Research Initiative for Long Term Neurological Conditions LTNC

UNIVERSITY OF OXFORD

THE NEEDS AND EXPERIENCES OF SERVICES BY INDIVIDUALS WITH LONG-TERM PROGRESSIVE NEUROLOGICAL CONDITIONS, AND THEIR CARERS.

A BENCHMARKING STUDY.

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Executive Summary

This report describes a project to assess experiences of health and social care services for patients with Motor Neurone Disease (MND), Multiple Sclerosis (MS) and Parkinson's Disease (PD), and their carers. The study was one of a number of related studies set up by the Department of Health's (DH) Policy Research Programme in 2006 (Research Initiative for Long-Term Neurological Conditions to assist implementation of the National Service Framework (NSF)).

The NSF for long-term conditions set out 11 quality requirements for health and social services to improve the care and quality of life of people with long-term conditions and their carers. The NSF is a key tool for delivering the government's strategy to support people with long-term neurological conditions. Individuals with MND, MS, and PD are central to this initiative. Despite the progressive nature of these conditions there is scope for improving quality of life for individuals with these conditions and their carers by delivering good quality health and social services.

The project consisted of four distinct phases:

Firstly, a series of three literature reviews were carried out to update the evidence reviewed and reported by the NSF in 2005. The purpose of these three reviews (one in relation to each of the three neurological conditions) was to identify any services or interventions not high-lighted by the NSF that might reasonably be a focus of the main survey.

Secondly, a series of in-depth qualitative interviews (n=46) were carried out with individuals with MND, MS or PD and carers of individuals with these conditions. The purpose of these interviews was to help focus and target the main survey both in terms of topics and issues but also appropriate formatting of questionnaire items. Participants were recruited from all over the UK.

Thirdly, a series of versions of survey instruments (for both patients and their carers) were drafted and tested partly by discussion with an advisory group of individuals with long term conditions and carers, and partly by interviews with a sample of respondents and partly by means of a pilot survey.

The process involved in developing the carer questionnaire was the same as for the patient questionnaire. However, there was only one NSF quality requirement that particularly referred to carers, and other sources of information were used to develop the dimensions and themes from which the original items were developed.

A pilot survey of patients and carers was then undertaken to determine the acceptability of the instruments to respondents with the help and collaboration of memberships and organisations of three main charities: Motor Neurone Association, Multiple Sclerosis Society and Parkinson's Disease Society.

Fourthly and finally, the main survey of patients and carers was then carried out, once again with the help and collaboration of memberships and organisations of three main charities. This survey was carried out during 2008-9. Five thousand and nine questionnaire packs were sent out. Patients were asked to complete the 'Patient'

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questionnaire and to select an informal carer to complete the 'Carer' questionnaire. For those responding, in the majority of cases both the patient and carer questionnaires were included (n=1812, 68.1%), for 751 packs (28.2%) only the patient questionnaire and for a small number (n=98, 3.7%) only the carer questionnaire had been included.

The survey asked about experience of a wide range of services and also included the SF-12 for patients and carers. Patients also completed a relevant condition-specific questionnaire (either MSIS-29 for multiple sclerosis, ALSAQ-40 for MND or PDQ-39 for Parkinson's disease).

Key findings are summarised in relation to Quality Requirements for patients.

Person Centred service (QR1)

- Almost all of the sample (95%) were in contact with a health professional about their neurological condition in the year before the survey and were most likely to have consulted a hospital specialist, followed by their GP, followed by a specialist nurse.
- A majority of the sample reported no difficulties of seeing a health or social care professional. Amongst the minority reporting a difficulty, it was most likely to be in relation to seeing a consultant, a specialist nurse or a physiotherapist.
- Experiences were mixed regarding coordination of services. Thirty-six percent of the sample felt that there was a single health or social care professional who coordinated their care and twenty four per cent felt that health and social services worked well together in planning of services
- Only 22% of the sample were aware of having a care plan. However of those who did have a care plan, three quarters felt that their care plan was kept up to date.
- The proportion of respondents (94%) who felt that they were given enough information about how and when to take their medication was very high.
- Only 27% of respondents felt that they had definitely been given support by health and social care professionals to develop self management strategies.

Early recognition (QR2)

- Of those able to provide an estimate, 66% reported that the time between first seeing their GP for their neurological condition and seeing a hospital specialist was less than 6 months, whereas for 34% the period was 6 months or longer. 65% of respondents reported a period of a year or less before they received a definite diagnosis and 35% reported a period of at least a year. However for the majority of respondents these experiences surrounding diagnosis related to more than five years prior to the survey.

Community rehabilitation and support (QR5)

- It had been difficult to find appropriate language and survey items to explore rehabilitation.
- In relation to support from health and social services, the majority of respondents did not need or received from elsewhere help with housework or personal care. However of the remainder, 52% did not receive help with housework and 16% did not receive help with personal care that they felt they needed.

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Vocational rehabilitation (QR6)

- The vast majority of the sample had not been in paid work in the last three years. Of the remainder, whilst the majority did not feel the need of support in relation to employment, between 19% and 27% cited different forms of support they would have wanted but did not receive. Equipment and accommodation (QR7)
- The vast majority of respondents did not cite problems with obtaining equipment from services either because it was not needed or they obtained equipment without difficulties.
- 12% reported not receiving the financial support that they needed from services for modifications to their accommodation.

Personal care and support (QR8)

- Three quarters of the sample described themselves as in receipt of financial support such as disability allowance in relation to their neurological condition. Only 6% reported not having received financial support but wanting such support.

Palliative care (QR9)

- 92% had not been offered hospice care and did not consider that they needed it. However 4% did report being offered and using hospice care and 3% were not offered hospice care and would have liked to be offered it.

Health-related quality of life was worse than normative data of the general adult population, for the sample as a whole and also for all three neurological conditions. Individuals experiencing more problems or negative experiences with services had poorer health-related quality of life scores. This pattern is consistent across the three neurological conditions. Multivariate analyses were conducted and established that the link between quality of life and experience of services remained after adjustment for age, gender, disease duration. No problem of experience with services was especially strongly associated with poorer quality of life.

Key findings from the carer survey were:

- Carers typically described themselves as having been a carer for more than five years, although for a somewhat shorter period for carers of MND. The majority of carers indicated that caring tasks required twenty hours or more a week.
- 34% of carers either felt the GP did not know they were carers, or were unsure.
- Less than half the sample of carers had ever had a discussion about the amount of caring they undertook.
- Only 21% of carer respondents reported having received a formal carer assessment. Twenty-three percent had not received an assessment and would have liked one.
- A majority of those who received a care assessment were given a specified contact person and 45% received a written plan. Of those who did receive a carer assessment only one third found it definitely helpful.
- Two thirds to three quarters of the sample described themselves as not needing help with various caring tasks, ranging from dressing and washing to lifting, moving the

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person cared for. On the other hand between 10% and 19% described themselves as having received none of the help they needed for various caring tasks.

- A large number of respondents (46%) felt that health and social services had provided them with equipment to help with caring tasks. Sixteen per cent felt they were in need of equipment to support their caring tasks.
- 23% of carers felt they needed some training in caring tasks and had not received any.
- Over one third of respondents did not feel their knowledge and experience as carers was recognised and valued.

In terms of self reported health, physical health was a little lower than norms from the general population. However, mental health was much poorer. As with patients, carers experiencing more problems or negative experiences with services had poorer health-related quality of life scores. This pattern is consistent across the three neurological conditions.

There are considerable challenges in obtaining data about health and experiences of services from a representative sample of individuals with long term neurological conditions. Potential limitations and possible biases need to be acknowledged with the chosen method of this study and caution applied in interpreting the results.

Overall the evidence from the survey carried out three years after publication of the NSF is of substantial but also mixed progress toward achieving the original goals of the NSF. Individuals with long term neurological conditions make use of a very broad and diverse range of health and social services. The NSF posed broad and ambitious goals to meet such diverse needs. It is important that momentum is maintained to develop and implement health and social services that work together to provide appropriate, effective, accessible and timely care. It is difficult to monitor that momentum when the three neurological conditions focused upon in the current survey, and indeed the majority of neurological conditions, are largely outside of the measurement and reimbursement system of Quality and Outcomes Framework (QOF) for primary care and also have limited attention in Indicators for Quality Improvement and the system of incentives in Commissioning for Quality and Innovation relevant to other providers such as acute and community trusts. Thought has to be given about how to overcome this potentially disadvantageous arrangement. Organisations such as Neurological Commissioning Support are beginning to work with local commissioning and could, with support from groups such as the Neurological Alliance, develop national-level indicators.

Further effort also needs to be invested in developing the evidence base for services that work in relation to long-term neurological conditions. Infrastructure, methods and research principles (for example partnerships to identify key questions and user-focused outcomes) are increasingly in place to develop the evidence base to inform the development of services.

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1 Introduction

In 2005, the Department of Health published the National Service Framework (NSF) for long-term conditions (1) which set out quality requirements for health and social services to improve the quality of life of people with long-term conditions and their carers. The NSF was a key tool for delivering the government's strategy to support people with long-term neurological conditions (1). Each of the 11 quality requirements (QR) presented in the NSF has a specific aim and rationale for long-term neurological conditions.

A key group of individuals for this strategic plan are individuals with long-term progressive neurological conditions such as motor neurone disease (MND), multiple sclerosis (MS) and Parkinson's Disease (PD). Affecting approximately 200,000 individuals in the UK, these conditions have in common patterns of impact on quality of life arising from wide-ranging physical deterioration and resulting disabilities. Despite the progressive nature of these conditions, the scope for improving services to improve quality of life for individuals with these conditions may be substantial.

This report describes a project to carry out a survey of individuals with MND, MS and PD and their carers focusing on their experiences of health and illness and of relevant services. The survey also invited respondents to identify a main carer to whom a separate questionnaire was sent concerning their experiences of services. The survey was carried out during 2008-9. The study was one of a number of related studies set up by the Department of Health's Policy Research Programme in 2006 (Research Initiative for Long Term Neurological Conditions (http://www.ltnc.org.uk/index.htm) to assist implementation of the NSF. It was intended that evidence from the research could be used to help measure the impact the NSF was making on the way services are designed and developed.

The project that is the subject of the current final report had a number of strands leading up to the main survey in 2008-9.

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Firstly, a series of three literature reviews were carried out to update the evidence reviewed and reported by the NSF in 2005. The purpose of these three reviews (one in relation to each of the three neurological conditions) was pragmatic: to identify any services or interventions not high-lighted by the NSF that might reasonably be a focus of the main survey.

Secondly, a series of in-depth qualitative interviews were carried out with individuals with MND, MS or PD and carers of individuals with these conditions. The purpose of these interviews was principally to sensitise the research team to the ways in which individuals with long term neurological conditions experienced services. This evidence would help focus and target the main survey both in terms of topics and issues but also appropriate formatting of questionnaire items.

Thirdly, a series of versions of a survey instrument were drafted and tested partly by discussion with an advisory group of individuals with long term conditions and carers, partly by cognitive interviews with a sample of respondents and partly by means of a pilot survey.

The main survey was then carried out with the help and collaboration of memberships and organisations of three main charities: Motor Neurone Association, Multiple Sclerosis Society and Parkinson's Disease Society. The detailed findings of the survey are presented in Chapter 5. A discussion of the key findings in relation to the NSF, which can be largely read independently of the full findings, can be found in Chapter 6.

A comment is required regarding the theoretical and analytic assumptions informing the main survey and the project as a whole. The overall objective of the NSF was to identify ways in which services could be improved to promote quality of life and independence for people with long term neurological conditions and their carers. Since relatively reliable and relevant measures exist to assess health-related quality of life for the three progressive neurological conditions targeted in the project, it was decided in advance that these measures would be used to examine possible associations between experiences of services and quality of life. In addition to condition-specific measures, a widely validated generic measure (SF-12) was to be used in the main survey. The rationale for adding this

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instrument is now commonly accepted in clinical trials and evaluative research, namely that condition-specific and generic measures assess complementary aspects of health-related quality of life. Condition-specific measures capture aspects of illnesses known or expected to be associated with them; generic measures are broader in scope and may capture less familiar or unexpected aspects of illness, for example in terms of outcomes of interventions. The same logic informs the PROMs (patient-reported outcome measures) mandated to assess outcomes for elective surgical procedures.

Most of the developmental work for the project focused on identifying aspects of services most salient and important for individuals with long-term conditions that could be explored and assessed via a survey. The assumption was that the survey could then be used to examine potential links between services and quality of life, the overall goal of the NSF itself, and might be especially informative if particular experiences of services were particularly associated with health-related quality of life. It was recognised that any links or associations observed between service experiences and quality of life would not demonstrate causality. Whilst appropriate multivariate analysis could take some account of association due to confounding and the effects of other variables, it could not address either unmeasured confounders or the problem of the direction of causality between variables.

The NSF itself reviewed available evidence about the effectiveness of services and had to acknowledge that very little research was found by way of robustly designed randomised controlled trials to produce least biased evidence of impact of services on outcomes for neurological conditions. Other kinds of evidence were therefore relied upon to produce recommendations. In the same spirit, the current survey sought to find potential links between services experienced and quality of life 'outcomes' using the most appropriate methods available short of randomised evidence. Whilst observational evidence of associations is not the strongest form of evidence of potential causal links, the survey method would ensure that the voices of individuals with neurological conditions received greatest emphasis in the search for possible links.

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2 Background

The three progressive neurological conditions with which this report is concerned pose diverse, complex, varying problems for individuals; these problems also change in unpredictable ways over the trajectory of the condition. The nature of the three conditions and the problems that they pose for individuals and their carers are briefly summarised in turn.

2.1. Motor neurone disease

The motor neurone diseases (MND) are estimated to affect about 5,000 people in the UK. By far the most common form is amyotrophic lateral sclerosis (ALS), which is sometimes synonymously used for MND. They are progressive neurodegenerative disorders characterised by persistent loss of motor neurones. With no nerves to activate them, muscles gradually weaken and waste. Symptoms may include muscle weakness and paralysis, as well as impaired speaking, swallowing and breathing. The course of the disease is usually relentless and at present there is no cure. The average survival time from diagnosis is approximately 2-3 years. Although the condition is associated primarily with loss of physical function, it is also often accompanied with psychological reactions of depression, feelings of loss of control, fear, frustration, isolation and anxiety and has a major impact on broader health-related quality of life (2).

People living with MND require a wide range of multidisciplinary medical and palliative care services. However, there is very limited research on the views of MND patients and carers about experiences of services. What research is available tends to suggest that both carers and patients feel the need for better information on available services and entitlements. One study suggested that there was evidence that communication between medical professionals and patients was not always good, especially when the disease was newly diagnosed. Patients felt confused and fearful of their condition and were unsure what services they would need as it progressed, as well as being uncertain as to which services they should expect and demand (3). Furthermore, patients are often unsure of the roles played by various clinical professionals (4). In part, this may be due to difficulties

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experienced by health professionals making and disclosing the diagnosis with planning care challenging because of the disorder's unpredictable course (5).

The severity of the disease can have major implications for carers. The quality of life of carers of individuals with MND has been found to be severely compromised both in terms of emotional and physical aspects of health (6). A national survey in Scotland found that over a third of carers had their sleep disturbed regularly and a similar proportion of carers felt they needed more help. The majority of respondents claimed that health and social services did not fully meet their needs (7). One obvious way in which needs were not being met was the fact that several respondents were currently on a waiting list for services or equipment. However, many also reported feeling isolated, and unable to gain information and support. Such feelings of powerlessness can have adverse effects upon carers' health. Indeed, it has been suggested that appropriate support from the medical and social services can mediate the impact of caring for someone with a serious disabling condition, such as MND, and can lead to better emotional and physical health not only for the patient but also the carer (8).

2.2. Multiple sclerosis

MS affects approximately 80,000 individuals in the UK (9). It is usually diagnosed in younger adults and has a highly variable and unpredictable course. Relapsing remitting MS involves unpredictable relapses for varying periods with partial or total remission. Secondary progressive MS involves relapsing remitting pattern with the majority experiencing progressive disability at later stages. Primary progressive MS is progressive without a history of clear-cut relapses or remission. Benign MS involves little or no disability after 15 years. Symptoms are highly variable in severity, duration and nature, and include sensory symptoms (such as numbness), visual symptoms (such as blurred or lost vision) and damage to motor nerves that can affect walking, balance and coordination.

The consequences of MS may be diverse. Progressive physical disability may influence walking and climbing stairs and therefore impact on range of movement and access within the home, at work and in public spaces especially when the environment is not

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made more accessible. Use of either a car or public transport may be difficult or impossible. Because it most commonly occurs in early adulthood, implications for employment and economic well-being may be substantial. There are diverse potential consequences for ability to carry out roles and maintain social relations (10). Activities such as bathing, dressing and feeding may require assistance. Loss of energy and fatigue can be major problems (11). Emotional problems such as depression appear particularly common. Consequences for emotional well-being are particularly likely to be judged differently by health professionals and patients (12).

Because of the varied difficulties posed by MS, individuals may need inputs from a wide range of formal and informal services. However, community services in the UK such as nursing, care attendants, physiotherapy and social work may not be readily accessed by individuals with MS, even those with moderate or severe disability (13). Lack of access to services may also mean lack of basic advice and information on such varied issues as urinary problems, diet, exercise and drug treatments (14). The general practitioner is an important potential source of support although, at least in some health care systems lack of specialist knowledge may reduce the contribution of the primary care physician (15).

Hospital services are also crucial and their contribution varies according to the stage of MS. In the early stage, prompt diagnosis is important and delay a source of anxiety. Implications of a confirmed diagnosis of MS have to be discussed over time (16). At late stages access to specialist multi-disciplinary assessment and rehabilitation services may be important. Elderly individuals with MS have to cope with additional effects of, for example, living alone and co-morbidities (17). A survey by the MS society of individuals with MS in England, Wales and Scotland carried out in 1999 highlighted a wide range of deficiencies and variations in the standards of services (18). Another survey, in 5 different European countries including the UK, found that MS patients reported an average of 2.9 unmet needs for themselves, and their carers and key health care professionals reported on average 2.4 (19). A total of 86% of the UK respondents reported having at least one unmet need, and UK respondents reported unmet service needs more frequently than the respondents from the other four countries. A qualitative study with MS patients and their carers also revealed problems with services (20). Two

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interlinking themes about services were described: lack of continuity of care and coordination of care; and lack of information about services, aids and adaptations, welfare benefits and end of life issues. A further theme the need to 'fight for everything' revealed a sense that people had to struggle for their needs to be met.

