. All patients signed a consent form (see Appendix 4).

The semi-structured interview schedule (see Appendix 5) covered questions concerning the experience of being diagnosed with MS and the people and processes that helped at that time. The researchers then covered five main issues related to the MS Specialist Nurse service. These were: Newly diagnosed people, MS people newly discharged from hospital, the education of health and social care professionals, the liaison and coordination of local services and identification of care needs and carer support. The semi-structured interview is well recognised as a suitable method for the exploration of perceptions and opinions (Barriball and While 1994).

The same interview schedule was used for all the interviewees the only difference being that the telephone respondents were sent the interview questions ahead of time to facilitate voice to voice contact in the absence of visual cues. Telephone interviews are becoming increasingly popular as a research method and have been shown to be an effective way of eliciting rich data when conducted by researchers, experienced in the method (Carr and Worth 2001). Telephone interviews have a number of advantages such as saving on researchers’ time by eliminating the need to travel to conduct the interviews and in the case of sensitive topics may be viewed by some respondents as less intrusive than face to face interviews. They may find it easier therefore to disclose personal information and speak openly because of the relative anonymity of a telephone conversation (Rose 1998, Carr 1999).

A Barthel Activities of Daily Living Index (Mahoney et al 1965) was also completed following the interview (Appendix 6). In order to standardise the interview process a checklist was devised for the researcher to follow (Appendix
3). Both the face to face and telephone interviews lasted between 45 minutes and one and a half hours.

Both sets of interviews successfully elicited a variety of rich and in-depth data in response to the questions. All interviewers were experienced health care practitioners who were able to engage with the respondents and establish a good rapport to obtain quality data. This observation concurs with the literature, which suggests the quality of data obtained from telephone and face to face interviewing are comparable. It was hoped therefore to be able to attribute any differences in the findings between the two cohorts at least in part, to the before and after effects of the MS Specialist Nurse’s appointment.

6.2.1.3 Analysis

Face to face interviews were recorded and transcribed verbatim. During telephone interviews detailed notes were taken and then typed up immediately. The subsequent data were then analysed using a number of frameworks for analysing qualitative data. These included Miles and Huberman's (1994) framework of data reduction, data display and conclusion drawing/verification and Field and Morse's (1985) notion of manifest and latent themes.

Themes were identified by reading and re-reading the interviews. Debriefing sessions were held between the researchers. Responses were clustered according to questions. Preliminary findings were presented to the Steering Group who offered constructive comments and insights for further analysis and interpretation. Interviewees were also given the opportunity to comment on the accuracy of main themes arising from the analysis.

As the analysis of the in-depth patient interviews continued, insights were gained in relation to the meaning of health related events such as diagnosis in an effort to understand and explain the factors which may contribute to the negative experiences reported by patients. These insights were further considered in relation to the literature in order to seek clues to better understand
this challenging phase of the disease and suggest changes to clinical practice to reduce the stress experienced at this time.

Analysis was also undertaken to identify the sources of support required by patients and their carers for managing the disease; its uncertain and unpredictable trajectory and its impact on personal and working lives.

In addition to the qualitative analysis each patient interview was scanned in order to identify the services or other sources of help they described in positive or negative terms at the time of diagnosis and subsequently. The findings were then summarised in Figures 1 and 2.

The underlying purpose of the data analysis was to see if it were possible to detect any differences in the perceptions of two cohorts of people with MS interviewed one year apart, regarding the quality of the service\(^1\), prior to and following the appointment of the MS Specialist Nurse.

6.2.1.4 Description of sample

Of the twelve people with MS interviewed in the first cohort, all but one had received their diagnosis from neurologists in the locality, and all but two were diagnosed prior to the MS Specialist Nurse being in post. In the second round, ten out of twelve had received their diagnosis from local neurologists and seven were diagnosed prior to the MS Specialist Nurse being in post. Eight and ten people in the first and second cohorts respectively out of a total of 12 people had had contact with the MS Specialist Nurse. The characteristics of the two cohorts are summarised in Tables 1 and 2 below.

\(^{1}\) In relation to five main issues: new diagnosis; hospital discharge; education of health and social care professionals; liaison and coordination of local services; identification of care needs and carer support.
Table 1: Characteristics of first cohort of interviewees

<table>
<thead>
<tr>
<th>Sex</th>
<th>Age:</th>
<th>Barthel Index</th>
<th>MS phase, probable duration* and years since diagnosis</th>
<th>Lives with:</th>
<th>At work?</th>
<th>Paid carer?</th>
<th>Contact with MSN?</th>
</tr>
</thead>
<tbody>
<tr>
<td>F</td>
<td>41 yrs</td>
<td>20</td>
<td>Newly diagnosed/ Moderate disability (17 years)* (1 year)</td>
<td>Partner and children</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>M</td>
<td>67 yrs</td>
<td>19</td>
<td>Minimal impairment (8 years)* (3 years)</td>
<td>Partner</td>
<td>Retired</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>M</td>
<td>55 yrs</td>
<td>20</td>
<td>Minimal impairment (2.5 years)* (1.5 years)</td>
<td>Partner</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>F</td>
<td>49 yrs</td>
<td>18</td>
<td>Moderate disability (20 years)* (10 years)</td>
<td>Alone</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>F</td>
<td>48 yrs</td>
<td>20</td>
<td>Minimal impairment (8.5 years)* (3 years)</td>
<td>Alone</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>F</td>
<td>48 yrs</td>
<td>18</td>
<td>Moderate disability (22 years)* (6 years)</td>
<td>Alone</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>F</td>
<td>44 yrs</td>
<td>19</td>
<td>Newly diagnosed (4 years)* (9 months)</td>
<td>Partner</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>M</td>
<td>54 yrs</td>
<td>20</td>
<td>Newly diagnosed (10 years)* (5 months)</td>
<td>Partner</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>M</td>
<td>37 yrs</td>
<td>9</td>
<td>Severe disability (13.5 years)* (13 years)</td>
<td>Carer</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>M</td>
<td>55 yrs</td>
<td>2</td>
<td>Severe disability (27 years)* (26 years)</td>
<td>Partner and carer</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>F</td>
<td>52 yrs</td>
<td>14</td>
<td>Moderate disability (7.5 years)* (7 years)</td>
<td>Partner and children</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>M</td>
<td>58 yrs</td>
<td>16</td>
<td>Moderate disability (14 years)* (12 years)</td>
<td>Alone</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
</tbody>
</table>

| Mean: 30.6 | Range: 37-67yrs | Mean: 16 | Range: 2-20 | Mean*: 12.8 | Range*: 2.5 - 27 | Mean: 6.9 | Range: 5 months to 26 years |

Table 1 shows that for the first cohort of interviewees, mean length of time since diagnosis was 6.9 years (range 5 months - 26 years), and in many cases people were able to trace the onset of their disease back to many years previously, mean 12.8 years (range: 2.5 - 27 years).
Table 2: Characteristics of second cohort of interviewees

<table>
<thead>
<tr>
<th>Sex</th>
<th>Age</th>
<th>Barthel Index</th>
<th>MS phase, probable duration * and years since diagnosis</th>
<th>Lives with:</th>
<th>At work?</th>
<th>Paid carer?</th>
<th>Contact with MSN?</th>
</tr>
</thead>
<tbody>
<tr>
<td>F</td>
<td>40</td>
<td>20</td>
<td>Minimal impairment (11 years)* (7 years)</td>
<td>Partner</td>
<td>Yes</td>
<td>Gardener</td>
<td>Yes</td>
</tr>
<tr>
<td>F</td>
<td>54</td>
<td>10</td>
<td>Severe disability (11 years)* (9 years)</td>
<td>Partner</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>F</td>
<td>66</td>
<td>7</td>
<td>Moderate/Severe disability (27 years)* (24 years)</td>
<td>Partner</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>F</td>
<td>43</td>
<td>20</td>
<td>Newly diagnosed (2 years)* (1 year)</td>
<td>Partner</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>M</td>
<td>56</td>
<td>5</td>
<td>Moderate/Severe disability (18 years)* (15 years)</td>
<td>Partner</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>M</td>
<td>46</td>
<td>19</td>
<td>Minimal impairment (12.5 years)* (12 years)</td>
<td>Partner</td>
<td>Sick leave</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>F</td>
<td>48</td>
<td>20</td>
<td>Newly diagnosed (1.5 years)* (1 year)</td>
<td>Partner and children</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>F</td>
<td>50</td>
<td>10</td>
<td>Moderate disability (10 years)* (7 years)</td>
<td>Partner</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>F</td>
<td>60</td>
<td>20</td>
<td>Moderate disability (21 years)* (20 years)</td>
<td>Partner</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>F</td>
<td>53</td>
<td>20</td>
<td>Minimal impairment (2 years)* (1.5 year)</td>
<td>Partner</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>M</td>
<td>34</td>
<td>15</td>
<td>Newly diagnosed (12 years)* (1 year)</td>
<td>Alone</td>
<td>Extended break</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>M</td>
<td>56</td>
<td>7</td>
<td>Severe disability (35 years)* (33 years)</td>
<td>Alone</td>
<td>Retired</td>
<td>Yes</td>
<td>Yes</td>
</tr>
</tbody>
</table>

Mean: 50.5 Range: 34-66yrs  
Mean*: 12.8 Range: 1.5-35 yrs  
Mean: 10.5 Range: 1-33 yrs

In the second cohort (Table 2), mean length of time since diagnosis was longer at 10.5 years (range 1- 33 years). Again most respondents were able to trace the onset of their disease back further than when they actually received a confirmed diagnosis with a mean of 12.8 years (range 1.5 - 35 years). The people in the 'newly diagnosed' category had received their diagnosis between 5 months and one year prior to the interview. Two respondents in the first cohort received...
their diagnosis five and nine months prior to the interview with the other four people in this category having received their diagnosis one year previously. It was considered important not to interview people too close to their diagnosis in order not to cause them undue distress.

Six male and six female interviewees made up the first sample, giving a range of perspectives although not exactly reflecting the typical sex ratio for MS (M:F = 1:1.7) (Robinson, Neilson et al 2000). The second sample were closer to this ratio being four men and eight women (M:F = 1:2). The mean age of the first cohort was 50.6 years (range 37 - 67 years) and mean age at onset of symptoms 38 years (range 24 - 59 years), broadly reflecting the typical range of between 20 - 50 years (Robinson, Neilson, et al 2000). The second cohort had a similar mean age at 50.5 years to the first sample and a similar age range at 34-66 years. Mean age at onset was only slightly older at 40 years with a range of 24-52 years and also matched the typical age range at onset of symptoms.

In other respects, for example in level of disability, MS phases (newly diagnosed, minimal, moderate or severe disability), living and working arrangements and reliance on carers, the samples presented a range of characteristics. Five people in the second cohort scored low Barthel scores (10-5) compared with the two people in the first cohort (9-2). There were more people living alone in the first cohort and a greater number with a paid carer. Similar numbers in both cohorts were in paid work (4) with more people (8) not working in both groups. One interviewee in each cohort was retired. In the second cohort one interviewee was on sick leave and another was taking an extended break.

Taken together the two cohorts provided a comprehensive sample of people in the West Berkshire area living with MS during the first eighteen months following the appointment of an MS Specialist Nurse.
6.2.1.5 *Patient Interview Findings*

The findings from the patient interviews are presented under two broad categories related to: (1) the time leading up to and surrounding diagnosis and (2) subsequent experiences and sources of help at different phases of the illness trajectory. The findings provide information about the people and processes in general and the MS nursing service in particular in terms of how they had helped patients, their carers and other professionals, manage their disease. It is important to note that although some patients had received their diagnosis over twenty years previously, a significant part of most interviews consisted of people recounting the events and experiences around that time, their reactions and thoughts and subsequent sources of help and support.

*i) Overview*

The findings derived from scanning the interviews to identify those services or other sources of help which patients described in positive or negative terms at the time of diagnosis and subsequently, are presented in Figures 1 and 2 below. The tables provide a useful summary and overview of the types of help patients sought around the time of diagnosis and later.

At the time of diagnosis, the GP and to a lesser extent, the hospital doctor, were both identified as being sources of help to the patient. However, it appeared that over half these encounters were perceived to be negative. The MS Specialist Nurse was mentioned by three interviewees in each cohort as being a source of help at diagnosis, although two also reported negative encounters. The frequency of three in both cohorts suggests that the newly diagnosed patients in this sample all had contact with her. Only one encounter (both positive and negative) was reported with hospital nurses and none with community nurses in this sample.
Figure 1: Sources of help at Diagnosis: positive and negative experiences (all patients N=24). See Appendix 7 for supporting data.

Figure 2: Subsequent sources of help: positive and negative experiences (all patients N=24). See Appendix 8 for supporting data.
Partners, other family, friends and work colleagues, taken together accounted for a core component of positive support. Religion was described as a positive source of help for one respondent only.

Information also featured as an important source of help, as did people with MS, the Multiple Sclerosis Therapy Centre (MSTC)\(^2\) and the “Getting to Grips” course. Two people indicated that contact with ARMS (forerunner of the Multiple Sclerosis Therapy Foundation) had been a source of help.

In Figure 2, subsequent sources of help accessed by people with MS, show that the GP and the hospital doctor continued to be identified as important sources of help. There were also fewer negative encounters recorded. The MS Specialist Nurse was identified as a source of help in both cohorts and the frequency of encounters increased, suggesting there was a growing awareness of her presence in the area. Hospital and community nurses were now both mentioned but again only infrequently.

In addition to the community nurse, other sources of help that had not featured at the time of diagnosis, subsequently emerged, such as Social Services, the MS Society (local and national), physiotherapy, occupational therapy and in-patient hospital care. Partners, other family and friends taken together also accounted for a core component of positive support. However, two interviewees indicated that partners as a source of help could also be viewed negatively. Work no longer featured as a positive source of help and three examples of negative experiences were mentioned. Information continued to feature positively as did the MSTC which provided a variety of resources later in the illness trajectory such as diet and counselling. There was some suggestion that people with MS as a source of help were viewed equivocally. The experience of religion as a source of help featured positively for two respondents and negatively for one other.

\(^2\) It should be noted that the MSTC is a unique facility and not generally available elsewhere.
In summary, inferences drawn from the findings presented in Figures 1 and 2, is that the GP and the hospital doctor featured throughout the illness trajectory both at the time of diagnosis and subsequently. The MS Specialist Nurse emerged as an important source of help both at the time of diagnosis and subsequently. Other sources of help and support (or otherwise) described by the patients changed according to which MS phase they were in. Taken together, the diverse sources of help that they described, particularly those categorised as “other” (see footnote 1 in Appendix 7 and footnote 4 in Appendix 8) reflects the uniqueness of the stories they each had to tell about their experiences of learning to live with MS. Further explanation for these findings are discussed below.

ii) Patient In-depth Accounts

The findings presented below are based on the in-depth qualitative analysis of the patient interview data. In this sample, people with MS and sometimes their carers, focused on a number of common issues. These issues addressed the following areas of concern: how the diagnostic phase was managed, patients' emotional responses at the time and the importance of MS specialist knowledge. For those people who had been diagnosed sometime prior to the interview, insights were also gained about the sources of support for managing the uncertain and unpredictable trajectory associated with MS and its impact on personal and working lives. These issues are presented in sections 6.2.1.5.1 and 6.2.1.5.2 below and include a discussion of the literature regarding the meaning of health-related events such as diagnosis, in an effort to understand and explain the factors, which may contribute to the often negative experiences reported by patients. By considering these factors, clues to understanding the challenges of different phases of MS were identified in order to suggest changes to clinical practice to help to reduce the stress experienced by patients at this time and later in the disease trajectory.

6.2.1.5.1 Experiences around the time of diagnosis

Account of patients' experiences of how the diagnostic phase was managed is followed by an illustration of themes related to a range of emotional responses
and MS knowledge. Knowledge about MS was related to the interviewee's own knowledge as well as that of the people they looked to for help. From the interviewee's point of view, their central need for knowledge to enable them to make sense of and manage the situation was very important. Feelings of abandonment and isolation were often linked to this perceived lack of knowledge and understanding about support services and sources of help identified at the time of diagnosis.

i) Experiences of being newly diagnosed with MS

In recalling how they had learned of their diagnosis of MS, patients described a variety of scenarios, and with one or two exceptions expressed some dissatisfaction with how they perceived this stage of their disease had been managed.

The period during which tests were completed, but before the diagnosis was discussed was a time of anxiety for many patients. This period could be very fragmented and time consuming as the following comment indicates: “Different doctors looked after different parts of me and it seemed to take forever” (P.2.2). Several patients decided to seek a private appointment “to speed the process up”. However, some of them thought that following the initial diagnosis, they were then more likely to “miss out” on being referred to other members of the multidisciplinary team such as the MS Specialist Nurse and the physiotherapist.

How they were told of the diagnosis left a lasting impression on many patients. Twenty-six years ago one man had been sent away from clinic with the recommendation to read a particular article about MS, although it was never stated that this was his diagnosis, and he was not invited to make another appointment to discuss its implications. Twenty years ago a woman described a very similar situation. She said: “I went to a private hospital who did not actually say what was wrong. I read an article and thought ‘that sounds like me’, so I went to my GP”. While one explanation for this situation might be the very different approach to doctor-patient communication in the past, patients
diagnosed relatively recently described ways of finding out their diagnosis which they felt tended to compound the naturally distressing realisation of having a long term, chronic disease. Another patient who was diagnosed in the last two years would have preferred the neurologist to have been “a bit up front” rather than inferring she “probably had MS”. Explanations for possible communication difficulties around this time are discussed later.

Several common perceptions of the way in which the neurologist handled their diagnosis, emerged from the interviews. For example, numerous patients in the first cohort, felt the neurologists' main concerns seemed to be solving the puzzle of what was wrong with them. Having arrived at a diagnosis where there appeared little cause for immediate medical treatment of symptoms, there was a perception that neurologists tended to withdraw and see their work as done.

P2 “My impression is… that was it. This is the answer to the problem, if you have any problems come back and see us”.
(diagnosed 3 years previously)

P3 “…he did say to me… ‘We’ve got no cure for it. I’m sorry we’ve got no cure for it. There’s a few things we’re trying to get done…’ and I said to him ‘when do I see you again?’ and he said ‘I don’t.’ Then I just sort of… it didn’t sink in till I went home and I went home… and there was no need for him to say that ‘cos, that really hurt me. That hurt me more… It looked as though I was just being pushed away and told to get on with it, and that really hurts.”
(diagnosed 1.5 years previously)

P5 “And I came out of there… full stop! ‘Goodbye! I don’t need to see you anymore’ he said….‘I don’t need to see you any more unless you have problems. Your GP can manage this, you know’”.
(diagnosed 3 years previously)
In the second cohort similar reactions were reported:

P.5.2 “Straight away he (the neurologist) said it was MS regardless of any tests he might do. He wanted to do more tests but he offered no support or advice.”
(diagnosed 15 years previously).

P.10.2 The follow-up appointment after the scan was awful. (The results) were relayed by the neurologist without compassion. I was given an information sheet with the impression the interview was at an end. I had come on my own and was just left to go home.
(diagnosed 2 years previously).

This situation was redeemed somewhat by the interviewee managing to speak to the MS Specialist Nurse a week later which in turn helped her to know she had someone at the end of a telephone to speak to.

The feeling of being cut off or excluded following diagnosis was a common impression not only of the neurologist's role, but also the GP's. One patient in the second cohort described how she had registered with a particular GP because she thought he would be interested in MS but was shocked when he told her on her first visit following diagnosis, that “there is nothing you can do”.

Patients in both cohorts described less distressing experiences related to both doctors and the MS Specialist Nurse. One patient (diagnosed 6 years previously) felt very supported by her GP at this time. Given the patient's history of emotional disturbance, the GP had found out the results from the hospital and contacted her at home to break the news and discuss it's implications. Two other respondents also spoke positively of the support given by their GPs. Another respondent diagnosed twenty four years previously reported that the diagnosing consultant had given her “the best piece of advice I ever had” when
he told her “not to go home and start reading books about it (MS) … just wait and see how thing progress”.

There were reports of the positive role played by the MS Specialist Nurse. Two recently diagnosed patients in the first cohort had been told of the MS Specialist Nurse. One had immediately been offered beta interferon treatment (which she declined), but was also told of the availability of the MS Specialist Nurse who was organising an evening course for newly diagnosed patients. The other was introduced to the MS Specialist Nurse on the day of diagnosis, and found this very supportive. In the second cohort three respondents also spoke of the positive contribution of the MS Specialist Nurse at the time of diagnosis. First, she arranged for the patient to attend a “Getting to Grips with MS” course; second she was described as being “at the end of a phone” and third she was available for one patient at the time of diagnosis and at frequent intervals after that.

In two instances respondents wanted to be able to access the MS Specialist Nurse on the day of diagnosis, rather than having to wait for one and seven weeks respectively. The reason for the seven week delay was because the MS Specialist Nurse was on holiday.

For many of the patients interviewed, however, particularly in the first cohort (nine patients), the idea that confirmation of diagnosis marked the end of this episode of contact with the neurologist (and it seemed, with the healthcare system) was a distressing revelation. This revelation came in addition to the understandable reactions to the diagnosis itself. It is possible to infer therefore that by the second round of interviews, there was an awareness amongst the patients that the MS Specialist Nurse was, or would have been available to mitigate the negative experiences of being newly diagnosed with MS. The following section outlines some of the most commonly described emotional

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A 6-8 week module course facilitated by local MS Society branches across the country, aimed at informing and supporting newly diagnosed people and their families.
responses to receiving a confirmed diagnosis of MS. A subsequent section
describes an associated theme about the importance of lay and professional
knowledge and the role it plays for the person with MS around this time.

\[\text{\textit{ii) Emotional responses around the time of diagnosis}}\]

A range of emotional responses was reported to be associated with being
diagnosed with MS. The range included devastation/shock; suspicion;
abandonment/isolation and a variety of related emotions such as anxiety,
frustration, fear, horror and in some cases relief.

\[\text{\textit{a) Devastation/shock}}\]

Devastation and shock may be seen as “natural” responses to being given a
diagnosis of MS. It is a sufficiently common disease for many to have at least
heard of it, and often what they have heard represents a bleak picture of
disablement, wheelchairs and dependence.

But for the majority of interviewees, a diagnosis of MS provoked an extreme
emotional reaction. For example a woman in the first cohort gave the following
account:

\[\text{P11. “Then I saw the neurologist and he informed me I had MS...which was a bit of a shock”.}\
\text{“Had that been in your mind at all?”}\
\text{P11. “No”.}\
\text{“Right. What had you been thinking?”}\
\text{P11. “Well I thought it was some kind of a tumour”.}\
\text{“Were you prepared for that?”}\
\text{P11. “No”.}\
\text{“How did you feel?”}\
\text{P11. “I came home and screamed for about two days”.}\
\]
In the second cohort one interviewee (P.6.2) said on learning her diagnosis, “fear” provoked “the screaming habdabs” whereas another interviewee (P.8.2) was “angry” and “screamed for three days”.

A third interviewee (P.5.2) said that on being told he had MS brought the realisation that: “It wasn’t just one person’s life that was being destroyed here, it was both of us, my wife and me”.

A fifth (P.9.2) described herself as “devastated” while a fourth interviewee (P.7.2) described “shock as the worst thing”. Yet a sixth interviewee (P.10.2) reacted by “shaking and crying” and a seventh (P.12.2) reported that being told he had MS was “mind-blowing”.

A further three patients described feeling “frightened” and/or “fear” on being told they had MS.

b) Suspicious
Despite reporting the period of diagnosis as being a very emotional time, surprisingly half the sample also talked about feeling suspicious that they might have MS prior to having it confirmed by the neurologist. For some, this tended to alleviate the shock.

P4. “Well I went to the doctor and told her I’d got it. And she kept telling me that I hadn’t.”.
“Was this your GP?”
P4.”Yes. And so I then said will you please send me to the neurologist”
“What made you so sure… it’s interesting, what made you so sure you had it?”
P4. “With all the symptoms that I had and I’d read about it and I knew about it. I’m not a hypochondriac and I think after three years of experiencing peculiar things, I thought I’m going to see her, please send me to a neurologist because I’ve either got MS or I’ve got ME and she said ‘no no no’. I went to see a neurologist and after the MRI scan and the
eye test he read out her letter which said ‘please convince this lady she does not have MS’ and he said ‘I can’t because you have!’ So that was my diagnosis”.

In the second cohort, P.9.2 had read an article about MS but only then did she suspect she might have it herself. P.6 said “It (the diagnosis) seemed to evolve after lots of tests, having suspected I had it (MS) for some time”. P.7.2 reported that although she herself did not suspect she had MS, her GP “knew what it was” when he decided to refer her to the neurologist. The husband of P3 “guessed” his wife had MS following a series of tests but before receiving the official diagnosis from the neurologist who came to her GP’s surgery to deliver the news in a “four way meeting”.

It was not uncommon during this time for patients to suspect they might have a terminal disease such as a brain tumour (6 patients), and so for some there was an initial sense of relief when eventually told of their diagnosis of MS. This was not so for one patient who was still “horrified” on learning she had MS.

To receive a confirmed diagnosis, irrespective of whether they suspected they might have a brain tumour or not was for one patient a relief “just to have a name put to it”. Another patient said that after two years of inconclusive investigations he needed a diagnosis and “felt happier” once having MS confirmed. It was only later the significance of the diagnosis “began to sink in”.

c) Abandonment/isolation

Feelings of abandonment and isolation were commonly reported to be experienced at the time of diagnosis. In common with findings from UK surveys (Robinson 1991) several patients reported the perception that they were expected to “go away and live with it” as best they could, as the following comments illustrate.
P4. “I really did feel that is it, that’s your problem, get on and live the rest of your life the best you can. It’s going to get a lot worse but …that’s it”.

P5. “…on the other hand having had the diagnosis I wasn’t any further forward and that was it, and that was my involvement with the medical profession - Yes you’ve got MS, go away”.

The feeling of isolation emerged as a distinct concept, although in some cases connected to feelings of being actively abandoned by the health-care system. Isolation involved a state of “feeling and being alone” in trying to cope with the disease. Mostly this was related to lack of identifiable support and advice following diagnosis and not knowing anyone else with MS. In this respect, isolation was connected to the theme of MS Knowledge outlined later. Half of the interviewees in the first cohort expressed strong feelings of isolation:

P3. “When I was first diagnosed, there was no one there for me… no one at all”.
(diagnosed 1.5 years ago)

P5. “I didn’t know anybody with MS so I was in an absolute vacuum… … I realised that my GP didn’t know anything about it, and therefore I was going to have to treat myself. And I found that very, very… I’m upset now even thinking… when I think back to how I felt then. I was very upset, because I’m on my own. I do think I’m on my own here. I am going to have to manage this, and I don’t know anything about it properly and I don’t know who I can talk to. There’s nobody to talk to, is what I was thinking. Medically there’s nobody to talk to. I can’t talk to my GP, and unless I’ve got a real problem I can’t go and see the neurologist. There was this absolute void”.
(diagnosed 3 years ago)
P. 12 diagnosed twelve years previously felt initial relief at being given a diagnosis of MS, but on arriving back at his flat felt “dumped” as the neurologist had offered no further help.

Other interviewees in the second sample also described feelings of abandonment and/or isolation:

P.2.2 said: “I was very worried. I felt nobody cared (but you do feel like that don’t you?). They (the health professionals) have other people to look after. You are left on your own and you do feel like that” (diagnosed 9 years previously).

P.10.2, quoted above, who was given an information sheet by the neurologist and the impression that the interview was at an end, described how she had come on her own and “was just left to go home”. She recalled how she “was shaking and crying and in no state to drive home … I don’t know how I did it”. (diagnosed 1.5 years previously).

In some cases patients also reacted to the diagnosis by actively isolating themselves. For example in the first cohort:

P.4 said: “No just blanked it out, yes didn’t tell anyone for a year.”

“But what did you do? Did you make contact with any MS groups of people?”

P.6 “No. As you say, very alone and don’t know what to do. I just stayed at home all day, every day, I never… I didn’t do anything at all. I didn’t meet people, didn’t do anything, but I’m not like that now you see”.

P.5.2 in the second sample described a similar reaction:

“…The way he (the neurologist) told me was appalling. It was the most outrageous thing … I wanted nothing more to do with that consultant …
My wife and I came out of that meeting and we didn't see any one about it (MS) for seven years”
(diagnosed 15 years previously).

P.11 diagnosed seven years previously summed up the complexity of the patient's emotional reaction surrounding diagnosis when she said:

“You need someone there for you, because the person who tells you is never going to be the right one to help you, I don't think, because you immediately …. my reaction was …. He told me, it's his fault! I don't want to see him”.

In other words, it would be difficult for the professional (usually the neurologist or GP) to be the appropriate person to help the patient at the time of diagnosis because of the negative reactions they evoked as the bearers of bad news.

In summary, the process of discovering their diagnosis was an emotional time for most interviewees. The period required to reach a diagnosis of MS could be quite extended and uncertain, during which time they speculated and suspected, sometimes correctly, about what could be the problem. Feelings of abandonment and isolation and/or devastation and shock were common on learning their diagnosis, as was a range of other emotional responses. There was a sense that although the time of diagnosis was associated with great emotional upheaval, having an awareness that an MS Specialist Nurse was available had assisted newly diagnosed patients to manage these emotions.

The following section describes the issue of MS knowledge as another central theme for patients around the time of diagnosis.

iii) The importance of MS knowledge
Knowledge in one form or another was an important multidimensional topic raised by all interviewees. It was referred to as it applied to the patient themselves, their friends, family and relevant professionals.

a) Interviewee's own knowledge

Getting to know about MS itself and the potential sources of help available were frequently highlighted as problematic. This lack of knowledge, or lack of any pointers to information further contributed to feelings of abandonment, isolation and helplessness for patients. Their own initial ignorance and fear of the unknown was commonly expressed.

P5. “I needed time spending with me and I needed it explaining to me. What it meant, how you handled it, what there was available. I knew nothing! I had no … I didn’t know there was an MS Society…”

Time was important for newly diagnosed patients in two ways. First, they needed sufficient time with the professional to gain information and hence increase their knowledge about MS at the time of diagnosis. Second, timing was important for them in the sense they were only able to take in information when the timing was right for them. For some this was at the time of diagnosis; for others it was some time later when the diagnosis “began to sink in” and/or they had “questions to ask”.

As one patient in the second cohort pointed out: “I needed someone to talk to … about everything … day to day things … things not medical that you need to talk to a neurologist about. What you really need to know is about the hundreds of people walking about with it, that you wouldn’t know had it”. (P.4.2)

They also needed “to talk to someone to talk to about everything … day to day things not medical that you would talk to a neurologist about” (P.4.2). The local MS Society branch and the MS Therapy centre played an important role for five patients in this respect.
That the MS Specialist Nurse helped newly diagnosed patients to gain knowledge was in evidence by the fact that two interviewees in each cohort attended the “Getting to Grips” course on her advice where they found speaking to other people in the same situation a help. As reported above, the MS Specialist Nurse was described as being at the end of the telephone not only for the person with MS but also their partner to answer questions and by implication build up their knowledge.

Some described finding out about services (such as access to private neuro-physiotherapy and rehabilitation) by luck:

P2. “…so had I not been working with N (physio) I suppose… we wouldn’t know about them would we?”

(Wife). “It really is a very chancy, serendipity sort of world.”

Chance discovery of information was sometimes helped by a network of concerned friends.

P1. “It’s only because people at work perhaps were looking out for me. They were reading things and they would bring snippets of information and I was gathering information from books, friends, and over a period of time I probably learnt more… self help than anything else… than any other help I was given professionally.”

As this comment suggests, having knowledge and actively seeking information for oneself was seen as very important. Another interviewee (P.7.2), also described accessing information as a positive experience which in turn helped him to maintain his self-esteem by taking responsibility for himself.

Furthermore, the assistance of friends, work colleagues and family in gaining knowledge was a common theme. Patients described how family and friends
collected leaflets, partners went to libraries, two daughters who were doctors sought out specialist information for their mothers, a boss who had a brother in ARMS (the forerunner of MSRT) obtained “lots of information” while a mother whose son had recently been diagnosed, sent away for booklets.

b) MS Knowledge and professionals
Frustration with professionals’ levels of knowledge was frequently raised, as patients expected health care professionals to be their first source of help and guidance. Some GPs’ lack of knowledge was seen as a major source of frustration, often in relation to the range of support services and practical help available, although patients were also understanding of the difficulties GPs faced.

P5. “I wish GPs knew more about MS, I wish they had a clue. My GP, he’s perhaps got three people out of his case load with MS. Is he going to spend a lot of time honing up on MS? Or is he going to find out more about childbirth or you know what I mean, Alzheimer’s… yes, something that he’s got people coming in all the time.”

Interviewees in the second cohort reported a mixed experience of the GP’s level of knowledge. P.3.2 found her GP particularly helpful around diagnosis and she attributed this to his interest in MS. P.7.2 also found her GP helpful at this time. Other interviewees reported more negative experiences. One GP was said to be “learning as he went along” whereas another interviewee thought it was difficult for GPs because they were “non-specialists”. Another respondent (P.12.2) diagnosed 33 years ago, felt “the medical profession clammed up” and was appalled at the lack of medical knowledge at that time.