MS has been shown to have a negative impact on health-related quality of life on individuals with the condition. Individuals with MS have scored significantly worse on the SF-36 than the general population. (21).

Individuals with MS may rely on family members or friends as carers. It has been shown that carers are engaged in a large spectrum of physical care activities, with lifting being the most frequent activity, and that the caring activities increase over time particularly for carers of individuals whose MS impact levels have increased (22). There is evidence that carers for individuals with MS have lower quality of life than comparable individuals in the general population (23). Quality of life was poorer the longer respondents had cared for someone with MS, the greater the amount of daily caring required and the more severe the symptoms of MS in the individual (24;25). In another study, depression in carers for individuals with MS was also related to the severity of both physical and emotional health of the individual with MS (26). Care-related health problems have been found to be positively correlated with disease severity of individual with MS, and the most common health problems were found to be anxiety, tiredness and depression (27). Although changes over time in the health of the carer tracked changes in the health of the individual with MS, some intervention-induced improvements in individuals with MS did not result in corresponding amounts of improvement for the carers.

Cognitive problems such as memory loss on the part of the individual with MS appear particularly to impact on the carers' well-being (28). A systematic review confirms the pervasive consequences of caring for someone with MS (29). Carers therefore have major potential needs. In-depth interviews with carers for MS in Northern Ireland found that their perceptions of need for support and help from outside was complex, with times and stages in the history of caring when external support was less sought after by carers (30). The systematic review found few helpful studies of how well-being of carers might be

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improved but perceived social support from others appeared to be important. Evidence of specific health care needs of carers and specific interventions to improve their health are lacking although a systematic review on the roles of MS specialist nurses found benefits to carers in terms of knowledge, coping and confidence (31).

2.3. Parkinson's Disease

The third condition included in this study is Parkinson's disease (PD), which is part of the Parkinsonism group of diseases. Other types of Parkinsonism include symptomatic parkinsonism (such as drug-induced or traumatic parkinsonism) or parkinsonism due to other neurodegenerative conditions including atypical parkinsonism (such as multiple systems atrophy); dementia with Lewy bodies and Alzheimer's disease (32). PD affects approximately 120,000 people in the UK. It is rare for PD to occur before the age of 50, and prevalence increases with increasing age. Key symptoms are tremor, slowness of movement, rigidity and difficulty with balance. It is a chronic and progressively disabling condition with individuals commonly passing through stages: a diagnostic stage, early periods or maintenance stage (during which symptoms can be well controlled), a period in which complications become more pervasive and disabling, and a palliative care period where interventions are less effective and individuals with PD are more severely disabled (33). The impact on the individual with PD is wide-ranging, with postural and gait problems reducing mobility or rigidity in the face affecting social interaction. There may also be cognitive effects including dementia in the later stages. Not surprisingly, PD may widely impact on health-related quality of life in terms of role function and emotional and social well-being (34;35). It has also been shown that PD has a negative impact on the carers' health-related quality of life, with increasing disease severity, duration of PD, patients' mental state and quality of life significantly reducing the carers' quality of life (36).

One review noted that no systematic large scale attempts have been made to assess quality of care in PD (37). One survey found that access to a wide variety of health care services continues to be a problem for individuals with PD, and that the self-reported health status was generally worse for those reporting dissatisfaction with access to

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services (38). Furthermore, a wide variety of health care services for PD may be required to treat PD, but evidence suggest that communication between health professionals is poor and this may lead to less than optimal treatment (39). Specialist multidisciplinary services have been advocated as more likely to improve health status and quality of life than non-specialist services (40). One small scale study of a multidisciplinary services suggested improved quality of life not only for patients but also for carers immediately after the intervention (41). In the long term, however, data suggested worsening of health for PD patients and increasing levels of strain in carers despite the programme itself being popular (42).

3 Introduction to the current study

As already stated the aim of the current study was to provide evidence of the experiences of health and social care of individuals with one of three progressive disabling neurological conditions (hereafter referred to as 'patients') and their carers. The main evidence was to be provided by a postal survey. The study took as its guiding assumption that, as with the NSF, there were sufficient experiences likely to be felt in common that, a single survey would be appropriate differing only in terms of specific health status measures for each of the three conditions.

There were distinct stages to the project including a review of the literature, a series of qualitative interviews, development and testing of two questionnaires (one aimed at patients and one aimed at the carers) a pilot and a main postal survey. The early stages (literature review, interviews and questionnaire development) lead into the final phase, the postal survey (as is shown by Figure 1). The study was conducted in collaboration with a research advisory group composed of users of health and social care services. For the purposes of this study, this included individuals with one of the relevant neurological conditions or carers of someone with one of the relevant neurological conditions. Details on the user involvement in this study are given in the next section and will be followed by a more detailed description of the different stages of this study. Finally, the results of the postal survey and conclusions of the study are presented.

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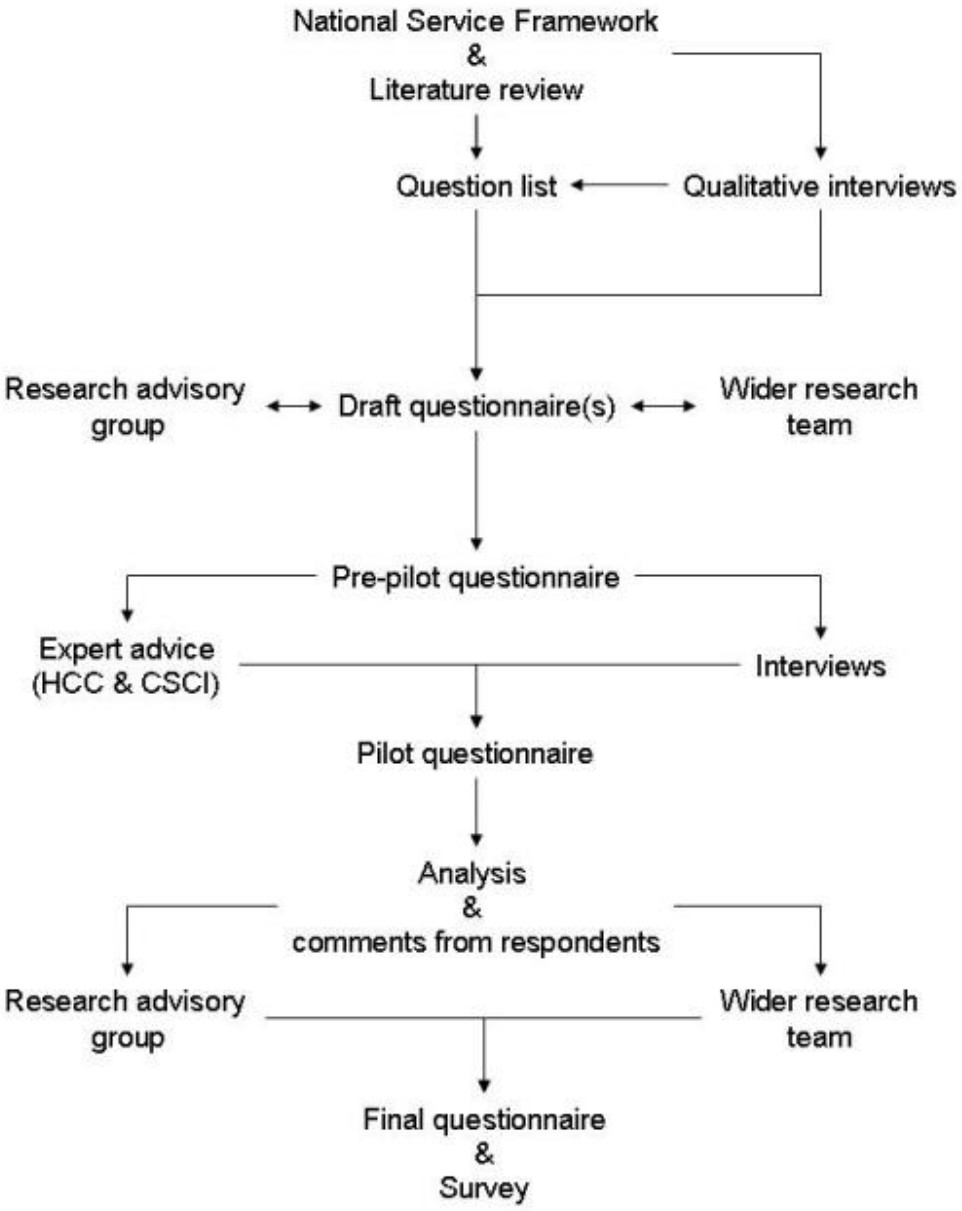
Figure 1: Stages in the survey on long-term neurological conditions



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4 Preparatory stages of the survey

4.1 User involvement

An early step was the establishment of a Research Advisory Group comprising individuals with one of the three neurological conditions or a carer of someone with one of the conditions. Some thought was given to the role and purpose of this group.

It is increasingly becoming practice that 'users' of health care services are involved in the research process. As this project aimed to gain information on experiences of health and social care of 'users' of services, it was important to involve 'users' in the research process to develop a survey that was as good as possible and as acceptable as possible to the potential respondents. A review of the literature highlighted that 'user' involvement can relate to different aspects of health, such as health care policy making, set up of health care services, health care education and health care research. The literature on 'health care research' was further explored and showed that there are different types of 'user' involvement in health care research, namely users as researchers; users as participants in qualitative research; users to design and set up research projects; users to advise on research projects (design, analysis and reporting of results). Two of these were of relevance for this study: 'users' are participants for qualitative interviews and 'users' as advisors on research projects. The 'users' contribution through qualitative interviews will be described below in the section on questionnaire development.

Specifically focusing on 'users' as advisors, the literature generally reports that the experience of being involved in research is positive for the 'users' (e.g. it makes 'users' feel positive to be involved) and for the research (e.g. making a difference in the content of a questionnaire) (43-45). However, there is little evidence to back this positive view , partly because it is still early days of user involvement, and partly because it is difficult to gather evidence on how the process and outcomes of research have been changed through user involvement (46). A systematic review found that most of the articles published on user involvement are descriptive articles of user involvement and have been written by the researchers conducting the study (47). Only a few reports were written by users, and

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fewer still by independent researchers. Challenges of involving users have also been described including for example needing more time to complete the project and increased costs (48;49).

The term ‘users’ implies that these are people who are actively using health care service or in other words ‘patients’. As this study aimed to collect data both from patients and their carers, the term ‘user’ was applied in a wider sense; and a Research Advisory Group, consisting of both individuals with a relevant neurological condition (‘patients’) and carers of someone with a relevant neurological condition, were involved in the study.

The members of this Research Advisory Group (RAG) were recruited through the respective patient societies. Each potential RAG member was approached formally by the principal investigator to be invited to be an advisor on the study. The aim was to recruit at least 6 advisors, with at least one patient for each condition. The initial group was composed of one MND patient and his carer, one MS patient, one MS carer and two PD patients. The MND patient died during the course of the study, and another MND patient and his carer were recruited as advisors.

Some authors give recommendations on how to involve users, and the 8 principles by Telford and colleagues (50) were considered helpful in terms of involving ‘users’ in this project. Members of RAG were involved during the different stages of the project. They attended meetings in Oxford when necessary, and there was additional email and telephone contact between the research team and RAG members. Table 1 outlines the principles and how they were addressed in this study. Further details on how RAG members were involved in the study will be given below within the section on the development of the questionnaires.

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Table 1: Eight principles of user involvement by Telford et al (2004) (51) and their application in this study

Principle	Definition	LTNC study
1st principle	Users would like to have clear guidance on what their role is in a research project	Terms of reference were discussed and agreed upon between the researchers and the users. For the development of the questionnaire, ask users to comment on the concepts and themes, rather than specific questions. But once specific questions have been devised, ask the users to comment on how comprehensible the questions are to users. Provide the users with a list of 'rough' questions/coding 'grids'.
2nd principle	Reimburse users for their travel expenses	Fully reimbursed for their travel costs. An honorarium was offered for attended meetings (not everyone accepted the honorarium).
3rd principle	Respect the different skills, knowledge and experience of the users	Introductory meeting to get to know users and to give them the opportunity to talk about their knowledge and experiences.
4th principle	Users need training to develop their research skills. Users need information about the project.	Introductory meeting during which different members of the research team explained specific aspects of the project. RAG members were given a copy of the slides of the introduction session and copies of documents relevant for the project including the literature reviews, the NSF document, and information on quality of life questionnaires for the 3 diseases developed by members of the research team. Further information sessions (for example on recruitment or the use of health-related quality of life instruments) were held throughout the project.

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Table 1 (contd) Eight principles of user involvement by Telford et al (2004) (52) and their application in this study

Principle	Definition	LTNC study
5th principle	Researchers ensure that they have the necessary skills to involve consumers in the research process (considering the users' needs and availability, reviewing the literature and consulting with other researchers experienced in user involvement).	Review of the literature on user involvement. Meetings were planned to suit the needs and availability of the involved users. Gave support in organising travel for them.
6th principle	Users are involved in decisions about participant recruitment and kept informed of the research project	RAG members were involved in recruitment for the validation interviews Recruitment strategy for survey was discussed in a meeting.
7th principle	Consumer involvement is described in research reports	Records were kept throughout the project on how users were involved in the project. Involvement is/ will be described in all reports and publications.
8th principle	Research findings available to consumers in format that they can easily understand.	A summary of the pilot study was put on website for access of users. Pilot study report was sent to all RAG members, and also to the chairs of the participating patient societies (national and local branches). The final report will also be made available to RAG members and the participating societies.

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4.2 Literature reviews

The reviews of the literature were intended to update the literature used in the NSF to identify services that might reasonably be the focus of respondents to the main survey. The aim was achieved by searching specifically for relevant articles that had been published after the NSF or at an earlier stage but not been included in the NSF. In total, 66 (12 MS, 33 MND and 21 PD) relevant articles, published after the publication of the NSF, were included in the reviews. The reviews were pragmatic mainly driven by the judgment that a publication might indicate a service that might reasonably be expected to be part of NHS provision. This evidence would update the NSF that gave a number of indications of types of service appropriate for individuals with neurological conditions. The ultimate goal was to identify aspects or features of services that might be noticed, expected or evaluated by individuals responding to the survey.

Since there are many aspects of service provision that are common to different neurological conditions, the NSF does not address neurological conditions separately. However, there are also elements that are dissimilar between the conditions in this study, thus justifying the description of services relevant to specific neurological condition separately. Consequently, where relevant, issues raised by the National Institute of Clinical Excellence (NICE) guidelines for MS (53) and PD (54;55) were incorporated into the literature reviews and differences between the NSF and NICE guidelines were highlighted. For PD, NICE have produced two different reports, one of which (55) is a short version and mainly presents the recommendations, whereas the full version (54) also describes the evidence from which the recommendations were derived. As this review aims to present a summary, predominantly the short version was used; however, when necessary, the full guidelines were referred to. At the time of writing the literature review, NICE had not published guidelines for MND, apart for guidance on the use of riluzole (56). Thus, additionally a set of guidelines by the MND Association were used to gain further information on issues such as making and communicating the diagnosis (57-59), nutritional (60) and respiratory management (61) of MND, and carer issues (62).

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Although the overall assumption of the study was that the main survey would be largely generic and standard, three separate reviews were produced, each focused on one of the conditions and highlighting services relevant to that particular condition. Thus, for each condition, the 11 Quality Requirements of the NSF were presented and discussed. Specific references to each condition were highlighted, and NSF recommendations, which are not supported by evidence were summarised. For each quality requirement, examples of markers of good practice from the Department of Health (http://www.dh.gov.uk/en/Healthcare/Longtermconditions/Bestpractice/DH_188) on Action on Neurology Programme were included.

The full reviews of the literature are included in Appendix 1 (Appendix 1.1 MND, 1.2 MS and 1.3. PD).

4.3 Qualitative Interviews

A series of in-depth interviews were planned, with the main aim to identify how individuals with neurological conditions and their carers experience and evaluate services. On the one hand the objective was to gauge the dimensions or broad categories of experience that would be relevant to the planned main survey. On the other hand the purpose was in a more focused way to guide the study in terms of generating appropriate survey items.

4.3.1 Participants

Participants in in-depth interviews were recruited through the respective charities, through an advertisement on their web-page. Participants were recruited from all over the UK. A total of 46 interviews were conducted, of which 26 were for MND (16 patients and 10 carers), 9 for PD (8 patients and 1 carer) and 11 for MS (10 patients and 1 carer) (further details Appendix 2). The patients mean age was mean 55.2 (range 25-80, n=36, 3 missing) and the carer mean 54.6 (range 36-73, n=11). The majority of participants were married. All the participants gave informed consent. All the participants were able to review the information they had given during the interview after the interviews had been

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transcribed. Ethics for this part of the project was covered by the overarching approval for DIPEx (Database of Individual Patient Experience) for this format of research.

4.3.2 Interview guide

A semi-structured interview guide was devised based on the NSF and findings from the literature. The interview schedule was intended to encourage respondents to express views and experiences that might be relevant to the different quality requirements of the NSF. The questions for the different conditions were similar, with the main differences being in the questions on treatment. The interview guide was adapted as interviews progressed to gain additional information that was useful for the development of the questionnaire.

4.3.3 Analysis

In a first instance, interviews were read as an ongoing process to inform the questionnaire design, and the qualitative researcher had regular input into the design of the questionnaire. In a second step, a more formal analysis was carried out. A coding frame was developed for each condition based. The content of the coding frames was closely matched to the concepts and themes that underpinned the questionnaire development (described below). The coding frames were disease-specific, which helped to highlight differences and similarities between the 3 conditions.

All interviews were transcribed verbatim, checked and analysed according to this coding frame in NUDIST6 (N6), a qualitative software package. The coding frame divided each quality requirement into themes etc, and definitions were given for each theme. Two researchers coded the data. One interview was coded by both researchers to help standardize the coding process. For interview extracts that contained information on more than one code, these extracts were coded with all the relevant codes.

When the data was coded, reports on each theme were printed to be reviewed by the team. The reports were organised in 4 sets: namely MS patient, MND patient, PD patient and carers. Each set was reviewed by 2 researchers, and one of the researchers reviewed

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all four sets. This aimed to identify additional themes to those identified from the literature review, and also to help guide the wording of the questions and response categories. The reports for each condition were reviewed by two researchers.

Table 2: Framework based on NSF quality requirements (QR) for coding qualitative interviews and for questionnaire development.

QR	DIMENSIONS	THEMES
QR1	Person-centred service	Health care (disease management, treatment and equipment) individualised to the patient. Integrated assessment and multi-disciplinary care Care plan
		Health care appropriate to the person's needs at any given point in time, including regular reviews and flexible care
		Patient involvement in their care, including patients being given the opportunity to be a decision-maker about their care or patients being able to self-manage their condition
QR2	Diagnosis	Correct & prompt diagnosis
		Breaking the news
		Diagnostic aids
		Information
	Treatment	Fast and flexible
		Early and ongoing
		Types of treatment
		Treatment of associated symptoms
		Information
QR3	Emergency and acute management	Hospital treatment
QR4	Early and specialist rehabilitation	
QR5	Community rehabilitation and support	Types and benefits such as physical care and support, nursing support, counselling, cognitive support Knowledge and expertise of community health care staff

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Table 2 (continued): Framework based on NSF quality requirements (QR) for coding qualitative interviews and for questionnaire development.

QR	DIMENSIONS	THEMES
QR6	Vocational rehabilitation	Vocational assessment Guidance and practical support to continue to work Guidance and practical support for leaving work Liaising with occupational therapist
QR7	Equipment and accommodation	Accommodation
		Equipment, including equipment for mobility, custom-built equipment, or equipment to prevent deterioration
		Information
QR8	Providing personal care and support	Patient preference
		Support in the community
		Support from health and social services in the community Co-ordinated support from general practice and community nursing teams in collaboration with neurologist Domiciliary health care services
		Access to care
		Information
QR9	Palliative care	Services that promote different types of well-being
		Timing of referral
		Symptom control
		Care provider
		Advance directives
		Choice of where to die
		Bereavement support
		Information
QR10	Supporting family and carers	Skills of the carers
		Support with adjustment to changes
		Carers' choice
		Carer's health and well being
		Information and type of support
QR11	Hospital/ other health and social care settings	Care plan
		Meeting neurological needs
		Information

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4.4 Questionnaire Development

For the purpose of this study, two questionnaires were developed, the first questionnaire for individuals with a neurological condition, and a second questionnaire for their carers. The questionnaire development included several stages, all of which are outlined in this section. Initial candidate questions were developed based on the findings from the literature review, and particularly on the NSF quality requirements, supplemented by items arising separately from the qualitative interviews. A pre-pilot draft of the questionnaire was assessed through a series of validation interviews. After a number of iterations of draft versions of the questionnaire, discussed and developed by the research group, supplemented by inputs from the Research Advisory Group of users and carers, a pilot study was carried out according to the methodology that was to be applied for the main survey. Expert input was also given by the Health Care Commission (HCC) and the Commission for Social Care Inspection (CSCI) because at the time they were intending to carry out a similar study and were willing to give advice on the evolution of the study questionnaire. The above flowchart (Figure 1) illustrates how different phases of questionnaire development led to the final version of the questionnaires.

4.4.1 Dimensions and themes for the questionnaires

From the literature review, a coding frame with 11 dimensions and 65 themes had been generated mainly to reflect the NSF quality requirements. This coding frame was used for the qualitative analysis and at the same time constituted the initial frame that the questionnaires were mapped upon.

Out of the 11 quality requirements, 9 were deemed relevant for the planned survey, 8 of which focused on the patients, and only one of which focused on the carer (Table 3). No questions on family and carers were included in the patient's questionnaire, as these were addressed in the carer questionnaire. The reason for excluding two quality requirements from the questionnaire was that these quality requirements were mainly relevant to either acute conditions or conditions where recovery or improvement is possible such as brain injury. Some quality requirements were given more weight in the questionnaire (i.e. were addressed by a larger number of items) as they were deemed more central to the survey

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such as patient-centred care, or the quality requirement covered a larger number of issues. Other quality requirements were covered more minimally for some relevant aspects. For example palliative care was only minimally covered as the targeted sample was more likely to be patients at the early or middle stages of their neurological condition.

Table 3: The NSF quality requirements and their relevance to the survey

	NSF QUALITY REQUIREMENT	RELEVANT
QR1	Patient-centred care	Yes
QR2	Diagnosis and treatment	Yes
QR3	Emergency and acute management	No
QR4	Early and specialist rehabilitation	No
QR5	Community rehabilitation and support	Yes
QR6	Vocational rehabilitation	Yes
QR7	Providing equipment and accommodation	Yes
QR8	Providing personal care and support	Yes
QR9	Palliative care	Yes
QR10	Supporting family and carers	Yes
QR11	Caring for people with neurological conditions in hospital or other health and social care settings	Yes

The discussions with RAG members highlighted an issue also raised by some participants of the qualitative interviews, namely 'financial aspects' in relation to their neurological condition. This became an additional dimension for the questionnaire. A second additional dimension identified by RAG members was 'needs for information' which was addressed by all the different quality requirements, but considered to require particular emphasis in the planned survey. Another issue that the RAG members highlighted was their view that rehabilitation was not a term or construct widely used by individuals with neurological conditions. Most items were underpinned by one quality requirement, but some questions (n=7) were underpinned by two overlapping quality requirements namely QR1 (Patient-centred care) and QR8 (providing personal care and support). The questions on information were underpinned by all the QRs, as every QR outlined the need of information in relation to that specific QR. Items in the carer questionnaire were

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underpinned by QR10 and additional literature that will be described further in the carer questionnaire section below.

4.4.2 Patient questionnaire

For the patient questionnaire, an initial list of questions (n=194) was devised on the basis of the main themes identified as important. All of these questions were reviewed by 4 team members to assess whether a question should or should not be included in the questionnaire with the aim to reduce the original list to about 80 questions. Questions rated 'yes' by three or more team members were retained (n=75), and questions rated 'no' by three or more team members were rejected (n=35), and 84 questions were rated as 'not sure'. After more in-depth discussion, most of the 84 'not sure' questions were discarded, either because they were considered not suitable or because the item was already covered by another question. Over the course of the development of the questionnaire, more of the retained questions were rejected, as well as new questions introduced to give a pre-pilot draft of the questionnaire containing 75 questions. Four general financial questions were introduced into the questionnaire even though this was not part of any of the NSF quality requirements (the NSF only covered financial aspects of modifications to accommodation). However, the qualitative interviews and discussions with the research advisory group had highlighted this as an important additional theme for the questionnaire.

Early versions of the patient questionnaire included both 'generic' (relevant to all 3 conditions) and 'disease-specific' (relevant to one of the conditions only) questions. In the later drafts, the disease-specific questions were either excluded (for example a question asking about riluzole use in MND) or made 'generic'. The reason for retaining some originally disease-specific questions as generic questions was that these questions were considered relevant for all three conditions, even if they were possibly more widely applicable in one of the conditions (for example, it was thought that respiratory support is more likely to be necessary in MND patients, but some MS or PD patients also require respiratory support).

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There had been 11 different drafts of the patient questionnaire before a group of patients were asked to participate in a validation interview.

4.4.3 Carer questionnaire

The process involved in developing the carer questionnaire was the same as for the patient questionnaire. However, there was only one NSF quality requirement that particularly referred to carers, and other sources of information were used to develop the dimensions and themes from which the original items were developed (Table 4). These documents were from mostly carer specific documents from relevant charities, including Carers UK, the MND Association, the PD Society and the MS Society (62-67). Further information was provided by some scientific publications, NICE guidelines (PD (55)and MS (53) and a hand book for carers (68). From these sources of information, 6 dimensions with 13 themes were developed.

The first draft of the carer questionnaire contained 46 questions, and the final questionnaire included 32 questions. Most of the deleted questions asked about the carer's health status, and it was decided that it was not necessary to include these issues as they were already addressed by two existing validated health status questionnaires (one generic and one specific to carer burden) already planned for the carer component of the survey.

There were 12 versions of the carer questionnaire before the validation interviews were conducted.

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Table 4: Dimensions, themes and sources for the development of the carer questionnaire

DIMENSION	THEME	SOURCE(S)
Carer's health and well-being	Well-being including ability to have a break or leisure time, social relationships.	Carers UK (2007a), MNDA carer booklet, PD Society (2004)
	Health including having any health problems, is their GP aware that they are a carer	Carers UK (2007a), MNDA carer booklet, PDS carer guide
Carer's assessment	Offered assessment Outcome of assessment	NSF, NICE, MND Association (2002)
Work/ education	Remaining in, returning to or leaving work. Does employer know they are a carer Time off for emergencies	Carers UK (2007a, 2002), PD Society (2004)
	Education	Carers UK (2002)
Help and support	Help with care	Carers UK (2007), MND Association (2002)
	Equipment	Carer book [reference]
	Training (Expert carer programme)	NSF, Simmons (2005), MND Association (2002)
	Support	NSF, Simmons (2005), NICE, PD Society (2004)
	Services for the person they care for	Carers UK (2007a), PDS carer guide
Finances	Carer's income	Carers UK (2007b), PDS carer guide
	Worries about finances	MND Association (2002)
	Paying for services	PD Society (2004), MS Society (2003)
Information		Carers UK (2007a), Hughes (2005), Bolmsjo (2003), NICE, PD Society (2004)

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4.5 Pilot testing

4.5.1 Expert input

Both the patient and the carer questionnaires were commented on by an expert in questionnaire development from the Health Care Commission (HCC) and an expert in social services from the Commission for Social Care Inspection (CSCI). These comments were considered in conjunction with the comments from the validation interviews to re-draft both the questionnaires for the pilot study.

4.5.2 Validation Interviews

As a prior step to the pilot survey a series of validation interviews were carried out with patients and carers. Patients are carers were recruited from the RAG members, friends and family of RAG members, and from some of the participants in the qualitative interviews. Each participant was sent the relevant questionnaire, and asked to complete the questionnaire, as well as a short list of questions on the questionnaire. There were 7 patients (4 MS, 1 MND and 2 PD) and 6 carers (2 MS, 3 MND and 1 PD) who participated in the validation interviews. Each participant was given the choice of a telephone interview or a face-to-face interview on University premises or their own home. All but two participants (a MND patient-carer couple) opted for telephone interviews. The MND patient-carer couple preferred being interviewed in their own home.

Participants were asked to record how long they needed to complete the questionnaire. This ranged from 15 to 60 minutes for the patient questionnaire and 10 to 30 minutes for the carer questionnaire. The majority of patients took less than half an hour to complete the questionnaire, but it took longer for patients who needed help with completing the questionnaire. However, regardless of how long it took to complete the questionnaire, none of the participants reported that the questionnaire was too long. The participants gave both general comments and specific comments (i.e. comments relating to one specific question).

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All the comments on each question were summarised in a table, together with the comments from the HCC and CSCI experts. Each question and their related comment(s) were discussed by the team members to make appropriate changes to the questionnaires, with particular attention being paid to the comments that had been made by more than one person. For the patient questionnaire, the main change was the deletion of one lengthy question on associated symptoms being deleted, and one question on medication being split into two questions to make it more specific. Other changes included some rephrasing of questions or changes to the response categories for specific questions. Changes to the carer questionnaire remained limited to re-wording of questions and response categories.

4.6 Pilot survey

After completion of the validation interviews and expert input, a pilot survey was carried out using the same strategy that was to be followed for the main survey. This meant sending each questionnaire pack to a member of one of the respective societies, and asking them to give the carer questionnaire to a family member or friend who they consider to be their main carer (if applicable). The main aim of the pilot survey was to test the questionnaires developed for this study. A secondary aim was to investigate whether the response rate would be affected by including different quality of life measures.

4.6.1 Procedure

Early in 2008, 484 questionnaire packs (MND n=160, MS = 154 and PD 170) were mailed out. Members of the respective charities were approached to participate in the study. As members are mostly people with the neurological condition, the carer questionnaire was sent alongside the patient questionnaire. The patient was asked to give the carer questionnaire to their main carer, if they have a carer. For the purpose of this study, ‘carer’ was defined as ‘a family member or friend who provides unpaid care (such as help with dressing and feeding or help with housework)’ to the patient. The questionnaire packs, as well as including both questionnaires, included covering letters and information sheets for patients and carers respectively, and pre-paid return envelopes.

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All the questionnaires were numbered with the patient and one carer questionnaire that were sent in one pack having the same number. This allowed matching the returned patient and carer questionnaires. No record of which ID number was sent to which member of the society was kept, thus keeping the study anonymous. A 'thank you' note / reminder was sent two weeks after the initial mail out of the questionnaires to everyone who had originally been sent a questionnaire.

4.6.2 Ethics

Ethical approval had been obtained through the University of Oxford Ethics Committee.

4.6.3 Pilot questionnaires

For the pilot study, approximately 50% of the participants were sent the questionnaire developed for this study (hereafter referred to as LTNC questionnaire) only, whereas the remaining participants were sent the LTNC questionnaire together with health status measures (one generic and common to all three conditions and one disease- or condition-specific instrument unique to each of the conditions). Including the health status measures added between 65 to 76 questions to the patient questionnaire, and an additional 49 questions to the carer questionnaire. The reason for sending different versions of the questionnaire was to test whether the response rate would be affected by also including health status measures which increased the length of the questionnaires.

The questionnaires for the different conditions were predominantly the same for patients (apart from the disease-specific health status measures) and exactly the same for the carer. In the LTNC questionnaire, the questions used the umbrella term 'neurological condition'. For the survey, the questionnaires were, however, given the appearance of being disease-specific by referring to the condition on the front page, rather than referring to 'neurological condition'. The questionnaires for the different conditions were printed on different colour paper (a lighter shade for patients and a darker shade for carer), so each questionnaire was easily identifiable in terms of whether they were patient or carer questionnaires, or which condition they related to.

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For the additional health status measures, two questionnaires were used to assess health status in both patients and carers. For the patients, this comprised a generic (SF-36 version 2) and a disease-specific health status measure. The disease specific measure was either the Amyotrophic Lateral Sclerosis questionnaire (ALSAQ-40) for MND, the Multiple Sclerosis Impact Scale (MSIS-29) for MS or the Parkinson's Disease Questionnaire (PDQ-39) for PD. For the carers, this included the LNTC carer questionnaire, a generic health status measure (the same that was used for the patients) and a carer burden questionnaire. The carer's health status was also assessed by the SF-36 version 2 and by a modified version of the Carer Strain Index (CSI).

The SF-36 has assesses health across 8 domains including bodily pain, general health perceptions, mental health, physical functioning, role limitations due to emotional health problems, role limitations due to physical health problems, social functioning and vitality (69;70). The SF-36 is scored using a weighted scoring algorithm, and scores are transformed into a scale from 0 to 100, where a score of 100 represents the best state of health. Two component scores for physical and mental health can also be calculated. The SF-36 is intended for application in a wide range of health conditions and in the general population.

The MSIS-29 is a disease-specific quality of life measure for MS that has two dimensions: physical impact (20 items) and psychological impact (9 items) (71). On the second version of the MSIS, which was used in this study, the questions are scored on a 4-point Likert-type scale (not at all, a little, moderately, extremely). The two summary scores are generated by summing individual items and transforming them to a scale of 0 to 100, with a higher score indicating worse health. The MSIS has been shown to be reliable and valid (72;73).

The ALSAQ-40 was developed for ALS (Amyotrophic Lateral Sclerosis) and MND as a disease-specific measure of quality of life (74). Each question is scored on a 5-point Likert-type scale (never, rarely, sometimes, often and always/cannot do at all). The 40 questions are incorporated into five scales: eating and drinking (3 items), communication (7 items), activities of daily living/independence (10 items), mobility (10 items) and

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emotional well-being (10 items). Each scale is transformed to have a range from 0 to 100 (best health status to worst health status). The ALSAQ-40 has been shown to have high validity and reliability (75-77).

The PDQ-39 is a well validated disease-specific quality of life instrument for Parkinson's Disease. The 39 items cover eight dimensions including mobility (10 items), emotional well-being (6 items), stigma (4 items), social support (3 items), cognitions (4 items), communication (3 items) and bodily discomfort (3 items) (78). Items are scored on a 5-point Likert-type scale (never, occasionally, sometimes, often and always). Data can be presented either as domain scores or as a single index figure (79). Scores for each of the eight dimensions and the single index score range from 0 (best, i.e. no problem at all) to 100 (worst, i.e. maximum level of problem). The PDQ-39 has been shown to be highly reliable and valid (80;81).

The CSI was developed to measure carers' reactions, including perceptions and emotional feeling with regards to their role as a carer (82). The CSI has 13 items, and the original version had two response categories ('yes' and 'no'). At a later stage, the items were re-phrased (although their meaning was the same) and a 'sometimes' response option was added (83). For the purposes of this study, a modified version of the CSI was used to include the original items but the 3 response categories of the second version of the CSI. A higher score on the CSI means a higher burden.

4.6.4 Sampling

The research team worked together with the respective charities (the Motor Neurone Disease Association, the Multiple Sclerosis Society and the Parkinson's Disease Society), and some of their local branches, for mailing the survey to their members. For reasons of data protection, the societies were not able to provide the research team with a list of their members. Therefore, the questionnaires were packed by the research team and couriered to the societies, who added their members address to mail out the questionnaires.

The MNDA mailed questionnaires to the members on their national database. The MNDA selected a random sample of members (n=160) who had previously agreed to be

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contacted for research purposes. Two local branches of the MS society and two branches of the PD society were recruited to mail the questionnaires to their members. As the societies are not able to give out addresses of their member, the pre-packed questionnaires were sent to the MNDA, and the local MS and PD branches who mailed the questionnaires to their members. This same method was used for sending the reminders.