Only one newly diagnosed patient spoke of hospital nurses as a source of help. She described this as a mixed experience. During the diagnostic phase, and prior to a confirmed diagnosis, she was admitted to a ward for “older people” which she found inappropriate to her needs. This was because she was much younger
than the other patients, there was no-one else with MS and the nurses were both very busy and “loath to give me information”. She was helped by the ward sister “ who did spend a little time with me and it was just nice to talk to somebody”.

Some Occupational Therapists, Physiotherapists and Community Nurses were seen to be quite knowledgeable, often providing key information if patients happened to come in contact with them. As previously shown, this could be a chance occurrence which had a positive impact on the patient's progress as the following comment illustrates.

P2. “The next identifiable breakthrough came with arranging some physiotherapy treatment at hospital. Because there, very fortunately… (we) made contact with a senior physiotherapist who really did move things through for us, didn’t she?”

In summary, despite the clear importance of information, most patients did not experience finding out the diagnosis, then gaining knowledge about the disease and sources of support as a natural, planned progression.

iv) Discussion of the Patients' experience at diagnosis
Possible explanations for these findings are outlined and related to other literature.

A diagnosis of Multiple Sclerosis clearly presents many challenges, both for the individual, their family and for the professionals who have the difficult task of explaining what this means. This is a particularly emotive time, and one where the potential for difficulty in communications between patients and professionals is very high. How imparting a diagnosis of MS is handled may have serious consequences for how effectively people are able to face future challenges posed by the disease (Thompson, 1994)
For most people with MS the role of the neurologist is potentially very important in their lives. Not only are they the professional with the knowledge to make differential diagnoses of MS, they also represent the main access point to continuing specialist medical care and advice throughout the course of the disease (Hatch, 1997). The process of arriving at a diagnosis of MS may take a considerable time, as investigations are completed and alternative diagnoses are rejected. The patient may see the neurologist several times during this period and begin to become dependent on him/her in their joint concern of finding out the nature of the disease.

Differing patient and neurologist expectations of the situation following the confirmation of MS could help to explain some of these commonly described feelings of abandonment and isolation. In practice, it is the patients' actual perceptions of how they were given their diagnosis, rather than factual accounts which leave lasting impressions and can influence the way they approach the future, and their relationships with the Healthcare team (Robinson, 1990). Understanding these perceptions may give clues to improving the way this difficult stage of the disease is managed.

Robinson outlines differing perspectives in relation to accounts of health status e.g. those of self, social perspectives and biomedical views (Robinson, 1990). At certain points in time, there may be agreement (congruence) or differences (lack of congruence) between the perspectives of patients and professionals. Robinson states that congruence may be particularly likely around the time of diagnosis, but significant differences may occur following this.

One explanation is that points in time occur where patient and neurologist may have similar and different perspectives, in an attempt to account for these strong feelings of abandonment and isolation. The patient and neurologist come to the initial consultation with similar questions in mind (i.e. What is wrong?) and with shared perceptions of the purpose of the interaction. The consultation
progresses through examination and in most cases a series of diagnostic tests, before a confirmed diagnosis of MS is reached.

At this point the differences in perspectives and aims between patient and neurologist become apparent. The neurologist has achieved the aim of finding out the diagnosis, and unless further medical treatment is required, feels justified in ending this series of consultations. The occasion brings closure and provides reasonably clear direction for subsequent decisions and actions from the doctor's perspective (Cohen, 1993). However, the patient’s main concern becomes how to live with this condition. For her/him, the process is just beginning, but the relationship with the neurologist now appears to have been withdrawn.

In emotive situations, what the patient hears may not necessarily be what is said, as unwanted information can be filtered out (Mills and Sullivan, 1999). On this basis, emotional reactions can appear out of proportion to the actual content of the consultation. At the point when diagnosis has been confirmed, most neurologists undoubtedly give some explanations about the disease itself, but patients' perceptions of how they “were told” and their reactions to what they hear have often, as in this study, been recalled as profoundly negative and devoid of helpful advice (Multiple Sclerosis Society, 1997; Robinson and Hunter, 1998).

This is well summarised by Cohen:

“(Diagnosis)... does not provide any sense of closure nor suggest how they should proceed. Their uncertainty, which until the time of diagnosis had been uni-dimensional, quickly becomes multi-dimensional and spreads to every aspect of family life, raising countless unanswerable questions and fears.” (Cohen, 1993 p.83-84)
The central need for, but in many cases lack of relevant information at this stage was highlighted by most of the interviewees. The importance of patient information is well recognised in all areas of Healthcare provision. Numerous studies in the field of oncology have identified the value patients place on information following diagnosis. These include: gaining control, reducing anxiety, creating realistic expectations, promoting self-care and participation and generating feelings of safety and security (Mills and Sullivan, 1999). These would appear to be similar to the needs of people contemplating life with an incurable, unpredictable, potentially disabling disease and the study reported here provides some verification of these needs in MS.

Service providers have been advised to make good quality information available so that patients can “look after themselves better and know when and how to seek help, so that they can play an active role in decisions about their care” (NHS Executive, 1997). However, patients' apparent expectation that neurologists would answer their questions about how to live with the disease may be misguided. Studies suggest that patients with MS often choose to consult doctors about non-medical as well as medical issues (Baker, 1997). In conjunction with findings that some medical professionals report frustration when presented with multiple patient-problems, further potential for unsatisfactory patient-physician communication concerning life with MS can be encountered (Levinson, Stiles, Inui, and Engle 1993). These differences in perspective and expectation between physician and patient may contribute to feelings of abandonment, isolation and frustration around the time of diagnosis if patients are not made aware of alternative support systems, such as MS Specialist Nurses who can help fulfil this variety of medical and non-medical needs.

The availability of an MS Specialist Nurse has implications for practice and service development. Ideally if ongoing support is available, perhaps in the form of an MS Specialist Nurse, this can be made clear at the time of diagnosis so that patients know where to go for help when they feel ready. Even without local MS
Specialist Nurse provision, sources of help and information do exist via local and national voluntary groups. However, the important point is that the neurologist imparting the diagnosis needs to appreciate that this is a period of transition from one phase of the disease to another, and that this needs to be actively managed. He/she needs to make it clear to the patient that, although the neurologist played a central role in diagnosing MS, the expertise of others will be needed to help address many of the questions arising following this.

As Figures 1 and 2 demonstrate the GP was frequently identified both at diagnosis and subsequently as one of the main professionals from whom patients sought help. However, given the variable knowledge of MS displayed by many GPs, recommendation of the GP as the sole source of ongoing support is likely to be limited.

In conclusion the findings on managing diagnosis, reflected those of other UK studies in demonstrating dissatisfaction with provision of care at this time. For many people, intense feelings of abandonment and isolation or devastation and shock, were generated at diagnosis, and stayed with the person for many months or years. Differing expectations following confirmation of diagnosis could contribute to these findings. It is suggested that imparting a diagnosis of MS should be seen as the start of a transition. This transition needs to be made explicit to the patient and closely linked to the provision of sources of information, advice and ongoing support as people learn to live with and manage the disease.

6.2.1.5.2 Subsequent experiences and sources of help at different phases of the illness trajectory

It was observed by one stakeholder at a meeting of the Steering Group that because stories around diagnosis are powerful and important, they may overshadow the equally needy but perhaps less dramatic issues surrounding chronic illness. Interview findings therefore were analysed to consider the ways in which people with MS managed their ongoing trajectory. Just as the process
of diagnosis could be protracted and uncertain, so was the progress of the
disease as the patients in this sample demonstrate. Tables 3 and 4 show that
four patients had been diagnosed with MS for twenty years and over. All of
them were classified as moderately or severely disabled. There were also two
patients who were classified as severely disabled who had been diagnosed more
recently at nine and 13 years respectively. Yet another person, diagnosed seven
years previously was still “minimally impaired”.

As the patients' stories unfolded it was striking that each person had a very
individual story to tell about the process of their illness, how it had developed
and progressed. A central message for many interviewees was that MS is a very
individual condition, affecting everyone very differently at different rates and in
different ways. Everyone responds in a very unique way. It was this diversity
and difference that patients felt the Health Service as an institution and
individual practitioners within it especially non-specialists, did not
comprehend. As one patient diagnosed seven years previously and
“moderately disabled” eloquently expressed:

“I think you should make it very clear that because you know one person
with MS doesn't mean the next person will have the same needs. This is
quite different with everyone. I think if the professionals know that
would be a good thing.”

The following accounts demonstrate the different experiences people in this
sample had of living with MS and the sources of professional and other support
they found helpful or otherwise. To a large extent this depended on their level of
disability and the type of help they required.

i) GPs
As Figure 2 demonstrates GPs and hospital doctors continued to be identified by
interviewees as sources of help or otherwise subsequent to their diagnosis.
Further analysis of the interview data revealed a variety of roles and quality of relationships.

The GPs received a mixed review and respondents described them in a number of ways. On the one hand, there were those GPs who were seen to have a particular interest in MS and/or a supportive approach to their patients’ individual needs. On the other, they were viewed as non-specialists who lacked sufficient MS knowledge to assist them. The following comments illustrate these extreme views:

One interviewee described his GP as “excellent”, to the extent that he had decided not to move house “in order to retain him”. At the other extreme there were patients who described their GPs as “non-specialists” who knew “absolutely nothing”.

Five patients were critical of their GPs for their lack of MS knowledge generally, and in two instances this was because they had been unable to advise them specifically on their medications prescribed by hospital consultants to control spasms.

P.3 explained how on first being diagnosed he went regularly to see his GP, but later stopped going because “his knowledge was not good enough to give me answers to my questions”.

GPs were viewed positively for referring their patients to a variety of services such as the physiotherapist, the MSTC and the neuro-rehabilitationist. For P.1, it was her GP who had assisted her to obtain an “orange (motobility) badge”. She explained how at first she had resisted his suggestion but that eventually he had helped her to accept it as her “entitlement”. By so doing she realized that having the badge made the “the difference between me staying in the house or going out and not having to walk very far” (in other words she was able to use her car and have access to designated parking zones).
Other ways the GPs helped were described as follows:

“I only have to phone and he will come. He really understands (MS)”; “I can't praise my GP (and the district nurses) enough. They keep me out of hospital”; “The GP advised me on fatigue and medication which helped”; “My doctor listens to me and that's terrific. He will give me his opinion and is very approachable … getting splints for my legs has been the most useful thing he has done” (P.8.2).

ii) Hospital doctors

As indicated in the discussion above, hospital doctors, particularly neurologists were expected to play a key role in the ongoing experience of learning to live with MS. Interviewees identified ways to ensure a smooth transition. P.4 said: “The initial diagnosis is everything… everything stems from there, continues from there”. In other words, the foundation on which the ongoing patient-doctor relationship was based, originated in that initial consultation. Continuity was also described as important by P.8 who had been told by the consultant that he needed to get to know the patient sufficiently to be able to “paint a little picture” of his likely prognosis. P.5 had felt cut off at diagnosis, and recommended an “automatic check-up” so that issues further down the disease trajectory could be discussed as they arose. Treatment with beta interferon was such an issue, which she had not had the opportunity to explore sufficiently.

One patient (P.9) who had been admitted to hospital with pneumonia and a bladder infection, who had almost died, not surprisingly described hospital doctors (the rehabilitation team) and particularly nurses in positive terms because he felt they had saved his life.

Referral to the neuro-rehabilitation consultant was found to be a positive source of help for two patients. Another patient with a continence problem was referred to an urologist. Other sources of help from hospital doctors included
prescribing steroids and medications to reduce muscle spasm and physiotherapy referral. In one extreme case a severely disabled patient had been hospitalized for three months for plastic surgery to treat a decubitus ulcer.

P.12 summed up the ideal doctor: “I want the doctor to be efficient and have something like a bedside manner and a (sort of) smile and be helpful and nice and kind and also to be able to come up with solutions.”

For one patient who had been diagnosed thirty-three years previously, hospital doctors who had been important in the early phases of diagnosis and management of the disease, were no longer seen to be a relevant source of help in terms of managing his current needs of living with severe disability.

iii) Hospital nurses

Only three interviewees identified hospital nurses as a source of positive (one) or negative help (two). The positive role played by hospital nurses in supporting P.9 during a very difficult episode when he was close to death has been described above. Other patients however, saw hospital nurses (one patient included district nurses in this group) in a less positive light because of their perceived lack of knowledge and understanding about MS in particular and disability in general. P. 5.2 described hospital staff as unable “to cope with people with disabilities”.

Another patient (P.9.2) who had been admitted with a fractured femur, found the nurses could not deal with MS specific problems (such as continence) alongside the acute crisis. She said: “Some people see the illness not the person. The nurses on the ward don't know much about MS. They don't understand the problems. Some are really unpleasant and one said ‘when are you going home?’ “

Despite these negative comments, P.5.2 noted that since the MS Specialist Nurse had been appointed she “has helped the hospital staff understand disability”.

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iv) Community nurses

Community nurses were mentioned as sources of help by four interviewees. Illustrative examples follow:

“I needed a commode and I went down to the health centre and the nurse was absolutely splendid” (Carer, P.2).

Another interviewee believed district nurses and her GP had positively contributed to keeping her “away from the hospital”. As previously mentioned, given the hospital staff’s difficulty in coping with disability, this was considered “just as well” (P.5.2).

Physiotherapists, were identified by most respondents as being particularly important in the later phases of MS who in conjunction with Occupational Therapists and the Social Services, supported independent living through home care, aids, adaptations and the promotion of mobility. Therapy was available from both the hospital and the MSTC.

v) Therapists

Physiotherapists contributed to well-being as reflected in the following comments: “I went away (following a therapy session) feeling better in myself” and “I’m walking not very far, but I’m walking”.

P.2 described referral to a senior specialist (neuro) physiotherapist as a “breakthrough”. When the therapist left the health service the patient decided to continue to pay for private treatment. She was particularly valued for her specialist neurological knowledge and arranged leg splints and a referral to the neuro-rehabilitation consultant (although meeting this physiotherapist was described above in terms of “serendipity” rather than systematically planned care.)
Finance was sometimes an issue, as in the case of P.3, who was unable to afford private physiotherapy once NHS treatment stopped after ten weeks.

Occupational therapists were described as “very helpful” and supported daily living activities by arranging equipment and adaptations for the home.

vi) Social Services
Occupational Therapists were often based in Social Service departments. These departments had an important role in supporting people with disability to conduct independent lives by providing home care and promoting mobility inside and outside the home.

Home care was required for three patients to assist with activities of daily living. One severely disabled person who lived alone was provided with “24/7” care organised by Social Services but provided by a private company. This arrangement was said to be “frustrating at times” because of the “very rude” and “abrupt” manner of the company which “even the carers” found difficult. Another interviewee paid for a home help from an agency to do washing, ironing and shopping and did not report such difficulties.

Interviewees also described adaptations and aids such as stair and bath rails, which had been provided. Outside the home, Social Services were responsible for arranging the “orange” disability disk to facilitate car parking and access.

During a “Getting to Grips with MS” course, however, P.5 described a member of the Social Services as “very barrier orientated” because she seemingly told people what they couldn’t do rather than what they could. He found this very frustrating and an initial obstacle to obtaining an “orange” badge.

Two other interviewees however, viewed the Social Services in a very positive light reporting they had provided “everything we needed”. Others reported delays in waiting for the adaptations to be completed.
vii) Transport

Carrying on the mobility theme, the availability of disabled friendly transportation (such as “Readibus”) and access to public buildings were also viewed positively as an essential source of help. The MS Therapy Centre was well received with regard to access, whereas hospital outpatient departments were not. One wheel chair user mentioned a recent visit to Barcelona where he had been able to access public transport much more easily than in his local area.

Getting the right design of wheelchair (e.g. light-weight; electrically powered) was also mentioned as important by three people.

Interviewees expressed a determination to drive a car as long as they could, in order to maintain their independence. Figure 2 shows, that for one patient MAVIS was seen as an important source of subsequent help. His car had been fitted with hand controls by the local motobility centre.

viii) The MS Therapy Centre and People with MS

Contact with other people with MS and the local therapy centre varied according to individuals. As described above, many people did not want to talk to anyone about their diagnosis or if they did they wanted reassurance like the respondent above that hundreds of people with MS were “walking about with it” and did not necessarily end up in wheelchairs. This was certainly why for some on first being diagnosed, or for people with minimum disability, they did not want to talk to people with MS who were moderately or severely disabled. Contact with people with MS tended to be seen by others as more relevant some time following diagnosis as they learnt to live with the condition.

P.1 said: “It's taken over a year to actually get to the MS Therapy Centre because I was frightened of seeing people in wheelchairs and I thought – ‘well, this could be me.’”
She found the counselling offered by the centre particularly helpful in this respect:

“We can talk about things I'm feeling uneasy about ... it means coming to terms with MS”.

P.2 found meeting other people with MS “who are really quite seriously ill ... difficult to cope with”.

The MSTC provided a range of facilities which people in this sample accessed according to their requirements. For some, counselling was clearly important, for others it was access to physiotherapy, oxygen therapy, dietary and treatment advice (both orthodox and complementary) which they valued, as well as discussing symptoms (such as fatigue, muscle spasms or urinary incontinence) and their management. For P.4, the centre offered: “Just all the support”.

It was also mentioned that a carers’ support group was being set up at the centre and that the MS Specialist Nurse had provided a link (to the centre) for some patients.

ix) Day Centres
Three respondents described day centres as positive sources of help. One person liked to go two or three times a week because the centre offered an opportunity to meet “nice people and nice things to do somewhere else (i.e. other than home)”. Another interviewee who was severely disabled was able to go weekly to a centre that was specifically designed and equipped to cater for his needs.

x) Family, Friends and Work colleagues
Family and friends, in particular spouses and partners were mentioned as the most valuable source of support at diagnosis and ongoing support and care. However, there were exceptions and two interviewees reported that having MS put a strain on their relationship. Partners could be a negative source of help,
however. One interviewee described her carer as “over caring” to the extent she believed she “became over-dependent on him”.

Many expressed concern for the lack of support and help for the carers of people with MS. They were often described as “blanking out” and refusing to discuss the implications of living with a close family member who had been diagnosed with MS. One man found it very difficult to discuss MS with his family and as described below, the MS Specialist Nurse was seen to have an important role in this respect.

The role that the spouse or partner played in terms of continued care and support in some cases over many years cannot be overestimated.

Work colleagues were described as supportive at the outset but interviewees gave examples of being put under organisational pressure to undergo a medical examination and face early retirement. (One respondent described how the MS Specialist Nurse had been an important source of help advising her to convert to part-time work rather than giving up all together). A number of respondents continued to work and found it to be very important for them to be able to maintain a job. One man found his company “totally supportive” throughout and he was encouraged to manage his workload to cope with fatigue and other symptoms. For one woman however, her suggestion to work more from home using the internet, was not received sympathetically and she found herself being requested to medically retire.

Previous experience of disability and chronic illness seemed to be a factor in developing understanding and support on the part of family, friends and colleagues. A number of families and work colleagues had had relatives or colleagues who had MS or other conditions such as polio or undergone a coronary by-pass. Having a family member who was a nurse or doctor was another factor which helped support people with MS.
xi) Information

Other considerations gleaned from the analysis of positive and negative experiences was that information played a positive role at all times both in terms of self-help and support from relatives, friends and work colleagues. Information was experienced negatively when it was seen to be difficult to access, described by one interviewee as “a brick wall”. P.1 reported that:

“People at work were looking out for me. They were reading things and they would bring snippets of information and I was gathering information from books, friends and over a period of time I probably learnt more ‘self-help’ than anything else professionally.”

A number of different sources of information were described, such as the MS Society, ARMS, local libraries, the Internet and Capital Radio Awareness week. Public awareness was described as very important given that the symptoms of MS could in one respondent's experience, be misinterpreted as “drunkenness”. For another, the “non-professional” organisations were described as important because they possessed “untapped expertise closer to the individual sufferers”.

Although the “Getting to Grips with MS” course was essentially designed to support people at diagnosis, two respondents described the information and contacts it provided as an important source of ongoing assistance.

The role of information overall gave people with MS a sense of independence in that as one interviewee reported: “It just makes you more aware of the facilities available without having to ask”. Furthermore, a theme associated with information as a vehicle for self-help was that of the person with MS, as a “fighter”.

xii) Other

Some expressed the hope that access to specialist care could be made easier for people with MS and that specialist medical care should be a right not a privilege.
For some there was the hope that beta interferon should be made more widely available. Others had not accepted the treatment even when it had been offered. One patient (P.1.1) who was receiving treatment, described the “Clinovia nurse, the one who supplies the injections”, as “wonderful. I can’t speak too highly of her, her approachability has been great ... she is definitely reliable ... she does what she says she will do”. A handful of interviewees were interested in the potential benefits of cannabis. The use of an antioxidant, “Revenol” to improve energy levels, was described by one respondent as a “miracle”. Acupuncture had been tried by another. Religion as a source of positive support was mentioned by two respondents. Another respondent found the intervention of the local clergy less than helpful.

No attempts to generalise from this small sample are made. However, the range and diversity of the interviewees’ experiences confirms the importance of professionals being able to appreciate the uniqueness of the MS trajectory and to respond sensitively to individual needs. The need for generalist education and training emerges as an imperative alongside the development of specialist roles. The concluding section of the patient interview findings therefore, is dedicated to an exploration of the MS Specialist Nurse role in supporting people living with MS and their carers.

xiii) The MS Specialist Nurse
The MS Specialist Nurse was reported to have been a continuous source of support and information since her appointment and particularly during the twelve months prior to the second set of interviews. The findings are presented according to the key areas covered in the interviews, in which the role played by the MS Specialist Nurse was investigated. These were: new diagnosis; hospital discharge; education of health and social care professionals; liaison and coordination of local services; identification of care needs and carer support, and were derived from the MS Specialist Nurse’s initial job plan on taking up post. The underlying question being addressed, was whether there were any
differences in perceptions detected in the two sets of interviewees, prior to and following the appointment of the MS Specialist Nurse.

*Did the appointment of an MS Specialist Nurse therefore make a difference?*

Indicators in the data regarding the usefulness of the MS Specialist Nurse service in both cohorts, were presented in Figures 1 and 2 above. Findings show the MS Specialist Nurse was seen as a source of help at diagnosis in both cohorts. The reporting of two negative incidents in the second cohort is indicative of the expansion and demands of her role. In Figure 2, identification of the MS Specialist Nurse as a positive source of help later in the illness trajectory is apparent in both cohorts, with an increase in the second cohort from four to seven. The reporting of negative experiences in both cohorts indicated that again it was related to patients feeling they were having to wait for what was clearly seen to be a valuable service.

The people who identified the MS Specialist Nurse as a source of help in the first cohort, had been diagnosed between one and six years previously. Two of them were moderately disabled. In the second cohort, of the seven people who had identified the MS Specialist Nurse as a source of help, four had been diagnosed relatively recently (between one and two years). In addition three people who identified her as a source of help, had been diagnosed seven, 12 and 15 years previously, and were classified as minimally impaired, moderately and severely disabled, respectively. Although these numbers are small, they demonstrate a trend indicative of the MS Specialist Nurse’s decision based on her experiences during her first year in post, to concentrate her attention on the newly diagnosed and those with moderate/severe disability usually but not always apparent, later in the illness trajectory.

For those who had had contact with her, the MS Specialist Nurse was described as the “lynchpin” and a link with other professionals, including neurologists. Other examples of her positive input included help with arranging aids and
appliances, such as a wheelchair and leg splints. She was also described as “my lifeline.”

The importance of telephone work was identified as one of the ways patients and others were able to keep in touch. It took the form of helping to sort out problems with other professionals or services e.g. P. 5 said the MS Specialist Nurse, “created miracles in 15 minutes of phone calls that would have taken (me) ages”. Others in the second cohort made comments such as: “It's in the back of my mind, I know I can phone her,” or “I phone her when I need her”. Other interviewees said “The MS Specialist Nurse is at the end of the phone if I have questions” while another reported that when she phoned with a particular problem (constipation), she received helpful advice.

The MS Specialist Nurse’s knowledge was clearly seen to enable her to liaise and coordinate people and services. The ever expanding remit and demands made on the MS Specialist Nurse, are typified by one interviewee who described the task before her as “huge”, while another described her role as “a bit of a fistful”. It was suggested therefore, that in order to contain her role and concentrate her nursing skills she needed to work with an administrator and social worker to “help with the intricacies of care and support”. Another interviewee was also concerned for the “nurse's load” and recommended she needed to work with a team. Another patient suggested that given the large patient catchment area served by the MS Specialist Nurse, two more nurses were required to reduce the amount of travelling currently required and prevent the role from becoming a “driving job”.

Selected examples of how she helped in the specific areas covered in the interviews are presented below.

a) Newly diagnosed

The importance of the MS Specialist Nurse at diagnosis has already been explored above (see Section 6.2.1.5.1 (i), (iii, a). It was at this time, the MS
Specialist Nurse was described “as being there” for the patient and carer in stark contrast to those patients who had been diagnosed prior to her appointment and therefore without the benefit of her support. One such patient, who had been diagnosed only three years previously, described how the specialist nurse was now “there as that link. I had nothing, no one and nothing”.

When asked how the MS Specialist Nurse might help at the time of diagnosis, a patient (P.11) who had been diagnosed seven years previously said:

“By reassuring the person that their life will go on. That this is a damn nuisance but really is nothing more. That your management is yourself. That you have to take your own reins I think. That is to me a useful thing she could do”.

In two instances (already reported) respondents wanted to be able to access the MS Specialist Nurse on the day of diagnosis, rather than having to wait for one and seven weeks respectively. The reason for the seven week delay was because the MS Specialist Nurse was on holiday i.e. she was operating on her own and there were no deputies. The clear implications here are that the role will expand as people get to know of her availability.

Interviewees described how she had provided useful leaflets at the time of diagnosis and “pointed us in the right direction”. She was also described by one interviewee in each cohort as having been more helpful to their partners, rather than themselves at this time.

b) Hospital discharge

The direct responses to this question were sparse. Respondents agreed in principle that the MS Specialist Nurse should provide continuity and co-ordination of services following hospital discharge. There were many examples where the MS Specialist Nurse was reported to have acted as a liaison and a link to other people and services, including contact on a number of occasions with
ward nurses. (See also section d) on co-ordination/liaison). One interviewee perceived that because “a lot of the wellbeing of MS patients is down to social services” hospital discharge could be effectively managed by the MS Specialist Nurse, which he described as “running round the triangle” in a three way process “between patient, hospital and social services”.

c) Education of health and social care professionals

There was reported to be a real need for education and training in the care of people with disabilities in general and MS in particular. The educative role of the MS Specialist Nurse in relation to other non-specialist practitioners, was seen to be important. The wife of one patient who was a district nurse was able to look at the role of the MS Specialist Nurse from the perspective of the professional. She herself had attended a course organised by the MS Specialist Nurse because she recognised the need for such programmes which were being offered to auxiliaries and care assistants as frontline carers, not only for herself as a district nurse but also for Social Service care managers.

One interviewee suggested the MS Specialist Nurse, could provide education for GPs and other professionals in order to prepare them for the wide variation in the disease. The MS Specialist Nurse was the recognised expert and as such could help the generalists by passing her knowledge on.

The role of the MS Specialist Nurse in advising the ward nurses has already been described. One patient who had been admitted with a fractured femur recalled that the MS Specialist Nurse had come to the ward to speak to them. It was also reported above that she had begun to positively influence the ward staff’s attitude towards disability.

For one severely disabled patient, home carers were said to have an “umbrella” view of MS which regarded it as “the worst thing... a very bad illness”. It was
thought that the MS Specialist Nurse had a very important role to educate them to “let them know the good and bad of what can happen with MS”.

The importance of manual handling training for home carers was highlighted by the carer of a severely disabled man who was said to have been “dropped” on one occasion by home carers due to inexperience in lifting techniques.

d) Liaison and coordination of local services
As already described, the MS Specialist Nurse service was seen as ideally placed to support and co-ordinate care for people with MS and one of her main functions was thought to be liaison and coordination. She was described as “Mrs. Fixit”, and particularly good at pointing out the “right people” who patients and their carers should contact.

Her perceived role in coordinating hospital discharge, has already been described as a three way process of “running round the triangle” of patient, hospital and social services. Another patient said: “The MS Specialist Nurse pulls the strings together … so that Social Services perform their bits at the right time”.

Reference to her role as a link person has also been made between the patient and a variety of services: physiotherapy, the MS Therapy Centre, the neurologist and GPs.

P.1 recalled how she had performed this role for her: “I mean the NHS can’t provide unless you are really ill with it. The MS Specialist Nurse is always around … she came in to see me at my physio sessions. She's that link”.

She was also described as acting “as link for patients with MS in hospital for other things” by providing advice on symptom management (see section e) below)
One patient summed up the MS Specialist Nurse coordination role as “pulling lots of groups together”.

e) Identification of care needs and carer support
The MS Specialist Nurse was important to patients during hospitalisation and was said to advise ward nurses on MS specific problems such as fatigue, spasticity, incontinence, constipation and decubitus ulcers. She also gave this advice directly to patients. Other examples of her positive input for patients in the later MS phases included help with arranging aids and appliances, such as a wheelchair and leg splints. P.2 said “she's helping me to be ready to judge when, if ever, the right time comes for a wheelchair”. P.5 suggested she was like “a signpost” in that she was able to help patients, “because what we don't always know is what to do”. Her nursing knowledge was reported to be essential “to push you in the right direction. She's a real filter (P.2)”.

Comments such as these show that the MS Specialist Nurse was valued for her expert advice in the sense that she “is actually trained to know what to expect” and what to do at different phases of the MS trajectory.

This knowledge meant that she was asked to act as an intermediary and advisor to both patients “as a friend to help understanding”, their partners and family and other professionals.

For P.2 she was helpful at different points in terms of being able to advise on the need for specialist treatments such as physiotherapy and rehabilitation. For P.8, she was also able to provide information in a systematic way as to the services available and how to access them, such as “benefit entitlements”. P.3 recalled: “It's helpful to have someone else to talk to, other than the family who knows what's going on”.

The MS Specialist Nurse was said to have acted as an intermediary between hospital consultants and GPs in cases where patients were confused about
taking their medications and GP knowledge was reported to be lacking. One patient said, “It is difficult to ask the doctor when you are feeling low. It is easier to ask the MS Specialist Nurse”.

Her role in carer (partners and family) support was frequently mentioned not only at the time around diagnosis as reported above, but in the subsequent period learning to live with the disease:

P.1 “The MS Specialist Nurse is very kind - she came up to see the family and talked to them … she gave them the opportunity to ask all sorts of questions”.

The family were reported as finding it hard to cope and reluctant to ask questions because they did not want to hear the answers. This was why the ongoing support of the MS Specialist Nurse was seen as essential to “keep an eye on the carers and their level of stress”.

P.6.2 explained how and why the carers needed “someone like the MS Specialist Nurse around to answer questions. They need some way of relieving the stress of full time care.”

The carer of P.2 described how the MS Specialist Nurse was able to “act for relatives” (in the sense of an advocate) to prevent them being seen as a “troublemaker”.

Several patients in both cohorts, said she was able to educate carers about the specific needs of living with MS “like fatigue … that you need to rest and don't fight it” (P.7.2).

P.8.2 summed up the MS Specialist Nurse's contribution to both carer and patient welfare when she described her as helping the carers to manage “their frustrations and feelings of helplessness. She can teach them … because (they)
can't possibly understand without it being explained to them, what it is like to have MS”.

That there was a psychological dimension to her expertise is clearly indicated in these and other comments. One patient diagnosed 12 years previously and “moderately disabled” described a period of hospitalisation as a difficult time because ward nurses did not understand that people with MS might behave “erratically”. He described living with MS as “constantly fighting a battle as well as conducting life”. In comparison to the ward nurses he saw the MS Specialist Nurse as “actually trained to know what to expect” and “to see funny things going on and to do something about it”. MS has already been reported as making one patient “feel low” and another described how “anxiety sets in very much with MS”.

The essential components of the MS Specialist Nurse role and the way in which she made a difference to patients, carers and professionals, have been distilled from the patient interview findings and are summarised below:

- Effective workload management to increase access and availability,
- Liaison and coordination with other professionals and services,
- Knowledge about MS to enable her to give both direct care and specialist advice in relation to:
  - support around the time of diagnosis and at the later phases of MS
    - symptom management
    - medications and other treatments
    - decision-making
    - education and advice
  - psychological dimensions
    - familiar with the psychological effects of MS on individuals
    - understands what the patient is going through
    - acts as independent intermediary and adviser for the patient
    - supports the partner and family
These findings confirm the importance of the MS Specialist Nurse as the key advisor, educator and facilitator on up-to-date knowledge and practice about MS in primary, social and hospital care. She was highly valued for the holistic support she gave to patients, partners and families in managing chronic illness and as an advocate and coordinator of services.

xiv) Discussion
The approach adopted by the MS Specialist Nurse to operationalising her role, appeared to relate to the components of specialist nursing practice outlined by Humphris (1994b). These included, acting as facilitator of learning, provider of care, nursing care consultant, collaborator and promoter of quality care. The importance of research and evidence based practice and enquiry as a component of specialist nursing practice, was not explicitly alluded to by patients in this sample and may represent more of a professional perspective. There was an expectation for the MS Specialist Nurse to have up to date, in depth knowledge, although research was not specifically mentioned.

Furthermore, the findings concur with literature concerning the crucial support role of the MS Specialist Nurse at the time of diagnosis (Mills and Sullivan 1999, p.76, British Soc. Of Rehabilitation Medicine 1993, p.20 and p.48). Introduction to potential support at this time represents an ideal opportunity not only to provide immediate support but to register as an ongoing contact for the future.

The role of the MS Specialist Nurse in relation to medication was also apparent in the findings. Although examples other than beta interferon therapy were discussed, the role of the MS Specialist Nurse in supporting patients' individual treatment regimes were along the lines described by Meyer et al (1998) and Mohr et al (1999) in relation to beta interferon. The authors of these studies suggest that nurses played an essential role in establishing and successfully maintaining patients on medication by working in a partnership with individuals. Furthermore, nurses were more likely to respond to patients'
concerns, expectations and emotional status than medical colleagues, with the result that adherence to these therapies appeared to improve.

The input of the MS Specialist Nurse in assisting patients to find their way through the bureaucracy of the Social Services and other systems have been highlighted in a number of surveys (DH 1998b, Freeman and Thompson 1997a). The MS Specialist Nurse provided help and support as a key coordinator of such services in relation to patients' and their carers' social needs in this case study.

Another important area highlighted was the need for the MS Specialist Nurse to contribute to interdisciplinary team work to promote a more holistic, patient approach (Winters et al). Patient accounts describing her as their “lynchpin”, “lifeline” or “link” suggest she was moving the service towards this unifying goal. As in Kirker and Young’s study (1995), the MS Specialist Nurse had a role as an intermediary on patients' behalf in increasing GP’s knowledge and understanding of MS (Multiple Scler. Soc, 1997, Kirker and Young 1995).

In this study, the MS Specialist Nurse also acted as an advocate and knowledgeable link worker helping patients and their partners to negotiate a complex medical and social care system as well as bridging the gap between primary and secondary care. The importance of MS Specialist Nurses in these roles in addressing the specific needs of this patient group, have been found by authors such as Sylph, 1996, Thompson et al 1997, and Freeman et al 1999.

The role of information in managing the ongoing MS disease trajectory was apparent in this case study. Mills and Sullivan (1999) highlight six far-reaching functions of information in health, most of which are apparent in these findings. These include: gaining control (the acquisition of information was described as an important step in taking responsibility for oneself); reducing anxiety (identified as a particular emotion associated with living with the unpredictability of MS); increasing compliance (inferred from the data as discussed above); creating realistic expectations (the MS Specialist Nurse was
said to act as a “signpost” for the disease); promoting self-care and participation (“Management is yourself, you've got to take the reins”) and feelings of safety and security. The concept of empowerment has been described by Gibson (1991) as recognising people’s ability to meet their own needs and promoting and enhancing this facility. People need to learn how to mobilise the resources to take control of their lives and patients in this study referred to the MS Specialist Nurse as supporting and assisting this process.

The role of the MS Specialist Nurse in supporting carers was a prominent theme. Her approach as an objective person who stood outside the family and offered practical and emotional advice was highly valued. These findings were apparent in the literature supported by authors such as Freeman et al (1997), Mohr (1999) and Sylph (1996). Living with MS and its impact on family relationships cannot be underestimated. In terms of “being there” for the patient, it was likely than the MS Specialist Nurse contributed to an overall sense of empowerment which was described as a key nursing contribution in assisting patients in learning to live with chronic illness by Miller (1993).

In conclusion these findings confirmed those of the stakeholders (see section 6.2.2 below) who said that the employment of an MS Specialist Nurse increased the emphasis on holistic care and chronic disease management. She was also identified as the key facilitator on up-to-date knowledge and practice about MS in primary, social and hospital care and her formal educational role was highly valued. She was described as a good half way house between people with MS, their carers, the professionals and other services.
6.2.2 Stakeholder interviews

6.2.2.1 Sample selection and recruitment

Nine semi-structured interviews were conducted with a general practitioner (GP), Therapists (including one neuro-physiotherapist and one Social Services occupational therapist), a district nurse, a Public Health Consultant, one community care service manager (Priority Care), one senior Social Services worker/manager and two partners of MS patients who acted as informal carers. Sampling was opportunistic and purposive and involved some Steering Group members and other stakeholders, contacted on their recommendation.

The semi-structured interview schedule was used for all respondents (Appendix 9). The questions covered similar areas to those addressed in the patient interviews but with the emphasis on finding out about their work with people with MS and actual and potential benefits of working with the MS Specialist Nurse Service, especially in relation to diagnosis and managing hospital discharge. The researchers rang to arrange the interviews, which were then conducted in the stakeholders' work place or home.

The interviews took place over the first eighteen months in which the MS Specialist Nurse had been in post. Six of the nine respondents had had personal contact with her during that period, two had had no contact and were unaware of her existence and the remaining respondent was unlikely to come in contact with her on a day to day basis because of the nature of his role. Approaching a broad range of stakeholders helped to elicit a mixture of salient and practicable views.

On the suggestion of one of the Steering Group members, the research team attended a Primary Care Group (PCG) Clinical Forum (involving 22 participants). The Forum provided the opportunity to consult a group of “stakeholders” which included nine GPs, eight district nurses, one pharmacist
and one medical student. The discussion preceded a presentation by the consultants in neurology and neuro-rehabilitation and the MS Specialist Nurse.

Prompt questions related to the management of people with MS and their perceptions of need in terms of their own support and those of patients in the community setting. Their views were noted and typed up following the session.

6.2.2.2 Analysis

Face to face interviews were recorded and transcribed verbatim. During the clinical forum, detailed notes were taken and then typed up. The subsequent data were then analysed using Miles and Huberman's (1994) framework of data reduction, data display and conclusion drawing/verification and Field and Morse's (1985) notion of manifest and latent themes.

6.2.2.3 Findings

Stakeholders' views focused on patterns of care with MS patients and addressed many issues, for example: quality of contact between organisations; communication and liaison between professions; economic and financial difficulties; psychological problems of working with the chronically ill; appropriate supervision and support of professionals; and the ways in which MS Specialist Nurses augmented care and the delivery of health and social services.

The themes and issues included below were mentioned frequently by respondents and are salient to MS patients, their families and informal carers, health and social service professionals. They are illustrated by a selection of pertinent statements on the MS Specialist Nurse service, the quality of life of MS patients, barriers to effective service delivery, and ways of moving the role of MS Specialist Nurses forward in the future.

Themes and the associated issues are presented under three main areas of interest:
1. Structural and economic issues in service provision
2. Social, medical and psychological care of people with MS
3. Bridging the gap with communication and liaison

A summary of the specialist role of the MS Specialist Nurse from the stakeholders' perspective is then given, followed by their service recommendations.

6.2.2.3.1 Structural and economic issues in service provision

i) Stakeholders’ responses to transitions in the structure of local health and social services

Freeman and Thompson (1997) point to the impact of such changes, which can lead to difficulties for patients and their relatives in accessing social services. MS Specialist Nurses are attempting to help people with MS and their carers to deal with the bureaucracy of social care agencies.

Several of the respondents mentioned that there had been a number of transitions and reorganisation of local services. There was some ambivalence to rapid organisational change. Restructuring had a knock-on effect, in so far as stakeholders felt that change was sometimes unclear, not for the better, was inconsistent and unplanned, and put the burden of care onto them rather than being supported by the organisation. According to the public health consultant:

“Approximately sixty percent of Health Authority staff have changed in the last six months following ‘turbulence’ and reorganisations, so consequently there are few people around who can give any historical perspective on events and policies in the area. Although there was a reorganisation six months ago, and it was hoped that there could now be minimal change, another reorganisation is planned. This relates to the need to provide the Primary Care Groups (PCGs) with more
administrative resources and so approximately thirty people from AHA will be allocated to work with PCGs- five each. However, this is likely to destabilise headquarters, as many of these people knew the system and were working well.”

Respondents said that structures and roles in the local trusts were in transition. Well functioning teams had been broken down and reorganised. This sometimes led to feelings of insecurity of providing continuous quality support and instability in techniques of managing MS patient care.

The reportedly large number of MS sufferers requiring palliative care in the areas surveyed, and the expanding need for carers, meant that organisational structures had undergone rapid change and roles had expanded in their scope. The Community Care manager said:

“"I started off as a service support nurse and used to support carers out there about ninety five percent of the time. But now it’s getting so big that the role has had to change. The district nurses’ jobs have changed as well over time. They get to do less hands-on care and they ask Priority Care to do more and more medical tasks. We’re trying to get the district nurses to write protocols for some of the things, but the carers do need some support out there.”""

This observation was confirmed by the district nurse who said:

“"In the past, nurses had the key function; the district nurse was the first port of call. Now the Social Services have taken over that role.”"

There was ambivalence among stakeholders to rapid transitions in organisational structures and changes in professional role.
In terms of MS, though, changes in service provision were seen positively, especially in terms of structuring more consistent and specialist service provision. There was seen to be a move from general to more specialised nursing and other services. According to a physiotherapist:

“When I walked into this in 1992 it was a hotch-potch. In 1984 a group of them had started an exercise group for MS patients who were motivated and wanted to get out and do something instead of just sitting back and waiting for a cure. They were all physiotherapy classes and some dietetics advice. Then they bought a port-a-cabin and set up hyperbaric oxygen- again it was whoever wanted to go, there were no priorities. It fluctuated over the year. When I arrived in 1992 they had a shortage of physiotherapists and a lot of people hadn’t had a physiotherapist for ages. When we moved here we made the biggest changes. As a physiotherapy group, we decided we weren’t giving enough physiotherapy to the eighty percent not in wheel chairs. The ten percent of the worst (affected cases of MS) were getting the most (physiotherapy) and probably had least benefit, in my opinion. We have different classes every day now.”

Introduction of PCGs were a particularly important structural change. PCGs were mentioned frequently with regard to specialist MS Specialist Nurses and other health and social services. The recent formation of PCGs and their relation to specialist MS nursing will be looked at in due course.

The introduction of MS Specialist Nurses was among several changes to local service structures. All stakeholders said that the introduction of MS Specialist Nurses was vital and a welcome change in the nursing role. All stakeholders advised that the MS Specialist Nurse was central in managing all aspects of care in the lives of MS sufferers.
ii) **Financial and economic constraints on services and clients**

Several respondents mentioned that the NHS was under great economic pressure. The majority of stakeholders touched upon the need for financial investment in the specialist MS nursing and related services.

Several respondents said there had been expansion and growth in MS nursing without appropriate financial backing and clear management. Services were economically constrained and further burdened by change and expansion. According to the Community Care manager:

“`The funding issue is a big problem. It’s not well sorted out at all. Things have just grown but nobody really wants to take responsibility for it all.”`

There were limitations on resources and budgets in health and social services. The occupational therapist said:

“It’s a budgetary thing in a way. You know, you do have to limit your resources. I did have a young woman not very long ago who wanted a fire taken out. She was in a bungalow. There were a lot of housing issues and she’d already fallen foul of the Housing Department. She wanted help with this, that and the other but when I went and actually spoke to her, she really didn’t meet our criteria… She could drive, she could walk. She was a bit tottery but she wanted someone to come and do her housework and she wanted the bath taken out and lots of things. I really didn’t feel I could justifiably say: ‘Yes, we’ll do all these things’, just because she had MS. Otherwise, why don’t we do it for early Parkinson’s or early everybody? We do have our criteria of need. It’s all financially assessed and at that time her husband was in work. She could drive. Their income was quite good. She was very knowledgeable. She was very intelligent. Somebody that knew their way around… In a way, there isn’t any arbitration to be had because, you know, you have to fill in a financial assessment form and if the answer is ‘yes’ then you’re assessed
to pay. There’s no arbitration, really. I would imagine that the MS Specialist Nurses sort of role would be quite good in that. Talking about the real impact on life. To work with those with MS.”

Close investigation of the above extract reveals at least four interrelated issues that should be tied together.

First, the respondent says that there are limitations to resources and spending arrangements. There are tight and needs based budgeting arrangements. “Money”, according to another respondent cited below, “is important”. Budgeting affects the quality of life of MS sufferers and is said to have a “real impact”.

Second, MS and other conditions such as Parkinson’s Disease are known to be progressive (a project to develop community based Parkinson's Disease Nurses and their impact on patients' quality of life are described by Hurwitz et al 1999). Those in the early stages of MS are not seen to be a priority for financial support unless they satisfy other more general needs based criteria, such as low income, difficult mobility or poor housing conditions, etc.

This would tend to indicate that funding is given to MS sufferers when they are more disabled by the illness. Funding is therefore an economic palliative, in so far as it is given when MS creates disablement. Money is given to help sustain support and care at home when MS is in its later stages. Funding is not given prior to disablement as a preventative measure or as an early intervention to increase the quality of life of MS sufferers. In one case touched upon by a stakeholder, late budgeting arrangements had a poor outcome. By the time the MS sufferer was allocated financial assistance, she/he had passed away.

Third, the above extract indicates that those willing and able to communicate their needs, and who are consequently perceived as assertive and intelligent, are most likely to come to the attention of services. MS sufferers who know their
way around the health and social care systems are more likely to be considered for financial assistance because they are able to articulate their financial and social care needs.

Fourth, this relates to the point that people with MS need help from a MS Specialist Nurse to help articulate their financial and social care needs, especially to those who hold funds. As the Social Services manager said:

“One of the issues facing people is the financial means testing… I’ve chipped away. I’ve had three way meetings on a number of occasions, just to get the realism back in, or to get home care. I had to actually bring in the home care organiser and the client to work through things in a very, very particular way. And that actually did resolve it in the end. Because one dreaded going in these situations because you felt, ‘well, I’m not going to get the point across here’.”

MS Specialist Nurses are said to act as advocates for MS sufferers in communicating their needs, including financial ones. They work with those with MS and explain possible financial and social care assistance. MS Specialist Nurses prioritise this assistance and help with purchasing appropriate care at appropriate times. The role of the patient advocate/link-worker is clearly most important, helping patients to deal with a fragmented and bureaucratic health service, as noted by the British Society of Rehabilitation Medicine (1993), Freeman et al (1999), Department of Health (1999b) and Thompson et al (1997a). Patients and their family members/informal carers have need for someone outside the family to listen to them and provide counsel in a non-judgemental manner.

Advocacy by MS Specialist Nurses was said to have multiple practical, emotional and psychological benefits for people with MS. An occupational therapist working in social services said:
“Let’s face it, we all have to make god knows how many ‘phone calls to get somewhere for anything. People get quite worried about it and I think that if they know they’ve got an advocate that’s actually there for them, I think that’s tremendous actually.”

Tait (1996) maintained that: “‘patient advocacy was more effective if the nurse had built up trust and credibility and had close relationships with the hospital teams”. A GP made a similar point but stressed the added vulnerability of patients caused by common feelings of guilt:

“I think it comes back to advocating. It means that someone has to sort of plead, as if you’re doing some sort of great favour. MS patients already feel guilty enough that they have to rely on people to do everything for them. They have to rely, usually, on their closest and dearest relation. They already feel incredibly guilty and then if people have to go sort of begging for extra help and pleading it makes it even worse. It comes back to advocating for people with MS.”

This calls for involvement of someone with official status, such as an MS Specialist Nurse, who also understands the needs of people with MS, if people are to receive their full entitlement of services.

MS Specialist Nurses are able to meet with people with MS and fundholders. This means that MS Specialist Nurses have a role in contextualising the arbitration of funds. They have a role that involves “talking about the real impact on life” and articulating needs in order “to get the point across” to support people with MS to convince fundholding stakeholders of their need.

This means that part of the MS Specialist Nurse’s work involves bridging the gap between users and stakeholders. Communication and liaison are substantive aspects of MS nursing that will be looked at in more detail in a later section.
iii) Primary care groups (PCGs) and liaison with primary care teams

In 1999/2000, Primary care groups (PCGs) were reported as a recent health and social care innovation at the local and national levels, with powerful roles in managing and beginning to commission services on behalf of patients in their locality.

GPs at a PCG clinical forum said that they felt uncomfortable with MS patient management. One GP described feeling out of his depth in the “alien” environment of a severely disabled MS patient’s home. The medical model of treating patients was said to be difficult and impracticable in long-term cases of MS. MS requires sustained, long-term and holistic care. The MS Specialist Nurse was reported to draw support systems and key services together. Patients were more likely to need practical help and social support which nurses were said to know more about. District nurses and other stakeholders thought that GPs did not recognise the full extent of problems for people with MS, as it was said to be nurses and Social Services who predominantly dealt with the main problems involved with the social care aspects of MS in the community.

The difficulties that GPs had with managing MS certainly have implications in currently developing PCGs and their relationship with the MS nursing service. Due to GPs’ role as “gatekeeper” and referrer to other services, recurrent reports that GPs tend to have limited understanding of the special needs of people with MS is of concern (Multiple Scler. Soc., 1997). More MS Specialist Nurses need to target GPs with educational initiatives. Evaluating an MS Liaison Nurse, Kirker and Young (1995) showed that the MS Specialist Nurse increased GPs’ knowledge of the management of MS.

Without some co-ordination, stakeholders said it was possible to have role-blurring, poor task allocation, lack of communication and liaison, ignorance about MS, and generally poor service provision, etc. According to the consultant in public health:
“Community Health Trusts will be disbanded and the existing eight PCGs will become six, roughly corresponding with the existing six Social Services Unitary Authorities by the year 2001. The boundaries are not necessarily clear, as GPs are entitled to choose which area they feel they belong with, rather than this being strictly geographically defined. Therefore there will be some fuzziness and mismatch between PCGs and SS areas. This is regrettable, but it is Government sanctioned, as GPs are now a powerful force and defining what they want. GPs are powerful and becoming more so in the current Government strategy. Their view that they can do everything and that acute services can be cut back to a minimum can be rather scary, given the evidence that GPs don’t know much at all about specialist problems, such as MS. Having one of each specialist nurse can be difficult when GPs are deciding what can be put into each Primary Care Trust. How can one nurse fit and relate to each of the six PCGs? Who takes management responsibility and gives leadership and vision. How do you ensure equality of access for the other five? You could get lost as no-one is ‘clued-up’.”

The MS Specialist Nurse could be seen as a bridge between services and the client. The MS nursing role can fill in gaps of knowledge, information, communication, support and practice. The MS Specialist Nurse can form a bridge between currently developing PCGs and clients with MS.

According to a Social Services occupational therapist:

“I would have thought that it might be useful if the specialist MS Specialist Nurse goes and talks to PCG teams. The GP practice team will be meeting regularly. The MS Specialist Nurse could be cascading information.”

And again, in the words of a stakeholder GP:
“I suppose that I wouldn’t actually necessarily be aware of how many MS labels there are out there. The one’s you’re aware of, of course, are the classic progressive ones. And whether that actually matters or not, I don’t know… There is uncertainty over, you know, when acute steroid treatment is appropriate or not appropriate during acute attacks. There doesn’t seem to be very good unanimity of opinion there. That’s the sort of area where it would be nice to have a specialist nurse… I mean, I think the role is very much like the Macmillan nurses... I think the contact between a MS Specialist Nurse and the local practitioners would be terribly important.”

A principal way forward was thought to be developing relationships with members of primary care teams in the new Primary Care Groups (PCGs). The MS Specialist Nurse is able to give advice and up-to-date information. The MS Specialist Nurse can build liaison and support in the community by establishing better links with the primary care team.

In this context the importance of working in a wider multidisciplinary team which fosters the growth of Nurse Specialists must be emphasised (McCaffrey Boyle, 1997). There is need for multi-disciplinary co-ordination of care and advocacy on behalf of patients (McGuire and Harwood, 1989; MS Soc., 2000; Robinson and Hunter, 1998; Thompson et al 1997b), regarding fragmentation of MS services, as noted above, (Freeman and Thompson, 1999). Winters (1989) et. al describe multidisciplinary, nurse-led clinics as a successful part of this effort to reduce fragmentation in service provision.

6.2.3.2 Social, medical and psychological care of people with MS

People with MS were said by stakeholders to have multiple medical, social and psychological care needs. The involvement of MS Specialist Nurses was endorsed by stakeholders in order to improve the quality of life of people with MS, and is presented here under five headings.
i) Mobility, transportation and escorting

Basic mobility and transportation was considered a problem that MS Specialist Nurses could help with when working with disabled MS sufferers. Transportation was required in order to keep hospital and other appointments. Wheelchairs needed to be requisitioned from disability funds. Appropriate beds, lifts, etc, were required for mobility and use in the home.

Transport in the community was a frustrating difficulty for many people with MS. As a general practitioner said:

“The ambulance service haven’t really got enough facilities for regular transport of people who are going on to a day unit once or twice a week. They say: ‘Well, we can’t do that. We can’t provide transport’. Often the person with MS is too immobile. One lady in particular hasn’t been able to get to the day unit simply because there’s no transport to get there. It’s that type of thing which is very frustrating.”

Transportation difficulties, if felt to be unmanageable, were said to get in the way of contacts, appointments and services in the wider community. According to an informal carer, speaking about her husband with more severe MS:

“We used to see a doctor about once every three months, but they don’t make appointments for him anymore because it is quite stressful to get him to the hospital.”

There was thought to be scope for the MS Specialist Nurse to help facilitate transportation. The MS Specialist Nurse could put people in contact with voluntary groups, gain free taxi transportation through social services or the health authority, advise on public transport routes, and contact escorts through social services or other organisations.
Mobility in the home was also another practical and often emotive issue that people with MS and their carers faced. The occupational therapist said:

“There are difficulties with housing. Difficulties of actually managing in a house, particularly when they start to be wheelchair-bound. You know, if it’s a house, there are difficulties getting up and down the stairs, getting in and out the front door, on and off the loo, the bath. It’s just the usual everyday activities of living, really. The MS patients would tend to have more of the things of sort of major adaptations, where possible, and through floor lifts. And there’s the care and, you know, assisting the carer with the home care and that side of it.”

Although the role of occupational therapists, MS Specialist Nurses were also reported as helpful in giving good information and practical help on all aspects of mobility. There was said to be scope for more escorting and/or arranging escorts with social services and voluntary organisations.

ii) Caseloads, waiting times and quick responses to MS care needs
There was estimated to be a large number of people with MS in the areas covered by the research, although none of the stakeholders knew why a high incidence of MS was especially the case in the area they worked or if there was any indication of possible aetiology.

Two statements made by managers of services were typical of gaps in information about the prevalence and needs of people with MS:

1. There are large numbers of people with MS in this area, you know, a lot more than in some areas for some particular reason. They’re a big drain on resources. They need such complicated care.

2. I don’t know a lot about the history to be honest. I haven’t really known in great detail about the history of any of these clients.
Only one stakeholder, from a medical background, hazarded an estimate of people with classical symptoms of MS in their Trust. Part of the problem, the stakeholder went on to say, was that many people with MS did not display “typical” symptoms for many years. In spite of widespread reports of the unpredictable nature and outcome of MS, there was therefore an underlying assumption here that MS followed a predictable course and that people with MS would become progressively disabled.

Some stakeholders were new to their organisation or said that they really had no information on figures or exact case histories that might be relevant to the services that they provided. Stakeholders were in agreement that there was a lack of information on MS.

All stakeholders said that an MS Specialist Nurse would be extremely helpful in clarifying the numbers of people with MS in the area. An MS Specialist Nurse would be helpful in information giving and co-ordinating methods of social support and health care with other teams.

As MS was recognised as complicated and requiring long-lasting care it was said to be necessary to have a quick response by services. Waiting times for services had proved disruptive in the past, according to several stakeholders.

A GP suggested that services needed to be switched on immediately for people with MS. Many said that services could be made more flexible to the needs of people with MS and the MS nursing service would facilitate greater flexibility with response times and care plans. There needed to be a guarantee of responsive care to people with MS. According to the GP:

“You actually need a real guarantee that when you do cry for help and say, ‘now I can’t cope’, that you can then switch something on. Rather than saying, ‘oh well, yes, we’ll fix something but not now’, that then
undermines confidence. People with MS need to have the confidence to know that they’re going to be looked after, that they can cope and if they need something it will be there. It won’t happen in a few weeks time, it will happen right today or tomorrow. That’s our great difficulty. If you can guarantee immediate care, then you can go in with great confidence and say we’re doing well.”

In this way, providing a responsive service was though to empower patients and carers and give them confidence in managing their own problems. Knowing there was a “safety-net” if necessary. This would reduce anxiety and the tendency to call for help prematurely.

The following extract illustrates this point and demonstrates how the district nurse provided back up to the carer of a person severely disabled by MS in response to recommendations of the MS specialist clinic and the emergency doctor. The wife, who acted as her husband’s carer said:

“My husband was having a lot of trouble with his bladder and they found out at the MS clinic that he had an enlarged bladder. So, the district nurse had come in to train me to drain my husband’s bladder. I think it was twice a day I had to do it. One night my husband was so ill I had to ring the emergency doctor in the night and the doctor came out and said, ‘I think his catheter needs to be changed’ … and so the district nurse then trained me how to put a catheter in.”

Helping spouses to cope with the “chronic sorrow”, which often afflicts both patients and their carers, is discussed by Hainsworth (1995). Gulick (1995) conducted research on coping strategies among carers of people with multiple sclerosis, pointing to the physical, social and emotional disabilities commonly affecting people with this condition, leading to dependence on carers. The latter need to develop problem-solving strategies, e.g. through various self-help organisations. Patients are often aware of the pressure put on family members,
especially when the terminal stage of the condition has been reached, as demonstrated in research by Hunt (1991). Davis et al (1996) also discuss pressures put on carers of patients at the end-stage of chronic or acute disease, noting the prevalence female relatives, performing this role.

Nearly all stakeholders indicated that they thought MS Specialist Nurses would reduce response times and increase quality of care. MS Specialist Nurses would give greater information to professions and people with MS, facilitating appropriate responses to MS needs.

iii)  "Typical’’ stages of MS and scope for input
Quick responses by MS Specialist Nurses and professions involved in caring for people with MS were encouraged to stabilise the lives of sufferers. MS had early and late stages that required different responses and measures, which should be facilitated better through contact with MS Specialist Nurses.

A GP stakeholder made a very interesting point that relates to quick response and guaranteeing care. The GP said:

“I think it really comes back to what I said earlier [see above]. I was saying when an acute situation arises you need to be able to turn on an acute service and say, ‘we’re on a crisis point here’. And then the orthopaedic ward says, ‘orthopaedically, you’re all right’. But actually the patient can’t cope at home. That’s when you actually want the specialist nurse facility to say: ‘Things have conspired against us in such a way that the patient can’t cope. Now, not in two weeks time, we want something to happen.’ I think that part of the difficulty is that MS is seen as a long-term illness. Everything is seen in the long-term. That misses out the fact that MS is punctuated by episodes of crisis.”

MS Specialist Nurses were said to have at least three central roles that related to difference stages of MS:
1. Educating people with MS in the early stages
2. Giving long-term care and constant support of a palliative nature
3. Managing episodes of severe crisis for people with MS, their families and carers.

iv) The social, emotional and psychological impact on people with MS, professionals and carers

Classical MS was depicted as a long-term illness with serious medical, social and psychological consequences. According to the Community Care manager:

“There are quite a few people with MS on our books. Some of them need a lot of care. MS people tend to be the most disabled. A few people need two hourly care and it takes two carers.”

MS was mostly depicted in its later stages, rather than during its early stage, where education and preventative interventions might be considered as necessary, or during moments of crisis where a quick and guaranteed response was vital. Much close contact and palliative care was required for people with disabling MS. Close contact entailed psychological and emotional difficulties for people with MS and their carers. A physiotherapist, who might be seen to deal predominately with the physical aspects of MS, said something quite revealing:

“I think a lot of physiotherapy is psychological. You encourage people, you enthuse people and we work very hard physically… But it’s a very emotional job and it can be very hard on staff. I’m used to it but I need to be sensitive to that.”

Frequently used terms such as “depression”, “stress”, “heaviness”, “coping”, “psychologically hard” indicated the pressures on all involved.
MS was a long-term illness that required difficult and often emotive palliative care. It wore away at sufferers and carers on a day-to-day basis. As the Community Care manager commented about people with MS who she described as some of the most difficult and complicated cases on her books:

“Some of these clients, the carers just don’t want to go in. This is one of the big management headaches for me: How to provide the proper care when the carers find it really hard to go in there every day? The carers say it can ‘do their head in’. They get very frustrated. You can’t blame them. There are psychological problems as well as it being so physically heavy. It is very hard, very demanding and very difficult. It’s work that ‘kills’ the carers. I do need to rotate the carers because they just can’t keep it up and cope. Social services are not happy because it doesn’t allow for continuity. But it’s a question of trying to find carers who will go in at all and trying to give them job satisfaction and to keep them on our books. I need to keep them. People and other services often don’t realise that it’s very hard work day after day and you have to compromise.”

She was clear education for her staff was a key tool in helping them understand the particular problems of people with MS. Some challenging aspects such as cognitive difficulties needed to be explored if care staff were to be able to develop and sustain job satisfaction. This might contribute to less staff turnover and more continuity of care for patients. This point is further explored in section 6.2.2.3.4 (v) below.

It was also thought more respite was necessary for people with MS, which would also alleviate the strenuous activity of day-to-day caring. Respite would give carers a break. A GP said:

“One does have sympathy for Social Services and families because they put in the care and there always seems to be an element of exploiting the
carer. The carer is not able to put limits on what they feel or what they do. If you say you can care this amount then the assumption is you can care for this amount plus however much you first of all said. They’re always expected to do more, however much they’ve been asked to do. And that, I think, is a very very bad strategy. It would be better if people said: ‘Yes, we will take this on. Yes, I do want to care for my loved one. I’m prepared to change my life majorly. But I do want guarantees of some breaks, some respites and if I cry for help I do want it to materialise.’

More respite for people with MS at day centres was thought necessary. More respite was mentioned as a way of alleviating the emotional and psychological pressures of caring for people with MS. An informal carer who looked after her husband with MS said:

“He’s got a problem with secretion coming off his lungs at the moment and coughing, choking and bringing-up mucous. It was just getting a bit too hairy for me to cope. He goes to a centre three days a week between nine and half-past three. That’s for me too. It gives me a chance to go to my art club, see my girlfriends, go to a lot of meetings. I’m going to the MS Society carers’ meeting this evening and I’ll have a nurse look after him tonight while I go to that.”

Stakeholders reported the MS Specialist Nurse has roles of sympathetically listening, talking through problems, informing and educating, explaining ways forward and assisting people with contacting other services. This helps to cope with the psychological and emotional problems that almost inevitably arise in MS.

v) Disclosing the diagnosis of MS and managing an uncertain future

Several stakeholders, including a GP and an occupational therapist, said that disclosing the diagnosis of MS was difficult and emotive. The GP said:
"I think the main fear is that you don’t actually want the diagnosis rammed down people’s throats because they’re already scared enough. I’m not sure you can make them less scared, especially as you don’t know at the time of diagnosis whether they’re going to be in the category of the odd attack, which then has no further implications for ten years. In which case, having gone through all the things that MS is about, is an absolute nightmare to them. Because they’re then waiting for it all to happen and nothing happens. They could have been getting on with their lives. I think that in a sense one has to play the initial diagnosis on the assumption that it’s going to be a good outlook, rather than the assumption that you’re going to be heading for, uhm. I’ve certainly found that most people with MS are fairly realistic about the inevitability of what’s going to happen. Uhm, I don’t know how they cope, really. I’m amazed how well they do cope."

There are several interrelated points that need to be mentioned that pertain to managing disclosure and actively sustaining quality patient care. While disclosure must be managed sympathetically, the GP feels that disclosure should occur at a time when the person with MS, and presumably their next of kin, is able to manage the psychological and emotional impact of diagnosis. Rightly or wrongly, he is against the disclosure of diagnosis straight away. This raises questions of full consultation with the patient. However, the GP’s main concern in the extract is managing disclosure sensitively and in a way that is not a “bombshell” given the potential medical consequences of MS. He also implies that being diagnosed with MS produces “fear”, makes people “scared” and seems to affect the GP on an emotional level.

In order to manage the disclosure of diagnosis in a sensitive way, the MS Specialist Nurse needs to help people to cope when they are ready. As mentioned in the preceding section, The MS Specialist Nurse has roles of
sympathetically listening, talking through problems, informing and educating, explaining ways forward and assisting people with contacting other services.

The MS Specialist Nurse’s close contact with people with MS would help in the evaluation of when and how much to disclose.

Appropriate disclosure starts to deal with psychological and emotional problems that will inevitably arise in MS and helps in managing long-term support and care plans. The MS Specialist Nurse can also give input into the final stages of MS when the need to manage a good death may become an issue for all concerned.

In the next section, the MS Specialist Nurse communicates between professionals, carers, families and people with MS. All stakeholders viewed it vital to preserve the dignity of those with MS as sacrosanct. The MS Specialist Nurse manages disclosures and a good death in a way that ensures dignity.

6.2.2.3.3 Bridging the gap with communication and liaison

i) Communicating information, co-ordinating service involvement and joint visiting
The MS Specialist Nurse was said to be an important source of up-to-date information. MS Specialist Nurses were said by social and health professionals to be more au fait with MS and possess a good degree of expertise on the medical, social and psychological aspects of MS.