4.6.5 Analysis

Data was entered into SPSS 15.0 for analysis. A random selection of 10% of the questionnaires (27 patient questionnaires and 21 carer questionnaires) was double-entered to check for mistakes in the data entry. Less than 0.5 % of differences were found between the two data sets. Data was analysed by descriptive statistics.

4.6.6 Pilot survey results

4.6.6.1 Response rate

A total of 297 (61.4%) patients responded to the survey. Twenty-six respondents were excluded from the analysis and 271 (56.0%) were included. Reasons to exclude questionnaires were that the respondent was too unwell to take part or had died (n=8), the respondent (n=4) did not have a diagnosis of MND, PD or MS; 7 PD respondents had already taken part (they had erroneously been sent two questionnaires); one respondent had participated in a validation interview; 2 did not want to participate; one PD questionnaire was sent to a carer, and two questionnaires were returned after the deadline. The response rate did not substantially differ for respondents who had been sent the longer questionnaire (including the health status measures) compared with those who had only been sent the LTNC questionnaire for MS (43.1% vs. 43.9%) and MND (70.0% vs.74.4%) but it did differ considerably for PD (35.3% vs. 68.2%) (Table 5).

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Table 5: Patient pilot questionnaires sent out and entered into analysis

		LONGER INSTRUMENT LTNC & QOL		SHORTER INSTRUMENT LTNC ONLY		TOTAL	
Disease		*Sent*	*Analysis*	*Sent*	*Analysis*	*Sent*	*Analysis*
MND	*N*	70	49	90	67	160	116
	%	-	70.0	-	74.4	-	72.5
MS	*N*	72	31	82	36	154	67
	%	-	43.1	-	43.9	-	43.5
PD	*N*	85	30	85	58	170	88
	%	-	35.3	-	68.2	-	51.8
Total	*Sent (n)*	227	-	257	-	484	-
	Analysis (n)	-	110	-	161	-	271
	Analysis (%)	-	48.5	-	62.6	-	56.0

For the carers, 238 (49.2%) responded, and 211 (43.6%) questionnaires were included in the analysis. Of the 27 questionnaires not included in the analysis, 16 had been returned blank (8 no reason was given, 6 patients did not have a carer, 2 patients had died), 3 questionnaires had been completed by paid carers, 4 had already completed the questionnaire, 1 was too busy to take part, one patient had a diagnosis other than MND, PD or MS; and one had taken part in a validation interview. As for the patient questionnaires, the response rate for PD carer was considerably lower when the quality of life questionnaires were included (25.9% vs. 55.3%), whereas for MS (22.2% vs. 26.6%) and MND (64.3% vs. 66.7%) the difference was minimal (Table 6).

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Table 6: Carer pilot questionnaire sent out and entered into analysis

	QOL	YES		NO		TOTAL	
Disease		*Sent*	*Analysis*	*Sent*	*Analysis*	*Sent*	*Analysis*
MND	*N*	70	45	90	60	160	105
	%	-	64.3	-	66.7	-	65.6
MS	*N*	72	17	82	21	154	38
	%	-	22.2	-	26.0	-	24.7
PD	*N*	85	22	85	47	170	69
	%	-	25.9	-	55.3	-	40.6
Total	*Sent (n)*	227	-	257	-	484	-
	Analysis (n)	-	84	-	128	-	212
	Analysis (%)	-	37.0	-	49.8	-	43.8

As the questionnaires had been numbered, the patient and carer questionnaires could be matched. Overall, of the 484 questionnaire packs sent out, for 289 (59.7 %) either patient, or carer, or both patient and carer were included in the analysis. For the majority of patient-carer dyads, both the questionnaires had been returned (Table 7). Some patients and a few carer questionnaires were returned without the matching patient or carer questionnaire.

Table 7: Distribution of patient and carer questionnaires per disease

DISEASE	PATIENT AND CARER		PATIENT ONLY		CARER ONLY		TOTAL	
	n	*%*	*n*	*%*	*n*	*%*	*n*	*%*
MND	96	33.2	20	6.9	9	3.1	125	43.3
MS	35	12.1	32	11.1	3	1.6	70	24.2
PD	62	21.5	26	9.0	6	2.1	94	32.5
Total	193	66.8	78	27.0	18	6.2	289	59.7

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4.6.6.2 Sample

The total patient sample was 271 including 116 MND, 67 MS and 88 PD. The mean age of the patients was 66.0 years (s.d. 11.6), with MS patients mean age being 57.8 (s.d. 10.4), MND 63.0 (11.5) and PD 72.3 (10.3). For MS, a larger proportion of respondents were female than male (69.7% vs. 30.3%), whereas with MND and PD respondents were more likely to be male than female (65.5% vs. 34.5% for MND and 63.6% and 36.4% for PD respectively). The majority of patients were white (British) and married or living as married. Only a small proportion of participants were in employment.

The total carer sample was 212 (38 MS, 105 MND and 69 PD). The carer's mean age was 63.0 years (sd 12.4), 59.0 (sd 15.1) for MS, 60.4 (sd 11.6) and 69.1 (sd 9.5) for PD. The majority of carers were women, 54.1% for MS, 71.4% for MND and 72.5% for PD. As with patients, the majority were married, and of a white (British) ethnic background. More details on patients and carer demographics can be found in Appendix 3.

4.6.6.3 Outcome of the pilot study

The main purpose of this pilot study was to highlight any issues with the questionnaires to be able to make appropriate and necessary changes before the main survey. A descriptive analysis had been carried out, and some key findings were presented in a short report to the participating patient groups and made available online: (http://www.publichealth.ox.ac.uk/units/hsru/PROGRESSIVE%20NEUROLOGICAL%20CONDITIONS). The findings from this report are in appendix 4.

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4.7 Changes to questionnaires based on comments from the pilot study

As for the comments from the validation interviews, all the comments from the pilot study were summarised in a table for both the patient and the carer questionnaires. This included comments from throughout the questionnaires or comments box in the back of the questionnaire. This served to highlight, and subsequently address, the comments that had been made by multiple respondents. Every comment was discussed in the team and appropriate changes were made. Furthermore, the results, and more specifically the frequencies of responses, were reviewed to assess if there were any problems with questions in terms of non-responses, 'wrong' responses (ticked several options when only one option possible) or respondents all giving the same response.

The main comments or issues with the patient questionnaire were length, the equipment section where there was a larger number of missing responses (more than 5%) and some comments highlighting that some questions were not appropriate (for example asking about equipment to help with walking was not applicable to respondents in a wheelchair). Hence, the main change to the patient questionnaire to be used in the main survey was to reduce the number of equipment questions (Table 8). For the pilot study, equipment questions investigated the use, source of supply and satisfaction with 7 different pieces of equipment. This was changed into one question to ask which piece(s) of equipment the respondent had particular difficulty in obtaining from health and social services. One question had a very large number of missing data (45.0%), but this finding led to discover that one essential response category was missing and this was rectified for the main survey. Some additional more minor changes included adding an 'I am not sure' response option to some relevant questions. Finally, a few other redundant questions were removed and Table 8 shows which of the dimensions these deletions applied to.

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Table 8: Number of questions per dimension for the pilot version and final version of the patient questionnaire

DIMENSION	PILOT VERSION	FINAL VERSION
Patient-centred care (QR1)	10	10
Diagnosis (QR2)	6	6
Treatment (QR2)	6	6
Community rehabilitation and support (QR5)	3	2
Vocational rehabilitation (QR6)	6	6
Accommodation (QR7)	3	2
Equipment (QR7)	23	1
Providing personal support and care (QR8) *	7	7
Caring for people with neurological conditions in hospital or other health and social care settings (QR11)	4	4
Information (All QRs)	3	2
Financial aspects	4	3
TOTAL NUMBER OF QUESTIONS	75	49

* QR1 was also relevant for the development of these questions

For the patient questionnaire, additional to the comments about the length of the questionnaire, for PD the response rate was lower when the quality of life questionnaires were included. Hence it was decided to shorten the questionnaire by reducing and simplifying the equipment section and by using a shorter generic health status measure. For the main survey, the SF-36 was to be replaced with the SF12- for both patients and carers. The change to the SF-12 was also applied to the carer to keep the method of collection health status data consistent.

Only a few other issues with the carer questionnaire were found, one being that one of the financial questions led to a lot of comments being written on the questionnaire. The financial questions were adapted appropriately for the main survey. The number of questions remained the same for the pilot version and the main survey version of the carer questionnaire.

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5 Main survey

5.1 Methods

5.1.1 Sampling

Members of the MND Association, PD society and MS Society were recruited from all over England. Members of the MND Association and of the MS Society were recruited through their national database, whereas members of the PD Society were recruited through local branches. As for the pilot study, for reasons of data protection, address lists could not be made available to the research team and the societies mailed out the pre-packed questionnaires on the research team's behalf. The survey was carried out from October 2008 to January 2009.

The aim had been to include 750 MND patient questionnaires in the analysis. However, it was not possible to send out enough questionnaires to achieve this sample size, due to a change in policy by the MND Association. Having asked all their members if they are willing to take part in research, the MND Association now only sends requests for research to members who have agreed to be contacted. Members who had been contacted for participation in the pilot study were also excluded from being contacted for the main survey. Therefore, MND questionnaires were sent to 890 members which constitutes the complete database of members who are willing to participate in research and who had not taken part in the pilot study. Of these 890 members, 700 preferred to be contacted by mail, whereas the remaining 190 preferred to be contacted via email. For the latter, an email was sent by the MND Association with a link to an electronic online version of both the patient and carer questionnaires. The online survey was set up by the MND Association using SurveyMonkey, a tool for setting up web-based surveys. More information on SurveyMonkey can be found in Appendix 5.

For MS and PD, a sample of the members of the MS and PD societies were invited to participate in the survey. The numbers of MS and PD questionnaires that needed to be sent out were based on the response rate achieved in the pilot study. The aim was to achieve a sample in the analysis of 1000 MS and PD patients. For MS, the response rate

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in the pilot study had been 43.5%, thus to achieve 1000 questionnaires in the analysis at least 2298 questionnaires needed to be sent for the main survey. For PD, the pilot study achieved a 51.7% response rate, meaning a minimum of 1934 questionnaires needed to be sent.

For MS, questionnaires were sent to 2345 members and for PD to 1974 members. The sampling was designed to ensure that members were recruited from 9 different geographical regions of England. The regions are based on the regions used by the PD society (http://www.parkinsons.org.uk/local_to_you/regional_teams.aspx).

Table 9 shows the number of questionnaires sent by geographical area for MS and PD. A total of 27 local PD groups participated with an average of 73 members (range 20-150). A total of 35 local MS areas were targeted with an average of 67 members (range 14-150). The national MS database provides information of which local area members belong to, and thus it was possible to recruit MS members by local areas that were as closely matched as possible to the PD local groups. Furthermore, for the majority of their members, the MS national database has information on which member is either an individual with MS, a carer or a health care professional. Questionnaires were sent only to members who were known to be individuals with MS. For each PD local area, an approximately 10% higher number of MS members were recruited, due to the lower response rate of MS members in the pilot study. When there were not as many MS as PD members in the matching local area, all the MS members in the matching local area were included with the remaining questionnaires being sent to MS members from an adjacent local area. If there were more MS than PD members in a local area, a random sample of MS members in that area were recruited. If there was no matching local MS area, an adjacent local area within the same geographical region was used.

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Table 9: Questionnaire packs mailed out by region for MS and PD

REGION	MS	PD	TOTAL
North-West	235	185	**420**
North-East	135	110	**245**
West Midlands	260	159	**419**
Yorkshire and Humberside	260	210	**470**
East Midlands	220	185	**405**
East England	260	250	**510**
Greater London	325	320	**645**
South-East	240	255	**495**
South-West	410	325	**735**
TOTAL	**2345**	**1974**	**4319**

5.1.2 Ethics

Ethical approval was obtained from the University of Oxford Ethics Committee.

5.1.3 Questionnaires

The patient and carer questionnaires each contained the relevant LTNC questionnaire and a generic health status measure (Appendix 6). Additionally the patient questionnaire included a disease-or condition-specific measure, the MSIS-29 for MS, the ALSAQ-40 for MND and the PDQ-39 for PD (all described in more detail above). The carer questionnaire also included the CSI (also described above) to measure carer burden.

The generic health status measure used for the main survey was the SF-12v2, which is derived from the SF-36v2 by selecting the 12 items that reproduced 90% of the variance in the overall Physical and Mental Health components of the SF-36 (84). The Physical Component Summary (PCS) and Mental Component Summary (MCS) scales are generated using norm-based methods. Normative data, which is standardized to a mean of 50 and SD of 10, is also presented to permit comparison of the findings from this sample to the general population. A higher score means better quality of life.

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5.1.4 Analysis

All questionnaires were double entered and verified. Any discrepancies found between the first and second sets of data entry were corrected before data analysis commenced. SPSS 15.0 was used for the analysis. A descriptive analysis was carried out for the total sample and for the different disease groups. Pearson's correlations were used to analyse the relationships between patients' and carers' health status.

A series of analyses were planned to examine possible relationships between patients' experiences of problems with their health care and their health related quality of life. Given the large number of variables and possible analyses, problems experienced with services were grouped (using judgments by the research team (RF, CJ, MP)) regarding clusters of items in related areas of health care. Questionnaire items concerned with experiences of problems were transformed into dichotomous variables according to whether or not respondents had reported a problem with receiving a service (responses 'no' and 'to some extent' were recoded as 1 i.e. a problem), or the care had been received (coded 0 i.e. no problem). This recoding was undertaken for both patient and carer variables. Additionally carer variables were also coded for services received ('yes' and 'to some extent' coded as 1 i.e. service received, and 'no' coded 0 as service not received). Summed problem scores were created for all the recoded patient variables in given areas. This approach also worked for some of the recoded carer variables. The relevant carer variables not included in the dimensions were analysed separately as individual items. Each summed problem score was assessed for its internal consistency, using Cronbach's alpha. Although it may be argued that, unlike pure attitudinal items, experiences of problems with care need not conform to scale-like properties, some changes to the scores were made based on internal consistency to give the final set of problem scores.

The resulting summed problem scores for different areas of patients' experiences of services are described in table 10. These scores of extent of problems reported in different areas of services were used to conduct analysis of variance (ANOVA) to assess the relationship between the patients' experiences of services and their health status, with

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similar analyses of carer experiences and health status. Regression analysis and ANOVA are broadly equivalent strategies, but ANOVA was chosen as method of analysis as it facilitates a clear focus on mean scores in dependent variables, highlighting the potential effects of experience of problems, which was our theoretical focus. For patients, both generic health status (including physical health status and mental health status) and disease-specific health status were used as dependent variables. Problem scores were the independent variables, with age, gender and length of time since the diagnosis of the neurological condition being used as covariates. Items were less readily grouped into summed scores for carers' experiences of services. Two summed scores were identified and created (table 11). For carers, generic health status and carer burden were the dependent variables, with two summed scores of carers services experiences being the independent variables. Carer age, gender, length of time as carer, and time spent caring (hours per week) were used as covariates in these analyses.

Table 10: Patient items grouped in summed problem scores in relation to various services

SUMMED PROBLEM SCORE	ITEMS	SCORE RANGE	CRONBACH ALPHA
Medication and treatment	• Adequate reviews for prescribed medication • Information about how and when to take medication • Enough information about side effects • Support to develop self-management • Support with nutrition • Respiratory support	0-6	0.61
Quality and responsiveness of health and social services	• Difficulties with consultations • Quality of collaboration between health and social services • Involvement in decisions about care • Wishes and preferences taken into account by professionals	0-4	0.71
Health professionals' understanding	• Are health and social care professionals understanding about the condition?	0-5	0.70
Dignity	• Do health and social care professionals treat patients with respect and dignity	0-5	0.70

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Table 10 (contd): Patient items grouped in summed problem scores in relation to various services

SUMMED PROBLEM SCORE	ITEMS	SCORE RANGE	CRONBACH ALPHA
Employment (for patients in employment)	• Work assessment • Occupational therapist talk to employer • Guidance about staying in work • Guidance about leaving work • Guidance about re-starting work	0-5	0.82
Resources	• Equipment • Receiving financial support from health and/or social services • Difficulties obtaining financial support	0-4	0.31
Social care	• Been offered help by health and/social care with housework • Been offered help with personal care • Been offered respite care	0-3	0.43

Table 11: Dimensions of services with which carers reported a problem

SUMMED PROBLEM SCORE	ITEMS	SCORE RANGE	CRONBACH ALPHA
Carer Assessment (for carers who had an assessment)	• Given a specific contact person • Written report of the assessment • Usefulness of assessment	0-3	0.55
Help with caring tasks	• Help by health and/or social services with different caring tasks	0-4	0.83

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5.2 Results of the main survey

5.2.1 Sample (patient)

For 2661 out of the 5209 packs sent out at least one, if not both, questionnaires had been returned and could be included in the analysis. For the majority of packs, both the patient and carer questionnaires had been included (n=1812, 68.1%), for 751 packs (28.2%) only the patient questionnaire and for a small number (n=98, 3.7%) only the carer questionnaire had been included. Table 12 shows how this is distributed between the 3 conditions.

Table 12: Type of questionnaire in the analysis for each condition

	PATIENT AND CARER		PATIENT ONLY		CARER ONLY	
	n	%	n	%	n	%
MS	701	15.3	456	19.4	20	0.9
MND	407	26.3	98	11.0	27	3.0
PD	704	26.5	197	10.0	51	2.6
Total	1812	68.1	751	28.2	98	3.7

The total number of patient questionnaires included in the analysis was 2563 (49.2%) with 505 being MND (56.7%), 901 PD (45.6%) and 1157 MS (49.3%). Fifteen questionnaires were excluded from the analysis as they had been completed by proxy and 22 questionnaires (1 MND, 6 MS and 15 PD) were excluded as they had been received after the deadline. An additional 158 responses had been recorded from telephone or email contact, letters or returned blank questionnaires with or without a note. These were 23 blank questionnaires, 3 who reported to be unable to participate, 60 patients had died, 2 patients felt their condition was not severe enough, 21 were not well enough to take part, 1 patient was in a nursing home, 1 patient was no longer being cared for by family, 10 did not want to participate, 15 were members of the patient society but neither a patient nor a carer, 16 questionnaires were undeliverable, 2 felt the questionnaire was not applicable, and 2 had received the questionnaire a second time.

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The majority of the patients were female (n=1374, 54.3%) with 858 (75.1% of MS patients) MS patients being female. The proportion of men was higher for MND (60.8% men and 39.2% women) and PD (63.9% men and 36.1% women). The mean age was 63.3 (sd 12.7) years, 67.1 (sd 10.2) for MND, 55.3 (sd 11.4) for MS and 71.1 (sd 9.0) for PD. The majority were married (n=1893, 75.3%), of a white ethnic origin (n=2474, 98.1%) and retired (including early retirement) (n=1749, 74.6%). A large proportion (n=860, 33.6%) were educated at university level. Full details on patient demographics for the main survey are in Appendix 7.1. Table 13 shows the geographical spread of the respondents.

Table 13: Number of patient respondents per geographical region

	TOTAL		MND		MS		PD	
	n	*%*	*N*	*%*	*n*	*%*	*n*	%
North-West	261	10.3	78	16.1	111	9.6	72	8.0
North-East	144	5.7	21	4.3	62	5.4	61	6.8
West Midlands	223	8.8	43	8.9	127	11.0	53	5.9
Yorkshire and Humberside	270	10.6	39	8.1	137	11.9	94	10.4
East Midlands	245	9.6	51	10.5	112	9.7	82	9.1
East England	286	11.3	37	7.6	141	12.2	108	12.0
Greater London	329	13.0	65	13.4	140	12.1	124	13.8
South-East	362	14.3	102	21.1	113	10.3	141	15.6
South-West	419	16.5	48	9.9	205	17.8	166	18.4

All three conditions can be classified into different types, and patients were asked about their type of MND, MS or PD. More than half of MND patients did not know which type of MND they had and the proportion of MS and PD respondents who did not feel sure about their exact diagnosis was also considerable. The distribution of the different types of MND, MS and PD in this sample can be found in Appendix 8.

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5.2.2 Patients' health related quality of life

Complete data for the SF-12v2 (generic health status) was available for 2016 participants (78.7%). It was found that the mean score for the Physical Component Score (PCM) was significantly different between the three disease groups ($p<0.001$), whereas the Mental Component Score (MCS) did not significantly differ between the groups (table 14). All scores for the 3 neurological conditions are significantly compromised when compared to normative data, as is shown in the table.

Table 14: Patient general quality of life

	N	Mean	SD	25th percentile	50th percentile	75th percentile
PCS						
Total	2016	30.73	9.87	23.49	29.24	36.55
MND	371	28.88	8.32	22.96	27.99	32.90
MS	973	30.78	10.50	23.28	29.04	36.51
PD	672	31.68	9.58	24.03	30.61	38.32
Norms	8207	50	10.0	47.06	53.20	56.14
MCS						
Total	2016	41.84	12.06	33.05	41.49	51.06
MND	371	41.7	13.01	31.73	41.45	52.22
MS	973	42.28	12.15	33.41	42.14	51.45
PD	672	41.27	11.35	33.06	40.65	49.52
Norms	8207	50	10.0	46.09	53.24	56.93

* $p<0.001$

Disease-specific health status was measured by the ALSAQ-40 for respondents with MND. Varying levels of complete data were found for the 5 dimensions of the ALSAQ namely 489 (96.8%) for 'eating and drinking', 462 (91.5%) for 'communication', 464 (91.9%) for 'activities of daily living', 434 (85.9%) for 'mobility' and 461 (91.3%) for 'emotional well-being'. The mean scores for the 5 dimensions are presented in table 15.

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Table 15: MND specific quality of life (assessed by the ALSAQ)

Dimensions	Score	SD
Eating and drinking (3 items)	40.6	36.0
Communication (7 items)	47.8	38.9
Activities of daily living/independence (10 items)	65.7	28.9
Mobility (10 items)	68.2	27.1
Emotional well-being (10 items)	49.6	38.9
TOTAL	53.05	22.01

The MSIS-29 was used to assess disease-specific health status in MS (table 16). A total of 984 (85.0%) of complete data was available for the total MSIS score. Slightly higher numbers of complete data were available for the two dimensions with 1009 (87.2%) of complete data for 'physical impact' and 1092 (94.4%) for 'psychological impact'.

Table 16: MS specific quality of life (assessed by the MSIS)

Dimensions	Score	SD
Physical impact (20 items)	60.5	25.9
Psychological impact (9 items)	49.0	25.2
TOTAL	56.8	23.4

The PDQ-39, which was used to assess disease-specific quality of life in respondents with PD, has six dimensions. A complete set of data was available for 651 (71.9%) PD respondents. Higher numbers of complete data were achieved for the different dimensions, namely 787 (87.3%) for 'mobility', 823 (91.3%) for 'emotional well-being', 837 (92.9) for 'stigma', 864 (95.9%) for 'cognitions', 854 (94.8%) for 'communication' and 847 (94.0%) for 'bodily discomfort'. The PDQ-39 scores for the different dimensions are presented in table 17.

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Table 17: PD specific quality of life (assessed by the PDQ-39)

Dimensions	Score	SD
Mobility (10 items)	60.8	28.7
Emotional well-being (6 items)	36.4	22.9
Activities of daily living (6 items)	51.4	28.2
Stigma (4 items)	28.9	25.8
Social support (3 items)	21.8	22.7
Cognitions (4 items)	45.4	24.8
Communication (3 items)	36.4	26.3
Bodily discomfort (3 items)	48.8	25.4
TOTAL SCORE	41.0	18.4

5.2.3 Patients' experiences with health services

5.2.3.1 Diagnosis

For the majority of the sample, a definite diagnosis had been given more than 5 years previously, however this did not apply to patients with MND for whom the majority had been diagnosed less than 2 years ago (table 18). A small number (n=26, 1%) of the sample reported never having been given a definite diagnosis.

Table 18: Time since definite diagnosis

	TOTAL		MND		MS		PD	
Responses	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
< 1 year	173	6.8	120	23.9	23	2.0	30	3.4
1-2 years	336	13.2	185	36.8	57	5.0	94	10.5
3-4 years	349	13.7	81	16.1	105	9.1	163	18.3
5-10 years	648	25.5	62	12.3	271	23.5	315	35.4
> 10 years	1013	39.8	49	9.7	687	59.7	277	31.1
Never given definite diagnosis	26	1.0	6	0.2	8	0.7	12	1.3

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Less than a fifth of patients reported their initial consultation with the specialist occurring less than a month after their first consultation with the GP (Table 19). A total of 41.7% had consulted the specialist within 2 months of their initial GP contact, and 59.8% in less than 6 months, leaving a considerable proportion of individuals (31.1%) for whom it took 6 months or more to be seen by a specialist.

Table 19: Length of time from first GP consultation to specialist consultation

	TOTAL		MND		MS		PD	
Responses	*n*	*%*	*n*	*%*	*n*	*%*	*n*	%
< 1 month	477	19.0	78	15.6	251	22.2	148	16.7
1-2 months	572	22.7	111	22.2	217	19.2	244	27.6
3-5 months	455	18.1	108	21.6	177	15.6	170	19.2
6-12 months	367	14.6	80	16.0	160	14.1	127	14.4
> 12 months	415	16.5	85	17.0	214	18.9	116	13.1
Not sure	228	9.1	37	7.4	113	10.0	78	8.8
Never consulted specialist	3	0.1	0	0	1	0.1	2	0.2

For only 37.6% of the sample it took less than 6 months to get a definite diagnosis, and 17.7% of the total sample reported it taking longer than 2 years (Table 20). A higher proportion of PD patients (51.8%) reported receiving their definite diagnosis within 6 months, compared with 28.4% of MND patients and 30.7% of MS patients. Also, fewer PD patients (9.8%) reported it taking longer than 2 years when compared with MND (17.8%) and MS (23.8%) patients. Private health care had been used by 21.0% of all the respondents (18.6% MS, 23.0% MND and 22.9% PD) for the diagnosis of their condition, and a higher proportion of these respondents (46.7%) reported having been diagnosed within the first 6 months of their initial consultation in comparison with those respondents who had not used private health care for their diagnosis (35.4%). The difference for MND was small (31.0% vs. 27.6%), but for MS and PD the difference was more remarkable with 42.5% of MS patients who had used private health care being diagnosed within 6 months versus 28.2% who had not used private health care, and for PD 60.2% versus 49.6%.

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Table 20: Time from first GP consultation to definite diagnosis

	TOTAL		MND		MS		PD	
Responses	*n*	*%*	*n*	*%*	*n*	*%*	*N*	%
< 6 months	947	37.6	142	28.4	349	30.7	456	51.8
6-12 months	549	21.8	124	24.8	244	21.5	181	20.5
13-24 months	362	14.4	112	22.4	171	15.1	79	9.0
> 24 months	445	17.7	89	17.8	270	23.8	86	9.8
Not sure	190	7.6	25	5.0	94	8.3	71	8.1
Never given a diagnosis	23	0.9	8	1.6	7	0.6	8	0.9

After the initial diagnosis, only a little more than half of all the respondents reported having been given a follow-up appointment with the specialist (Table 21), with MS patients being the least likely to report a follow-up appointment (43.3%) and PD patients the most likely to have been followed up (58.1%). For the respondents who were not offered a follow-up, a large proportion said that they would have liked to have been given an appointment. This view was particularly strong in MS patients.

Table 21: Follow-up appointment after receiving diagnosis

	TOTAL		MND		MS		PD	
Responses	*n*	*%*	*n*	*%*	*N*	*%*	*n*	%
Yes	1342	53.2	335	67.5	494	43.3	513	58.1
No, not needed	370	14.7	79	15.9	143	12.5	148	16.8
No, but would have liked one	795	31.5	79	15.9	500	43.8	216	24.5
Never given a diagnosis	14	0.6	3	0.6	5	0.4	6	0.7

5.2.3.2 Medication and treatment

The majority of respondents (n=1979 (78.0%) including 361 (72.1%) MND, 754 (65.7%) MS and 864 (97.2%) PD) reported currently taking prescription medication for their neurological condition. For the respondents currently using prescription medication, only about two thirds of respondents reported having adequate reviews of their prescription medication, with a considerably lower number of MS patients reporting adequate reviews

(table 22). Furthermore, over a quarter of respondents (n=520, 27.1%) reported not having been given adequate information about possible side effects, this being true of 54 (15.5%) MND, 207 (28.0%) MS and 259 (31.1%) PD patients. On the other hand, 1814 (93.9%) of respondents reported having been given enough information about how and when to take their prescription medication (Table 22).

Table 22: Reviews and information about prescribed medication

	ADEQUATE REVIEWS FOR PRESCRIBED MEDICATION							
	TOTAL		**MND**		**MS**		**PD**	
Responses	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
Yes	1171	61.2	228	66.1	393	53.7	550	65.9
To some extent	526	27.5	79	22.9	228	31.1	219	26.2
No	215	11.2	38	11.0	111	15.2	66	7.9
	GIVEN ENOUGH INFORMATION ABOUT HOW AND WHEN TO TAKE MEDICATION							
	TOTAL		**MND**		**MS**		**PD**	
Responses	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
Yes	1814	93.9	337	96.8	708	95.3	769	91.5
No	117	6.1	11	3.2	35	4.7	71	8.5

As far as support with nutrition was concerned, only about a quarter of respondents (n=598, 23.5%) reported having been given any such support in the last twelve months, with a much larger proportion of MND patients reporting nutritional support in comparison to MS and PD (table 18). It could be concluded that MND patients are more in need of nutritional support, and indeed the majority of respondents who had not had nutritional support reported not having needed it. However, there are still a considerable number of respondents who were not given nutritional support but who would have liked it (n=680, 26.8%) (table 22), and this view was predominantly expressed by MS and PD patients.

For respiratory support, the majority of respondents reported not having needed it (n=1790, 70.9%) in the last 12 months (table 23). However, 15.7 % (n=396) reported that they may need it despite not having received it, with PD patients reporting the possible need for respiratory support more frequently than patients from the two other disease

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groups. Again, probably due to the different nature of the condition, a much larger number of MND patients reported having received respiratory support in comparison with the other two conditions.

Less than a third of respondents reported having been given support to develop self-management strategies in the year preceding the survey, with MND patients reporting it more frequently than either MS or PD patients (table 22). About a quarter of the respondents reported having been given support 'to some extent' and nearly half the respondents (47.1%) said they had been given no support about self-management strategies.

Table 23: Support with nutrition, respiration and self-management in the last 12 months

	SUPPORT WITH NUTRITION							
Responses	**TOTAL**		**MND**		**MS**		**PD**	
	n	*%*	*n*	*%*	*N*	*%*	*n*	*%*
Yes	598	23.5	283	56.3	158	13.8	157	17.6
No, not needed it	1264	49.7	175	34.8	640	55.7	449	50.4
No, would have liked it	680	26.8	45	8.9	350	30.5	285	32.0
	RESPIRATORY SUPPORT							
Responses	**TOTAL**		**MND**		**MS**		**PD**	
	n	*%*	*n*	*%*	*N*	*%*	*n*	*%*
Yes	339	13.4	202	40.6	65	5.7	72	8.1
No, not needed it	1790	70.9	223	44.9	936	82.1	631	71.1
No, but may need it	396	15.7	72	14.5	139	12.2	185	20.8
	SUPPORT TO DEVELOP SELF-MANAGEMENT STRATEGIES							
	TOTAL		**MND**		**MS**		**PD**	
Responses	*n*	*%*	*n*	*%*	*N*	*%*	*n*	*%*
Yes	686	27.0	212	42.4	245	21.3	229	25.8
To some extent	655	25.8	157	31.4	265	23.1	233	26.2
No	1196	47.1	131	26.2	638	55.6	427	48.0

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5.2.3.3 Health care provision

The majority of respondents (n= 2417, 94.5%) reported having consulted one or more health care professional in the last 12 months (figure 2). The number of health care professionals consulted ranged from 0 to 12 out of 15 possible response options. The average number of health or social care professionals consulted in the last 12 months was significantly higher ($p<0.001$) for MND (5.48 sd 2.6) than for MS (2.88 sd 2.09) and PD (3.44 sd 1.90). The health care professional consulted by the largest proportion of patients was the consultant. For the majority of health care professionals, MND patients reported higher rates of consultations in comparison with MS and PD (Figure 2).

Difficulties obtaining consultations when necessary were not encountered by the majority of the sample, with 1346 (52.6%) reporting no difficulties and 448 (17.5%) reporting not having wanted to consult anyone. A larger proportion of MND patients reported not having had any difficulties (n= 434, 68.1%) in comparison with MS (n= 533, 47.8%) and PD (n= 450, 50.2%), and a lower proportion of MND patients had reported not having wanted to consult anyone (n=45, 9.3% vs. 253 (21.9%) MS and 148 (16.5%) PD). The highest level of difficulty was reported for the consultant (289, 11.3%), the specialist nurse (n=215, 8.4%) and the physiotherapist (n=167, 6.7%). For all the other health and social care professionals, problems were reported by fewer than 5% of the total sample.

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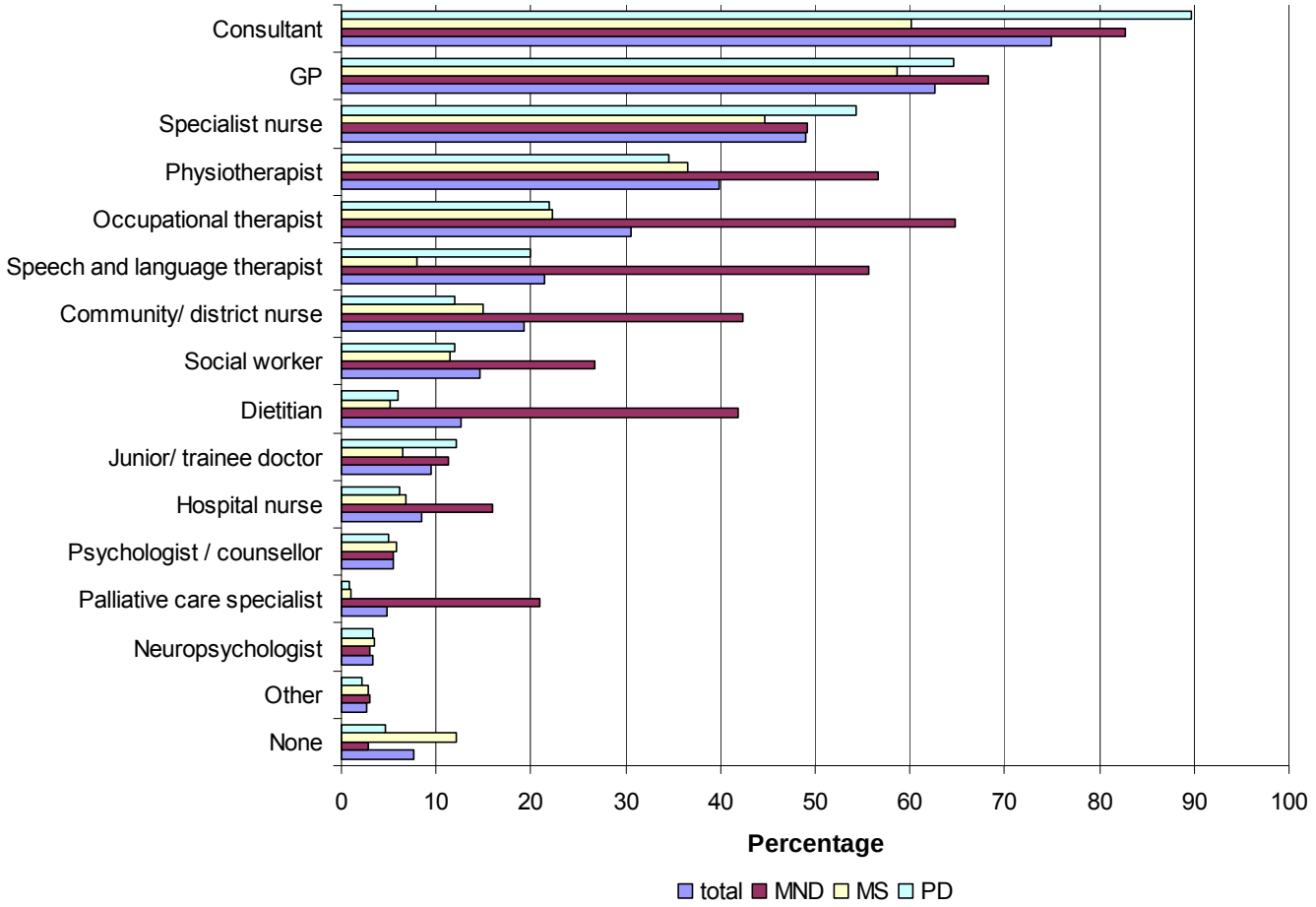
Figure 2: Consultations in the last 12 months



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Most of the respondents reported having been to a specialist clinic at least once in the last 12 months, however nearly a quarter had not been (n=615, 24.5%) (Table 24). MS patients were the most likely to report not having been to a specialist clinic.