Carers from the MS person’s family also stressed the MS Specialist Nurse’s role in this regard. They also indicated that having a nursing input (which could be a district nurse or private nurse) was of benefit in giving basic advice and practical suggestions, such as help with the “little things”. One woman who acted as a carer for her husband said:
“We had a trained nurse here for a week once and it was amazing: the practical tips, ways of doing things, little things, the knack of transferring, dealing with spasms. I mean, I know the basics now about bending him forward if he starts to shoot out of the chair. But there are other details that you can pick up from someone who is trained and understands these things. I mean, no-one actually told us what a spasm was. And then there are things to do with the bladder. You know, that can be very difficult and very frightening trying to manage the catheter sometimes.”

Stakeholders in the social and health services said that MS Specialist Nurses were good at giving detailed information and advice and brought a holistic approach to MS care. They organised and were able to give up-to-date advice on medical, social and psychological interventions, which might not be possible from, for example a Social Services link person.

One GP said an MS Specialist Nurse would be able to say when acute steroid treatment was appropriate or not appropriate during acute attacks. An MS Specialist Nurse would help carers understand how to deal with spasms and convulsions. Bladder problems and infections were also reported as advised upon. Benefits and allowance agencies and other relevant organisations could be contacted by carers on the advice of MS Specialist Nurses. Psychological and emotional difficulties of people with MS and their carers could be discussed, actively worked on and managed with the help of MS Specialist Nurses.

The MS Specialist Nurse was seen as an available source of information and acted to co-ordinate holistic care. Several stakeholders indicated that MS care plans were not made in isolation but were best planned with other services and with the able facilitation of the MS Specialist Nurse. The importance of multidisciplinary care, as stressed in the literature, has already been noted above.
The MS Specialist Nurse would act as a bridge and point of communication between different organisations and the person with MS. According to three respondents:

1. Physiotherapist:
   I’ve worked in a hospital a lot. I miss the medical colleagues. You’re very cut-off here, so having the MS Specialist Nurse means I can ask. Catheter problems and pressure sores are mega-things.

2. Social Services manager:
   The MS Specialist Nurse has a role in making sure that clients and carers are given information and helping people to see things holistically. The MS Specialist Nurse helps understanding the language and the system. It’s about bringing people together.

3. District nurse:
   The MS Specialist Nurse is a great resource. She knows the latest information and trends such as what to do for urinary incontinence or at different stages of the illness.

Again this essential input by the MS Specialist Nurse to multidisciplinary teamwork was emphasised.

Communication between MS Specialist Nurses and newly formed PCGs was seen as especially important. A GP suggested joint visits as a way of encouraging more involvement between specialist MS nursing and primary services:

“I don’t know our local MS Specialist Nurse but I think it’s very much the case that you start using someone and referring if you know them and think, ‘oh, yes, this is a sensible person’. I think a joint visit of the MS Specialist Nurse to the patient would be an eminently sensible way for everyone to proceed. It would allow us to indicate to the patient when they should contact the nurse and when they should contact the doctor.”
Joint and multi-agency working was seen by all respondents as a crucial way forward in developing the MS nursing service. Attendance at the PCG Clinical Forum by the neurology team, including the MS Specialist Nurse had been identified as a way of publicising the service to the local GPs and district nurses to encourage better communication and liaison between the primary and secondary sectors (cf. Winters, 1989).

ii) Working around difficulties and bridging communication breakdowns
Stakeholders said that MS Specialist Nurses bridged gaps and breakdowns in communication between services, people with MS and their carers. The MS Specialist Nurse brought a knowledgeable and fresh perspective on MS. The occupation therapist said:

“I mean, with the best will in the world, people don’t always know. I had a lady on the ‘phone this morning who’d been told that her husband needed metal walking sticks and she’d been to the physiotherapist at the hospital as an outpatient. Then she’d been to here, there and everywhere. And somebody said, I think the GP practice said, “‘phone social services”. Well, of course, we don’t do them, it’s the community physiotherapist. She was getting so stressed. She said: “My husband is getting so cross with me. He thinks it’s my fault”. I said, “I’m terribly sorry” when I phoned her back because I know that’s what I would have said in Reading, but I wasn’t a hundred percent sure about Wokingham, but it was the same. So I had to ‘phone her back and say, “I’m terribly sorry, but I can’t help you”. You know, you think “this poor woman”. Really the GP should have known. So I then have to point to the community physiotherapist… There are times when you think it would be better if somebody else did go and see the MS patient because it’s somebody with new ideas looking at it from a different view.”
The Social Services manager mentioned that the MS Specialist Nurse was a specialist who would cut through red tape. The MS Specialist Nurse facilitated communication between services and clients and gave empathetic advice and support on how to proceed. According to this respondent:

“...My experience of the MS Specialist Nurse is just somebody who knows what they’re talking about. The MS Specialist Nurse was liaising with housing. She was doing all these things that overlapped with us, and I was really pleased not having to put up with all of it. I was really impressed by her sort of holistic way... It’s really important to get through that red tape. One person actually said they had four occupational therapists: one at the hospital, one at the GP unit, one at the community and goodness knows. The same questions were being asked, over and over again, and the client said ‘don’t you ever communicate’. The carer was really cross. I can actually say that the MS Specialist Nurse has called me and told me about what needed to be done. The MS Specialist Nurse works across the board and affiliates. I know that if anything happens on a particular client I can actually ring her up and share my concern. I feel she was very empathetic to the sort of thing we’re doing.”

She was therefore thought to be tuned into the perspective of the patient, but also into the perspective and way of working of the Social Services.

The MS Specialist Nurse was perceived by stakeholders as a good half-way house between services and clients. MS Specialist Nurses were good arbiters of need and advocates for those with MS. The occupational therapist said:

“In a way, there isn’t any arbitration to be had because, you know, you have to fill in a financial assessment form and if the answer is ‘yes’ then you’re assessed to pay. There’s no arbitration, really. I would imagine
that the MS Specialist Nurse’s sort of role would be quite good in that. Talking about the real impact on life. To work with those with MS.”

As stated previously, the Social Services manager dreaded being in situations where people were facing financial means testing for services and not being able to get her point across. The implication was that having an MS Specialist Nurse on board would assist her to argue her point.

There was one striking example that illustrated the need for more respite care and the potential role of the MS Specialist Nurse in arbitration if communication with other professionals breaks down. If families took on all the burden of care, and were not advised by a key worker such as the MS Specialist Nurse to be involved with other services where necessary, the results could be devastating. An occupational therapist said:

“I had a very nice couple. She had really severe MS and he insisted on doing everything. He was kind of staggering up and down the stairs with a heart condition. He had a social worker going in and was quite antagonistic because he was quite convinced that the social worker was there to get his money off him, which in a way was true because the social worker wanted to put in care to help him look after his wife. I don’t think they had much money. It would so have helped, if he would have agreed to a morning and evening assistant, but he never ever would. And now he’s dead. There isn’t any arbitration and someone to work with them and explain these problems”.

The MS Specialist Nurse was recommended by stakeholders as a key worker who organised care plans and necessary assistance. Their face-to-face work was thought to make it possible for MS Specialist Nurses to act as arbiters and exponents of care. She was perceived to have a role to play in bringing services and people together. If breakdowns in service provision or communication occurred, as is often the case in highly complex health and social care systems,
the MS Specialist Nurse had several roles: including, (a) sustaining good information giving to clients and services and (b) communicating and advocating for the needs of clients.

6.2.2.3.4 Stakeholders views of the specialist role of the MS Specialist Nurse

All stakeholders broadly welcomed the involvement of the MS Specialist Nurse and their specialist knowledge and skills in helping manage the problems of people with MS locally. Their comments are presented as five potential areas of involvement where MS Specialist Nurses could make a valuable contribution, given current problems for people with MS and the way services are organised.

i) An expert resource of specialist knowledge for people with MS, carers, acute and primary care professionals

First, most stakeholders said that MS Specialist Nurses had considerable expertise of MS. It was said that there had been a move from general to more specialised nursing services. Specialised nursing was for the most part greeted as a positive step. MS Specialist Nurses were seen as vital. A GP said:

“We’re aware that as GPs our knowledge is not in-depth in every area. It’s not going to be, because no-one’s perfect. I think that most GPs will regard an acute episode as something that the patient’s neurologist should be advising on rather than them having to decide. The area of lack of knowledge is when you get all different suggestions of ‘what about this special regime’ or ‘what about that regime?’ That’s when you really do hold up your hands in horror and say, ‘well, I don’t know, I don’t know. Do I go along with it? Don’t I go along with it? You know, do I give them vitamin B12 or drug treatments?’ I’m very much pro a specialist nurse who could advise on that sort of acute scenario”.
ii) Making a difference - a knowledgeable link-worker

The MS Specialist Nurse was portrayed as an accessible link worker who services felt able to call upon and who made a substantial difference to the lives of people with MS.

MS Specialist Nurses were link workers between services, people with MS and carers. They updated these groups with information and had face-to-face contact that clarified steps to be taken in patient care. In particular, MS Specialist Nurses had specialist knowledge and a wealth of experience by which to give input to organisations and patients and families on palliative care.

Key working with primary care services, PCGs which were soon to become Primary Care Trusts (PCTs) was thought particularly important to the success of MS specialist nursing in the community.

Interestingly, one respondent said that several issues needed to be worked through in respect to perceptions of general and specialised nursing. According to the public health consultant:

“The Health Authority has no particular stance on specialised nurses as such. Just thinking about it now, Reading is small and there would be a tendency to look towards generic developments rather than specialisation as a conscious way forward. The trend toward primary care led services would tend to encourage that. Primary care is generic care and it is likely that this would be their choice. GPs are powerful and are becoming more so in Government strategy. GPs don’t know much at all about specialist problems of MS. Having one of each specialist nurse can be difficult when GPs are deciding what can be put into each primary care trust. How can one nurse fit and relate to each of the six PCGs? Who takes management responsibility and gives leadership and vision?”
PCGs are once again conceived of as a point at which the MS nursing service needs to develop its contact. Building relationships and meeting training/information needs of primary care staff gives input to general nursing staff and GPs from the informed perspective of an MS nursing specialist. Stakeholders indicated that the MS Specialist Nurse cascades the latest information, educates, gives practical advice on MS cases as issues arise, and informs about appropriate practice techniques. The MS Specialist Nurse was also thought to be more available and able to give immediate feedback to aid management.

iii) Advocacy
Stakeholders stated that it was important that people with MS had an advocate available when they needed one. The close proximity and face-to-face nature of specialist MS nursing, when combined with their extensive knowledge and experience of MS, was thought by stakeholders to equip MS Specialist Nurses as capable advocates. The importance of patients having an advocate to promote their interests has already been stressed by others (British Soc. of Rehab., 1993; Freeman et al 1997b; DH 1999b; Thompson et al 1997a).

iv) The revolving door- promoting continuity and breaking the cycle of re-referral
One respondent in occupational therapy mentioned that some MS patients tended to get trapped in a revolving door of referral for reason ‘X’, closure of the case, later breakdown, re-referral for the initial reason ‘X’, and so on. As we have seen, one GP classified MS as a long-term illness with episodes of occasional but severe crisis. Situations are particularly likely to recur in MS and this is not in keeping with the current way Social Services care is organised.

The occupational therapist said:

“What did happen was you did the work, you closed the case, something blew-up, it’s re-referred. It would not necessarily go back to the same OT. I mean, in some cases you would say: “Look, I’ll take the case. I
know ‘Mrs. Bloggs’ and she knows me. I can probably sort her out very quickly”. And of course that was a great advantage of having been in the job for a long-time because you knew everybody”.

Close knowledge of people with MS by one individual, such as an MS Specialist Nurse could help referrals to be made appropriately and re-referred to the same professional where possible. Many respondents saw it as vital that continuity in service provision was maintained. They said that the MS Specialist Nurse would assist in ensuring continuity of care.

v) Education, training and support for professionals

The MS Specialist Nurse was thought of as a specialist and expert in the area of MS care that stakeholders could call upon for information, advice and support. Both practical and theoretical advice about MS was sought by stakeholders. The Social Services Social Worker said:

“I think it would be quite helpful for our home care people to know how far they can go or not and what they should do. It would be helpful for case co-ordinators to know more general things about MS”.

The MS Specialist Nurse would be able to help in educating professionals, carers, families and sufferers about pertinent issues involving MS. When asked, most stakeholders depicted MS in its disabling and late stage when the illness was most debilitating. MS was depicted as requiring palliative and long-term care rather than preventative techniques and immediate interventions. Interventions were favoured at the later stages of MS. This probably reflects traditional models of care and the usual times when these professionals have become involved in MS care. The MS Specialist Nurse appears to have a role in consciousness raising and educating on all stages of MS and the role of potential disability prevention. Clearer understanding and improved training were thought to be a vital step in the right direction. The Community Care manager said:
“I think the key to it all is training and improved training about MS for the carers. It would be good if carers had more understanding of what is going on with patients. It would be better if carers had more understanding that some of the more difficult cases are not being ‘bloody-minded’ but that it relates to the disease itself. Carers need to be aware of the memory problem that people with MS might have. Carers really need some sessions where they learn how to handle situations at the front line. They need some practical sessions or workshops where they can raise some of the difficulties they are having and talk about what’s going on and how to handle it. They need to know that MS causes some of the client’s attitudes and about some of the emotional issues about how MS affects families. I think that if families and carers had a better understanding it would make them feel less worn down”.

Resources for training, however, were limited. She continued:

“Unfortunately, though, there is no budget for training. For the MS we used to be allowed free training” (at the MS therapy centre).

She then went on to suggest a solution:

“It would be nice to have several sessions that are linked and that could be certified. They could include a combination of theory and practice, because we know that sometimes a few of the carers who work here will eventually go on to do their nurse training. So, it would give them an idea of what to expect and it would be helpful for them. We could do with a resource pack for health care assistants about MS, like the MS society does for nurses. We could use something like an open learning pack that carers could take at their own speed”.
Work groups, joint training sessions and open learning packs on MS were ways in which the MS Specialist Nurse was thought to be able to facilitate education and training. There was felt to be a key need to develop MS training and education in the future and the MS Specialist Nurse would be a linchpin to this advancement.

6.2.3.5 Conclusion

These consultations with stakeholders in the local management of MS and in the MS Specialist Nurse's service are very positive about the potential to make a difference in MS care. They broadly concur with patient views of need, namely for a source of information, holistic expertise in management of MS problems, continuity of care, co-ordination of services and psychological support. These are all real issues which are also frequently reflected in the MS literature. However, it is also useful in emphasising the vulnerability of professionals, in terms of their own lack of knowledge and skills as well as their need for emotional support. This further underpins the need for a source of advice, education and support for professionals in this area. It is also interesting to note the levels of anxiety and added communication problems caused by major organisational change in the healthcare system, with the move towards Primary Care Groups at this time. This also brings dilemmas regarding the potential lines of management and siting of specialist nurses in future healthcare delivery systems such as large PCTs, if people with MS are to have equitable access to the service. These are issues for further exploration as the transition to PCGs and then PCTs rolls out across the UK.

6.2.3.6 Key service recommendations made by stakeholders on ways forward in developing MS care and supporting the delivery of MS nursing services

- “There needs to be more respite for people with MS and their families”

Many stakeholders indicated that increasing respite care, for example attendance of an MS patient at a day centre, had ameliorated the family’s situation. More respite for people with MS was necessary in order to fairly
distribute the burden of care and in order to prevent over-work by the spouse or relative.

- **Introducing a 24hr telephone line and an extended nursing service**

  One informal carer said it had sometimes been difficult to contact the MS Specialist Nurse. A GP suggested that MS nursing needed a 24 hour telephone line and said that it would be good if MS nursing would operate for extended periods outside office hours. The national MS society was known to have a national 24 hour telephone service. As stakeholders indicated that primary care services were a vital point of contact, it would probably be the case that liaison with NHS Direct will be a further step in increasing communication on MS in the future.

- **Maintaining the continuity of service provision**

  Most stakeholders said that there had been several structural and economic transitions in the local NHS that had affected the continuity of service provision for people with MS. Despite great changes in the NHS at national and local levels, it was seen as a positive step to introduce specialist MS Specialist Nurses and these nurses were seen as key workers in ensuring high quality of care.

- **Close liaison with PCGs/PCTs- Joint visits with GPs and district nurses**

  This innovative suggestion was made by a GP and touched on the need for closer working between primary care services and MS Specialist Nurses. The GP and MS Specialist Nurse would initially visit together, helping to establish trust and clarifying what each professional would do for the person with MS.

- **Modify rates of attrition**

  Stakeholders suggested that rates of carer attrition would be high in cases where professionals and carers gave palliative support to people with MS. Mechanisms of support needed to be clear and made available to all people that worked in such a demanding role. Peer and professional support and education could decrease attrition of carers and professionals. Peer and social support
could alleviate the burden of care on family members who acted as informal carers.

- **Mentoring and support for the MS Specialist Nurse**
  Mentoring and supervision were mentioned several times as ways of giving support to MS Specialist Nurses, but because MS nursing was quite recent, many said that they did not know where responsibilities lay and where MS Specialist Nurses would turn to for their own support during difficult times. Several stakeholders said that it was necessary to have clear management and leadership structures available for MS Specialist Nurses so that they were supported in their relationships with MS clients. This needed to be explored in the new PCG structures.

- **Encouraging self-help, the use of local support groups, and users’ views**
  MS Specialist Nurses were said to be in a good position to encourage self-help, especially when they worked together with primary care professionals. They could encourage the establishment and use of local support groups and keep people with MS and professionals updated about their existence.

- **Raising the visibility of MS nursing**
  Stakeholders felt that MS nursing needed to be made more visible locally. Stakeholders said the visibility of MS nursing could be raised in several ways:
  - Increased contact and advertising the service with PCGs/PCTs
  - Continued networking with health and social services
  - Undertaking joint meetings with health and social services, in particular, joint meetings or joint patient visits with primary care staff
  - Being actively involved with user meetings
  - Advocating for people with MS and communicating users' views to stakeholders
Increasing the visibility of the MS nursing would forge strong networks in the community, lead to quicker service responses and more consistent patterns of care.

- Others valuing and using the skills of MS Specialist Nurses
  One GP said there had been a tendency in the past to view nursing as general and sometimes even menial. Nursing had become more specialised and all stakeholders welcomed the change to a MS Specialist Nurse. MS Specialist Nurses had clear expertise, were aware of contemporary practice issues, and had a wealth of experiences by which to help people with MS. It was said to be vital to cascade the expertise of MS Specialist Nurses to other professionals, carers and clients and advertise the value of their input.

6.2.3 Local Audit and the standard setting approach

Audit and Quality Assurance is not strictly research in the sense of contributing to a scientific body of knowledge and adherence to rigorous methods of conducting research (Bowling 1997). Instead it is mainly concerned with monitoring the achievement of standards which have been set for a particular service. Whilst standards should aim to be methodologically rigorous, they are often designed to be part of periodic routine clinical practice and characteristically use small samples to give an indication of current practice and patients' experiences of the service. Audit can be a useful component of an action research project as, “in theory …it should lead to change in clinical practice by encouraging a reflective culture of reviewing current practice, and inducing changes which lead to better patient outcomes and satisfaction” (Bowling 1997).

One of the challenges of evaluating nursing is to adequately sample the wide range of activities where nurses play an active role. Differentiating outcomes arising from nursing intervention from those resulting from other multi-disciplinary team involvement can be difficult and in some cases impossible.
However, careful identification of the contributory factors leading to successful outcomes can begin to identify where strengths or weakness in the current system lie. Donabedian (1980) was influential in identifying a standards framework where structure, process and outcome components have an underlying cause and effect relationship in healthcare. This framework has been a useful tool in helping nurses to monitor and evaluate their service. Wilson-Barnett states that, “The different approaches to evaluation, namely through measurement of structural, process and outcome measures, provide useful and complementary information necessary for comprehensive evaluation of the role of the Clinical Nurse Specialist” (Wilson-Barnett and Beech 1994). Analysis of relevant structures and processes and their relationship to outcome can help identify which components are directly under the influence of the nurse and which are dependent on other team members or departments to achieve the specified outcomes. This exercise necessarily draws in others and promotes a focused multidisciplinary approach, once the contribution of each member is acknowledged.

The important perspective of patients, as well as other potential “stakeholders” in the nurse's service is outlined by Humphris when evaluating quality (Humphris 1999). In the current project, a range of “stakeholders” were consulted at various stages in attempting to identify problem areas and priorities for further development. In terms of standard setting and audit, Steering Group “Stakeholders” decided on two priority areas to develop in detail, based on recurrent themes from initial in-depth interviews. These two standards involved:

- the management of patient care at and after diagnosis and
- the education of paid, formal carers such as community staff, Social Services carers and hospital nurses.
6.2.3.1 **Standard 1: management at and after diagnosis**

6.2.3.1.1 **Method**

The researcher facilitated writing an overall standard statement to apply to the local service at diagnosis, based on the MS Specialist Nurse's own clinical judgement and knowledge of resources and reflecting the MS Society Standards of Healthcare during the diagnostic phase (Freeman, Johnson, et al 1997).

**STANDARD STATEMENT:** *Patients with suspected Multiple Sclerosis will have their diagnosis confirmed by a consultant neurologist within a minimum time, will be provided with initial information and the offer of support from the MS Specialist Nurse, and feel confident they have a reliable contact for further information and support if/when required.*

Component outcomes were then identified which would contribute to the overall statement. The MS Specialist Nurse described the existing service in structure and process terms and the researcher and MS Specialist Nurse identified potential gaps and proposed modifications to the system which should enable the outcomes to be achieved. The resulting draft standard was then circulated or discussed with the other main team members identified as having a role in its achievement (neurologists, secretaries, departments conducting investigations) and further modifications made. The standard was also presented for discussion and approval at a “Stakeholders” Steering Group meeting. (See Appendix 10 for full structure-process-outcome standard).

Three sources of available evidence were identified to monitor the audit trail. These aimed to follow how the service was delivered and how it was experienced by the patient. Like most audit, monitoring relied heavily on the availability of documentary evidence to allow an outside person to follow what went on, and was therefore based on the premise that unless documented in some way, intervention could not be confirmed as occurring.
Simple audit tools were developed to sample key structure, process or outcome issues from the medical records, nursing records and from patients themselves (see Appendix 11-13). These were designed with a view to becoming part of routine periodic clinical practice for the MS Specialist Nurse in continuing to audit her service beyond the time-scale of the project, although the researcher carried out data collection in this instance.

The MS Specialist Nurse held lists of newly diagnosed patients with a view to inviting them to attend “Getting to Grips with MS” courses in the near future. These lists were used to identify relevant samples for audit. Baseline audit of the standard took place in January 2000, with review in January 2001. Consequently patients receiving a diagnosis in the 12 months prior to each date formed the main target groups.

6.2.3.1.2 Baseline audit January 2000:
From the list of 29 patients who were invited to attend “Getting to Grips with MS” courses during 1999, 20 were randomly selected to receive patient questionnaires. There was a 75% response rate to this single mailing. Of the 20 who were sent questionnaires, a sample of nine randomly selected Medical/MS Nursing notes were reviewed. Six of these had received their diagnosis during 1999, two in 1998 and one in 1996.

6.2.3.1.3 Re-audit January 2001:
Twenty patients were randomly selected to receive patient questionnaires from a list of 39 who were invited to attend “Getting to Grips with MS” courses during 2000, with a 65% response rate. Again, nine randomly selected Medical/MS Nursing notes were reviewed. All of these patients received their diagnosis during 2000.

Sex distribution and exact time since diagnosis were unknown in the final groups due to the anonymous nature of the questionnaire.
Questionnaires were mailed with stamped, addressed envelopes and a covering letter indicating the purpose of the audit, how their name was chosen and giving guarantees of anonymity (see Appendix 13). From results of each of the three measurement tools a simple percentage analysis was made, based on the total number of responses for each question.
Comparative audit of standard when patients were diagnosed with Multiple Sclerosis

Results
Date of audits: January 2000 and 2001

Results are presented as they relate to each question in the audit tool. Audit of the standards took place from 3 perspectives: a review of evidence from a sample of medical and nursing notes and a postal patient satisfaction questionnaire.

A) Review of medical records:

1. Does time from receipt of GP referral to 1st appointment correspond to consultant's view of clinical need?

   Note: In both cases it was not possible to detect neurologist's view of urgency from clinic letters, but actual times between referral and clinic appointment fall into following categories:

<table>
<thead>
<tr>
<th></th>
<th>2000</th>
<th></th>
<th>2001</th>
</tr>
</thead>
<tbody>
<tr>
<td>Urgent = with 1 week?</td>
<td>4/9 (44.4%)</td>
<td>Urgent = with 1 week?</td>
<td>4/9 (44.4%)</td>
</tr>
<tr>
<td>Semi-urgent = within 4 weeks?</td>
<td>1/9 (11.1%)</td>
<td>Semi-urgent = within 4 weeks?</td>
<td>1/9 (11.1%)</td>
</tr>
<tr>
<td>Routine = within 12 weeks?</td>
<td>4/9 (44.4%)</td>
<td>Routine = within 12 weeks?</td>
<td>4/9 (44.4%)</td>
</tr>
</tbody>
</table>

2. Is appointment to discuss diagnosis within 8 weeks of initial consultation with neurologist?

<table>
<thead>
<tr>
<th></th>
<th>2000</th>
<th></th>
<th>2001</th>
</tr>
</thead>
<tbody>
<tr>
<td>YES</td>
<td>6/9 (66.6%)</td>
<td>YES</td>
<td>8/9 (88.8%)</td>
</tr>
<tr>
<td>NO</td>
<td>2/9 (22.2%)</td>
<td>NO</td>
<td>1/9 (11.1%)</td>
</tr>
</tbody>
</table>

   1 x unclear as date not recorded (notes missing in clinic)

3. If no, how long between appointments?

<table>
<thead>
<tr>
<th></th>
<th>2000</th>
<th></th>
<th>2001</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 x 10 weeks</td>
<td></td>
<td>1 x 12 months</td>
<td></td>
</tr>
<tr>
<td>1 x 13 weeks</td>
<td></td>
<td>(referred by Ophthalmologist and lengthy tests to confirm diagnosis)</td>
<td></td>
</tr>
<tr>
<td>(delay also related to notes missing in clinic)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

4. Who gives the patient their diagnosis?

<table>
<thead>
<tr>
<th></th>
<th>2000</th>
<th></th>
<th>2001</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Consultant</td>
<td>9/9</td>
<td>(100%)</td>
<td>Consultant</td>
<td>8/9</td>
</tr>
<tr>
<td>Specialist Registrar</td>
<td>0/9</td>
<td>(0%)</td>
<td>Specialist Registrar</td>
<td>1/9</td>
</tr>
<tr>
<td>SHO</td>
<td>0/9</td>
<td>(0%)</td>
<td>SHO</td>
<td>0/9</td>
</tr>
<tr>
<td>Other</td>
<td>0/9</td>
<td>(0%)</td>
<td>Other</td>
<td>0/9</td>
</tr>
</tbody>
</table>

5. Evidence that patient is given written contact details of MS Specialist Nurse / MS Society / MS Therapy Centre in clinic for future reference?

<table>
<thead>
<tr>
<th></th>
<th>2000</th>
<th></th>
<th>2001</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>No mention of MS Society / MS Therapy Centre</td>
<td>0/9</td>
<td>(0%)</td>
<td>No mention of MS Society / MS Therapy Centre</td>
<td>0/9</td>
</tr>
<tr>
<td>Patient told of MS Specialist Nurse</td>
<td>3/9</td>
<td>(33.3%)</td>
<td>Patient told of MS Specialist Nurse</td>
<td>8/9</td>
</tr>
<tr>
<td>Copy of clinic letter to MS Specialist Nurse</td>
<td>3/9</td>
<td>(33.3%)</td>
<td>Copy of clinic letter to MS Specialist Nurse</td>
<td>5/9</td>
</tr>
</tbody>
</table>

(1 patient with no mention of MS Specialist Nurse was Private)

No evidence from notes that any written details were given to patients in either audit.

B) Review of MS Specialist Nurse records:

1. Do records show contact with patient (phone or face to face)?

<table>
<thead>
<tr>
<th></th>
<th>2000</th>
<th></th>
<th>2001</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Within 7 days of diagnosis in clinic?</td>
<td>YES</td>
<td>3/9      (33.3%)</td>
<td>Within 7 days of diagnosis in clinic?</td>
<td>YES</td>
</tr>
<tr>
<td>At a later date?</td>
<td>YES</td>
<td>5/9      (55.5%)</td>
<td>At a later date?</td>
<td>YES</td>
</tr>
<tr>
<td>Time elapsed: 5wks, 6wks, 8wks, 10 wks and 3 yrs (diagnosed pre 1998)</td>
<td>i.e. 3/9</td>
<td>had contact within 1 month of diagnosis</td>
<td>(33.3%)</td>
<td>i.e. 7/9</td>
</tr>
</tbody>
</table>

No nursing notes x 1
2. Do records show evidence of written/audio/video information given/sent/offered to patient?

<table>
<thead>
<tr>
<th>Year</th>
<th>YES</th>
<th>NO</th>
<th>No nursing notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>2000</td>
<td>5/9 (55.5%)</td>
<td>3/9 (33.3%)</td>
<td>x 1</td>
</tr>
<tr>
<td>2001</td>
<td>6/9 (66.7%)</td>
<td>2/9 (22.2%)</td>
<td></td>
</tr>
</tbody>
</table>

3. Do records show evidence that patient is made aware of or invited to “Getting to Grips” courses?

<table>
<thead>
<tr>
<th>Year</th>
<th>YES</th>
<th>NO</th>
<th>No nursing notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>2000</td>
<td>3/9 (33.3%)</td>
<td>5/9 (55.5%)</td>
<td>x 1</td>
</tr>
<tr>
<td>2001</td>
<td>1/9 (11.1%)</td>
<td>8/9 (88.9%)</td>
<td></td>
</tr>
</tbody>
</table>

**Note:** All patients in these two samples should have, by definition received an invitation to attend “Getting to Grips” courses although this was not often recorded as a nursing intervention in their individual notes.

C) **Patient postal questionnaire**

Twenty patients were randomly selected from each of two groups: these groups consisted of those who were invited to attend “Getting to Grips with MS” courses during 1999 and during 2000. Patients in each group had received a diagnosis of MS in the previous 6 to 12 months.

<table>
<thead>
<tr>
<th>Questionnaire in 2000</th>
<th>Questionnaire in 2001</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. At the time of diagnosis, did you feel that the explanation of MS you were given by the doctor was ....</strong></td>
<td><strong>Too brief</strong></td>
</tr>
<tr>
<td>Too brief</td>
<td>8/13 (61.5%)</td>
</tr>
<tr>
<td>About right</td>
<td></td>
</tr>
<tr>
<td>Too detailed</td>
<td>0/13 (0%)</td>
</tr>
</tbody>
</table>

*2 of the 15 patients did not respond.

2. On the day you were diagnosed, were you given contact numbers for:

<table>
<thead>
<tr>
<th>The MS Specialist Nurse?</th>
<th>The MS Society?</th>
<th>The MS Therapy Centre?</th>
</tr>
</thead>
<tbody>
<tr>
<td>5/15 (33.3%)</td>
<td>0/15 (0%)</td>
<td>0/15 (0%)</td>
</tr>
</tbody>
</table>

Any other helpful services?

| 0/15 (0%) |

The MS Specialist Nurse? | The MS Society? | The MS Therapy Centre? |
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>8/13 (61.5%)</td>
<td>2/13 (15.4%)</td>
<td>0/13 (0%)</td>
</tr>
</tbody>
</table>

Any other helpful services?

| 0/13 (0%) |
Note: In addition, two patients were told that their details would be given to the MS Specialist Nurse who would contact them. One was told to ring the doctor's secretary to find out the MS Specialist Nurse's contact details. So in effect, approximately ½half of the sample were aware of the existence of a local MS Specialist Nurse.

Note: In addition, one person was told that the doctor would pass on her details to the MS Specialist Nurse, who got in contact. Another was given details of the MS Specialist Nurse and MS Society at a later date, she feels “because she was upset”. Therefore over ¾ three quarters of the sample were aware of the existence of a local MS Specialist Nurse. One commented that although told about the above, “a written information pack would be better as by then you are just intent on not bursting into tears.”

3. Did you speak to the MS Specialist Nurse during the following week?

<table>
<thead>
<tr>
<th></th>
<th>YES 4/15 (26.6%)</th>
<th>NO 11/15 (73.3%)</th>
<th>YES 5/13 (38.5%)</th>
<th>NO 8/13 (61.5%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>If not, was this your choice?</td>
<td>YES 4/15 (26.7%)</td>
<td>NO 6/15 (40%)</td>
<td>YES 4/13 (30.8%)</td>
<td>NO 4/13 (30.8%)</td>
</tr>
</tbody>
</table>

Note: One patient who had the Nurse's details chose to delay contact for 4 weeks to “let it sink in”. It is not known whether the 6 (40%) who felt they had no choice were dissatisfied with this. 12 of the 15 (80%) eventually had contact with the MS Specialist Nurse.

Note: Of the 8 who did not see the Nurse during the following week, for 4 people this was their own choice. Again it is not known whether the 4 (30.8%) who felt they had no choice were dissatisfied with this. 10 of the 13 (76.9%) eventually had contact with the MS Specialist Nurse.

4. If you had contact, did you feel that the information/help you were given by the MS Specialist Nurse was:

<table>
<thead>
<tr>
<th></th>
<th>Too brief? 0/12 (0%)</th>
<th>About right? 12/12 (100%)</th>
<th>Too detailed? 0/12 (0%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Too brief? 0/9 (0%)</td>
<td>About right? 9/9 (100%)</td>
<td>Too detailed? 0/9 (0%)</td>
</tr>
</tbody>
</table>

Note: One patient commented that although OK, information tended to be about general symptoms rather than his own.
5. In the months following your diagnosis how did you feel about knowing where to find MS information?

**Figure 3  Confidence in knowing where to find MS information**
- year 2000 & 2001

From 1=confident to 10=no idea where to find information

- 2000 N=15
- 2001 N=13
6. In the months following diagnosis, to what extent did you feel support was available to help you cope with your MS?

**Figure 4** Did you feel support was available?

1 = feeling support was available to 10 = feeling totally alone in coping with MS

<table>
<thead>
<tr>
<th>Year</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>2000</td>
<td>15</td>
</tr>
<tr>
<td>2001</td>
<td>13</td>
</tr>
</tbody>
</table>

1=feeling support was available to 10=feeling totally alone in coping with MS
7. Were you given information about any courses or meetings for people newly diagnosed with MS, for example “Getting to Grips with MS” courses?

<table>
<thead>
<tr>
<th>Year</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>2000</td>
<td>12/15 (80%)</td>
<td>3/15 (20%)</td>
</tr>
<tr>
<td>2001</td>
<td>8/13 (61.5%)</td>
<td>4/13 (30.8%)</td>
</tr>
</tbody>
</table>

8. If you attended one of these courses, how helpful did you find it?

**Figure 5 Usefulness of "Getting to Grips" courses**

From 1=very helpful to 10=not at all helpful

- 2000 N=11
- 2001 N=6
<table>
<thead>
<tr>
<th>Year</th>
<th>Suggestions</th>
</tr>
</thead>
<tbody>
<tr>
<td>2000</td>
<td>a. Advise patients to take someone with them. Quicker service between diagnosis and useful contacts.</td>
</tr>
<tr>
<td></td>
<td>b. Speak to Nurse about MS to let you know what you might experience.</td>
</tr>
<tr>
<td></td>
<td>c. I had my consultations and MRI scan privately, so I think that had I used the NHS I would have been</td>
</tr>
<tr>
<td></td>
<td>more aware of the support available. As it was, I found out myself and friends helped.</td>
</tr>
<tr>
<td></td>
<td>d. I do suggest that when a patient goes in for results, that it's emphasized that they do have company,</td>
</tr>
<tr>
<td></td>
<td>whether results are good or otherwise.</td>
</tr>
<tr>
<td></td>
<td>e. Provide details of the MS Therapy Centre at the time of diagnosis. Apart from N (MS Specialist</td>
</tr>
<tr>
<td></td>
<td>Nurse) I did not know where else to go for help. I stumbled upon the Centre by accident approximately</td>
</tr>
<tr>
<td></td>
<td>5 months after diagnosis. When I did find it I felt a lot less alone and was able to help myself more.</td>
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<td></td>
<td>f. The consultant at the hospital had the attitude ‘This is what you have, there is no cure, so just go</td>
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<tr>
<td></td>
<td>away and get on with it’.</td>
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<td></td>
<td>g. I was diagnosed and told that possibly in 10 years time I would be in a wheelchair. If I had an</td>
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<td></td>
<td>opportunity then to see the positive approach taken by the MS Therapy Centre, this would have been</td>
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<tr>
<td></td>
<td>helpful. GP’s attitude tended to be ‘It’s up to you to get on with your life. There’s nothing that can</td>
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<tr>
<td></td>
<td>be done’.</td>
</tr>
<tr>
<td></td>
<td>h. Some sort of MS Group for people with MS - it would have been so helpful to talk to other MS people</td>
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<tr>
<td></td>
<td>and no matter how helpful other people are, they fail to understand how you feel.</td>
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<tr>
<td></td>
<td>i. A house call from somebody eg. MS Specialist Nurse to explain or answer questions at that time, or</td>
</tr>
<tr>
<td></td>
<td>a counselor - someone who has MS maybe, but not very bad MS as that would only scare.</td>
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<td></td>
<td>j. When given diagnosis I was alone - it would have been helpful to have been advised to bring a</td>
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<tr>
<td></td>
<td>partner/spouse. Appointment when diagnosis was given was very short/to the point - ‘Yes you’ve got MS -</td>
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<tr>
<td></td>
<td>sorry nothing we can do for you’. N (MS Specialist Nurse) and MS Therapy Centre have been a lifeline and</td>
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<tr>
<td></td>
<td>made accepting the disease much easier.</td>
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<tr>
<td></td>
<td>k. Perhaps if you could see the MS Specialist Nurse straight after the diagnosis.</td>
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<tr>
<td></td>
<td>l. I think it would be very helpful if various leaflets about MS with contact numbers were given to</td>
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<td></td>
<td>patients at the time of diagnosis.</td>
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<td></td>
<td>m. When you do the courses make sure you can fit on the course everyone who you have sent a letter to,</td>
</tr>
<tr>
<td></td>
<td>as I want to attend but there was only 12 spaces.</td>
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<table>
<thead>
<tr>
<th>Year</th>
<th>Suggestions</th>
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<tbody>
<tr>
<td>2001</td>
<td>a. Everybody’s needs are different at the time of diagnosis. I felt that all the help was there if</td>
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<tr>
<td></td>
<td>needed. ‘Getting to Grips with MS’ course was very helpful.</td>
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<td></td>
<td>b. N (MS Specialist Nurse) was excellent. I am a mild case if a case at all (!) so don’t need any</td>
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<td></td>
<td>services.</td>
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<td></td>
<td>c. I was quite disappointed when I sent a letter back regarding the ‘Getting to Grips with MS’</td>
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<tr>
<td></td>
<td>asking for them to put me in touch with someone with mild MS - I heard nothing. I wasn’t ready for a</td>
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<td></td>
<td>group course but felt I could have benefited from a one-to-one with someone who had the same type as</td>
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<tr>
<td></td>
<td>me. N (MS Specialist Nurse) has been wonderful though.</td>
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<td></td>
<td>d. I think a follow-up appointment with the neurologist would have been helpful, maybe a month later</td>
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<td></td>
<td>- not just to be told ‘If you need to talk, call me’, because I felt that I didn’t want to bother him.</td>
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<td></td>
<td>e. Have all the information, photos, results at hand as I was left on my own whilst the specialist</td>
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<tr>
<td></td>
<td>went to find the pictures of my MRI, after he told me that the scan had found something. I was then</td>
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<td></td>
<td>too nervous when he got back to take on board anything that was explained to me.</td>
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<td></td>
<td>f. An information pack at diagnosis. Maybe a follow-up after 6 months so you don’t feel like ‘You’ve</td>
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<td></td>
<td>got MS - goodbye’.</td>
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<td></td>
<td>g. A conversation about MS and how it might develop.</td>
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<td></td>
<td>h. I think it would help if there was some sort of ‘case conference’ between the MS Specialist Nurse,</td>
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<tr>
<td></td>
<td>MS Society and Social Services (with the patient) to discuss the condition, the severity, the help</td>
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<td>that can be provided and how to get it.</td>
</tr>
<tr>
<td></td>
<td>i. Be more truthful. I was simply told to go out, live as normally as possible. I was not told until</td>
</tr>
<tr>
<td></td>
<td>I saw N (MS Specialist Nurse) about the irritating and annoying aspects of MS.</td>
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<tr>
<td></td>
<td>j. Talk to the consultants. If only they could come over more positive to patients. It does not help</td>
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<tr>
<td></td>
<td>when one is told ‘I don’t want to see you again - there is nothing I can do for you’.</td>
</tr>
<tr>
<td></td>
<td>k. Initial contact was with a neurologist at ‘Hospital A’. The doctors I have seen at ‘Hospital B’</td>
</tr>
<tr>
<td></td>
<td>have been much better that at ‘A’, so thank you!</td>
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6.2.3.1.4 Discussion

i) Audit of written records

a) Medical records

The intervals between receipt of GP referral and first appointment with the neurologist were identical in 2000 and 2001. Although not possible to detect the neurologist's view of urgency from clinic letters in either sample as planned, in both cases over half the sample (5/9) had appointments with the neurologist within four weeks of GP referral. In addition, most of these were seen within one week of referral. No patient waited longer than 12 weeks for an initial appointment and there were no patient comments expressing dissatisfaction with this waiting time, although this was longer than recommended in the MS Society Standards of Healthcare (Freeman, Johnson, et al 1997).

In the first sample 66.6% (6/9) completed investigations and were told their diagnosis within eight weeks of the initial consultation, as per MS Society recommendations and the related local standard based in this, although one patient waited ten weeks and one 13 weeks. Two occasions of medical notes being missing from clinic contributed to delays.

In the second sample 12 months later, those meeting this eight week deadline for completing investigations and being told their diagnosis had increased to 88.8%. The one patient exceeding this had an atypical presentation and required extensive tests to confirm the diagnosis.

All patients in the first sample and all but one in the second received their diagnosis from a Consultant Neurologist as per MS Society and local standards.

Evidence of appropriate support at diagnosis was less clear. In the first sample in 2000 there was circumstantial evidence from the medical
records that 33.3% (3/9) patients were referred to the MS Specialist Nurse and 33.3% told of her existence. It is unclear from the notes whether patients were given any written information at this time. This corresponds to patient reports that only a third were given contact numbers for the MS Specialist Nurse and none had additional sources of information, for example MS Society or MS Therapy Centre details at diagnosis.

However, in the second sample there was an improvement, with written evidence of 88.9% (8/9) of patients being told of the MS Specialist Nurse's service and a copy of the clinic letter being sent to the MS Specialist Nurse in 55.5% of cases. This also corresponds to an improvement noted in the patient questionnaires, where over ¾ three quarters of this sample were aware of potential support available from the MS Specialist Nurse following the consultation. Again, there was no documentary evidence of other services such as the MS Society or MS Therapy Centre being discussed by neurologists, and no evidence of written information being given to consolidate discussions in the sample of nine records audited.

It is interesting to note that the one patient without evidence of MS Specialist Nurse referral or information in the second sample was treated privately, a point which was also raised by a patient in the first audit questionnaires, as well as in initial stakeholder interviews. It would be interesting to explore the prevalence and the likely mechanisms of this among patients diagnosed privately.

Therefore, although only a proportion of the standard was met, there appeared to be a moderate improvement and more consistent referral to the MS Specialist Nurse, as indicated through the documentation. However, not all patients were empowered to make contact with the MS Specialist Nurse themselves during the early stages.
b) Nursing records

Nursing notes were available either as separate files or as comments in the medical notes or both.

In the first sample in 2000, 8/9 records showed contact with the MS Specialist Nurse, but in the one remaining case, nursing notes were not available. For 33.3% (3/9) of patients, contact occurred within seven days of diagnosis, as identified by the local standard. The remaining 5/9 had contact at a later date, mostly between five to ten weeks following diagnosis. However, only 33.3% of the whole sample in 2000 had had contact within one month of their diagnosis.

In contrast, none of the second sample had contact with the MS Specialist Nurse within the first seven days after diagnosis, but this was replaced by more consistent contact within one month of diagnosis (77.8% within one month compared to 33.3% in the first sample). This was thought likely to be a reflection of the changing workload as the post became established, moving from a caseload of approximately 69 around the time of the initial audit to over 200 by the second. In addition, information from the patient questionnaires in both samples demonstrate that, for a proportion of patients (approximately 30%), delaying contact with the MS Specialist Nurse beyond one week from diagnosis was their own choice.

MS Society Standards recommend written information or packs be provided at or around diagnosis to consolidate any verbal information given (Freeman, Johnson et al 1997). This acknowledges the limited ability of many patients to assimilate information during such emotionally charged consultations, a point which was echoed in a comment from one of the patient questionnaires.
In the first sample 5/9 (55.5%) of records suggest written/audio/video information being given or sent to patients. There was slightly more evidence of this in the second audit (66.7%), although on discussion with the MS Specialist Nurse, written records in either case may not fully demonstrate the extent of this practice.

By definition, patients in both 2000 and 2001 samples should have been invited to attend “Getting to Grips with MS” courses for the newly diagnosed, as their names were selected from lists of these. Such courses contribute towards meeting the MS Society Standards of Healthcare recommendations that continuing education in the form of information sessions should be available locally, bringing people and their families in contact with others in the same situation. Although lists were available of those invited to attend, in both 2000 and 2001 this was not consistently mentioned as part of the care in all relevant individual patient records. In addition, documentation of this tended to decrease in the second sample. 33.3% of the first sample but only 11.1% of the second sample showed evidence that “Getting to Grips with MS” courses had been discussed. Lack of documentary evidence may not reflect the actual support offered to patients, but given the high value patients place on attendance at these courses (see patient questionnaire results) this could be seen as one important indicator of the quality of the service provided. Systematic documentation was highlighted as an area for further development.

Overall, written records suggested the pattern of the MS Specialist Nurse’s service to newly diagnosed patients changed over the audit period, probably to accommodate the demands of a developing caseload. In addition, reflection on the process components of the standard over the previous year suggested that a long-term secretarial shortage may have contributed to delays in notifying the MS Specialist
Nurse about newly diagnosed patients in time to meet the seven day target.

However, the audit demonstrated improvements in that considerably more patients in the second sample had contact with the MS Specialist Nurse within four weeks of diagnosis. It can be argued that providing contact for patients more consistently between one and four weeks following diagnosis is a more appropriate and achievable standard and represents a high quality service, providing patients who needed to make contact urgently were given sufficient information at diagnosis to be able to do this. Medical records and patient questionnaires suggested this was not always consistent and formed another area for potential service development.

ii) Patient satisfaction questionnaire

Twenty nine patients were invited to attend “Getting to Grips with MS” courses during 1999, and this increased by over a third to 39 in 2000. Despite local support services (i.e. MS Specialist Nurse, MS Society branches, MS Therapy Centre) being available for newly diagnosed patients in 1998/99, the patients' perspective from the first questionnaire in January 2000 also suggested some inconsistency in providing patients with sufficient information and contact details to meet their needs. The following is a summary and discussion of points from the questionnaires.

Almost two thirds of patients (61.5%, 8/13) in the first sample felt the explanation of MS from the doctor at the time of diagnosis was too brief, while the remainder (38.5%) felt it was about right. There was an improvement in the second sample, where slightly more patients felt the explanations given were about right (46.2%), but just over half (53.8%) still felt that explanations were too brief. In no cases did patients feel that too much information was offered.
In the first sample only a third of patients reported being given direct contact details for the MS Specialist Nurse and none received details of the MS Society or Therapy Centre. Two patients were also told that their details would be given to the MS Specialist Nurse who would contact them. One was told to ring the doctor's secretary to find out the MS Specialist Nurse's contact details. So in effect, approximately ½ half of the sample were aware of the existence of a local MS Specialist Nurse, although not all of these were able to contact her themselves. This broadly corresponded with findings from the medical records.

In the second sample, the number receiving MS Specialist Nurse contact details increased to 61.5%, with 15.4% also receiving details of the local MS Society. A further person was told that the doctor would pass on her details to the MS Specialist Nurse, who then got in contact. Another was given details of the MS Specialist Nurse and MS Society at a later date, she felt “because she was upset” following the consultation. Therefore, although the standard was not met, there was progress towards it, with over three quarters ¾ of the sample being aware of the existence of a local MS Specialist Nurse. One commented that although told about the above, “a written information pack would be better as by then you are just intent on not bursting into tears.” This highlights that although the availability of support from the MS Specialist Nurse was more widely known in 2001, receiving a diagnosis of MS was still a very emotionally demanding time for patients, with implications for the amount of information some patients can assimilate at that time.

In both 2000 and 2001, half of the patients who were made aware of the MS Specialist Nurse did have contact during the week following diagnosis, as proposed by the standard. However, one patient's comment that time was needed to “let it sink in” (four weeks)
suggested this may not suit all patients and an important principle would seem to be the provision of sufficient information for patients themselves to choose if and when to make contact. In both samples, patients who eventually had contact with the MS Specialist Nurse were unanimously satisfied with the level of information and help they were given. As individuals, these patients also tended to be located in the positive half of the Likert scale in terms of feeling they knew where to find information and feeling support was available.

In the first sample, the degree of confidence in knowing where to find MS information was variable. Encouragingly a third felt confident, but one person had no idea of where to find information. In the second sample in 2001, over 45% felt confident of where to find information but there were a number who were still unsure. None in the second sample reported having no idea of where to find MS information (Figure 3). It was not possible to determine whether the main cause of this shift towards confidence can be attributed entirely to the availability of a local MS Specialist Nurse, given the small sample, but the trend is encouraging.

The extent to which patients felt that support was available to help them cope with their MS was again variable (Figure 4). There was little substantial difference between the two audits. The most common responses were that patients did feel that support was available, but there were still a number who felt alone in coping with MS.

With reference to the six monthly local “Getting to Grips with MS” courses, the audit process highlighted a potential problem with the administrative system of inviting all newly diagnosed people and their families to attend (Figure 5). The questionnaire sample in each case was randomly selected from populations who were listed as having been invited to attend courses during the previous year. The finding that
only 80% of the first sample and 61.5% of the second sample reported being given any information about such courses suggested the need to develop a more robust system of recording those who had been invited. The audit of nursing records raised corresponding issues for further development.

Of those who attended “Getting to Grips with MS” courses, over 80% of the first sample and 100% of the second sample found them helpful. However, more patients in the first sample were emphatic about this (72.7% found them very helpful compared to 50% in 2001). This corresponds with the MS Specialist Nurse's reflections on courses in the second year and comments from the evaluation forms, where accommodation had been an issue. This problem prevented partners meeting separately from people with MS and having the opportunity to discuss their own concerns. This was seen as a factor contributing to slightly less well evaluated courses in the second year. However, the “Getting to Grips with MS” courses emerged as a very valuable aspect of the support available to newly diagnosed patients in both audits.

The section asking for comments on how to provide a better service to patients around the time of diagnosis provided some powerful evidence and useful insights into their experiences. The feeling of abandonment by the healthcare system was an obvious feature of the first set of comments, for example:

“Provide details of the MS Therapy Centre at the time of diagnosis. Apart from N (MS Specialist Nurse) I did not know where else to go for help. I stumbled upon the Centre by accident approximately five months after diagnosis. When I did find it I felt a lot less alone and was able to help myself more. I used the Centre's Counsellor and know that there are many more facilities to use should I need them. Approximately a
month after finding the Centre I was invited to the ‘Getting to Grips' course”.

“If it wasn't for N (MS Specialist Nurse) and the MS Therapy Centre I would have felt very alone, as the consultant at the hospital and my own GP didn't provide me with any information on the disease or help. The consultant at the hospital had the attitude ‘This is what you have, there is no cure, so just go away and get on with it’.”

“GPs’ attitude tended to be 'It's up to you to get on with your life. There's nothing that can be done”.

“Appointment when diagnosis was given was very short/to the point - 'Yes you've got MS - sorry nothing we can do for you'. N (MS Specialist Nurse) and MS Therapy Centre have been a lifeline and made accepting the disease much easier”.

These comments on abandonment clearly reflected another main theme arising from the first round of in-depth patient interviews. As with findings from the subsequent round of interviews, this feeling of abandonment was less obvious in the second audit, but was still referred to by some people. This suggested further work to review how future support and follow-up arrangements are presented to people at the time of diagnosis. Patients' suggestions of a routine medical follow-up six months after diagnosis was one potential service development to be considered.

Other recurrent themes from patients' suggestions provided useful evidence on which to base future practice developments. One theme highlighted the desirability of being accompanied by a relative or friend where possible when the diagnosis is discussed. Another
common theme was how valuable contact with the MS Therapy Centre had been for most patients, underlining the importance of giving contact details about this as soon as possible. Again, early provision of sufficient information for patients to choose who or where to contact would seem appropriate. This reflects the need for information, frequently expressed in the literature, in order for people with MS to have a sense of personal control (Hatch 1997, Miller 1993, Mills and Sullivan 1999, Sheridan 1997, Freeman, Johnson et al 1997).

Overall, patients' comments gave a clear indication of the valuable role that many of them felt the MS Specialist Nurse had played in giving information and support around the time of diagnosis:

“Apart from N (MS Specialist Nurse) I did not know where else to go for help”.

“If it wasn't for N (MS Specialist Nurse) and the MS Therapy Centre I would of felt very alone…”

“N (MS Specialist Nurse) and MS Therapy Centre have been a lifeline and made accepting the disease much easier”.

“Perhaps if you could see the MS Specialist Nurse straight after the diagnosis”.

“Be more truthful. I was simply told to go out, live life as normally as possible. I was not told until I saw N (MS Specialist Nurse) about the irritating and annoying aspects of MS”.

“N (MS Specialist Nurse) was excellent”.

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6.2.3.1.5 Conclusion

This audit provided multiple perspectives on local management at and around the time of diagnosis, highlighting strengths and weaknesses and providing the impetus for future multidisciplinary service developments. Although the standard was fully met in only a few areas, an improving trend was demonstrated. Detailed analysis of the audit trail and patient experiences identified key areas for the MS Specialist Nurse and other members of the team to focus on and contributed to a more informed revision of the standard for future use.

6.2.3.1.6 Recommendations

Suggested action plans for improvements in service:

- Consider ways of suggesting (without causing alarm) that patients bring along support when the diagnosis is discussed.

- Consider ways of ensuring patients feel the early explanation of MS from the neurologist is adequate. For example the MS Specialist Nurse routinely checks this on first contact and offers further explanations/answers questions when the patient has had time to think these through. Consider routine follow-up appointments with neurologist for all newly diagnosed patients or longer initial appointment time with neurologist.

- Compare structure and process aspects of diagnosis as a private patient with the NHS system to identify potential ways of ensuring patients receive adequate support and information.

- Devise, and ensure all neurology clinics have supplies of written contact details for the MS Specialist Nurse, MS Therapy Centre and MS Society to be routinely given to patients at time of diagnosis by neurologists. Include an outline of the MS Specialist Nurse role and, in an attempt to avoid feelings of abandonment by the doctor, include a statement that the focus for the patient following diagnosis is likely to change from medical to one of learning to live with MS. In this case more non-medical sources of advice such as
the MS Specialist Nurse, MS Therapy Centre and MS Society are likely to prove helpful. Explore option of giving out ready-made local Reading Branch newly diagnosed information leaflet routinely in clinic.

- Ensure all clinic letters sent to GPs regarding newly diagnosed patients are consistently copied to MS Specialist Nurse for information within four days.
- Review labour-saving ways of consistently recording that nursing interventions are carried out, for example, more use of signed, dated “tick-boxes” to enable easy review of quality indicators (for e.g. patients invited to “Getting to Grips with MS” courses) for audit purposes.

6.2.3.2 Standard II: Education for Formal Carers

6.2.3.2.1 Method

The researcher facilitated writing a second overall standard statement to apply to the local MS Specialist Nurse’s programme of activities for providing educational support to paid formal carers (i.e. any hospital or community staff employed to provide day-to-day care to people with MS).

STANDARD STATEMENT: Paid/formal carers will feel that their MS related knowledge, skills and care-giving is enhanced by support and education initiatives provided by, or with input from the MS Specialist Nurse.

This standard was identified as an important area for development following preliminary analysis of patient interview data and the priority given by the MS Specialist Nurse to formal and informal teaching of staff engaged in the paid care of people with MS. The findings from the interviews revealed that patients identified an urgent need for education and training of staff at all levels to enable them to
understand the complex needs of people with MS and to meet those needs more effectively. Following presentation of the findings to the Steering Group it was agreed that the standard should be developed on structure-process-outcome lines drawing on the interview findings, the MS Specialist Nurse's expertise and the MS Society's document, *Standards of healthcare for people with MS* (Freeman, Johnson et al 1997). The authors highlight the need for MS specialists to disseminate their considerable expertise and experience to their non-specialist colleagues and recommend the following standards as a means to achieve this:

- Education and training programmes should be developed for qualified and unqualified staff and carers. These could be provided in local clinics and resource centres and in addition to individual teaching for carers and staff, as part of a period of inpatient rehabilitation for people with MS.

- Neurological specialists should act as education and training consultants in order to maximise professional expertise. Experienced professionals should take responsibility for disseminating specialist information through publications and conferences. (Freeman, Johnson et al 1997, p.8)

Stakeholders (see section 6.2.2 above) identified the MS Specialist Nurse in this light and described her as the key facilitator on up-to-date knowledge and practice about MS in primary, social and hospital care. Furthermore, her formal educational role was highly valued.

Following the preparation of a draft, drawing on the identified sources, the Steering Group were invited to make comments for further modification of the standard (see Appendix 14). A number of pertinent issues were also raised by Steering Group members. For example, it was noted that given the pattern of social services provision, 80% of
“hands on” care was delivered by private care agencies where time out for staff education was difficult to establish. In particular it was suggested that staff who did not provide continuous care to clients had specific educational needs in terms of learning to develop effective strategies for caring for people with complex problems associated with chronic conditions. The head of Priority Care viewed continuity as crucial to the provision of quality care. In the case of MS, the issue of continuity was reported to be compromised because employers found difficulty retaining staff who experienced caring for some people with MS as frustrating and difficult. This was why the head of Priority Care saw education as a key way to enable carers to understand and hence support them to provide better care, improve continuity and increase their job satisfaction. The need for private agencies to incorporate staff training into their service provision as a feature of the Social Services' purchasing strategy was one way to increase the likelihood that carers' educational requirements would be met.

Other issues raised concerned who should be the recipients of educational initiatives in terms of levels of hospital and community nursing staff. A number of approaches were proposed. One approach was to “train the [potential] trainers” i.e. F,G grade ward nurses and district nurses with the purpose of cascading knowledge to less experienced and more junior staff. Another approach was for the MS Specialist Nurse to take advantage of existing educational opportunities (including local forums and courses aimed at D and E grade nurses) to reach a wide range of staff.

6.2.3.2.2 Evaluation

Standard II was evaluated by means of postal questionnaires and an educational evaluation of a series of study days provided by the MS Specialist Nurse. Postal questionnaires were sent to nurses working on hospital wards where the MS Specialist Nurse was based and
community care staff who worked in the local Priority Care service with an accompanying letter (Appendix 15). Two postal questionnaires were specifically designed for this purpose (See Appendix 16 and 17). In addition the form used by the MS Specialist Nurse to evaluate study days attended by Social Services home carers provided valuable data which could be applied to the standard (See Appendix 18). In summary the data sources were as follows:

6.2.3.2.3 Sample

i) Registered Nurse Questionnaires
A total of 24 forms were sent to four wards, following telephone agreement from a senior member of the ward nursing staff. A total of six completed forms were received. Follow up telephone calls did not elicit any further responses and the reason for this was assumed to be because of high work load and lack of direct contact with the researcher.

ii) Carers' Questionnaires
A total of ten questionnaires were sent to Priority Care staff via a senior staff member, for distribution to carers. No responses were received by the return date and follow up proved difficult despite a number of follow up telephone calls. Sickness, holidays and workload on both sides, were acknowledged to have contributed to this situation.

6.2.3.2.4 Data Sources
- Evaluation form summaries from Social Services Carers who had attended a half day study day provided by the MS Specialist Nurse.
- Questionnaire results from Registered Nurses working within the local hospital, on wards that provide care/services for people with Multiple Sclerosis.
• Questionnaires sent to the Community Care service manager for distribution to paid carers (no data obtained).

i) Evaluation Form Summaries
A total of four summary forms were analysed from single half day study days given by the MS Specialist Nurse. The study days were arranged by the Social Services Department and were primarily for paid non-registered care staff. Some care staff had NVQ in Care qualifications. Some Social Workers also attended, though numbers were not recorded.

The summaries consisted of a total of 49 individual evaluation forms. The evaluation form had eight questions which were rated from 1 = Poor through to 5 = Excellent.

The questions asked were:

1. How well did the training meet the course aims and objectives?
2. How well did the trainer present the training?
3. How well did the pace and content of the course suit you?
4. How well did the running of the training and its content address equalities issues?
5. How well will what you have learnt help you in your work?
6. What are the most useful things that you have learnt?
7. How well did the training room, refreshments and other practical arrangements meet your needs?
8. Do you have any further training needs on this topic?

6.2.3.2.5 Analysis
The data gathered to audit the standard for the education of paid carers was analysed according to the responses and comments obtained to the structured questionnaires and evaluation forms. The
data was then used as evidence to compare against each outcome statement (1-7) within the standard as elaborated below:

6.2.3.2.6 Findings

i) Appropriate staff are offered opportunities to attend courses which cover practical aspects of MS care provision.
Registered nurse questionnaires indicated that staff would like to have study days/ in service training offered to them.

The carers’ programme was devised by the County Council Department Training Officer in conjunction with the MS Specialist Nurse in response to carers’ requests. Course content was planned by the MS Specialist Nurse and Training Officer to meet group needs. Further requests for training were received from Social Workers and additional courses were planned for 2001.

ii) Staff attending formal courses feel the content and approach is relevant and effectively addresses potential MS related problems they encounter in practice. The responses to this outcome can be identified from the extent to which the carers felt the course met its intended aims. Thirty respondents rated it as excellent (score 5), 19 rated it as good (score 4) and only one rated it as average (score 3).

In relation to pace and content 21 scored it as excellent, 23 as good and 4 as average.

More specific feedback on how it could have assisted them in practice is described in the following section.
iii) Paid carers report:

a) increased understanding of MS related problems and their effects on the individual and the family

Comments indicating that the carers had a greater understanding of the effects on the individual and family are listed below, as are comments on how the Registered Nurses’ considered the MS Specialist Nurse’s advice/support would affect their care delivery.

Carers

- That pain is real! It can hurt just to touch a client with MS
- That it could be the climate, MS is not hereditary
- How important it is to monitor urine and bowel movements
- That the victim cannot help it with muscle spasm (pain can be severe)
- Back up is there for the different problems with this complaint
- A better knowledge of emotional and basic needs of clients and their families who have MS
- A better understanding of the complaint itself and its wide ranging problems including family involvement
- Understanding their needs and the disease and how it progresses
- How to deal with difficult clients with spasms etc
- Useful contact numbers
- Effects of disease and social and medical issues that are from MS
- Effects of finance on client/service provider
- What causes the disease and how it affects the patient and can vary from person to person
- Understanding of an MS client i.e. results of not being given enough time and the problems that can occur
• About spasms and control of them. Also spasms and the use of the hoist
• Frustrations and pain of muscular spasms
• Depression
• Problems with pain relief
• Uncertainty of the disease
• Medication

Registered Nurses:
Q - How has it (contact with The MS Specialist Nurse) affected your care?
• Helped with counselling and have become more aware of problems
• Made us more efficient with caring for MS patients
• Changed how I dealt with a problem
• Enabled us to liaise with the appropriate family member

b) increased confidence and job satisfaction in negotiating and providing practical care for people with MS following formal or informal teaching sessions
This was not assessed following the course in relation to long term learning, although short term reactions included:
• very informative and helpful
• I found the whole course useful
• The overall course is a great help
• All that was mentioned during the course - it is very informative to what MS is, very knowledgeable in every way.
• Know how to deal with certain problems
• A good insight into the condition
• Invaluable for future reference
• I can have a more understanding on MS
iv) More effective resolution of difficulties where carers and clients experience problems in negotiating care

This outcome was not assessed for the carers. Registered nurses indicated they might contact The MS Specialist Nurse in the following circumstances:

- For advice regarding specific patients or advice on certain areas e.g. bladder control/therapies
- If I was experiencing problems with caring for my MS patient
- For newly diagnosed MS patients, for MS patient who had deteriorated or was struggling with problems
- If we had particular problems with discharge planning

Also the section above on how contact with the MS Specialist Nurse had affected their care, gives a further indication of how the registered nurses would deal with situations.

v) Community carers feel able to share and cope more effectively with stress in their MS related work

A response to this outcome was not asked for specifically, although evaluations from the study day includes comments such as:

- That the MS Specialist Nurse is around
- All information useful to pass on to other Health Care Assistants
- All the back up is there for the different problems with this complaint
- What help is available
- Various phone numbers of voluntary agencies e.g. MSS
- Useful contact numbers
- There is a lot of information if needed
- Knowing that there is actually an MS Specialist Nurse available out there
• Occupational Therapy suggestions
• Who to consult for assistance e.g. physiotherapists, district nurses
• Other training courses such as those offered by the Red Cross viz. transferring patients course - for me as a driver of the minibus

vi) **MS Specialist Nurse is made aware in advance of any planned admissions for MS clients with complex needs**

Responses to this outcome statement were not indicated in the Registered Nurse Questionnaire, though responses indicated they would contact the MS Specialist Nurse on admission of patients, especially as they were now aware of how she could help.

One respondent who had not met her indicated s/he would contact her for the reasons indicated in section 4 above.