Table 24: Frequency of specialist clinic consultations in the last 12 months

	TOTAL		MND		MS		PD	
Responses	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
Never	615	24.2	98	19.6	400	34.9	117	13.0
Once	811	31.9	118	23.6	425	37.1	268	29.9
Two to three	916	36.0	183	36.5	289	25.2	444	49.5
Four or more	202	7.9	102	20.4	32	2.8	68	7.6

Only just over half of the respondents reported having a named health care professional whom they could contact and even fewer patients had a single professional coordinating their care (Table 25). MND patients were more likely to report having either a named single point of contact or a single care coordinator. Only 24.3% (n=616) of respondents totally agreed that health and social care professionals work well together in the planning of care. More MND than other patients reported that they believed health and social care professionals worked well together (table 25).

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Table 25: Care planning and coordination

	ASSIGNED NAMED HEALTH / SOCIAL CARE PROFESSIONAL TO CONTACT WHEN NEEDS HAVE CHANGED							
	TOTAL		**MND**		**MS**		**PD**	
Responses	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
Yes	1355	53.4	351	70.3	537	46.9	467	52.2
No	919	36.2	94	18.8	477	41.7	348	38.9
Not sure	265	10.4	54	10.8	131	11.4	80	8.9
	SINGLE HEALTH / SOCIAL CARE PROFESSIONAL WHO CO-ORDINATES CARE							
	TOTAL		**MND**		**MS**		**PD**	
Responses	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
Yes	910	36.0	266	53.5	328	28.7	316	35.6
No	1010	40.0	118	23.7	551	48.2	341	38.4
Not sure	607	24.0	113	22.7	263	23.0	231	26.0
	DO DIFFERENT HEALTH AND SOCIAL SERVICES WORK WELL TOGETHER IN PLANNING OF CARE							
	TOTAL		**MND**		**MS**		**PD**	
Responses	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
Yes	616	24.3	237	47.3	176	15.4	203	22.9
To some extent	662	26.1	128	25.5	275	24.0	259	29.2
No	486	19.2	58	11.6	283	24.7	145	16.3
Not sure	420	16.6	53	10.6	211	18.4	156	17.6
Not applicable	350	13.8	25	5.0	201	17.5	124	14.0

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Few respondents reported having a care plan (n=548, 22.0%), and within the 3 disease groups MND patients were more likely to report having one (n=197, 40.1%) (table 26). For those who have a care plan, it is mostly kept up to date in response to changes in their condition (table 26).

Table 26: Care plan

	FORMAL CARE PLAN							
	TOTAL		**MND**		**MS**		**PD**	
Responses	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
Yes	548	22.0	197	40.1	186	16.4	165	19.0
No	1947	78.0	294	59.9	950	83.6	703	81.0
	FOR THOSE WHO HAVE A CARE PLAN, IS IT KEPT FULLY UP TO DATE IN RESPONSE TO CHANGES IN CONDITION							
	TOTAL		**MND**		**MS**		**PD**	
Responses	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
No changes in condition	93	17.6	38	19.8	34	19.1	21	13.3
Yes	386	73.1	143	74.5	123	69.1	120	75.9
No	49	9.3	11	5.7	21	11.8	17	10.8

Only about 40% of respondents felt that they were as involved as they would like to be in making decisions about their care, or that their wishes and preferences are taking into account in the planning of the care (Table 27). Differences were found between with disease groups, with more MND patients (approximately 60%) reporting either of these, than PD (approximately 40%) or MS (approximately 30%).

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Table 27: Involvement in their care

	AS INVOLVED AS WOULD LIKE TO BE IN MAKING DECISIONS ABOUT CARE							
	TOTAL		**MND**		**MS**		**PD**	
Responses	*N*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
Yes	1003	39.7	309	62.4	337	29.4	357	40.3
To some extent	687	27.2	107	21.6	312	27.2	268	30.3
No	415	16.4	39	7.9	232	20.2	144	16.3
Not sure	207	8.2	27	5.5	105	9.2	75	8.5
Not applicable	213	8.4	13	2.6	160	14.0	40	4.5
	WISHES AND PREFERENCES TAKEN INTO ACCOUNT IN PLANNING OF CARE							
	TOTAL		**MND**		**MS**		**PD**	
Responses	*N*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
Yes	1012	40.1	295	59.5	359	31.4	358	40.5
To some extent	655	26.4	115	23.2	293	25.7	257	29.0
No	312	12.4	32	6.5	177	15.5	103	11.6
Not sure	229	9.1	33	6.7	108	9.5	88	9.9
Not applicable	305	12.1	21	4.2	205	18.0	79	8.9

Various levels of agreement were found for how understanding a range of health care professionals were felt to be about the participants' neurological needs, with often MND patients being more positive than MS and PD patients (Table 28). However, MS and PD patients more frequently replied 'not applicable' for some professionals. Higher levels of agreement were found in terms of whether participants felt that a variety of health and social care professionals treated them with respect and dignity (Table 29). For this, MND respondents also responded positively more frequently, with a larger number of MS and PD patients replying 'not applicable'. Even though many respondents felt they had been treated with respect and dignity by a variety of health care professionals, there was still a sizeable minority that felt that they had not been treated with respect and dignity, or that they only had been treated with respect and dignity 'to some extent'.

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Table 28: Patient views of whether a variety of health care or social care professionals are understanding about their needs

	CONSULTANTS IN HOSPITAL							
	TOTAL		**MND**		**MS**		**PD**	
Responses	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
Yes	1362	55.7	340	70.2	480	43.3	542	63.2
To some extent	670	27.4	86	17.8	332	30.0	252	29.4
No	230	9.4	33	6.8	154	13.9	43	5.0
Not applicable	185	7.6	25	5.2	139	12.6	21	2.4
	OTHER HEALTH CARE PROFESSIONALS IN HOSPITAL							
	TOTAL		**MND**		**MS**		**PD**	
Responses	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
Yes	1041	44.9	258	55.8	454	42.2	329	42.0
To some extent	616	26.5	106	22.9	295	27.4	215	27.5
No	242	10.4	40	8.7	112	10.4	90	11.5
Not applicable	90	11.5	58	12.6	215	20.0	149	19.0
	GP							
	TOTAL		**MND**		**MS**		**PD**	
Responses	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
Yes	1162	48.1	272	56.7	473	43.1	417	49.9
To some extent	893	37.0	153	31.9	438	302	893	37.0
No	270	11.2	43	9.0	137	12.5	90	10.8
Not applicable	89	3.7	12	2.5	50	4.6	27	3.2
	COMMUNITY HEALTH CARE PROFESSIONALS							
	TOTAL		**MND**		**MS**		**PD**	
Responses	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
Yes	813	34.6	303	63.1	273	25.4	237	29.8
To some extent	521	22.2	104	21.7	243	22.6	174	21.9
No	292	12.4	37	7.7	135	12.5	120	15.1
Not applicable	726	30.9	36	7.5	425	39.5	265	33.3

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Table 28 (continued): Patient views of whether a variety of health care or social care professionals are understanding about their needs

	SOCIAL SERVICES							
	TOTAL		**MND**		**MS**		**PD**	
Responses	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
Yes	441	19.1	147	32.1	147	13.9	147	18.6
To some extent	351	15.2	93	20.3	147	13.9	111	14.1
No	324	14.0	50	10.9	152	14.3	122	15.4
Not applicable	1192	51.6	168	36.7	614	57.9	410	51.9

Table 29: Patient views on whether a variety of health and social care professionals treat them with respect and dignity

	CONSULTANTS IN HOSPITAL							
	TOTAL		**MND**		**MS**		**PD**	
Responses	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
Yes	1914	76.9	403	82.6	749	67.1	762	86.2
To some extent	334	13.4	56	11.5	189	16.9	89	10.1
No	100	4.0	10	2.0	72	6.4	18	2.0
Not applicable	141	5.7	19	3.9	107	9.6	15	1.7
	OTHER HEALTH CARE PROFESSIONALS IN HOSPITAL							
Responses	**TOTAL**		**MND**		**MS**		**PD**	
	n	*%*	*n*	*%*	*n*	*%*	*n*	*%*
Yes	1550	65.4	353	75.9	688	62.9	509	62.7
To some extent	321	13.5	47	10.1	167	15.3	107	13.2
No	102	4.3	15	3.2	45	4.1	42	5.2
Not applicable	398	16.8	50	10.8	194	17.7	154	19.0

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Table 29 (continued): Patient views on whether a variety of health and social care professionals treat them with respect and dignity

	GP							
Responses	**TOTAL**		**MND**		**MS**		**PD**	
	n	*%*	*n*	*%*	*n*	*%*	*n*	*%*
Yes	1915	78.5	395	81.3	842	75.9	678	80.2
To some extent	354	14.5	58	11.9	183	16.5	113	13.4
No	84	3.4	16	3.3	38	3.4	30	3.6
Not applicable	88	3.6	17	3.5	47	4.2	24	2.8
	COMMUNITY HEALTH CARE PROFESSIONALS							
Responses	**TOTAL**		**MND**		**MS**		**PD**	
	n	*%*	*n*	*%*	*n*	*%*	*n*	*%*
Yes	1183	49.6	383	80.0	428	39.6	372	45.1
To some extent	277	11.6	44	9.2	132	12.2	101	12.0
No	115	4.8	14	2.9	57	5.3	44	5.3
Not applicable	809	33.9	38	7.9	464	42.9	307	37.3
	SOCIAL SERVICES							
Responses	**TOTAL**		**MND**		**MS**		**PD**	
	n	*%*	*n*	*%*	*n*	*%*	*n*	*%*
Yes	657	28.1	203	44.0	241	22.5	213	26.5
To some extent	227	9.7	59	12.8	91	8.5	77	9.6
No	175	7.5	24	5.2	83	7.7	68	8.4
Not applicable	1280	54.7	175	38.0	658	61.3	447	55.5

5.2.3.4 Hospital care

Only a minority of respondents had been admitted to hospital in the year prior to the survey, either in relation to their neurological condition (n=383, 15.2%) (Table 30) or unrelated to their neurological condition (n=500, 20.1%) (Table 31). When admitted for their neurological condition, 220 (58.8%) reported that their needs for their neurological condition had been met, for 107 (28.6%) their needs had been met to some extent, and for 47 (12.6%) their needs had not been met (table 30).

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Table 30: Hospitalisation in last 12 months for neurological condition

	ADMITTED TO HOSPITAL							
Responses	**TOTAL**		**MND**		**MS**		**PD**	
	n	*%*	*n*	*%*	*n*	*%*	*n*	*%*
Yes	383	15.2	141	28.4	147	12.9	95	3.8
No	2130	84.8	356	71.6	995	87.1	779	89.1
	IF ADMITTED TO HOSPITAL, WERE NEEDS FOR LTNC MET							
Responses	**TOTAL**		**MND**		**MS**		**PD**	
	n	*%*	*n*	*%*	*n*	*%*	*n*	*%*
Yes	220	58.8	93	68.9	85	58.2	42	45.2
To some extent	107	28.6	30	22.2	42	28.8	23	37.6
No	47	12.6	12	8.9	19	13.0	16	17.2

For respondents admitted to hospital in the last year for problems unrelated to their neurological condition, less than half (n=220, 45.9%) reported that their neurological needs had been met whilst in hospital, for 136 (28.4%) their needs had been met 'to some extent' and 123 (25.7%) reported that their needs had not been met (table 32).

Table 31: Hospitalisation in last 12 months for a problem unrelated to neurological condition

	ADMITTED TO HOSPITAL							
	TOTAL		**MND**		**MS**		**PD**	
Responses	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
Yes	500	20.1	84	17.1	201	17.7	215	25.1
No	1985	79.9	406	82.9	995	87.1	779	89.1
	IF ADMITTED TO HOSPITAL, WERE NEEDS FOR LTNC MET							
	TOTAL		**MND**		**MS**		**PD**	
Responses	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
Yes	220	45.9	38	46.9	90	46.2	92	45.3
To some extent	136	28.4	18	22.2	54	27.7	64	31.5
No	123	25.7	25	30.9	51	26.2	47	23.2

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5.2.3.5 Experiences with social and community care services

The majority (1944, 77.2%) of the sample had not been in paid employment in the 3 years preceding the study. Respondents with PD were less likely to have been employed during that period of time than respondents with MND and MS. For respondents who had been employed in the last three years, 307 (53.5% or 12.2% of total sample) were still working and 267 (46.5% or 10.6% of total sample) were not currently working. Only a minority reported having been given various types of support about employment. The most common type of support was having had a work assessment (n=112, 20.0%), but other types of support (including an occupational therapist liaising with the patient and the employer, guidance about staying in work, leaving work or re-starting work) were reported by 10-15% of the respondents who had been in work at any point in the last 3 years. The majority of respondents (50-60%) who had been in employment felt that they did not need such support, but between 19.4 to 26.7% reported that they would have liked support with employment issues. MND patients were less likely to report the need for support for all variables, apart from support about leaving work. A table with the full details about employment issues can be found in appendix 9.

Only small numbers of respondents reported having had problems with obtaining equipment, with 47% (n=1151) having had no problems and 32.6% (n=798) not having tried to get equipment from health and social services. MND patients (n=44, 9.2%) were less likely to not have tried to get equipment than MS (n=409, 36.3%) or PD patients (n=345, 40.7%). The proportion of respondents reporting difficulties with a specific piece of equipment ranged from 0.7% to 6.3%.

As far as modifications to accommodation were concerned, approximately a fifth of the sample reported either needing modifications or needing additional modifications to their current accommodation. MND respondents were more likely to report having had all the modifications to their accommodation, and less likely to report that they did not need any changes in comparison with MS and PD patients. For the respondents who have had modifications to their house (n=1168, 48.7%), 30.3% (n=339) had received financial support for the modifications. Only 12.3% (n=138) reported not receiving financial

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support but having needed it, whereas 25.8% (n=289) either thought they did not need it or they had not applied for it (n=353, 31.5%).

In terms of other financial support, 1867 (74.8%) of respondents reported receiving financial support from health and social services. The most likely disease group to receive financial support was MND (n=412, 83.2) followed by MS (n=874, 76.0%) and finally PD (n=581, 67.2%). Only a small number of respondents (n=139, 5.6%) reported not having received financial support but needing it. Personal finances had been affected 'to some extent' (n=1121, 44.6%) or 'to a large extent' (n=721, 28.7%), with only a quarter of respondents reporting it not having been affected (n=672, 26.7%).

It was found that the majority of the respondents had not been offered help from health and social services with household tasks or with personal care. This represented a problem only in 11.0% (n=272) of the sample for help with housework and for 3.8% (n=95) for personal care (Table 32), as a large proportion of the sample either did not need such help, or received this type of help from elsewhere.

Table 32: Support offered from health and social services in the last 12 months

	HELP WITH HOUSEWORK							
	TOTAL		**MND**		**MS**		**PD**	
Responses	*N*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
Yes, have used it	178	7.2	41	8.5	84	7.4	53	6.1
Yes, but not used it	71	2.9	22	4.6	23	2.0	26	3.0
No, not needed it	1056	42.7	202	41.9	475	42.1	379	43.9
No, would have liked some	272	11.0	39	8.1	141	12.5	92	10.7
No, receive help elsewhere	897	36.3	178	36.9	406	36.0	313	36.3

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Table 32 (continued): Support offered from health and social services in the last 12 months

	HELP WITH PERSONAL CARE							
	TOTAL		**MND**		**MS**		**PD**	
Responses	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
Yes, have used it	409	16.4	115	23.6	174	15.3	120	13.7
Yes, but not used it	93	3.7	41	8.4	25	2.2	27	3.1
No, not needed it	1242	49.7	176	36.1	634	55.8	432	49.3
No, would have liked some	95	3.8	21	4.3	30	2.6	44	5.0
No, receive help elsewhere	662	26.5	135	27.7	273	24.0	254	29.0

Similarly, the numbers of respondents reporting not having been offered respite care or hospice care despite needing it were 10.1% (n=254) for respite care and 2.5% (n=2.5%) for hospice care (Table 33). In the last 12 months, the majority of respondents did not need this type of help, with 75.2% (n=1884) reporting not to need respite care, and 91.5% (n=2297) reporting not needing hospice care. Patients with MND were more likely to have used hospice care, and less likely to report not needing this type of care, in comparison with MS and PD patients.

Table 33: Respite or hospice care offered in the last 12 months

	BEEN OFFERED RESPITE CARE IN LAST 12 MONTHS							
	TOTAL		**MND**		**MS**		**PD**	
Responses	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
Yes, have used it	226	9.0	68	14.0	93	8.2	65	7.4
Yes, but not used it	140	5.6	51	10.5	42	3.7	47	5.3
No, not needed it	1884	75.2	323	66.5	877	77.0	684	77.8
No, would have liked some	254	10.1	44	9.1	127	11.2	83	9.4

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Table 33 (continued): Respite or hospice care offered in the last 12 months

	BEEN OFFERED HOSPICE CARE IN LAST 12 MONTHS							
	TOTAL		**MND**		**MS**		**PD**	
Responses	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
Yes, have used it	106	4.2	77	15.6	14	1.2	15	1.7
Yes, but not used it	44	1.8	37	7.5	3	0.3	4	0.5
No, not needed it	2297	91.5	364	73.8	1090	95.8	843	95.9
No, would have liked some	63	2.5	15	3.0	31	2.7	17	1.9

5.2.3.6 Information

At the time of diagnosis, nearly the same number of respondents felt that they had been given all the information that they wanted than the number of respondents that they had not been given all the information they wanted (n=1058, 41.7% vs. n=1046, 41.2%) (Table 34). A further 16.9 % (n=16.9) were not sure if they had been given all the information they wanted at diagnosis. It was particularly patients with MS who felt they had not received all the information they needed at the time of diagnosis.