There was also a suggestion that there was need for increased information on wards/information notices about when, why and how to contact the MS Specialist Nurse.

vii) **In-patient and Nursing Home staff feel they have access to helpful advice and support from the MS Specialist Nurse which enables them to manage moderately to severely disabled MS admissions successfully.**

Nursing Home staff were not questioned on this occasion, although there was a suggestion during one of the Steering Group discussions that local Nursing Homes could be contacted in terms of offering training initiatives. It was thought likely that such an offer would result in one of the Nursing Homes offering to host a study day.
In-patient staff indicated that they understood the MS Specialist Nurse's role to be:

- To support and advise patients who already have Multiple Sclerosis, and those who are newly diagnosed.
- To provide information and advice to ward staff regarding specific patients/queries
- To support staff, families and carers
- To ensure that the patient’s hospitalisation runs as smoothly as possible
- Helps sort out problems
- Helps with discharge planning
- Acts as a resource for family history/dynamics
- Provides information/advice regarding equipment

Specific examples given of her advice on consultation included:

- To obtain an update on MS
- To refer patients
- To ask for advice and further information
- To ask about transferring/specialist equipment
- To obtain advice on urinary/bowel problems
- To gain specific information about the family dynamics of a patient

Hospital staff questioned had not attended any formal study sessions provided by the MS Specialist Nurse, but had consulted her/discussed specific issues and found her to be helpful and supportive.

In response to whether they would like training, most responded positively and indicated that they wished to know more about her role. The use of a ward based information pack was suggested.
6.2.3.2.7 Discussion and Summary

The evidence obtained from questionnaire responses from hospital ward staff and an evaluation of a carers' programme, indicated that the role of the MS Specialist Nurse in advising and teaching formal carers was having a positive effect on their level of understanding and increasing their awareness of the needs of people with MS.

Hospital nurses did not receive but would have liked formal training in the care of people with MS. The MS Specialist Nurse and County Council Training Officer responded to carers' requests and jointly planned a programme to meet group needs.

Comments indicated that community carers had a greater understanding of the effects of MS on the individual and family as suggested by qualitative comments. The Registered nurses also considered that the MS Specialist Nurse’s advice/support would positively affect their care delivery.

For the community carers their immediate assessment of the course was positive and can be summed up in the following two comments: “it was very informative and helpful” and “I can have more understanding on MS”.

There was evidence from the ward nurses' questionnaire that they had been able to resolve difficulties with MS patients and their carers more effectively following contact with the MS Specialist Nurse because she would advise them at critical points of the patient's trajectory. These points included the newly diagnosed, discharge planning and symptom control such as in the case of an exacerbation of physical problems e.g. loss of bladder control.
Community carers commented they felt able to share and cope more effectively with stress in their MS related work following attendance at the study day because they knew help was available from the MS Specialist Nurse, physiotherapist or occupational therapist and they now had an idea of how and where to access information.

Responses to the Registered Nurse Questionnaire, indicated they would contact the MS Specialist Nurse when a patient with MS was admitted especially as they were now aware of how she could help.

The hospital staff viewed the MS Specialist Nurse's role as advising not only the patients but also themselves. The MS Specialist Nurse was described as a problem solver and adviser, but also a resource for the complex physical and psychological problems and family dynamics which they associated with MS patients.

In-patient staff questioned had not attended any formal study sessions provided by The MS Specialist Nurse, but had consulted her/discussed specific issues and found her to be helpful and supportive. In response to whether they would like training, most responded positively and indicated they wished to know more about her role. The use of a ward based information pack was suggested.

The positive evaluation of the carers' courses had resulted in further requests for additional courses in 2001.

Although the data were limited the findings were both positive and promising and suggested the continuation of need for both formal and informal teaching from the MS Specialist Nurse to sustain knowledge about and awareness of MS among non-specialist staff. A more successful response rate to the questionnaires may have been obtained if the researcher had been able to have more direct contact with the
nurses and community carers. The use of evaluation forms however, proved invaluable and suggests a role for such information to be used to monitor and develop educational programmes.

During Steering Group discussions, the MS Specialist Nurse described plans to train nurses specifically to care for people with MS who required intermediate respite care. A designated respite bed was to be identified for this purpose.

It was also noted that if non-specialists were well trained, informed and felt adequately supported in the care of people with MS, they would be enabled to access her expertise more effectively for difficult issues rather than overwhelm her with unfocused requests. In this way, contrary to one of the dangers of role specialisation often quoted in the literature (Humphris 1994a), the MS Specialist Nurse’s aim was to ‘up-skill’ rather than to ‘de-skill’ generalist nurses in this setting.

6.2.4 **Review of hospital medical records**

Comparative quantitative analysis of MS patient admission data from hospital medical records before and after establishment of the MS Specialist Nurse.

6.2.4.1 **Background**

As well as exploring local perceptions of change for people with MS through qualitative methods, the study also aimed to investigate potential effects on measurable outcomes related to hospital care, following the establishment of the MS Specialist Nurse.

Alongside perceptions of quality, the cost effectiveness of a service is an important aspect to be quantified and demonstrated in any current service evaluations (Carroll and Fay 1997). According to Holmes et al (Holmes, Madgwick, et al 1995) in most cases the highest costs
associated with MS care usually relate to hospital and nursing home admission. An audit of the effectiveness of one MS Specialist Nurse post in Manchester (Campion 1996) found the total number of “MS in-patient days” with stays over five days had decreased by 60%, comparing equivalent six month periods before and after the MS Specialist Nurse was in post. Such financial savings helped to offset the cost of employing the MS Specialist Nurse.

Reasons for acute or frequent admissions and extended hospital stays vary but often involve urinary tract problems, with infections being a significant cause of MS relapses and symptom exacerbation (Campion 1996). An evaluation of one nurse-managed MS clinic in the USA (Wahlquist 1984) found that, before the service was set up, 43% of MS hospitalisations of longer than seven days were due to urinary tract infections. In the year following active involvement from the MS Specialist Nurse there were no such admissions. This indicates an aspect of MS Specialist Nurse care which can have a direct financial impact.

Therefore, in view of the significant cost implications of in-patient care and given the limited time-scale of the project, hospital admissions were chosen as a focus for the retrospective comparison of data from medical records before and after the MS Specialist Nurse was established.

As well as following a sudden relapse and symptom exacerbation, non-elective/emergency MS patient admissions are likely to occur when care at home reaches crisis point. This may be due to poor co-ordination of, or difficulty accessing appropriate services. It may be due to poor understanding of MS specialist symptom management by patients, carers or community professionals, leading to difficult to manage physical problems. It could also be due to emotional crises and
breakdown of family/carer relationships (Robinson and Hunter 1998). These typical causes of acute admissions often relate to and reflect the five main areas which were identified as key roles for MS Specialist Nurses in the national survey (see Part I). In this local case-study, the MS Specialist Nurse was clear that she regularly used strategies to rationalise admissions and optimise use of hospital beds in appropriate specialities for MS patients, where possible. On the basis of this, significant changes in the pattern of hospital admission might be predicted in this case-study following active MS Specialist Nurse involvement.

It was hypothesised that a more informed, planned approach to in-patient care might result from the MS Specialist Nurse's role as patient's advocate, advisor, care co-ordinator and counsellor, as well as information source and educator of professionals regarding MS best practice. The following hypotheses regarding hospital admissions were therefore developed.

6.2.4.2 Hypotheses

Employment of an MS Specialist Nurse will be associated with:

a. A reduction in the overall number of hospital in-patient episodes.

b. A reduction in the number of emergency/non-elective rather than elective hospital admissions.

c. A reduction in length of stay - bed days occupied.

d. Increased involvement/referral to other agencies.

e. An increase in planned use of day-case facilities.

f. A reduction in medical outpatient appointments due to (MS Specialist Nurse) preventable causes.
6.2.4.3 Method

A tool was devised (Appendix 19) to collect data from hospital medical records to test these hypotheses. This was passed by the hospital Clinical Audit and Effectiveness Facilitator as complying with the terms of the initial project ethical approval, and was piloted with five records. Following minor modification it was used to collect data from a total of 70 MS patient medical records by the researcher and an assistant, both of whom had extensive clinical experience in neuro-medical nursing.

With the help of the hospital Clinical Audit and Effectiveness Facilitator and the Clinical Audit Team, two 12 month sample periods were identified (September 97 - August 98 and March 99 - February 00). The first included the period immediately prior to the MS Specialist Nurse taking up post, where, according to the hospital database a total of 42 patients were admitted with a primary diagnosis of MS. The second commenced six months after the MS Specialist Nurse had started and in this period 47 patients were admitted with a primary diagnosis of MS. The Audit Team collected all available records for inspection by the researchers. Reasons why some notes were not available at the time included these being untraceable or required by other departments. In the first sample 32 records (76% of the total) were available and in the second sample 38 (81% of the total) were available and reviewed. In addition, a calculation of the gross cost of employing an MS Specialist Nurse in this setting was made.

6.2.4.4 Analysis

Data were entered into the Minitab database from the data collection tool and analysed by an experienced statistician. There were no statistically significant differences between the two samples in terms of age, gender, years since diagnosis and level of disability. Samples were therefore sufficiently well matched to undertake statistical analysis of
the research questions. The Chi-square test was used to look for significant relationships between variables and the two-sample T-test was used to test for a difference in sample means.

For an indication of the difference in inpatient costs between the two twelve month periods, the actual number of days spent in hospital during each patient episode were calculated using prices applicable at the time and provided by the local Trust's Finance Department.

6.2.4.5 Results

6.2.4.5.1 Sample:

As reported, there were no statistically significant demographic differences between the two samples:

- 62.9% of the total sample were female and 37.1% were male.
- Mean age was 48.9 years (range 21 to 78 years).
- Mean time since diagnosis was 13.3 years (range 1 to 42 years).
- Disability profile on admission according to the MS Society Standards of Healthcare framework (Figure 6):

![Figure 6: Disability profile of sample on admission to hospital](image)

The MS Specialist Nurse had personally seen 25 (66%) of the patients making up the second sample.
6.2.4.5.2 Findings in relation to hypotheses:

i) A reduction in the overall number of hospital in-patient episodes?
There were slightly more inpatient episodes in the 12 months after the establishment of the MS Specialist Nurse (60) than in the previous period (52). Total in-patient episodes per patient were also calculated. There was no statistical difference in number of episodes per patient before the MS Specialist Nurse was in post compared to afterwards. Before the MS Specialist Nurse: mean episodes per patient = 1.5 (median=1.0), after MS Specialist Nurse: mean = 1.447 episodes (median=1.0). The data therefore do not support this hypothesis, but possible explanations are given in the discussion.

ii) A reduction in the number of emergency rather than elective hospital admissions?
Before the MS Specialist Nurse was in post the proportion of emergency/non-elective rather than elective hospital admissions was higher, although this difference did not reach statistical significance. The main body of data related to episodes 1, 2 and 3, as very few were in-patients on four occasions in one year. Thirty five out of 46 admissions (i.e. 76%) were emergencies pre-MS Specialist Nurse, while only 33 out of 50 (i.e. 66%) were emergencies post MS Specialist Nurse employment (see Figure 7). Therefore, although not reaching statistical significance, the trend suggests some support for the hypothesis.

![Figure 7: Percentage of emergency compared to elective hospital admissions (episodes 1, 2 & 3) before and after MS Nurse](image-url)
iii) A reduction in length of stay - bed days occupied?
There was evidence of reduced lengths of stay post MS Specialist Nurse employment, although these relationships were not strongly significant. As the sample sizes progressively diminished through episodes 1, 2 and 3, statistical significance became difficult to establish, but the mean number of days appeared to be almost halved in each episode (see Figure 8).

In episode 1 the mean length of stay pre-MS Specialist Nurse was 26.5 days (N=28) while this was only 14 days post MS Specialist Nurse (N=33), showing a considerable reduction by almost half (p=<0.10). In episode 2 the mean length of stay pre-MS Specialist Nurse was 21.3 days (N=12) while this was only 10.7 days post MS Specialist Nurse (N=13), again showing a reduction by half, although only approaching significance at p=0.10. In episode 3 the mean length of stay pre-MS Specialist Nurse was 43.7 days (N=6) and approximately half this after the MS Specialist Nurse's employment (mean 22.5 days, N=4), but did not reach statistical significance due to the small sample sizes. The validity of these findings is strengthened by the pattern of reduction by half being repeated in all three episodes. The data therefore tend to support this hypothesis and have considerable cost saving implications (see below).
iv) Increased involvement/referral to other agencies?

It was hoped that increased referral to and involvement by other agencies might be an indicator of better knowledge of the complexity of MS among professionals, as well as a more positive attitude to active management. It was suggested that these changes might result from the MS Specialist Nurse's education, information and liaison role in the area.

However, it was not possible to gather sufficient data to show any statistically significant difference between the two samples. From a practical point of view, available evidence of referral to other agencies could not be fully established from the medical notes as this was rarely systematically recorded. Recording of referral to specific disciplines or named individuals was very variable. Some evidence was available from letters to GPs but in others there was no record. In other instances referral to a service such as rehabilitation implied a review by the full multi-disciplinary team, but the extent of this could only be inferred. To give an accurate picture, such data would need to be collected prospectively in a more systematic way in future.

v) An increase in planned day-case admissions?

These data suggested some increase in planned use of day case facilities but sample sizes were too small to draw any major conclusions and by definition, data collection was limited to patients who already had at least one in-patient admission during the sample 12 month periods, so may not give a true picture of total usage.

In the period before the MS Specialist Nurse was in post, four patients in this sample spent twelve days as day cases and all were for administration of intravenous steroids following relapses.
In the second period, nine patients spent a total of 27 days as day cases, 77.8% to receive intravenous steroids, one to have an assessment of swallowing and one to have investigation for urinary retention. In both samples the mean number of days attended per patient was three.

Therefore in the first 12 months, 12.5% of the sample had day case episodes compared to 23.7% in the second 12 months, an increase of 11.2%.

vi) A reduction in medical outpatient appointments due to (MS Specialist Nurse) preventable causes?

Within the time constraints of the project it was not possible to systematically review the causes of all MS outpatient attendance, as in the 12 month period immediately before the MS Specialist Nurse was in post there were 1,985 patient attendances with a primary diagnosis of MS. In the 12 month period commencing six months after the MS Specialist Nurse had taken up post there were 2,048 attendances, an actual increase of 73 appointments, but amounting to only 3.6% of the total and therefore not a substantial increase.

The focus of the review primarily involved hospital admission as this was thought to have most cost implications. However, data were collected regarding those in-patients who also had outpatient attendance during the two review periods to determine if there were any corresponding changes in service use.

Twenty patients in the before sample attended a total of 50 times, giving a mean per patient of 2.5 attendances. Thirty patients in the after MS Specialist Nurse period had a total of 70 outpatient attendances with a mean per patient of 2.3. This suggests a slight increase in outpatient appointments corresponding with the trend for shorter inpatient stays in the second year (62.5% of the first sample had
outpatient attendance, while this increased to 78.9% in the second sample, an increase of 16.4%.

Exact reasons for outpatient attendance were difficult to rigorously establish from the medical records, but there was also a suggestion that continence issues were specifically referred to more frequently in the second sample (in 25% of the first sample and 33.3% of the second sample).

Thus, there was no significant change in the overall number of MS patient appointments between the two periods, although some increase in attendance by patients who had a recent history of admission in the sample periods was noted. Details of whether appointments involved MS Specialist Nurse preventable causes were difficult to establish.

vii) Other differences:
One incidental finding concerned the specialities which patients were admitted under in the pre-MS Specialist Nurse phase compared to afterwards. There was a strong, statistically significant shift away from predominantly acute general medical ward admissions towards rehabilitation, neurology or Young Disabled Unit care (see Figure 9).

Thirty one patients were admitted to general medical wards compared to 15 to other wards/units in the pre-MS Specialist Nurse period (when combining data from episodes 1, 2 and 3). This compared with only 16 admitted to general medical wards and 34 to other wards/units in the post-MS Specialist Nurse period. Statistically this was a strongly significant development (p=<0.005).
viii) Cost implications

A simple illustrative calculation was made to estimate the cost difference between the two sample years purely in terms of admissions, and to relate this to the cost of employing an MS Specialist Nurse. No attempt was made here to cost any of the qualitative benefits of the MS Specialist Nurse's service.

Trust costs for the financial year 1999-2000 were quoted as £255.61 per day for non-elective and £179.77 per day for elective admissions. Calculations of cost were based on the premise that patients admitted non-electively into Acute Adult Medical or Emergency Medical Unit beds were eventually transferred to more appropriate specialities such as neurology, rehabilitation or the Young Disabled Unit, with subsequently lower costs. Clear dates of transfer were not consistently available through medical records, therefore, for the purposes of costing, it was estimated that patients admitted non-electively would
spend half their stay in beds costed at the higher rate before being transferred appropriately. Anecdotal evidence suggests that this was a conservative estimate of total cost.

All patients in the sample had at least one inpatient episode during the year, but diminishing numbers had further admissions, ranging from two up to a maximum of five episodes for a very few patients. Episodes were costed separately and then totaled to give the overall cost for each year.

A total of 1274 bed days were occupied by patients with a primary diagnosis of MS in the year 1/9/97 to 31/8/98. The total cost of these MS patient admissions i.e. prior to the MS Specialist Nurse being in post was £271,573.22 (see Appendix 20 for individual episode calculations)

Total bed days occupied for the year 1/3/99 to 29/2/00 i.e. commencing after MS Specialist Nurse had been in post six months amounted to just 820. The total cost of MS patient admissions for this year was £167,243.57 despite the fact that there were slightly more admissions in this second year (60 vs 52 in the first year).

The difference in costs between the two years was therefore: £104,329.65

Cost calculation of employing local MS Specialist Nurse per annum:

- **Salary @ H grade:** £26,816.0
- **Employer's pension contribution:** £1,340.8 (5%)
- **National Insurance contribution:** £3,217.9 (12%)
- **Travel:** £1,640.0 (4100 miles @ 40p per mile)
When the cost of the MS Specialist Nurse per annum is subtracted from the above, a saving of £64,611.45 remains.

ix) Discussion

Although it might be anticipated that a sample of patients selected by hospital admission might be expected to vary from the average population of people with MS in the community at large, these samples were generally consistent with other demographic data for MS in the UK. In a study involving 713 geographically stratified, randomly selected UK MS Society patient members, Hobart et al (2001) reported 71% being women (62.9% in this study), a mean age of 52 years (48.9 years in this study), but a typical disease duration of slightly longer (19 years compared with 13.3 years in this study).

Degree of disability was noted at admission, but the nature of MS suggests that this was unlikely to be static throughout the admission. Although patients with moderate disability made up the largest group of those admitted, the next largest group were those with minimal physical impairment, closely followed by the severely disabled (see Figure 6). Again, these findings were generally consistent with UK demographic data quoted by Hobart et al (32% walking unaided, 40% with an aid, 28% in a wheelchair). The smaller group of newly diagnosed in the current study were likely to represent those admitted for investigation to confirm the diagnosis. The degree of disability did not therefore appear directly related to the need for admission.

The slight increase in number of admissions in the second year would be consistent with the view that introduction of a specialist practitioner
is likely to identify previously unmet need (Carroll and Fay 1997; Williams 1993) and there are numerous reports of unmet need for people with MS in the UK (Freeman and Thompson 1999; McLellan, Martin, et al 1989). This increase could be of concern from a purely financial point of view if it were not seriously offset by the reduction in length of stay in this sample. Identification of unmet need and resulting action however is likely to be warmly welcomed by people with MS and their families/carers.

In addition to the reduction in length of stay, the trend towards more elective and less emergency admissions in the post-MS Specialist Nurse year reduced costs further, as well as representing a more planned, probably less stressful experience of admission for patients and carers. The highly significant shift away from predominantly general/acute medical wards towards more relevant specialist wards such as neurology, rehabilitation or the Young Disabled Unit suggested a more rational use of resources. This may also have contributed to the considerable reduction in length of stay, where specialist knowledge and experience of complex MS management may speed the process of treatment, liaison, multi-disciplinary management and discharge. The suggestion of a corresponding increase in use of day-case facilities and a 16.4% increase in outpatient attendance in these selected groups with a history of recent admission is likely to be related to reduction in length of stay and a rationalisation of service use. However, for the Trust these are modest increases in relatively inexpensive services compared to the cost of hospital admission.

The relationship between these findings and the active involvement of an MS Specialist Nurse cannot be directly proven. However, discussion with a local Consultant Neurologist identified no real administrative changes or changes in admission/patient management strategies between the two periods. Neither were any changes in available bed
numbers, more pressure on in-patient services or changed decision making regarding admission to different wards from the Accident and Emergency department evident during this time.

The rationale for inferring a link between the MS Specialist Nurse's activities and the altered pattern of MS patient admissions is two-fold:

First there may be a direct effect resulting from the MS Specialist Nurse's personal involvement in individual patient care. The MS Specialist Nurse had evidence of involvement in the care of 66% of patients admitted in the second sample year and described her strategies of rationalising and optimising MS patient admissions as an important aspect of her work.

If she knew of a patient's planned admission with complex problems, she would alert the ward staff in advance, perhaps with regard to specialist equipment needs. She may also suggest the most appropriate ward to meet the patient's needs, or if admitted non-electively to a general medical ward, she would encourage duty medical staff to refer and transfer the patient to an appropriate speciality as soon as feasible. She would also advise staff on the effective management of some specialist problems and streamline discharge plans by providing appropriate contacts in the community. Such interventions were often enhanced by her previous in-depth knowledge of the patient and their family/circumstances, and could add to the relationship ward staff themselves developed with the patient. In terms of direct care, she was also able to provide counselling and support to some patients and their families while in the hospital, as well as offering to visit or liaise on discharge. This may have contributed to patient and staff confidence in earlier discharge plans.
Secondly, the MS Specialist Nurse may have had an indirect effect on the quality and effectiveness of patient care through staff education, information giving, leadership and role-modelling, without necessarily being directly involved in a patient's care (Carroll and Fay 1997). Non-specialist perceptions of MS as a progressive disease with little scope for active management in the absence of a cure may be influenced by educational initiatives directed at both acute and community professionals (Kirker and Young 1995). In this case-study, the MS Specialist Nurse had been actively involved in the education of professionals and carers as demonstrated by the development, application and auditing of a specific education standard (see 6.2.3.2) as part of this project.

Although the results demonstrate a considerable difference in the simple cost of in-patient MS care when comparing the two sample years, it is possible that other cost implications are inherent in this situation.

No attempt was made to estimate the additional potential positive effect of these more focused hospital stays on lost income for patients who are normally in employment (Holmes, Madgwick et al 1995). On the other hand, there may be added costs in other areas of Health and Social Care resulting from these changes. The effect on neurologists’ time is unknown. The MS Specialist Nurse may relieve them of some time consuming or inappropriate aspects of MS patient care or may involve them in more frequent communication and liaison about individual cases in attempting to advocate for patients and rationalise the service. No cost difference can be inferred here as the number of neurologists in the Trust remains the same.

Although retrospective review of hospital medical records was not sensitive enough to identify changes in the rate of referral to other agencies in this study, Kirker and Young (1995) found an increase in
referral to others from an average of 5.1 to 6.8 per month following the introduction of an MS Specialist Nurse. This could produce an added financial burden on some departments. Kirker and Young also found that the MS Specialist Nurse organised previously unclaimed social welfare benefits for 41% of the patients interviewed, estimating this cost as approximately £1800 per patient seen by the MS Specialist Nurse per annum. On the basis of many qualitative comments Kirker and Young concluded that: “This service seems to improve lives, but it does not necessarily reduce the cost to the public purse of caring for patients with MS” although in their study the specific effect on hospital admissions was not quantified and costed.

x) Conclusion

Differences in the pattern of MS patient admission were identified between the 12 month period directly before employment of an MS Specialist Nurse, compared with a 12 month period commencing after the MS Specialist Nurse had been established for six months. These differences occurred in the absence of any obvious change in local strategy and included a reduction in the number of emergency rather than elective hospital admissions, a reduction in length of stay and a strong shift away from predominantly acute general medical ward admissions towards rehabilitation, neurology or Young Disabled Unit care. The degree of disability did not appear related to the need for inpatient care.

In addition to the likely qualitative benefits of a more rationalised approach to in-patient care for patients and their families, these changes appeared to show considerable cost benefits to the Trust. It is proposed that the establishment and active involvement of an MS Specialist Nurse, providing a focus of expertise, leadership and a combination of direct and indirect intervention may have contributed to the observed differences in patient admission patterns in the two sample years.
A simple calculation of reduced cost, as indicated by a comparison of bed occupancy between the two years amounted to £104,329.65. When the cost of employing an MS Specialist Nurse for one year was offset against this sum, a total saving of £64,611.45 remained. Although there may be other hidden cost implications associated with this change, the multiple research methods employed in this case-study identified a wealth of additional qualitative benefits for patients, carers and professionals following the introduction of a local MS Specialist Nurse service. No attempt has been made to put monetary value on these benefits. However, such developments are in line with government initiatives to ensure that the NHS delivers more responsive and informed services for people in general in the UK (NHS Executive 1998).

6.2.5 **MS Specialist Nurse Activity**

In addition to the quantitative measures designed to indicate the effect the MS Specialist Nurse had on patients and professionals, she also kept a reflective diary and personal log of her activities. Diaries primarily describe behaviours but can also be used reflectively to capture emotions, thoughts and ideas. In recording activities during an agreed time span, the issue arises as to how typical or representative the ensuing data are. Bell (1999) notes that completing diaries can be difficult for busy professionals and that face to face contact with the researcher is very important to ensure clarification and commitment to completing the diary. The Research Fellow spent some time discussing the best approach to capture a representative “snapshot” of the MS Specialist Nurse's workload.

The MS Specialist Nurse recorded her activities in two ways. First she recorded critical incidents in an audio-taped reflective diary. The critical incident was first used as a method of data collection by
Flanagan (1954) and has been applied to nursing research and practice to assist practitioners to “identify incidents by concentrating on ‘moments in time’ during their work and recording briefly what happened” (Clamp 1980). Positive and negative incidents (and associated emotions) in relation to both patients and colleagues are recorded. Second, the MS Specialist nurse kept a detailed log of her activities during a two week period using a pro-forma (see Appendix 21). The pro-forma was divided into columns to record psychological, social and physical interventions. Information giving/education was also recorded with a final column for the MS Specialist Nurse to make notes on the outcome of her activities. The MS Specialist Nurse was also asked to record the duration of each activity, where it took place, whether travel was involved and the type of contacts she was making e.g. with patients, relatives, professional and lay carers. She was also asked to note the type and mode of activities she undertook with other professionals. Such self-report activity logs were developed by Dunnell and Dobbs (1982) in a study of community nursing.

Both records allowed the MS Specialist Nurse to reflect on ways in which she had been able to assist patients and their formal and informal carers, but also factors that might have limited her effectiveness. She was also able to reflect on the development of her role.

The tape-recorded diary was analysed reflectively to identify ways in which the MS Specialist Nurse had been able to assist patients and their formal and informal carers. The pro-forma log of activities over a two-week period was analysed according to type and frequency of intervention and process and outcomes were identified.
6.2.5.1 MS Specialist Nurse's Reflective diary

The researcher met with the MS Specialist Nurse on a number of occasions to discuss her role. Recordings from her audio diary were used to identify critical incidents in which she had played a key role. Discussions during Steering Group meetings in response to data presentations were also used to build up a picture of the MS Specialist Nurse's role and the ways in which she was able to work with patients and their carers in learning to live with and manage MS.

In commenting on preliminary findings during a Steering Group meeting, the MS Specialist Nurse gave an example of how she acted as a "broker" for patients and families. She described how one patient had been suffering with a back problem associated with his MS. The private insurance company would not pay for physiotherapy to "treat" problems associated with MS because it was a chronic/pre-existing condition. The MS Specialist Nurse and the physiotherapist were able to argue on the patient's behalf that the back problem was an acute condition. On this basis the insurance company paid for the physiotherapy.

On issues of abandonment and other powerful emotions associated with diagnosis, the MS Specialist Nurse felt she was able to make patients "more comfortable with their condition". She believed that their emotional state had "an impact on how they handle life and their whole mental attitude … (which) is so important. If they are really distressed, they don't seem to do well".

On one occasion when the researcher and MS Specialist Nurse were discussing the development of her role she described two different aspects of uncertainty that she was required to manage. One was the uncertainty of the disease i.e. the course that MS takes with each individual patient which is different and unpredictable. The other was
the uncertainty of the job, which required the MS Specialist Nurse to be constantly responsive to “emergent problems coming in all the time”. She described how she had to be ready to change her priorities “depending on what is coming in”. For this reason she built in an element of routine, such as conducting fortnightly clinics and attending weekly ward rounds. The re-organisation taking place in the health and social services also contributed to a sense of unpredictability in that the personnel and systems the MS Specialist Nurse liaised with, frequently changed. The potential for isolation and burn-out therefore was recognised as being high.

The other dimension to the MS Specialist Nurse's role was her advisory and support role with non-specialist professionals. She described the professionals as asking for “remedies and options” which did not exist (in the sense there was no cure for MS) and having to come to terms with “no easy options, no right decisions nor good outcomes.” The MS Specialist Nurse found herself working with other professionals to assess problems presented by patients, work out solutions and reassure them they had done the best they could in the circumstances. She therefore had to manage professionals' potential distress when the management of MS went contrary to their expectations to always be able to improve patients' situations. The MS Specialist Nurse believed it was important professionals understood the importance of balancing clinical interventions with psycho-social support given that in her experience it was important to “lift the patient's mood”.

The MS Specialist Nurse shared an office with a Parkinson's Disease Specialist Nurse and worked closely with a team of neurologists, but had no direct colleague undertaking a similar role locally. She dealt with this by organising her own support systems through regular external counselling and contact with MS Specialist Nurses in other
areas. Keeping a reflective diary was something she did as part of her routine and not just for the purposes of the research.

Recordings from the MS Specialist Nurse's audio diary were used with the researcher to identify a series of critical incidents in which she had played a key role. The incidents covered a range of complex psychosocial and physical interventions with clearly identified outcomes. These outcomes included delaying the hospitalisation of a severely disabled patient so that she could stay home longer with her children, resolving problems of incontinence and constipation, reducing the risk of aspiration pneumonia and arranging respite care.

The following vignettes have been selected to illustrate the diversity of her role. The patient details have been anonymised. The vignettes range from “quick-fix” rapid responses to complex negotiation, liaison and care management.

Vignette 1
A female patient with a twenty-year history of MS with minimal impairment rang the MS Specialist Nurse because she had suffered a sudden deterioration which she attributed to a recent bereavement. The MS Specialist Nurse spent one and a half hours on the telephone getting to know the patient and familiarising herself with her situation. She was also able to negotiate future contacts over the phone, including referral to the neurologist and a physiotherapist. The MS Specialist Nurse kept in frequent contact with this patient by telephone in which she had been able to “lift her mood” and supply her with locally appropriate information. The patient later sought advice about receiving beta interferon.
Vignette 2
A female patient with MS and severe disability was the mother of two young children (five and three years old). A Case Conference had been held with the MS Specialist Nurse and the Social Services to discuss ways of assisting her to stay at home. The MS Specialist Nurse had helped her to negotiate extra funding from a voluntary agency to pay for more social care. The patient's tendency to choke had increased for which referral had been made to a Speech and Language therapist. The MS Specialist Nurse had worked closely with the consultant in neuro-rehabilitation in managing this patient's complex physical and psycho-social needs and made home visits to assess and closely monitor the situation. Over the past six months, the children had become increasing traumatised by seeing their mother experiencing severe swallowing difficulties. Following in-depth discussion and negotiation with the MS Specialist Nurse, she had agreed to be admitted to hospital for respite care to alleviate family stress.

Vignette 3
A male patient who was severely disabled was “going off his legs” due in part to difficulties in establishing a regular bowel pattern associated with use of analgesics for back pain. The MS Specialist Nurse initiated a medical referral to investigate the back pain. “Crush” fractures of several vertebrae were identified. The patient was referred for physiotherapy as a result of which, both the pain and need for medication, decreased. The MS Specialist Nurse was then able to advise the patient on re-establishing a satisfactory bowel pattern. During this process, the patient was admitted for respite care. His wife, who was his principal carer, was able to have a much needed break. On his return home the patient and his wife, were able to be much more self-sufficient.
Vignette 4
A newly diagnosed patient did not fully understand the neurologist's explanation of his diagnosis. The MS Specialist Nurse was able to spend time responding to his queries giving what she described as a second line explanation of a primary discussion with the neurologist. The outcome of this intervention was that the patient was better able to cope once having been assisted to acquire a deeper understanding of his condition.

These vignettes demonstrate some of the priorities established by the MS Specialist Nurse in relation to newly diagnosed and severely disabled patients. In analysing the type and mode of intervention with the researcher she was able to show how she responded to crises and looming problems. Her counselling sessions assisted her to recognise that many times she was dealing with confusion on the part of both people with MS and their lay and professional carers. Confusion she said was distressing but she assisted people to recognise and accept confusion and learn to deal with it. “All my patients go down at some time or other. The disease brings them down but they ask for help. Often there is an emotional component rather than a physical one”.
She summarised one of the main outcomes of her interventions as promoting people’s wellbeing by reducing the emotional impact on their physical state.

6.2.5.2 Detailed diary of MS Specialist Nurse activity
The MS Nurse Specialist kept a two week detailed diary using a format described above, which assisted her to record her activities in terms of the people, venues and timing involved in a variety of interactions. In the breakdown of activities, psychosocial interventions (32) were most common followed by physical (19), social (16) and information giving/education (8). In terms of activities the most common was telephone work, followed by patient contact in clinic, home or ward.
and patient related meetings/discussions. Looking at these activities in greater detail revealed that the MS Specialist Nurse had frequent contact with all members of the multidisciplinary team in both hospital and community care. The hospital medical team, ward nurses, therapists, GPs and district nurses were all represented. Two case conferences were held during the fortnight under review, when contact was made with social workers. Teaching/preparation, contact with relatives and administration were the next most frequent cluster of categories with activities associated with own professional development being recorded on three occasions during the two week period. These included a training session with one of the companies supplying products, counselling supervision and a meeting with clinical nurse specialist colleagues. Throughout each day, the MS Specialist Nurse scanned her phone messages from her answer machine and planned and prioritised her work depending on the type of issues being presented.

The MS Specialist Nurse recorded a number of outcomes from her interventions during the first week, which involved negotiation and liaison with a variety of agencies on behalf of patients or carers. These outcomes resulted in an initiation or a change of treatment to control symptoms, obtaining information or benefits for patients and/or their families. A selection of individual outcomes are listed below:

- Alert ward to patient dependency level prior to admission
- Negotiate hospital admission for “at-risk” patient
- Retrieve information from patient’s relative
- Alert Citizen’s Advice Bureau of patient’s difficulties
- Arrange out-patient treatment for patient in need of symptom control
- Attend consultation and support newly diagnosed patient
- Successful liaison to set up a case conference
- Alert patient to possible drug incompatibility
- Negotiate with GP on symptom management
- Facilitate start of new drug therapy
- Negotiate earlier out-patient appointment for a patient with the consultant

The two types of record keeping provided supporting evidence to demonstrate the range and diversity of MS Specialist Nurse activity and the type and mode of intervention required to achieve effective outcomes.

6.2.6 *Service Development and the role of the Steering Group*

The service development phase of the case study began during the middle period of the evaluation (November 1999-July 2000). The development of the service was conducted using an action research approach, involving not only dialogue between the researcher and the MS Specialist Nurse but also the “stakeholder” Steering Group members during their two monthly meetings. Action research engages participants in formulating solutions to identified problems. External researchers take on the facilitator role to investigate how people interpret problems and situations in order to negotiate, develop consensus and handle conflict. Webb (1990) views action research as highly suited to the kind of problem solving and evaluation research which the nursing profession needs.

While action research is usually associated with qualitative, practitioner led approaches, in its crudest form it can be conceptualised as an experiment in which the researcher makes a change and then sees what happens (Sapsford and Abbott 1992). Authors such as Holter and Schwarz-Barcott (1993) and Hart and Bond (1995) have classified action research according to different philosophies and methods. In particular
Hart and Bond identify seven criteria which distinguish action research from other types of research. These criteria are as follows:

- It involves a cyclical process in which research, action and evaluation are interlinked
- It is educative
- It deals with individuals as members of social groups
- It is problem-focused, context specific and future-orientated
- It involves a change intervention
- It aims at improvements and involvement
- It is founded on a research relationship in which those involved are participants in the change process

Sparrow (1997) citing Hart and Bond (1995) suggests that `action research is a hybrid that generates a variety of approaches’ requiring a definition for each individual study.

Sparrow (1997) notes there has been a confused and mixed response to action research on the part of nurse researchers. In the first place it was adopted uncritically as an antidote to the predominance of biomedical research which emphasised experimental method and quantitative data. Furthermore, many nurse researchers have not adequately considered the variety of philosophies and designs that can inform action research to address a range of research questions and contexts.

In the present study, participatory action research was selected for its suitability for studying the development and evaluation of a new specialist service and the use of reflective discussions during the Steering Group meetings. Challenges included the need to respond to rapid change in health and social care; manage complex research and practice relationships; and decide on collaborative dissemination strategies.
The stakeholder Steering Group formed an important reference point and focus for discussion regarding the MS Specialist Nurse's service, and the wider picture for people with MS in West Berkshire. Occurring on a two monthly basis throughout the project, this was a well supported, mutually beneficial opportunity to pool experience and ideas, promoting effective care for people with MS, providing a strong local drive for the project and enhancing group members' understanding of the local systems and dilemmas in MS care.

The purpose of the group was agreed at the first meeting as follows:

- To receive progress reports on the research project and service developments;
- To provide an expert perspective on the needs of people with MS;
- To provide insight into specific MS service provision in the locality and provide a professional perspective on the needs of service providers and commissioners in relation to MS care;
- To advise on practical issues and research strategies within the framework of the current project;
- To form a subgroup to consider findings from the project and agree priorities for service development, in collaboration with the MS Specialist Nurse.

The membership of the group was drawn from sixteen potential "stakeholders" representing people with MS, their carers, the multidisciplinary team from primary and secondary care, health and social services, the voluntary sector and researchers including the director from a university MS Research Unit. Attendance varied between six and twelve people, with a core group of members attending throughout the life of the Steering Group. The core group included the MS Specialist Nurse, the MS Research Trust.
representatives, the occupational therapist, the chair of the local MS Society, the manager of the MS Therapy Centre and the researchers.

The Steering Group provided continuity and validity to the research and support to the MS Specialist Nurse in a number of ways. During the first year, the business manager's attendance was key since he was presented with evidence to support the case being negotiated at the time to establish the MS Specialist Nurse as a permanent post. The presence of the neurologist and neuro-rehabilitationist at some meetings was particularly important when issues such as management of diagnosis or ongoing MS patient management were discussed. The Research Fellow observed that “when we had medical involvement we got a lot sorted out in terms of understanding. …. (the neurologist) came up with dynamic ideas of how to get through (and round) things”. The Priority Care Manager, Social Services member and district nurse provided a primary and social care perspective, during a time of intense organisational change. The Director of Nursing from the local Trust was unable to attend meetings and resigned from the group at the end of the first year. Although other members were not always able to attend, they were available at the end of the phone to advise the MS Specialist Nurse and the researchers.

All Steering Group meetings were taped with members' permission. One member described the Research Fellow and her “machine” as always willing to listen. The recordings were used to prepare detailed minutes for two reasons. First the research fellow was aware that members needed clear information to assist them to understand the ramifications of the discussions that had taken place, especially if they had not been present at the meeting. Second, the minutes provided a record of the research process. They were written in jargon free language and mailed to members well in advance of the next meeting.
As such the minutes could be seen as both a learning tool and as an
invaluable source of data.

During the final meeting, a *reflective discussion* was conducted on the
experience of being part of a stakeholder research/local project
Steering Group. Six core group members attended and were asked to
consider their thoughts, expectations, hopes or concerns. One other
member sent written comments.

Overall, the Steering Group was reported by members to have been a
positive experience assisting them to appreciate the “whole picture” of
MS care. Furthermore, as the discussion progressed, it became clear it
had met its main terms of reference i.e. to guide the research; support
local service development and obtain an expert perspective on the
needs of people with MS, their lay and professional carers. Other less
positive points were raised, such as there had been no hospital
(nursing) personnel on the group especially given their perceived lack
of specialist knowledge. The MS Specialist Nurse noted it was difficult
to maintain continuity with hospital staff because in any 24 hour
period she would need to liaise with at least three different nurses. The
carer would have liked direct GP representation on the group
(attempts to recruit a GP had been unsuccessful). One member felt
angry on the MS Specialist Nurse’s behalf that attendance at meetings
had declined. The observation was made that at the height of the
project and service development, attendance had been good. Two
“lay” members commented that the Steering Group had been a
positive learning experience for them. At first they felt that the “work
was over my head” or “went into areas I had no experience (of)”.  
However, they quickly recognised the need to talk and create “a
common denominator language” which had been supported by the
“user friendly” minutes.
The following key issues were raised in relation to the development of the MS Specialist Nurse post; the progress and validity of the research; and accountability to the research commissioners.

6.2.6.1 MS Specialist Nurse Post

The Steering Group was reported to have provided a reference group for the MS Specialist Nurse and there was some discussion as to whether such a group was a “luxury” or a “necessity” for the establishment and support of such posts. A positive outcome of the interface of research and practice was seen to be the demonstration of how one specialist nurse had communicated and worked effectively in a local setting. As the specialist nurse reflected, the Steering Group meetings helped her to answer the question “What do you want this post to be?” It would also provide future specialist nurse post holders with information on how to plan and set up a service in the most time effective way.

It was observed that the wide geographical, multi-professional and lay representation on the group was invaluable for providing information on different organisational and service issues. As one member said: “it was lovely getting different people’s view points”. Consequently the group members constituted a network both for each other and for the MS Specialist Nurse in particular. As another member noted “conversations were going on outside the Steering Group”. The MS Specialist Nurse described the network she had built up as her “lifeline”. The inference here was that her networking activities had been enhanced by the existence of the Steering Group.

The period of the research was a time of major re-organisation in the health and social services and group members were able to advise each other and the MS Specialist Nurse in particular of local changes taking place. The introduction of Primary Care Groups and Trusts and unitary
authorities which affected the delivery of Social Services was “picked up first hand” by members sitting round a table together. Such key information, described as an important “by-product” of the Steering Group, could then be acted upon. The existence of the Steering Group therefore, assisted members to keep abreast of changes, make connections and take appropriate action.

It was observed that for the MS Specialist Nurse in particular, who was continually developing her networks, the backdrop of continual change could be a source of “frustration and challenge”. However, once having “built contacts on the back of the project” she was seen to be in a stronger position to transcend organisational change through personal connections.

6.2.6.2 The Research Project

The Research Fellow experienced the group “as a rare opportunity for all disciplines to put their heads together … to find logical ways round (issues) ”. As described previously, priorities were identified on the basis of the interviews, which in turn gave direction to the research. The researcher was described as “always willing to listen”.

One member said: “I felt so much a part of what was happening, so linked with what was happening on the ground - it was so positive, I didn't really consider it as research. It was an added bonus to be an actual part of what was going on”

The MS Specialist Nurse who on first being appointed had been unaware that she was to be involved in researching her post said: “ It is vital to make it meaningful to the area being researched. It's no use in doing your own thing if it doesn't reflect on other people's needs”.
She also saw the research as providing “different perspectives on how the project was developing and the need to measure things in the local context” as illustrated by the use of tailor made audit tools. This information was able to validate the research and demonstrate to managers the effectiveness of the post in terms of cost savings made.

6.2.6.3 The Research Commissioners

The Steering Group was reported to have demonstrated to the MS Research Trust the great value of bringing users of the services and the multidisciplinary advisers together to decide on the “best way of going about the research”. The regular meetings were also a way of reassuring the Trustees that the project was “on course”. The Research Fellow worked to the deadlines imposed by the two monthly meetings and prepared material for presentation and review by the group members.

6.2.6.4 Other Issues

The Steering Group was said to have demonstrated for some members the interplay of politics and financial restrictions on the development of services for people with MS. In particular the funding divide between health and social services was seen to contradict the blurred boundary between health and social care need and the rhetoric of health and social care reform. One associated difficulty was reported to be the management and education of home carers, the majority of whom (80%) were employed by private agencies rather than Social Services.

6.2.6.5 Summary

The resulting themes and comments from a stakeholder discussion provided interesting and convincing evidence to support the use of “stakeholder” groups and the importance of considering a variety of local perspectives in such initiatives. Taking part was seen to benefit
and inform the research in terms of its direction and meaning. However, it also appeared to benefit and inform the “stakeholders” themselves, both personally and professionally. The information also provided the basis for one of several potential publications from the project.

6.3 Case Study Conclusion

- Evidence from the case study supports survey findings which suggest the service offered by MS Specialist Nurses attempts to address the needs that have frequently been highlighted as unmet by previous NHS services. These include the lack of information, fragmentation and lack of continuity in services, poor understanding of the disease among professionals and lack of psychological support, particularly around the time of diagnosis.

- People with MS experienced strong emotions around the time of diagnosis including abandonment/isolation; shock/devastation, fear and frustration with the perceived lack of professional knowledge. They wanted professionals to understand that MS is a unique experience for each individual requiring an individualised response. Support for partners and family was also seen as vital. Those who had had contact with the MS Nursing Service at or around the time of diagnosis, had found it to be very helpful in terms of both support and information given.

- Patients and neurologists had differing expectations of how the process of diagnosis and subsequent support should be managed. GPs played a role throughout the illness trajectory but with variable effect, depending on their level of expertise and interest. The key role of specialist physiotherapists in treatment was emphasised. Occupational therapists were said to be “very helpful” and supported daily living activities by advising on and arranging
equipment and home adaptations. Social Service departments were
described as key to “the wellbeing of MS patients” by providing
home care and mobility assistance inside and outside the home. The
availability of disabled friendly transport and easy access to public
places was viewed as currently restricted but an essential source of
help. The role played by spouses or partners both at the time of
diagnosis and later in terms of continued care and support, in some
cases over many years, could not be overestimated.

➢ The MS Specialist Nurse was described as a “lynchpin” and link
with other professionals, who was well placed to act as an overall
service co-ordinator. She was able therefore to provide a bridge
between patient and professionals, both at the time of diagnosis,
and in the long-term management of MS.

➢ Stakeholders experienced the employment of the MS Specialist Nurse as
increasing the emphasis on holistic care, chronic disease management and
improving liaison between the primary and secondary care sector.

➢ The case study demonstrated that employment of an MS Specialist
Nurse can have a significant effect on patterns of MS patient
management in hospital, with cost saving implications. The case
study supported survey findings that the MS Specialist Nurse is a
relatively independent practitioner working in a job, which is
complex, isolating and demanding given the unpredictability
associated with MS itself and the need to liaise and interact with a
wide range of individuals and services. The MS Specialist Nurse
can be more effective if she has adequate clinical and management
support and access to counselling supervision. She also played a
key educational role for patients, carers and non-specialist
professionals.
The case study design demonstrated one approach to exploring and evaluating the complexity of specialist nursing intervention and highlighted issues which are responsive to MS Specialist Nursing involvement using hospital medical and nursing records and specially designed tools. The documentation of critical incidents indicated the positive effect she could have on a range of patient and carer outcomes.

The value of systematically involving users or “stakeholders” in reviewing, planning, developing and evaluating services using an action research approach demonstrated and provided a framework within which tools could be developed to audit the service as part of clinical practice, beyond the span of the project. Priorities were identified to develop standards to monitor management at diagnosis and education of formal carers.

The involvement of “stakeholders” was shown to be a mutually beneficial activity, which enhanced the research process, developed strategies to close gaps in service provision and demonstrated positive outcomes following MS Specialist Nurse activity. The period of service development gave further time for the MS Specialist Nurse to develop her networks, establish her service and make an impact on local MS care.
6.4 **Recommendations and the way forward**

*Specific to the MS Specialist Nurse:*

- All newly diagnosed patients, their partners and family should be referred to the Specialist Nursing service at diagnosis in order to bridge the gap between patient and physician expectation and to meet a variety of medical and non-medical needs in the longer term management of MS.

- Parity of access to the MS Specialist Nurse in both the public and private sector needs to be ensured.

- Adequate administrative and clinical support is required to ensure that her workload is manageable and to consider the development of a team of specialist nurses to assist her to manage the increasing demands of her role.

- Additional support should be provided to ensure the MS Specialist Nurse has access to information technology.

- Local workforce development and planning needs to ensure that the post of MS Specialist Nurse is permanent. In areas where the need for service development and leadership is particularly high there should be the possibility to extend it to Consultant Nurse level.

- Management recognition of the need to put mentoring and supervision systems in place to support the MS Specialist Nurse and prevent burnout from her demanding role.
- Management support for networking opportunities to enhance professional and career development and to encourage innovation.

- Recognition that the MS Specialist Nurse should play a key role in relation to local Trust/organisational business planning strategies to maximise effectiveness and enhance visibility.

- Ongoing development of a core set of MS Specialist Nurse audit data to be routinely collected to best represent the impact and effectiveness of the role.

- Close liaison, joint visits and meetings between the MS Specialist Nurse, the Primary Care Trusts and members of the primary care team, in particular GPs and district nurses to be maintained.

- Consider ways of providing 24 hour telephone help to extend the MS Specialist Nursing service, e.g. NHS Direct information package from MS Specialist Nurses.

- Where possible, the MS Specialist Nurse to extend her educational role to the public as well as lay carers of people with MS.

- Ensure mechanisms are in place to support patients and their partners to attend “Getting to Grips with MS”, or other similar courses for the newly diagnosed.

- Ongoing joint planning and monitoring of educational programmes between the MS Specialist Nurse, Social Services and the hospital sector so that MS Specialist Nurses play a key role in the education of non-specialist practitioners.
Mechanisms for service development and joint working to be set up across a range of stakeholders as exemplified by the Steering Group members who met on a regular basis throughout the span of the project.

More general recommendations:

- Understanding and appreciation on the part of professionals that MS is a unique experience for each individual, requiring an individualised response.

- Encouragement of patients to bring personal support with them at the time of diagnosis.

- Appreciation by neurologists that patients are in a period of transition when they are first given a diagnosis of MS and to consider routine follow-up appointments.

- Appropriate timing and availability of good quality information by service providers to patients to allow them to play an active role in their care.

- Availability of information packs about MS on hospital wards, nursing homes, social services and private care agencies.

- Training of non-Specialist Nurses and home carers on a routine basis to meet the needs of people with MS at different stages of the illness trajectory e.g. in the provision of respite care.

- More respite care for people with MS and their families.
➤ Greater support and help for the carers of people with MS, such as that provided by the specialist voluntary sector (MS Therapy Centres).

➤ Record systems to be set up to improve information exchange between patients, professionals, the public, private and voluntary sector.
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I am writing to local people with MS to invite you to take part in a small study, looking at ways to improve some of the services we provide in the West Berkshire area. As you may know, we now have an MS Nurse Specialist who is partly funded by the hospital and partly by the local MS Society. Everyone is keen that this service is directed at providing the most useful things for local people with MS, so it is important that we find out your views as potential users of this and other services, as well as the views of other professionals and local voluntary MS groups.

Enclosed is some information about the study. It is being carried out by a small team with experience in healthcare research and MS, based at the South Bank University, London and with input from the MS Research Trust in Letchworth, Hertfordshire. If having read about it, you decide you would like to volunteer or would like to find out more details, it is important that you contact the researcher — Mrs. Jane Johnson directly so that your participation in the study can be kept confidential. I must stress that your decision whether to volunteer or not will in no way affect the care you receive, either in hospital or in the community.

If you are interested in putting your name forward please contact Mrs. Jane Johnson directly by returning the reply slip in the envelope provided. She will then be able to contact you, probably by phone initially, and will be happy to discuss things in more detail.

If you are not interested in taking part in the study, thank you for taking the time to read it and please disregard this letter.

Yours sincerely,

Dr.
Consultant Neurologist.
APPENDIX 2

Evaluation of an MS Nurse Specialist service: a review and development of the role

PATIENT INFORMATION SHEET

Today, there is an increasing interest in making sure that all Health or Social services are provided in the most effective and efficient way. The new appointment of an MS Nurse Specialist in 1998 was seen as an ideal opportunity to review some of the needs of people with MS in the West Berkshire area. This 2 year project has consulted some of the potential users of MS related services, including patients, carers, professionals and various voluntary groups, to find out what key things are needed. These ideas have then been used to review and further develop the MS Nurse service, before consulting a second group of “users” about their views and experiences this year.

Rather than carry out a large, impersonal survey, we have chosen to speak to a smaller number of people in more detail. Up to 25 people with MS may be contacted over the 2 year period.

Finding out your true opinion is essential if we are to develop the service realistically. Although there is a partnership between the MS Nurse, Consultants and the researcher, with a common aim of providing an effective local MS service, there are strict controls to make sure that the identities of those interviewed are not revealed to any members of the clinical team. Only common ideas and suggestions, with no reference to names will be reported back to them as members of the planning group.

If you were to volunteer, what would it involve?

Your name would be put forward with other MS volunteers from the West Berkshire area. A small number of people (up to 12) would be contacted by the researcher to invite them to take part in an informal, private interview. This could be carried out in your own home, on the telephone or wherever convenient for you, and would probably last between 45 minutes and 1 hour. You would be asked about your experiences of living with MS whilst in the West Berkshire area. In particular, your views of what has been helpful and your suggestions for further improvements would be an important part of the discussion. To be accurate and with your agreement your interview would be tape recorded, then typed. You would then be given the opportunity to review the main points arising from your interview and change anything you were not happy with before the information was grouped together with that from other interviews. You could choose whether to include a carer or a close family member/friend in the interview, or whether to keep the interview private.

How would the information you give be kept private?

It is important for this study that you feel able to express your views freely. Your identity and participation in the study will not be revealed to anyone other
than the research interviewer. Written consent forms and tape recordings will be stored in the researcher’s locked cabinet at the South Bank University during the study. Extracts from typed interviews and patient’s notes will be made anonymous before being used in any report. At the end of the study, all written and recorded interviews will be destroyed.

Would your decision either to volunteer or not to take part in the study have any effect on your care?

Only you and your close family/carer (if you choose to involve them) will know of your decision to take part in the study. Your decision to volunteer or not will have no effect on the standard of your care, and you would be free to withdraw from the study at any time, without explanation.

What would be the benefits of taking part in the study?

The ideas of those interviewed will be used to guide and develop the service provided by the local MS Nurse Specialist. For people with MS in the West Berkshire area this is an opportunity to help make the service more responsive to local needs. Although there is no guarantee that your specific views will change the service, your joint efforts may benefit members of the MS community in the area. In addition, some ideas from the study will contribute to national guidelines for other areas of the country wishing to set up Specialist MS Nurse services. They will also contribute to an education programme being developed at the South Bank University preparing MS Nurses for their role. Those people who take part in the interviews will also have feedback in the form of a short report about plans and progress of the service during the period of the study.

What to do next?

If you do not wish to be considered as a volunteer for this study, please ignore this information. It will not prevent you being considered for any other research in the future, should you wish to be. If you do wish to volunteer or if you would like some more information before deciding, it is important that you contact me – Jane Johnson, directly so that your potential participation in the study can be kept confidential.

Please complete and return the attached slip in the envelope provided if you would like me to contact you to discuss it further.

I look forward to hearing from you.
Replies would be appreciated by...........................(date).

My contact details for further reference are:

Mrs. Jane Johnson, (Research Fellow-MS)
Faculty of Health,
South Bank University,
East London Campus,
Whipps Cross Hospital,
Study title: Evaluation of an MS Nurse Specialist service: a review and development of the role.

Name…………………………………….  Telephone…………………………
Address………………………………..  Best times to contact me are:………………
………………………………………  …………………………………………………

I have read the attached PATIENT INFORMATION SHEET and I would like you to contact me about taking part in the study.

Signed…………………………………………………………

__________________________________________________
APPENDIX 3

INTERVIEWS – CHECKLIST

1. Remind of Information Sheet:
   - aim is to consult some of the potential "users" of an MS Specialist Nurse’s service to help develop it effectively.
   - It will not be possible to trace any issues discussed back to a particular person. Only common ideas and suggestions, with no reference to names will be incorporated in the reports.
   - You are free at any time to decide not to take part. Taking part or not taking part will have no effect on any care you may need.

2. Offer to answer any questions/explain further….

3. Sign consent form.

4. Set up tape recorder and microphone – start up.

5. INTERVIEW.

6. Stop tape.

7. Thank you – re-iterate confidentiality.

8. Go through Barthel Index – from bottom upwards.

9. Go through demographic information on back of Barthel Index.

10. Make arrangements to interview carer/partner if appropriate:
    - sometimes carers/partners of people with MS have particular concerns of their own, perhaps about their experiences or the services provided. They might hold different views, but this is all useful information for us to help evaluate the service.
    - Arrange to meet or continue.

11. Explain what happens next:
    - I write back to you summarising the main points I understood from the interview (or the full transcript), and if that’s not what you really wanted to say, you can clarify that for me.
    - Common themes from all the interviews will be put together into a report and compared to issues raised by a group of people with Ms interviewed last year, before the MS Nurse’s service was well established. Your thoughts and ideas will provide more information to help the MS Nurse develop a service appropriate to the needs of people in this area. I’ll circulate a short report to let you know what plans have been made at this stage.
CONSENT FORM

Title of the Project:
**Evaluation of an MS Nurse Specialist service:**
*a review and development of the role*

To be completed by the person to be interviewed:

Have you read the invitation letter/information sheet? Yes / No

Were you given an opportunity to ask questions and discuss this study before taking part? Yes / No

Are you satisfied with the answers to your questions? Yes / No

Do you feel you have received enough information about the study to make a decision about taking part? Yes / No

Please indicate who discussed it with you:

Mrs. Jane Johnson .........................

Someone else (name) .........................

Do you understand that you are free to refuse to take part in this study and to leave the study at any time without having to give a reason for leaving, and without affecting the standard of your care in any way? Yes / No

Signed: ................................. Date: ....................

Name: .................................

(in block letters)

Code........
APPENDIX 5

Proposed semi-structured interview schedule: People with MS

Preamble: Your experiences and ideas are vital in helping us understand the needs of people with MS, and helping us plan effective services. There are no right and wrong answers here. Your thoughts are what count. This is roughly in 3 parts: I’d like to ask a little about your experiences when you first found you had MS, then your thoughts about the services available in general for people with MS in this area. Thirdly, I’d be interested in your suggestions of what an MS Nurse might be able to help with more specifically.

1. Were you living in the West Berkshire area when you were diagnosed as having MS? If not, where?

2. How did you first find out your diagnosis? (Describe events leading up to, during, after etc.) What kind of an experience was that? What were your reactions at the time?
   (clarify: who gave the diagnosis if not clear? Possibilities to explore – GP involvement, Neurologist, other Dr, NHS/privately, locally/elsewhere)
   When was this? (Note: newly diagnosed if 6-12 months ago)

3. What things or what people helped you cope at that time?
   How did they help?
   With hindsight, what else could have helped you or your family to cope around that time?

4. In general, what have been your experiences in the past in trying to get the help you feel you need?

5. Who has been useful recently (newly diagnosed) or during the last year (other groups) when you needed help or advice about MS or related problems?
   (possibilities to explore – GP, Neurologist, SS support, Care Manager, family/carers, D/N, MS/N, OT, PT, MS.Soc-local/national, MS Therapy centre, Counsellor, Disablement Employment Advisor.)
   (If not mentioned, check whether they have ever had contact with an MS Specialist Nurse.)

6. What did each person or service do that was useful? (in the last year).

7. Who do you feel has been the most useful? Why?

8. Getting information is often important for people with MS. What kind of information have you needed in the past about managing your MS, or about MS itself?

9. Where do you go or who do you ask if you need information like this? How satisfactory has that been as a way of finding out?

Specific to MS Nurse Service:
10. The MS Support Nurse attached to Battle Hospital is partly paid for by the local MS Society. Everyone wants to make sure this service is as useful as
possible for people with MS in the area. What would you hope that as service like this might hope to achieve?

11. At the moment the focus is on 5 main issues:
   1. Newly diagnosed people,
   2. MS people newly discharged from hospital (for whatever reason,)
   3. Educating staff (eg NHS, SS etc) about caring for people with MS,
   4. Liaison and co-ordination of other local services,
   5. Helping identify care needs and carer support.

I’m interested in your experiences and ideas about each of these 5 issues. Can we go through them one at a time? That would help us get a picture of what people who live with MS think are worthwhile things for a Specialist Nurse to help with.

Let’s start with the newly diagnosed…. 

   a. What could an MS Nurse do to help newly diagnosed patients? Where, how, when? (e.g. see there and then in the clinic? she contact you? you contact her?)

   b. What could an MS Nurse do to help people with MS who are about to be discharged from hospital? Where, how, when?

   c. What do you wish professionals knew more about, when providing care for people with MS? (+same question about paid carers) Who, among these people should the nurse provide education or information to as a priority? What would be the most effective ways of doing this?

   d. Finding the right help from local services – healthcare, therapies, Social Services or anything else can sometimes be difficult. How could an MS Specialist Nurse help people with MS get what they need from local services?

   e. Getting help in the home can also be difficult sometimes. What could the MS Nurse do to make this easier? Carers and close family need help too sometimes. What could the MS Nurse do to help and support them?

12. We’ve gone through the 5 issues that are being focused on at the moment. Would you like to see any other main issues on the list of priorities?

13. If you had to pick just one area for improvement (a magic wand!) in services for people with MS in West Berkshire, what would it be?

Thank you for all your thoughts and ideas. These will be added to the ideas from some other people with MS in the West Berkshire area, and will be used to help develop the MS Nurse Service. Although your identity will be kept secret, I will make sure you get a copy of the recommendations that the Steering Committee make for the further development of the service.
# APPENDIX 6

## BARTHEL ACTIVITIES OF DAILY LIVING INDEX

**Date:** ………………………………..    **Patient code:**……………………………..

### Scoring:

#### BOWELS
0=incontinent
1=occasional accident
2=continent

#### BLADDER
0=incontinent or catheterised and unable to manage
1=occasional accident (max 1x per 24hrs)
2=continent over last 7 days

#### GROOMING
0=needs help
1=needs help
2=continent over last 7 days

#### TOILET USE
0=unable
1=needs some help
2=independent (on and off, dressing, wiping)

#### FEEDING
0=unable
1=needs help cutting, spreading butter etc.
2=independent

#### TRANSFER
0=unable
1-major help (1-2 people)
2=minor help (verbal or physical)
3=independent

#### MOBILITY
0=immobile
1=wheelchair independent including corners etc
2=walks with help of 1 person (verbal or physical)
3=independent (but may use any aid eg. stick)

#### DRESSING
0=dependent
1=needs help
2=independent

#### STAIRS
0=unable
1=needs help (verbal, physical, carrying aid)
2=indepent up and down

#### BATHING
0=dependent
1=needs help
2=independent

### Notes on scoring:

#### BOWELS (preceding week)
- if needs enema from nurse then incontinent
- occasional = once a week

#### BLADDER (preceding week)
- occasional = less than once a day
- patients who completely manage catheters/sheaths alone = continent

#### GROOMING (preceding 24-48hrs)
- implements can be provided by helper

#### TOILET USE
- should be able to transfer onto toilet/commode, undress sufficiently, wipe, dress and leave

#### FEEDING
- able to eat any normal, not only soft food
- food cooked and served by others but not cut up.
- help=food cut up but patient feeds self

#### TRANSFER
- from bed to chair and back
- dependent = no sitting balance, 2 people to lift
- major help = 1 strong skilled or 2 normal
- minor help = 1 person easily or supervision for safety

#### MOBILITY
- refers to mobility indoors

#### DRESSING
- able to select and put on all clothes although may be adapted
- needs help = with buttons, zips etc

#### STAIRS
- must carry any walking aid to be independent

#### BATHING
- must get in and out unsupervised and wash self, bath or shower

### General guidelines:
- The index should be used as a record of what the patient does, not what they could do.
- The main aim is to determine degree of independence from any help, physical or verbal.
- A patient’s performance should be established using the best available evidence. Asking the patient, friends or relatives will be the usual source, but direct observation and common sense are also important. However, direct testing is not needed.
- Usually the performance over the last 24-48hrs is important.
- Use of aids to be independent is allowed.
- Comparisons with previous scores should not be made during completion as this undermines any scientific validity.

Demographic information:

Male
Female
D.o.B. / age

Living arrangements/carers:
Lives alone
Lives with partner
Lives with partner and children
(ages)
Lives with

others

Roughly how long had MS symptoms?
When diagnosed?

Rough idea of disability:
Out during day? Work/shopping/visiting/day centre etc?
Has paid carer (how often)?
Has live-in paid carer?
How gets around – home/community?

Contact with another MSN
Contact with local MSN

Venue of interview: Home / MS Therapy Centre / other venue

Carer/family member present during interview? Who?

Carer/family member to be interviewed individually? Date

Any other comments:

<table>
<thead>
<tr>
<th>Newly diagnosed</th>
<th>Minimal Impairment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Moderate disability</td>
<td>Severe disability</td>
</tr>
</tbody>
</table>

Comments on interview:
**Definitions of the four MS phases for the project (MS Society Standards of Healthcare)**

**Newly diagnosed**
Informed of diagnosis in the last 6-9mths in the West Berkshire area.

**Minimal impairment**
MS itself has minimal physical or cognitive effect on current occupation or lifestyle. However, emotional factors may create significant difficulties in many areas and cause added anxiety e.g. in home/work relationships, self esteem, future planning.

**Moderate disability**
The person with MS experiences disability and a change in lifestyle as a result of intrusive physical and/or cognitive symptoms. These may be longstanding or newly acquired e.g. needing to use a wheelchair for the first time. Some aspects of daily life may require the help of others e.g. a family member or regular carer.