Table 34: Given all the information wanted at diagnosis

	TOTAL		**MND**		**MS**		**PD**	
Response s	*n*	*%*	*N*	*%*	*n*	*%*	*n*	*%*
Yes	1058	41.7	295	59.4	341	29.7	422	47.2
No	1046	41.2	127	25.6	620	54.0	299	33.4
Not sure	430	16.9	73	14.7	187	16.3	170	19.0
Never given a diagnosis	6	0.2	2	0.4	1	0.1	3	0.3

Of the respondents who had seen a consultant in the last 12 months, the majority (n=1552, 61.4%) reported having been given verbal information, and 21.3% (n=539) had received copies of letters to other health care professionals (Table 35). Receiving information in other formats, such as information sheets or a letter outlining an individual's care was reported by a minority of respondents. As many as 18.0% (n=454)

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of respondents reported not having received any information from the consultant in the last 12 months.

Table 35: Information given by the consultant in last 12 months (several answers possible)

	TOTAL		MND		MS		PD	
Responses	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
Verbal information	1552	61.4	326	65.9	549	47.9	677	76.3
Recording of consultation	16	0.6	5	1.0	4	0.3	7	0.8
Copies of letters to health professionals	539	21.3	122	24.6	182	15.9	235	26.5
A letter outlining care	129	5.1	17	3.4	36	3.1	76	8.6
Information sheet	175	6.9	51	10.3	54	4.7	70	7.9
None	454	18.0	86	17.4	243	21.2	125	14.1
Not consulted	456	18.0	56	11.3	346	30.2	54	6.1

The patient organizations were the most frequently reported helpful source of information (n=1463, 57.6%), followed by the consultant (n=12.73, 50.1%). Fewer MS patients reported the consultant to have been a helpful source of information (n=431, 37.5%) than MND (n=300, 60.0%) and PD (n=542, 60.8%). The third most frequently reported source of information was the specialist nurse (n=1215, 47.8%). MND patients reported significantly more helpful sources of information (4.4 SD 2.5) than MS (3.1 SD 1.8) and PD (3.3 SD 2.0) respondents.

A total of 861 (35.0%) respondents reported not needing further information (Figure 3). Out of 20 possible responses, respondents reported needing another 2.1 (SD 2.7) types of information. The amount of different types of information was significantly different between the diseases (p=0.02), with MND patients needing 1.8 (SD 2.6) types of information, MS 2.3 (SD 2.7) and PD2.1 (SD 2.6). A large range of information was needed, with the most frequently wanted information being about alternative therapies (n=476, 19.3%), nutrition and diet (n=441, 17.9%), their neurological condition (n=420, 17.1%), disability benefits (n=408, 16.6%) and medications (n=409, 16.0%). The need for all other types of information was reported by fewer than 16% of the sample.

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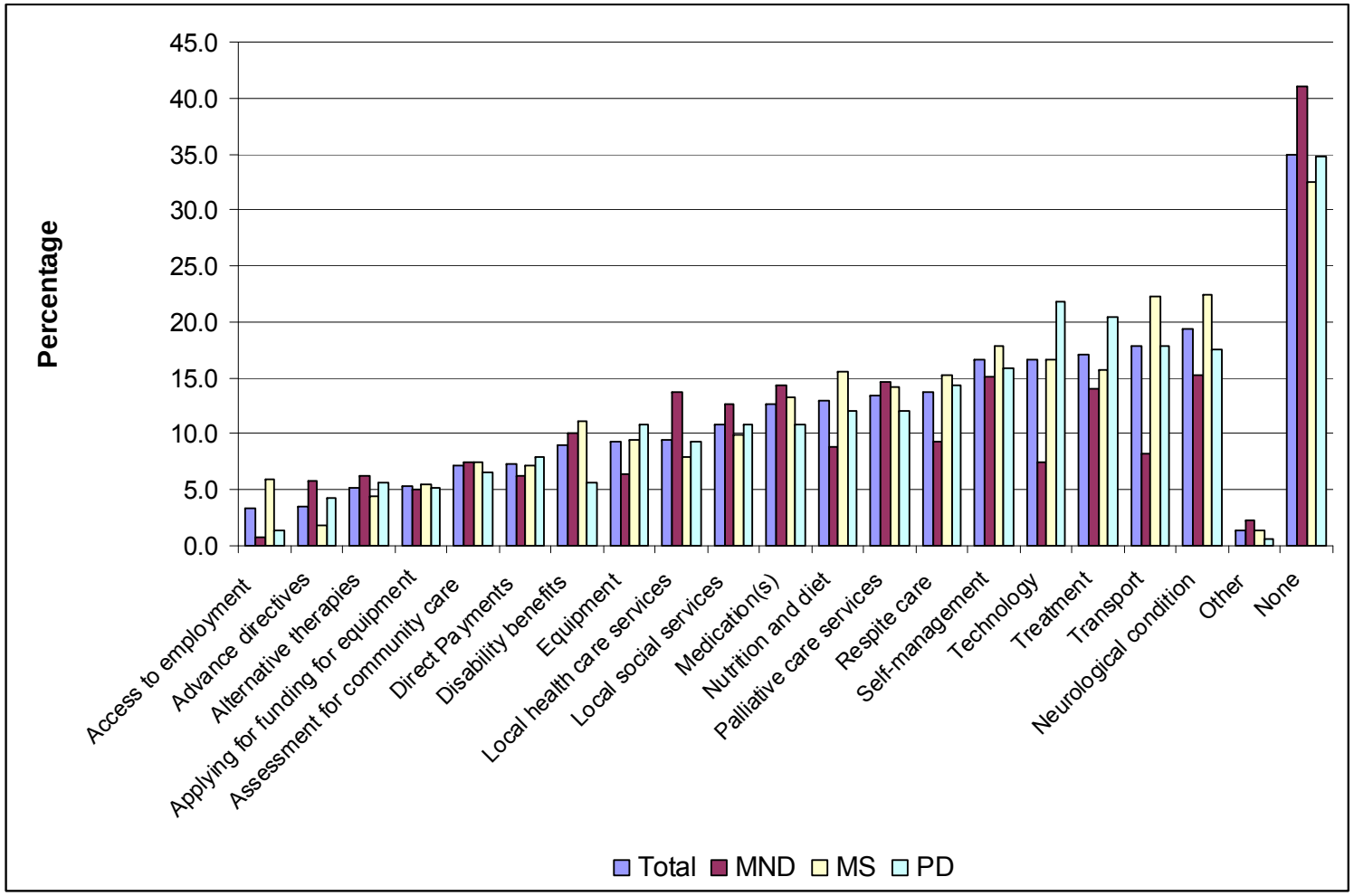

Figure 3: Types of information still needed

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5.2.4 Relationship between patient health status and experience of health and social care

The relationships between experiences of services and health status were examined for PCS (Table 36) and MCS (Table 37) and the three condition-specific measures (Table 38). As explained earlier in methods of analysis, to reduce the number of analyses, experiences were summed into problem scores for different types of service and analyses examined relationships between extent of problems with particular services and patients' health status. Health status was found to be poorer good when patients reported more problems with receiving services, although the relationship between health status and number of problematic experiences was not necessarily linear (for example for 'medication and treatment').

Significant relationships were also found between generic health status and some of the problem scores for each of the three conditions. There were differences in which relationships were significant according to the different conditions, and according to PCS and MCS scales of SF-12. 'Medication and treatment', 'resources' and 'health and social care' were significantly related to PCS only for MS. 'Health professional's understanding' was significantly associated to PCS for MS and MND, whereas 'quality of services' was significant for all three conditions. 'Employment' was found to be significantly related to PCS for MND.

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Table 36: Relationship between patient experience and physical health status (PCS measured by SF-12) (adjusted for age, gender and disease duration)

Medication and Treatment												
Score	**TOTAL *****			**MND**			**MS *****			**PD**		
	N	Mean	SE	N	Mean	SE	N	Mean	SE	N	Mean	SE
0	338	31.65	0.63	14	28.98	1.08	128	30.79	1.21	96	34.68	1.08
1	696	32.86	0.53	133	29.08	0.99	355	32.87	1.02	208	33.90	0.86
2	401	30.36	0.60	62	29.25	1.26	225	28.68	1.07	114	32.55	1.00
3	251	29.63	0.72	25	28.44	1.81	132	27.73	1.18	94	31.87	1.09
4	107	29.82	1.02	6	22.30	3.49	53	27.07	1.61	48	33.05	1.48
5	65	30.43	1.26	5	24.87	3.79	22	27.61	2.22	38	32.82	1.62
6	19	26.98	2.26	0	--	--	5	18.60	4.49	14	29.48	2.54
Quality of services												
Score	**TOTAL*****			**MND ***			**MS *****			**PD ****		
	N	Mean	SE	N	Mean	SE	N	Mean	SE	N	Mean	SE
0	474	33.54	0.58	143	29.71	0.98	192	34.14	1.11	139	35.82	097
1	376	31.93	0.62	77	30.75	1.18	181	30.59	1.13	118	33.69	1.00
2	314	30.98	0.65	42	25.84	1.42	152	30.05	1.16	120	32.95	0.99
3	470	30.11	0.59	63	28.66	1.22	243	28.73	1.05	164	32.54	0.90
4	289	28.46	0.69	29	27.24	1.67	161	26.37	1.15	99	31.32	1.08
Health professional's understanding												
Score	**TOTAL *****			**MND**			**MS *****			**PD ****		
	N	Mean	SE	N	Mean	SE	N	Mean	SE	N	Mean	SE
0	467	33.12	0.61	110	30.94	1.29	202	32.46	1.15	155	34.97	0.95
1	393	31.89	0.63	74	28.81	1.28	195	31.67	1.14	124	33.27	1.01
2	306	30.96	0.69	51	30.27	1.55	156	29.66	1.21	99	32.44	1.09
3	235	29.31	0.74	43	29.50	1.61	138	28.21	1.20	54	31.62	1.34
4	177	29.12	0.84	30	27.70	1.80	83	27.57	1.43	64	31.78	1.30
5	140	28.44	0.94	14	26.99	2.41	81	28.17	1.47	45	29.54	1.51

* $p \leq 0.05$** $p \leq 0.01$ *** $p \leq 0.001$

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Table 36 (contd): Relationship between patient experience and physical health status (PCS measured by SF-12) (adjusted for age, gender and disease duration)

Treated with respect and dignity												
Score	**TOTAL ****			**MND**			**MS**			**PD**		
	N	Mean	SE	N	Mean	SE	N	Mean	SE	N	Mean	SE
0	1031	32.06	0.51	207	29.64	1.14	455	30.92	1.02	369	34.00	0.74
1	349	30.61	0.66	59	28.28	1.41	204	29.53	1.11	86	33.03	1.14
2	176	31.03	0.85	27	29.22	1.86	96	30.01	1.34	53	32.72	1.39
3	105	28.90	1.04	20	28.76	2.01	53	27.71	1.66	32	30.78	1.75
4	64	29.10	1.29	4	27.80	4.24	39	29.75	1.87	21	28.46	1.07
5	37	29.67	1.66	5	25.24	3.83	22	28.63	2.37	10	32.52	2.99
Resources												
Score	**TOTAL *****			**MND**			**MS *****			**PD**		
	N	Mean	SE	N	Mean	SE	N	Mean	SE	N	Mean	SE
0	954	33.53	0.49	170	29.84	1.06	437	33.40	0.97	347	34.57	0.74
1	593	29.10	0.56	009	28.53	1.14	306	27.27	1.03	178	31.84	0.94
2	186	28.24	0.79	37	29.69	1.62	107	26.79	1.25	42	29.03	1.49
3	43	27.56	1.49	11	25.44	2.69	26	27.37	1.09	6	32.37	3.71
4	6	4.98	3.90	0	--	--	6	24.57	4.06	0	--	--
Health and social care												
Score	**TOTAL *****			**MND**			**MS *****			**PD ****		
	N	Mean	SE	N	Mean	SE	N	Mean	SE	N	Mean	SE
0	1550	32.11	0.46	87	29.50	0.85	735	30.99	0.94	525	33.88	0.71
1	252	28.15	0.69	129	28.10	1.15	153	26.29	1.17	91	30.44	1.14
2	275	26.03	1.34	61	24.20	2.86	38	24.68	1.84	10	30.53	2.98
3	19	28.91	2.23	38	25.30	4.87	7	30.44	3.87	9	29.23	3.09
Employment												
Score	**TOTAL**			**MND ***			**MS**			**PD**		
	N	Mean	SE	N	Mean	SE	N	Mean	SE	N	Mean	SE
0	1519	31.25	0.45	289	28.78	0.83	658	29.93	0.97	572	33.35	0.67
1	169	31.19	0.87	20	26.97	2.06	123	30.17	1.30	26	32.86	2.01
2	53	33.45	1.42	11	32.53	2.64	40	32.07	1.84	2	39.42	6.61
3	48	31.95	1.48	11	29.36	2.62	33	30.67	1.99	4	37.51	4.71
4	49	30.27	1.46	4	29.82	4.16	39	28.23	1.85	6	34.28	3.85
5	25	33.74	2.00	1	56.05	8.20	15	32.39	2.74	9	29.94	3.18

* $p \leq 0.05$** $p \leq 0.01$ *** $p \leq 0.001$

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As far as MCS was concerned, there was more likely to be a significant relationship to patient experience for all three conditions (including 'quality of services', 'health professionals' understanding' and 'being treated with respect and dignity'). Significant relationships for MS and PD were found between MCS and 'medication and treatment', 'resources' and 'health and social care'. No significant relationship was found between MCS and 'employment' for any of the three conditions.

Table 37: Relationship between patient experience and mental health status (MCS measured by SF-12) (adjusted for age, gender and disease duration)

Medication and Treatment												
Score	**TOTAL *****			**MND**			**MS *****			**PD *****		
	N	Mean	SE	N	Mean	SE	N	Mean	SE	N	Mean	SE
0	338	43.74	0.78	114	43.10	1.69	128	44.76	1.44	96	45.80	1.28
1	696	44.50	0.64	133	43.10	1.55	355	46.55	1.21	208	43.97	1.02
2	401	40.58	0.74	62	41.64	1.97	225	41.51	1.28	114	41.03	1.20
3	251	39.18	0.88	25	38.10	2.84	132	40.02	1.41	94	39.97	1.30
4	107	37.90	1.25	6	37.01	5.49	53	37.62	1.93	48	40.23	1.76
5	65	37.53	1.54	5	36.37	9.95	22	37.69	2.65	38	39.33	1.93
6	19	34.91	2.76	0	--	--	5	31.18	5.36	14	37.46	3.03
Quality of services												
Score	**TOTAL *****			**MND ****			**MS *****			**PD *****		
	N	Mean	SE	N	Mean	SE	N	Mean	SE	N	Mean	SE
0	474	45.80	0.70	143	44.06	1.56	192	47.24	1.33	139	47.41	1.14
1	376	43.66	0.76	77	42.86	1.87	181	44.63	1.35	118	44.62	1.17
2	314	41.23	0.80	42	42.43	2.25	152	42.56	1.39	120	40.89	1.16
3	470	40.58	0.72	63	41.80	1.94	243	41.48	1.26	164	40.47	1.06
4	289	36.97	0.84	29	33.73	2.66	161	38.51	1.38	99	37.84	1.26
Health professional's understanding												
Score	**TOTAL *****			**MND ****			**MS *****			**PD *****		
	N	Mean	SE	N	Mean	SE	N	Mean	SE	N	Mean	SE
0	467	45.28	0.75	110	43.47	2.04	202	46.66	1.37	155	46.01	1.14
1	393	43.62	0.78	74	42.85	2.02	195	44.95	1.35	124	43.81	1.22
2	306	40.60	0.85	51	38.79	2.44	156	42.84	1.44	99	39.98	1.32
3	235	39.83	0.92	43	40.28	2.54	138	40.52	1.42	54	40.63	1.61
4	177	37.27	1.04	30	34.64	2.85	83	38.76	1.69	64	38.73	1.57
5	140	35.83	1.15	14	33.45	3.81	81	37.13	1.74	45	36.24	1.82

* $p \leq 0.05$ ** $p \leq 0.01$ *** $p \leq 0.001$

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Table 37 (continued): Relationship between patient experience and mental health status (MCS measured by SF-12) (adjusted for age, gender and disease duration)

Treated with respect and dignity												
Score	**TOTAL *****			**MND *****			**MS *****			**PD *****		
	N	Mean	SE	N	Mean	SE	N	Mean	SE	N	Mean	SE
0	1031	43.67	0.62	207	43.41	1.81	455	44.71	1.22	369	43.93	0.87
1	349	40.60	0.81	59	40.05	2.22	204	42.78	1.33	86	38.06	1.35
2	176	38.26	1.04	27	34.81	2.95	96	40.13	1.61	53	37.87	1.65
3	105	37.99	1.28	40	37.05	3.32	53	39.22	1.99	32	39.60	2.08
4	64	37.44	1.59	4	29.19	6.70	39	39.91	2.24	21	35.09	2.46
5	37	33.14	2.05	5	27.07	6.05	22	34.63	2.83	10	35.19	3.45
Resources												
Score	**TOTAL *****			**MND**			**MS *****			**PD ****		
	N	Mean	SE	N	Mean	SE	N	Mean	SE	N	Mean	SE
0	954	44.21	0.60	170	44.14	1.60	437	45.88	1.17	347	43.80	0.90
1	593	40.46	0.70	109	39.59	1.71	306	41.51	1.24	178	41.20	1.15
2	186	38.16	0.98	37	38.25	2.44	107	39.16	1.52	42	38.40	1.82
3	43	32.63	1.85	11	32.02	4.05	26	33.56	2.54	6	34.64	4.51
4	6	34.51	4.83	0	--	--	6	35.85	4.91	0	--	--
Health and social care												
Score	**TOTAL *****			**MND**			**MS *****			**PD *****		
	N	Mean	SE	N	Mean	SE	N	Mean	SE	N	Mean	SE
0	1550	43.19	0.57	290	42.76	1.35	735	44.33	1.12	525	43.02	0.85
1	252	38.58	0.85	46	39.12	2.30	153	39.22	1.39	91	38.96	1..8
2	275	35.87	1.66	9	40.15	4.53	38	36.49	2.19	10	34.90	3.60
3	19	30.39	2.75	3	34.25	7.72	7	26.04	4.60	9	34.51	3.74
Employment												
Score	**TOTAL**			**MND**			**MS**			**PD**		
	N	Mean	SE	N	Mean	SE	N	Mean	SE	N	Mean	SE
0	1519	42.20	0.56	289	41.98	1.34	658	42.95	1.18	572	42.48	0.81
1	169	42.77	1.08	20	46.35	3.33	123	42.66	1.56	26	44.81	2.43
2	53	44.04	1.76	11	47.48	4.26	40	44.11	2.22	2	50.80	7.98
3	48	40.09	1.83	11	40.48	4.22	33	40.82	2.40	4	41.59	5.68
4	49	40.77	1.81	4	38.36	6.72	39	43.27	2.23	6	33.42	4.65
5	25	38.62	2.47	1	49.23	3.24	15	36.72	3.31	9	39.93	3.84

* $p \leq 0.05$ ** $p \leq 0.01$ *** $p \leq 0.001$

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Apart from 'employment', significant relationships between patient experience of services and health status were found for all the dimensions for at least two of the conditions. 'Medication and treatment', 'health professionals' understanding' and 'resources' were significantly related to disease-specific health status for all three conditions, whereas 'quality of services' was significantly related to health status for MND and MS; and 'being treated with respect and dignity' and 'health and social care' were significant for MS and PD. The scores on the disease-specific measures increased (higher scores reflect lower quality of life) with increasing problems with health and social care. As with generic health status, the relationships were not necessarily linear.