**Severe disability**
A range of complex and interacting physical, cognitive and psychosocial problems make the person with MS heavily dependent on others to maintain normal activities of daily living. This may require significant carer input in the home or a move to residential care.
### APPENDIX 7

**Sources of Help at Diagnosis: Positive and Negative experiences**

<table>
<thead>
<tr>
<th>Source</th>
<th>COHORT 1 (N=12)</th>
<th>COHORT 2 (N=12)</th>
<th>TOTAL</th>
</tr>
</thead>
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<tr>
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<td>Negative</td>
<td>Positive</td>
</tr>
<tr>
<td>GP</td>
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</tr>
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<td>Hospital. Dr</td>
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<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Hospital. Nurse</td>
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<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Comm. Nurse</td>
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<td>0</td>
<td>0</td>
</tr>
<tr>
<td>MS Specialist Nurse</td>
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<td>3</td>
</tr>
<tr>
<td>PT - hospital.</td>
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<td>0</td>
<td>0</td>
</tr>
<tr>
<td>MSTC - general</td>
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<td>2</td>
<td>1</td>
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<tr>
<td>MSS</td>
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<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Partner</td>
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<td>2</td>
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</tr>
<tr>
<td>Other family</td>
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<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Friend</td>
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<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Religion</td>
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<tr>
<td>Info①</td>
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<td>Work</td>
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</tr>
<tr>
<td>Getting to Grips</td>
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<td>0</td>
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<tr>
<td>Other examples 4</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
</tbody>
</table>

① Other examples: Positive: ARMS (2); Self (1); Negative: Nobody else can help you (2); missed out as a private patient (1).
## APPENDIX 8

### Subsequent Sources of Help: Positive and Negative Experiences

<table>
<thead>
<tr>
<th>Sources</th>
<th>COHORT 1 (N=12)</th>
<th>COHORT 2 (N=12)</th>
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<td>2</td>
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<tr>
<td>MSS</td>
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<td>Partner</td>
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<tr>
<td>Other examples7</td>
<td>2</td>
<td>2</td>
<td>6</td>
</tr>
</tbody>
</table>

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5 Day Centre  
6 Mobility Advice and Vehicle Information Service  
7 Selected examples: Positive: Aids, Adaptations and “mobility”; “Management is yourself”;
Klinova nurse; ARMS; acupuncture; gym. Negative: private insurance wouldn't pay; missed out as a private patient; transport not disability friendly; people don't talk about death from MS.
INTERVIEW SCHEDULE – “STAKEHOLDERS”

General:
1. How would you describe your role or involvement with people with MS?
   - perhaps with one person, a small local group, a geographical area, practice area, Health Authority wide?

2. What would you see as some of the problems facing people with MS in this area?

3. What are some of the difficulties for you as a professional or as a responsible carer/helper?

4. Can you suggest any practical ways of improving the situation –
   - For people with MS?
   - For the service you provide?

5. What factors (if any) may limit or prevent these changes happening in reality?

Specific to MS Nurse Service:
1. The new MS Support Nurse attached to Battle Hospital is partly paid for by the local MS Society. Everyone wants to make sure this service is as useful as possible for people with MS in the area. What would you hope a service like this would try to achieve?

2. At the moment the focus is on 5 main issues:
   1. Newly diagnosed people,
   2. MS people newly discharged from hospital (for whatever reason,)
   3. Educating staff about caring for people with MS,
   4. Liaison with other local services,
   5. Helping identify care needs and carer support.

   What are your reactions to this list?
   Would you like to see any other main issues on the list of priorities?

8. I’m interested in your views about each of these 5 issues. Can we go through them one at a time? That would help us get a picture of what people who have some responsibility towards people with MS think are important aims, and where an MS Specialist Nurse may make a contribution.

   a. What concerns (if any) do you have about the time surrounding diagnosis for people with MS? Do you have any examples to illustrate this? Do you see any role for an MS Nurse in this situation?

   b. What (if any) are your concerns about people with MS being discharged from hospital? What would you be hoping for if a person with MS were discharged well from hospital? (quality indicators to a professional?) How might the MS Nurse contribute to achieving these outcomes?
c. What concerns (if any) do you have about other professional’s levels of knowledge about MS? (+ same question about paid carers) Do you have any examples to illustrate this?

Is this, in your view an issue where the MS Nurse could make a useful contribution? (If not, why not?)

If so, what would be the most effective ways of doing this? Which staff or professionals are most in need of education in your view?

d. Is getting access to local Health or Social services an issue for people with MS in West Berkshire?
Do you have any examples to illustrate this?

Could an MS Specialist Nurse contribute to helping people with MS get what they need from local services? (If not, why not?)
If so, what would be effective ways of doing this?

e. What concerns (if any) do you have about close family members or unpaid carers of people with MS in the West Berkshire area?

Do you have any examples to illustrate this?
Could an MS Specialist Nurse have a role in this situation? (If not, why not?) If so, what would be effective ways of contributing?

9. Do you have any other comments or views about services which MS Specialist Nurses may or may not be able to provide in West Berkshire?

10. Assuming no further dramatic treatment options become available in the near future, what would be the one thing you would change if you could, to improve the situation for people with MS in this area?

Thank you for all your thoughts and ideas. These will be added to the ideas from others with an interest in MS in the West Berkshire area, and will be used to help develop the MS Nurse Service. Although your identity will be kept secret, I will make sure you get a copy of the recommendations that the Steering Committee make for the further development of the service.
**APPENDIX 10**

**Standard 1 Management at and after diagnosis (January 2000)**

**Standard statement:** Patients with suspected Multiple Sclerosis will have their diagnosis confirmed by a consultant Neurologist within a minimum time, will be provided with initial information and the offer of support from the MS Nurse Specialist, and feel confident they have a reliable contact for further information and support if/when required.

<table>
<thead>
<tr>
<th>Structure</th>
<th>Process</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>GP referral letters contain sufficient information to suggest demyelination.</td>
<td>Neurologists screen referral letters weekly and mark those suggestive of MS for appropriate appointment according to perceived urgency. Neurology secretaries negotiate appropriate appointments with Admissions Dept.</td>
<td>On receipt of referral from GP, patients are seen by a Neurologist according to clinical need - urgently = within 1 week, - semi-urgent = within 4 weeks, - routinely = within 12 weeks. Investigations are completed within 4 weeks of initial consultation. Results of investigations are communicated to patient by a Consultant Neurologist within 4 weeks of completion. Patients feel they have an opportunity to discuss the meaning of MS with the Neurologist at the time of diagnosis. They will leave the clinic with contact details (MS Soc, Therapy Centre, MS Nurse) and an awareness of the MS Nurse’s role. Patients will have had contact with the MS Nurse and be aware of this and other potential support networks and sources of help, should they wish to pursue them, within 1 week of receiving their diagnosis. Patients’ feel that their immediate, individual need for knowledge is met and that they have a reliable contact for further information and support when required. Patients and family will be aware of and have the opportunity to attend a “Getting to Grips with MS” course within 6 months of diagnosis.</td>
</tr>
<tr>
<td>Sufficient investigation slots available (MRI, VEPs, LP - daycases)</td>
<td>Bearing in mind how much each patient wishes to know at this stage, Neurologist explains principles of MS, outlines role of MS Nurse in providing ongoing support and gives patient written information sheet which includes her contact details and details for the MS Society / MS Therapy Centre. Neurology secretaries forward referral to MS Nurse (a copy of GP letter from clinic) within 4 days of any patient receiving a diagnosis of MS.</td>
<td></td>
</tr>
<tr>
<td>20 minute (minimum) appointments booked for discussion of diagnosis.</td>
<td>Patients feel they have an opportunity to discuss the meaning of MS with the Neurologist at the time of diagnosis. They will leave the clinic with contact details (MS Soc, Therapy Centre, MS Nurse) and an awareness of the MS Nurse’s role. Patients will have had contact with the MS Nurse and be aware of this and other potential support networks and sources of help, should they wish to pursue them, within 1 week of receiving their diagnosis. Patients’ feel that their immediate, individual need for knowledge is met and that they have a reliable contact for further information and support when required. Patients and family will be aware of and have the opportunity to attend a “Getting to Grips with MS” course within 6 months of diagnosis.</td>
<td></td>
</tr>
<tr>
<td>Copies of initial information sheet including contact details - MS Nurse, MS Society, MS Therapy Centre available in clinic.</td>
<td>MS Nurse phones newly diagnosed patients at home within 1 week of clinic appointment to introduce self and outline potential support available / arranges consultation (home or clinic) according to patient’s needs. Various MS Society written information given to consolidate any discussions. MS Nurse responds to any answerphone messages from newly diagnosed patients as a priority (within 24 hours).</td>
<td></td>
</tr>
<tr>
<td>Copies of MS Society information booklets available for MS Nurse to give out as required, following individual discussions.</td>
<td>MS Nurse negotiates with MS Society and MS Therapy Centre to set up and develop “Getting to Grips with MS” courses twice a year.</td>
<td></td>
</tr>
<tr>
<td>Patients and MS Nurse have access to 24 hour answerphone.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>“Getting to Grips with MS” course dates available at least 6 months in advance.</td>
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<td></td>
</tr>
</tbody>
</table>
## Audit measurement tools: A & B

### Audit of service provided when patients are diagnosed with Multiple Sclerosis

<table>
<thead>
<tr>
<th>Methods of measurement</th>
<th>Frequency of audit: 12 monthly</th>
<th>Sample size: 5 - 10</th>
</tr>
</thead>
<tbody>
<tr>
<td>A) Review of medical records:</td>
<td>1. Does time from receipt of GP referral to 1st appointment correspond to consultant's view of clinical need?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Urgent = within 1 week?</td>
<td>YES</td>
</tr>
<tr>
<td></td>
<td>Semi-urgent = within 4 weeks?</td>
<td>YES</td>
</tr>
<tr>
<td></td>
<td>Routine = within 12 weeks?</td>
<td>YES</td>
</tr>
</tbody>
</table>

If not, briefly why not?

………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………

2. Is appointment to discuss diagnosis within 8 weeks of initial consultation with Neurologist?  YES NO
If not, briefly why not?

………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………

3. Who gives the patient their diagnosis?  Consultant Specialist Reg SHO Other

4. Evidence that patient is given written information sheet which includes MS Nurse/MS Society/MS Therapy Centre contact details in clinic?  YES NO

B) Review of MS Nurse records: 1. Do records show contact with patient (phone or face to face)

   a) within 7 days of diagnosis in clinic?  YES NO

   b) at a later date?  YES NO  Time elapsed

If not, briefly why not?

………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………

2. Do records show evidence of written or video information given/sent/offered to patient?  YES NO  Patient declines information

3. Do records show evidence that patient is made aware of "Getting to Grips" courses?  YES NO
Audit measurement tools: C

Postal Questionnaire to patients:

Patient Questionnaire

The Neurology Department is keen to develop services which are effective and meet patients needs, and as part of this process, we would like to consult patients about their experiences. We would be grateful if you would help us by completing this brief questionnaire.

You are under no obligation to do so, and if you choose not to, this will in no way influence any care you may receive in the future. The questionnaire is anonymous, so no member of the clinical team will be aware of your identity. Thank you in advance for your help.

(Please put a tick in the appropriate box)

1. At the time of diagnosis, did you feel that the explanation of MS you were given by the doctor was

   Too brief?      About right?      Too detailed?

2. On the day you were diagnosed, were you given contact numbers for

   The MS Specialist Nurse?      The MS Society?      The MS Therapy Centre?
   Any other helpful services?

   Please give details:........................................................................................................................................

3. Did you speak to the MS Specialist Nurse during the following week?   YES   NO
   If not, was this your choice?   YES   NO

4. If you had contact, did you feel that the information/help you were given by the MS Specialist Nurse was

   Too brief?      About right?      Too detailed?
5. In the months following your diagnosis, how did you feel about knowing where to find MS information?

I felt confident that I could find information and advice if I needed it. 0 ___________________________ 10 I had no idea of where to find information or advice if I needed it.

6. In the months following diagnosis, to what extent did you feel support was available to help you cope with your MS?

I felt support was available to help me cope with my MS if I needed it. 0 ___________________________ 10 I felt totally alone in coping with my MS.

7. Were you given information about any courses or meetings for people newly diagnosed with MS, for example "Getting to Grips with MS" courses?

   YES  NO

8. If you attended one of these courses, how helpful did you find it?

Very helpful 0 ___________________________ 10 Not at all helpful

3. Do you have any suggestions for how we could provide a better service to patients around the time of diagnosis?

........................................................................................................................................................................
........................................................................................................................................................................

Please return in the envelope provided. Thank you.
Dear M

The Neurology Department is keen to develop services which are effective and meet patients needs, and as part of this process, we would like to consult patients about their experiences. I am working with Judy Percy, the MS Nurse to audit some aspects of the service, and in this case we are looking at experiences around the time of diagnosis. Your name was chosen randomly from a list of those who received a diagnosis of MS last year. We would be grateful if you would help us by completing this brief questionnaire.

You are under no obligation, and if you choose not to complete the questionnaire this will in no way influence any care you may receive in the future. The questionnaire is anonymous, and I am co-ordinating replies so that no member of the clinical team needs to be aware of your identity. If you have any queries I can be contacted on: 020 7815 4738 or via e-mail at johnsoje@sbu.ac.uk or you could write to me c/o Judy Percy at the above address.

We carried out a similar review of patient opinion about a year ago and identified some things which were successful and where improvements needed to be made. This review will give us feedback about the success of any improvements and help identify other issues which we need to work on.

Thank you in advance for your help.

Yours sincerely

Jane Johnson, Research Fellow-MS
**APPENDIX 14**

**Standard II  Education for Paid Carers**

*Standard statement*: Paid/formal carers* will feel that their MS related knowledge, skills and care-giving is enhanced by support and educational initiatives provided by, or with input from the MS Specialist Nurse. (*This includes any hospital or community staff employed to provide day-to-day care*)

<table>
<thead>
<tr>
<th>Structure</th>
<th>Process</th>
<th>Outcome</th>
</tr>
</thead>
</table>
| Dates available for MS related teaching sessions repeated 4 X per year for Priority Care staff in the community (minimum No. to run session=5 staff). | MS Nurse will liaise with:  
   a) Co-ordinator of Priority Care,  
   b) Trust Staff Development Co-ordinator,  
   c) Community and Trust Lifting and Handling Co-ordinators,  
   d) Rehabilitation Specialists,  
   e) SS Team Leaders,  
   f) District Nurses | Appropriate staff are offered opportunities to attend courses which cover practical aspects of MS care provision. |
| 2 dates per year available for joint PD and MS study days on the Trust Staff development Programme for D and E grade nurses. | to develop appropriate MS specific input to courses for community based carers and hospital staff nurses. | Staff attending formal courses feel the content and approach is relevant and effectively addresses potential MS related problems they encounter in practice. |
| Regular Community and Acute Trust Lifting and Handling Programmes that include specialised skills in handling clients with MS. | Involve client or caring relative to help advise on programme content. | Paid carers report:  
   a) increased understanding of MS related problems and their effects on the individual and family,  
   b) increased confidence and job satisfaction in negotiating and providing practical care for PwMS following formal or informal teaching sessions. |
| Sufficient appropriate local venues available for teaching sessions. | If appropriate, MS Nurse acts as mediator between care providers/nurses and client/family where difficulties are experienced in negotiating care, using this as a learning opportunity where possible. | More effective resolution of difficulties where carers and clients experience problems in negotiating care. |
| Supply of evaluation forms for each session. | If necessary and in agreement with line managers, MS Nurse provides support/debriefing opportunity for regular community carers if a long-term client with MS dies (within 1 week). | Community carers feel able to share and cope more effectively with stress in their MS related work. |
| Time can be made available as necessary by managers for occasional staff debriefing/reflection. | Where possible PwMS/relatives inform MS Nurse of any planned hospital admissions in advance. | MS Nurse is made aware in advance of any planned hospital admissions for MS clients with complex needs. |
| Posters encouraging PwMS or relatives to alert the MS nurse if they are due to be admitted to hospital displayed in Outpatients dept, MS Therapy Centre, GP surgeries. | MS Nurse contacts ward staff to anticipate any difficulties prior to planned admission of people with complex care needs. | In-patient and Nursing Home staff feel they have access to helpful advice and support from the MS Nurse. |
| main aspects of MS Nurse role and encouraging contact if experiencing difficulties. | MS Nurse uses admission of people with complex problems as an opportunity for ward-staff support and teaching. | Nurse which enables them to manage moderately to severely disabled MS admissions successfully. |

**Potential measurement tools:**

1. Copies of existing evaluation forms from each formal teaching session and numbers of staff /carers attending:
   - a. Community Trust sessions (x 4 per year)
   - b. Acute Trust Staff Development Programmes (x 2 per year)
   - c. Lifting and Handling sessions (Negotiation with the facilitators).

2. Number of staff attending informal sessions facilitated by MS Nurse in Community eg. support /debriefing sessions, mediation sessions.

3. Number of ward based educational sessions, facilitated by MS Nurse arising from admission of patients with complex needs.

4. Questionnaire to a sample of Community / in-patient staff to assess understanding and confidence in managing MS related problems and satisfaction with advice and support available from MS Nurse.
STANDARD II: EDUCATION FOR FORMAL CARERS

Covering letter:

Re: Research Project – Evaluation of an MS Nurse Specialist Service; a review & development of the role

Dear Colleague,

My name is Karen Giles and I am currently working as a lecturer at South Bank University. I am assisting a colleague in a case study into the Multiple Sclerosis Nurse Specialist role. I would like to obtain your views regarding this role and how you feel that it relates to your practice, through the format of a short questionnaire. The information will be incorporated into a wider case study being undertaken into the role of MS nurses in the UK by Jane Johnson, Research Fellow, South Bank University.

You will not be personally identifiable from your responses, but hopefully they will provide valuable information into the effectiveness of the MS nurse specialist role. In turn this information will assist in the future development on MS nurses’ roles in order to provide best practice for people with Multiple Sclerosis and for other professionals.

If you are willing to assist, could you kindly return the completed questionnaire to me, in the stamped addressed envelope provided by Monday 25th September 2000.

Thanking you in anticipation of your response

Karen Giles

Karen Giles
Principal Lecturer Clinical Skills
South Bank University
Erlang House
103 Borough Road
London
SE1 OAA

Gileskp@sbu.ac.uk
APPENDIX 16

STANDARD EVALUATION: EDUCATION FOR FORMAL CARERS

MS Nurse questionnaire: – Registered Nurses

1a. Ward  Tilehurst    Caversham    Francis Greenlands    Minster

1b. Grade  D    E    F    G    Other    please state

1c. Years qualified  less than 1    1 – 2    2 – 5    5+

1d. Post registration qualifications:

1e. Study days attended related to Multiple Sclerosis in last year:

1f. How often do you care for Multiple Sclerosis patients?

Never    Rarely    Sometimes    Regularly

Answer the next question if you have not had any experience of the MS Nurse Specialist.

2. What do you think is the role of an MS Nurse Specialist?

Please proceed to question 9.

If you have had contact with the MS Nurse Specialist, please answer all the remaining questions.

3. What is your understanding of the MS Nurse Specialist role (name of current post holder)?

4. How did you get to know of (current post holder) & her role?
5. Briefly describe ways in which you have consulted with (current post holder) in your clinical practice:

6. How has it affected your care?

7. Have you attended any training provided by (current post holder)?
   Yes □ No □

8. If yes, describe what it was and its affect on your care in relation to the care of people with Multiple Sclerosis.

9a. Would you consider contacting an MS nurse (again, if you have already) for work related help or support?
   Yes □ No □
   If YES, what situations might make you contact him/her?

9b. If not, why not?

10. Please feel free to add any further comments about Multiple Sclerosis Nurse Specialists/ Nurse Specialist roles:

Thank you for your time.
Please return, in the enclosed envelope to:

Karen Giles
Principal Lecturer Clinical Skills
South Bank University
Erlang House
103 Borough Road
London SE1 OAA
STANDARD EVALUATION: EDUCATION FOR FORMAL CARERS

MS Nurse Specialist Carer Questionnaire

1. Number of years employed as a carer.
   - Less than 1
   - 1 – 2
   - 2 – 5
   - 5 – 10
   - 10 +

2. Please give details of the study sessions taught by (current post holder) that you attended:

3. What do you feel were the main things that you learnt from attending the day?

4. Please describe how it has affected your care for people with multiple sclerosis.

5. In what areas do you feel that you need further education/training in relation to caring for people with multiple sclerosis?

6. Please give details of any other relevant qualifications you have, or study days that you have attended over the past year which relate to multiple sclerosis.
7. Would you consider contacting an MS Nurse (again, if you have already), for work related help or support?

   Yes ☐       No ☐

If YES, what situations might make you contact him/her?

If not, why not?

Please feel free to add any other comments that you have regarding the role of the MS nurse specialist:

Thank you for your time
Please return to:

Karen Giles
Principal Lecturer Clinical Skills
South Bank University
Erlang House
103 Borough Road
London SE1 OAA
APPENDIX 18

WOKINGHAM DISTRICT COUNCIL
COMMUNITY SERVICES DEPARTMENT

Name of Training Event: ........................................................................................................

Dates: ....................................................................................................................................

Please circle your answers from 1 = poor to 5 = excellent

1. Aims and Objectives
   How well did the training meet the course aims and objectives?
   1 2 3 4 5

2. How well did the trainer present the training?
   1 2 3 4 5

3. How well did the pace and content of the course suit you?
   1 2 3 4 5

4. How well did the running of the training and its content address equality issues?
   1 2 3 4 5

5. How well will what you have learnt help you in your work?
   1 2 3 4 5

6. What are the most useful things that you have learnt?
   .............................................................................................................................................
   .............................................................................................................................................
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   .............................................................................................................................................
   .............................................................. continued overleaf

..............................................................

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7. How well did the training room refreshments and other practical arrangements meet your needs?

   1  2  3  4  5

8. Do you have any further training needs on this topic?

   ..............................................................................................................
   ..............................................................................................................
   ..............................................................................................................
   ..............................................................................................................
   ..............................................................................................................

Your name: ..............................................................................................................
Your job title: ...........................................................................................................
Your work address: ................................................................................................
APPENDIX 19

Medical Records Audit tool

Review of Hospital Records before MSN ☐ after MSN ☐
(1.9.1997-31.8.98.) (1.3.99-29.2.00)

Hospital number ………………. Current level of disability
(MS Society Standards of Healthcare framework)

Age …………. yrs
Sex: male ☐ female ☐

Years since diagnosis …………. yrs

1. Inpatient episodes

<table>
<thead>
<tr>
<th>Episode</th>
<th>Total days</th>
<th>Speciality</th>
<th>Elective Y/N?</th>
<th>Main reason?</th>
<th>Steroids given Y/N?</th>
<th>No. of referrals to MD team</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>2</td>
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<td>4</td>
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<td>5</td>
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<td>6</td>
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<tr>
<td>7</td>
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</tbody>
</table>

? Quality of nursing assessment/care plan can be assessed.

2. Day Case attendance:

<table>
<thead>
<tr>
<th>Episode</th>
<th>Speciality</th>
<th>Main reason?</th>
<th>Steroids given Y/N?</th>
<th>No. of referrals to MD team</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
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<td>7</td>
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</tbody>
</table>

Speciality Codes:
N = Neuro
G = General Med
R = Rehab
U = Urology
Op = Ophthalmology
Or “other”

Reason Codes:
A = MDT assessment
DR = to start drugs
C = constipation
U = urinary problem
P = pressure sores
CH = chest infection
SW = swallowing
SP = spasticity
P = pain
SOC = social/carer distress/need.
D = depression/emotional distress
F = falls
R = relapse/mobility
Or "other".

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3. Outpatient attendance:

<table>
<thead>
<tr>
<th>Episode</th>
<th>Speciality:</th>
<th>New or follow-up?</th>
<th>Main issues:</th>
<th>No. of referrals to MD team:</th>
<th>Speciality Codes:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>MSN = MS Nurse</td>
</tr>
<tr>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>N = Neuro</td>
</tr>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>G = General Med</td>
</tr>
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<td></td>
<td>R = Rehab</td>
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<td></td>
<td></td>
<td>U = Urology</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>Op = Opthalmology</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>TH = Therapy</td>
</tr>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Or &quot;other&quot;</td>
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</tbody>
</table>

Issue Codes:
A = assessment  
DR = drugs  
C = constipation  
U = urinary problem  
P = pressure sores  
M = mobility  
SW = swallowing  
SP = spasticity  
P = pain  
SOC = social/carer distress/need.  
D = depression/ emotional distress  
PA = psychological adjustment  
F = falls.  
CG = cognition  
R = relapse  
SX = sexual/relate  
OT = Occ. Therapy  
PT = Physio  
Or "other".

Explanatory comment:
Comparative analysis of in-patient costs before and after MS Nurse was in post

The Trust Finance Department quoted costs for the financial year 1999-2000 as £255.61 per day for non-elective and £179.77 per day for elective admissions. Calculations of cost were based on the premise that patients admitted non-electively, for example into Adult Medicine or Emergency Medical Unit beds would eventually be transferred to more appropriate specialities such as Neurology or Rehabilitation, with subsequently lower costs. Clear dates of transfer were not consistently available in medical records, therefore for the purposes of costing, it was estimated that patients admitted non-electively would spend half their stay in beds costed at the higher rate, before being transferred appropriately. Anecdotal evidence suggests that this was a conservative estimate of total cost.

All patients had one inpatient episode during the year, but diminishing numbers had further admissions, from 2 up to 5 episodes.

<table>
<thead>
<tr>
<th>BEFORE MS NURSE</th>
<th>AFTER MS NURSE</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>INPATIENT EPISODE 1</strong></td>
<td><strong>INPATIENT EPISODE 1</strong></td>
</tr>
<tr>
<td>Patients admitted NON-ELECTIVELY: bed days occupied = 644</td>
<td>Patients admitted NON-ELECTIVELY: bed days occupied = 290</td>
</tr>
<tr>
<td>Cost: 322 days @ £255.61 = £82,306.42 322 days @ £179.77 = £57,885.94</td>
<td>Cost: 145 days @ £255.61 = £37,063.45 145 days @ £179.77 = £26,066.65</td>
</tr>
<tr>
<td>Patients admitted ELECTIVELY: bed days occupied = 96</td>
<td>Patients admitted ELECTIVELY: bed days occupied = 172</td>
</tr>
<tr>
<td>Cost: 96 days @ £179.77 = £17,257.92</td>
<td>Cost: 172 days @ £179.77 = £30,920.44</td>
</tr>
<tr>
<td><strong>Total cost:</strong> £157,450.28</td>
<td><strong>Total cost:</strong> £94,050.54</td>
</tr>
<tr>
<td><strong>Total bed days occupied:</strong> 740 days</td>
<td><strong>Total bed days occupied:</strong> 462 days</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>INPATIENT EPISODE 2</strong></th>
<th><strong>INPATIENT EPISODE 2</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients admitted NON-ELECTIVELY: bed days occupied = 244</td>
<td>Patients admitted NON-ELECTIVELY: bed days occupied = 78</td>
</tr>
<tr>
<td>Cost: 122 days @ £255.61 = £31,184.42 122 days @ £179.77 = £21,931.94</td>
<td>Cost: 39 days @ £255.61 = £9,968.79 39 days @ £179.77 = £7,011.03</td>
</tr>
<tr>
<td>Patients admitted ELECTIVELY: bed days occupied = 11</td>
<td>Patients admitted ELECTIVELY: bed days occupied = 85</td>
</tr>
<tr>
<td>Cost: 11 days @ £179.77 = £1,977.47</td>
<td>Cost: 85 days @ £179.77 = £15,280.45</td>
</tr>
<tr>
<td><strong>Total cost:</strong> £55,093.83</td>
<td><strong>Total cost:</strong> £32,260.27</td>
</tr>
<tr>
<td><strong>Total bed days occupied:</strong> 255 days</td>
<td><strong>Total bed days occupied:</strong> 163 days</td>
</tr>
</tbody>
</table>
### Inpatient Episode 3

<table>
<thead>
<tr>
<th>Patients admitted</th>
<th>床日数</th>
<th>床占用天数</th>
<th>Total床占用天数</th>
<th>Cost：</th>
<th>Patients admitted</th>
<th>床日数</th>
<th>床占用天数</th>
<th>Total床占用天数</th>
<th>Cost：</th>
<th>Patients admitted</th>
<th>床日数</th>
<th>床占用天数</th>
<th>Total床占用天数</th>
<th>Cost：</th>
</tr>
</thead>
<tbody>
<tr>
<td>NON-ELECTIVELY</td>
<td>234</td>
<td>262</td>
<td></td>
<td></td>
<td>ELECTIVELY:</td>
<td>28</td>
<td></td>
<td></td>
<td></td>
<td>NON-ELECTIVELY</td>
<td>90</td>
<td></td>
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</tr>
<tr>
<td>ELECTIVELY:</td>
<td>28</td>
<td></td>
<td></td>
<td></td>
<td>45 days @ £179.77 = £8,089.65</td>
<td>11 days @ £179.77 = £1,977.47</td>
<td>31 days</td>
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<td>262</td>
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<td>Cost:</td>
<td>28 days @ £179.77 = £5,033.56</td>
<td>117 days @ £255.61 = £29,906.37</td>
<td>117 days @ £179.77 = £21,033.09</td>
<td>117 days @ £179.77 = £21,033.09</td>
<td>45 days @ £179.77 = £8,089.65</td>
<td>11 days @ £179.77 = £1,977.47</td>
<td>31 days</td>
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### Inpatient Episode 4

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<th>床日数</th>
<th>床占用天数</th>
<th>Total床占用天数</th>
<th>Cost：</th>
<th>Patients admitted</th>
<th>床日数</th>
<th>床占用天数</th>
<th>Total床占用天数</th>
<th>Cost：</th>
<th>Patients admitted</th>
<th>床日数</th>
<th>床占用天数</th>
<th>Total床占用天数</th>
<th>Cost：</th>
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<tbody>
<tr>
<td>NON-ELECTIVELY</td>
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<td>17</td>
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<td>NON-ELECTIVELY</td>
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<tr>
<td>ELECTIVELY:</td>
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<td></td>
<td></td>
<td>8.5 days @ £255.61 = £2,172.69</td>
<td>14 days @ £179.77 = £2,516.78</td>
<td>31 days</td>
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<td>Total床占用天数</td>
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<td>Total床占用天数</td>
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<tr>
<td>Cost:</td>
<td>17 days @ £179.77 = £3,056.09</td>
<td>8.5 days @ £179.77 = £1,528.05</td>
<td>8.5 days @ £179.77 = £1,528.05</td>
<td>8.5 days @ £179.77 = £1,528.05</td>
<td>14 days @ £179.77 = £2,516.78</td>
<td>14 days @ £179.77 = £2,516.78</td>
<td>31 days</td>
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<td>总成本：</td>
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### Inpatient Episode 5

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<th>Patients admitted</th>
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<th>床占用天数</th>
<th>Total床占用天数</th>
<th>Cost：</th>
<th>Patients admitted</th>
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<th>Cost：</th>
<th>Patients admitted</th>
<th>床日数</th>
<th>床占用天数</th>
<th>Total床占用天数</th>
<th>Cost：</th>
</tr>
</thead>
<tbody>
<tr>
<td>NON-ELECTIVELY</td>
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<td>ELECTIVELY:</td>
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<td>NON-ELECTIVELY</td>
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<tr>
<td>ELECTIVELY:</td>
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<td>24 days @ £255.61 = £6,134.64</td>
<td>15 days @ £179.77 = £2,696.55</td>
<td>63 days</td>
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<tr>
<td>Total床占用天数</td>
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<td>Total cost:</td>
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<td></td>
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<td>Total床占用天数</td>
<td>15</td>
<td></td>
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<tr>
<td>Cost:</td>
<td>24 days @ £179.77 = £4,313.46</td>
<td>24 days @ £179.77 = £4,313.46</td>
<td>24 days @ £179.77 = £4,313.46</td>
<td>24 days @ £179.77 = £4,313.46</td>
<td>15 days @ £179.77 = £2,696.55</td>
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<td>63 days</td>
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<td>总成本：</td>
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</tbody>
</table>

总住院日数 = 1274.

总MS患者住院费用为1/9/97至31/8/98，即MS护士上任前：

£271,573.22

总住院日数 = 820.

总MS患者住院费用为1/3/99至29/2/00，即MS护士上任后6个月：

£167,243.57
# MS Specialist Nurse - Diary of activity

Day..... Date: ............... (to be completed for 2 weeks - 10 consecutive working days)

<table>
<thead>
<tr>
<th>Times</th>
<th>Place</th>
<th>Travel</th>
<th>Number of contacts</th>
<th>Breakdown of activities with other professionals etc</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time</td>
<td>Time</td>
<td><strong>Brief description of activity</strong></td>
<td>Where did this take place?</td>
<td>Travel time: hours/ mins</td>
</tr>
</tbody>
</table>

**See over page**
Day..... Date: ..............(continued)

<table>
<thead>
<tr>
<th>Psychological intervention:</th>
<th>Social intervention:</th>
<th>Physical intervention:</th>
<th>Information giving/education:</th>
<th>Outcomes:</th>
</tr>
</thead>
<tbody>
<tr>
<td>E.g. emotional support/counselling/assessing mood/ coping/ assessing and managing family dynamics etc</td>
<td>E.g. welfare and benefits/employment issues/ home care negotiations etc</td>
<td>E.g. assessments of physical health/any nursing treatments/ interventions etc.</td>
<td>If this is part of any of the 1st 3 just put - yes. Otherwise outline content.</td>
<td>Nurse activity</td>
</tr>
</tbody>
</table>

Breakdown of activities with P=patients, R=relatives, C=carers (to expand on entries in columns 3 and 6 overpage) | Notes on outcome of activities:
**Summary sheet**  Types of activity:  Number  Duration  No. of people involved

Meetings/discussions (patient related)

Other meetings/discussions

Patient contact – clinic
  - home visit
  - ward

Relatives/carers contact – clinic
  - home visit
  - ward

telephone work – patients
  - relatives / carers
  - professionals

Teaching/preparation

Own professional development

Administration

Travel

Other –