Table 38: Relationship between patient experience and disease-specific health status (measured by ALSAQ, MSIS and PDQ) (adjusted for age, gender and disease duration)

Medication and Treatment									
Score	**MND ***			**MS *****			**PD *****		
	N	Mean	SE	N	Mean	SE	N	Mean	SE
0	111	51.95	2.73	128	54.22	2.64	99	30.43	2.03
1	139	52.33	2.48	355	47.26	2.22	194	32.21	1.73
2	68	58.83	3.05	224	57.57	2.34	119	35.17	1.86
3	23	59.65	4.84	138	64.96	2.61	93	42.25	2.07
4	7	66.22	8.50	59	73.45	3.35	47	39.92	2.74
5	5	60.99	9.98	21	70.88	4.96	36	45.03	3.00
6	1	97.03	22.16	5	92.21	9.87	15	40.37	4.41
Quality of services									
Score	**MND ****			**MS *****			**PD**		
	N	Mean	SE	N	Mean	SE	N	Mean	SE
0	147	50.62	2.46	189	44.05	2.48	138	26.56	1.86
1	76	52.57	3.02	184	53.41	2.52	107	32.75	2.01
2	44	58.83	3.54	156	55.50	2.55	113	37.23	1.93
3	72	56.98	2.99	255	61.72	2.28	162	39.03	1.81
4	30	67.29	4.32	158	67.84	2.56	98	43.66	2.00

* $p \leq 0.05$ ** $p \leq 0.01$ *** $p \leq 0.001$

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Table 38 (continued): Relationship between patient experience and disease-specific health status (measured by ALSAQ, MSIS and PDQ) (adjusted for age, gender and disease duration)

Health professional's understanding									
Score	**MND ***			**MS *** **			**PD *** **		
	N	Mean	SE	N	Mean	SE	N	Mean	SE
0	112	54.83	3.11	202	46.83	2.63	152	29.47	1.83
1	77	54.66	3.05	188	49.74	2.62	120	34.94	1.98
2	52	55.81	3.82	162	56.70	2.73	97	38.66	2.09
3	46	62.46	3.95	134	63.29	2.78	61	40.51	2.47
4	28	65.34	4.70	80	65.80	3.25	65	43.59	2.42
5	16	66.90	5.95	86	68.44	3.25	38	48.96	2.99
Treated with respect and dignity									
Score	**MND**			**MS *** **			**PD *** **		
	N	Mean	SE	N	Mean	SE	N	Mean	SE
0	209	54.15	2.67	458	52.83	2.43	359	32.38	1.49
1	61	57.35	3.52	205	55.35	2.64	83	40.46	2.10
2	34	63.16	4.18	92	58.29	3.17	58	40.24	2.47
3	21	61.62	5.36	51	69.14	3.87	34	44.53	3.09
4	5	64.17	10.10	40	62.45	4.25	20	50.63	3.86
5	4	88.79	11.29	26	75.06	5.03	8	56.03	5.92
Resources									
Score	**MND *** **			**MS *** **			**PD *** **		
	N	Mean	SE	N	Mean	SE	N	Mean	SE
0	170	49.61	2.46	443	47.66	2.12	338	30.90	1.53
1	114	57.48	2.67	310	62.44	2.23	179	39.47	1.84
2	36	60.42	4.03	105	66.40	2.76	45	47.21	2.61
3	15	69.24	5.84	28	80.64	4.47	3	51.89	9.37
4	0	--	--	6	76.13	8.94	0	--	--
Health and social care									
Score	**MND**			**MS *** **			**PD *** **		
	N	Mean	SE	N	Mean	SE	N	Mean	SE
0	302	54.08	2.05	743	53.00	2.09	509	35.22	1.51
1	45	60.77	3.71	146	68.39	2.65	95	43.53	2.29
2	8	61.51	7.90	40	70.70	3.94	8	46.47	6.19
3	3	63.38	12.77	7	75.98	8.64	1	51.83	5.34

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Table 38 (contd): Relationship between patient experience and disease-specific health status (measured by ALSAQ, MSIS and PDQ) (adjusted for age, gender and disease duration)

Employment									
Score	**MND**			**MS**			**PD**		
	N	Mean	SE	N	Mean	SE	N	Mean	SE
0	305	55.65	2.05	673	57.64	2.21	542	35.76	1.44
1	21	47.27	5.28	122	57.68	2.95	29	33.42	3.60
2	10	44.80	7.28	35	46.16	4.42	3	24.16	9.86
3	11	51.42	6.93	36	56.78	4.39	6	30.18	7.10
4	3	68.01	12.87	39	55.62	4.23	5	45.77	7.69
5	1	29.13	21.98	15	61.07	6.32	10	39.23	5.56

* $p \leq 0.05$ ** $p \leq 0.01$ *** $p \leq 0.001$

5.2.5 Carers

A total of 1910 (36.7%) carer questionnaires were included in the analysis including 434 (22.7%) MND, 721 (37.7%) MS and 755 (39.5%) PD. Fourteen carer questionnaires were excluded from the analysis as they had been completed by proxy (n=5) or by a paid carer (n=9). Eighteen carer questionnaires had been received after the deadline. An additional 232 responses (not included in the analysis) had been recorded from telephone or email contact, letters or returned blank questionnaires with or without a note. These were 143 questionnaires that had been returned (107 blank, 32 where no carer was needed, 2 as they did not think they were a carer, 2 where there was no main carer) 23 where the patient had died, 7 where the patient was in a nursing home, 1 where patient was no longer cared for by family, 8 who reported that the patient had a paid carer, 1 where they felt the disease was not severe enough, 3 were not well enough to take part, 1 was unable to participate, 15 who were members of one of the societies but who were neither a patient nor a carer, and 2 who had received two copies of the questionnaire.

While the majority of the carer sample overall was female (n=1096, 57.8%), although the majority of MS carers were male (n=453, 63.4%). The mean age for the total was 62.8 years (SD 12.2). The mean age for carers of the different disease groups was significantly different ($p<0.001$) with the mean age being 63.0 (SD 12.0) for MND

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carers, 58.0 (SD 12.1) for MS carers and 67.3 (SD 10.5) for PD carers. The majority of carers were married (n=1742, 92.2%), were the spouse of the person they cared for (n=1647, 87.0%), lived in the same household as the person they cared for (n=1699, 90.1%), of a white ethnic background (n=1839, 97.6%) and retired (including early retirement) (n=1010, 59.7%). The largest proportion of the sample (n=593, 33.0%) was educated at university level. Further details of the carers' demographics are in Appendix 8.2. Table 39 shows the geographical spread of the carers included in the analysis.

Table 39: Number of carer respondents per geographical region

	TOTAL		**MND**		**MS**		**PD**	
	n	*%*	*n*	*%*	*n*	*%*	*n*	*%*
North-West	202	10.7	69	16.7	70	9.7	63	8.3
North-East	124	6.6	26	6.3	46	6.4	52	6.9
West Midlands	166	8.8	38	9.2	80	11.1	48	6.4
Yorkshire and Humberside	193	10.2	28	6.8	91	12.6	74	9.8
East Midlands	153	8.1	31	7.5	60	8.3	62	8.2
East England	240	12.7	53	12.9	89	12.3	98	13.0
Greater London	230	12.2	54	131	78	10.8	98	13.0
South-East	263	13.9	71	17.2	79	11.0	113	15.0
South-West	317	16.8	42	10.2	128	17.8	147	19.5

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5.2.5.1 Carer health status

General quality of life data (using the SF-12) was available for 1630 (85.3%) of the carers. The sample of carers as a whole and carers for each of the three conditions reported poorer physical and mental health than is found in normative samples. Significant differences between groups of carers for different conditions were found both for the physical component scale (PCS) and the mental component scale (MCS) ($p<0.001$) (Table 40). The highest (i.e. the best) PCS score was found for the MS carers, followed by the MND with the PD carers scoring the lowest. The MCS score was the highest for MS, followed by PD with MND scored the lowest. Carer specific burden was assessed with a modified version of the Carer Strain Index (CSI). The CSI score was significantly different between the three disease groups ($p<0.001$) (Table 41). The highest burden was reported by MND carers with the level of burden between MS and PD being similar.

Table 40: Carer general quality of life

	N	Mean	SD	25th percentile	50th percentile	75th percentile
PCS*						
Total	1630	47.64	11.56	40.78	51.10	56.71
MND	363	48.04	11.72	41.22	51.96	57.20
MS	641	48.79	11.12	42.26	52.63	57.20
PD	626	46.24	11.78	38.12	48.70	55.88
Norms	8207	50	10.0	47.06	53.20	56.14
MCS*						
Total	1630	44.62	11.15	37.17	45.85	53.39
MND	363	43.01	11.60	35.77	43.66	52.00
MS	641	46.12	10.83	38.83	47.81	54.37
PD	626	44.02	11.03	36.63	44.67	52.62
Norms	8207	50	10.0	46.09	53.24	56.93

* $p<0.001$

Table 41: Carer specific quality of life (assessed by the Carer Strain Index)

	TOTAL			MND			MS			PD		
	n	*Score*	*SD*	*n*	*Score*	*SD*	*n*	*Score*	*SD*	*n*	Score	SD
CSI *	1566	12.4	6.6	362	14.7	6.6	633	11.4	6.5	571	11.9	6.4

* $p<0.001$

5.2.5.2 Caring role

The majority of carers (approximately 60%) had cared for someone with a long-term neurological condition for 5 years or more, although for MND over 60% of respondents had been a carer for less than 2 years (Table 42). Nearly half of the MS carers had been a carer for more than 10 years. Approximately half of the sample cared for more than 35 hours per week. MND carers were more likely to spend more hours per week providing care than were MS and PD carers.

Out of the 4 caring tasks, respondents reported regularly carrying out an average of 2.7 (SD 1.1) tasks, with MND carers reporting significantly more tasks (3.1 SD 1.1) than MS (2.5 SD 1.1) or PD (2.7 SD 1.1) carers ($p<0.001$). The most frequently reported task was 'household duties' reported by 96.0% (n=1802) of respondents, but the three other tasks ('personal care', 'physical care' and 'health care') were also reported by more than half the sample (table 42). 'Personal care' was reported more frequently by MS carers than by MND and PD carers. On the other hand, MND and PD carers reported higher levels of providing 'health care'. 'Physical care' was reported less often by PD carers than MND or MS carers.

Table 42: Time as a carer, time spent caring and caring tasks

	HOW LONG BEEN A CARER							
	TOTAL		**MND**		**MS**		**PD**	
Responses	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
< 1 year	130	6.9	90	21.0	20	2.8	20	2.7
1-2 years	322	17.0	173	40.3	55	7.7	94	12.6
3-4 years	319	16.8	70	16.3	70	9.8	179	23.9
5-10 years	531	28.0	61	14.2	220	30.7	250	33.4
> 10 years	592	31.3	35	3.2	352	49.1	205	27.4
	HOW MUCH TIME CARING PER WEEK							
	TOTAL		**MND**		**MS**		**PD**	
Responses	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
1-19 hours	600	32.4	99	23.2	256	36.4	245	34.1
20-34 hours	318	17.2	123	17.5	80	18.7	115	16.0
35-70 hours	410	22.2	92	21.5	156	22.2	162	22.5
More than 70 hours	522	28.2	156	36.5	169	24.0	197	27.4

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Table 42 (continued): Time as a carer, time spent caring and caring tasks

	CARE TASKS DONE REGULARLY							
	TOTAL		**MND**		**MS**		**PD**	
	n	*%*	*n*	*%*	*n*	*%*	*n*	*%*
Personal care	1119	59.6	112	26.0	372	52.6	274	37.1
Physical care	1151	61.3	293	68.0	454	64.2	404	54.7
Household duties	1802	96.0	415	96.3	683	96.6	704	95.3
Health-care	1048	55.8	288	66.8	316	44.7	444	60.1

Fewer than half of the participants (n=451, 43.7%) reported that they have had the opportunity to discuss the amount of care they provide with a health or social care professional. MND and PD fared somewhat better than MS, with 49.2 (n=154) MND and 45.3% of PD carers having discussed the amount of care with a professional in comparison with 37.4% (n=133) MS carers. Furthermore, only about a third of respondents feel that they are as involved as they would like to be in the planning of the care as they would like to be (Table 43), with MND carers being more likely to feel completely involved (n=141, 44.8%). Thirty percent of the total sample feel involved 'to some extent', and 19.6% do not feel involved, with a larger proportion of MS and PD carers not feeling involved enough. Additionally, fewer than half of the sample (n=484, 47.2%) felt that their knowledge and experience in caring for a person with a long-term neurological condition was valued by health and social care professionals (Table 44). MS carers were less likely to report that their knowledge and experience was valued.

Table 43: Carers' involvement in care of patient

	TOTAL		**MND**		**MS**		**PD**	
Responses	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
Yes	330	32.1	141	44.8	86	24.4	103	28.5
To some extent	308	30.0	96	30.5	104	29.5	108	29.9
No	202	19.6	39	12.4	90	25.6	73	20.2
Not applicable	188	18.3	39	12.4	72	20.5	77	21.3

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Table 44: Carers' knowledge and experienced valued by professionals

	TOTAL		MND		MS		PD	
	n	%	*n*	%	*n*	%	*n*	%
Yes	484	47.2	172	55.0	134	38.1	178	49.4
No	375	36.6	88	28.1	168	47.7	119	33.1
Not applicable	166	16.2	53	16.9	50	14.2	63	17.5

5.2.5.3 Community support for carers

A total of 390 (20.8%) of carers reported having had a carer assessment by health or social services (Table 45). A similar proportion who had not had an assessment reported that they would like to have one. More MS and PD carers reported not wanting a carer assessment in comparison with MND carers.

Table 45: Carer assessment

	TOTAL		MND		MS		PD	
Responses	*n*	%	*n*	%	*n*	%	*n*	%
Yes	390	20.8	107	25.1	121	17.0	162	21.9
No, but would like one	425	22.6	158	22.2	113	26.5	154	20.8
No, was offered but refused	17	0.9	7	1.6	4	0.6	6	0.8
No, don't want one	829	44.1	140	32.9	355	49.8	334	45.1
Not sure	218	11.6	59	13.8	75	10.5	84	11.4

Of the carers who reporting having had an assessment, 231 (61.3%) were given a specific contact person. MND and PD carers were more likely to have been given a contact person. Of the carers who were not given a contact person, twice as many carers reported that they would like to a specific contact than not needing a specific contact. Fewer than half of the carers (n=169, 45.1%) who had had an assessment had been given a printed or written report on the assessment. A similar number of respondents who had not received a report felt that they did not need one or that they would like one. Only a third (n=122, 33.3%) reported that the assessment had been helpful, with MS carers being less likely to report this. Findings about the outcome of the carer assessment are presented in Table 46.

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Table 46: Outcome of carer assessment

	GIVEN SPECIFIC CONTACT PERSON AS RESULT OF ASSESSMENT							
	TOTAL		**MND**		**MS**		**PD**	
Responses	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
Yes	231	61.3	70	66.7	56	47.9	105	67.7
No, but would like one	58	15.4	16	15.2	23	19.7	19	12.3
No, did not need one	27	7.2	8	6.7	13	11.1	7	4.5
Not sure	61	16.2	12	11.4	25	21.4	24	15.5
	GIVEN PRINTED / WRITTEN REPORT ON ASSESSMENT							
	TOTAL		**MND**		**MS**		**PD**	
Responses	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
Yes	169	45.1	39	37.1	59	51.3	71	45.8
No, but would like one	74	19.7	21	20.0	22	19.1	31	20.0
No, did not need one	77	20.5	29	27.6	18	15.7	30	19.4
Not sure	55	14.7	16	15.2	16	13.9	23	14.8
	WAS ASSESSMENT HELPFUL							
	TOTAL		**MND**		**MS**		**PD**	
Responses	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
Yes	122	33.3	36	35.3	31	26.7	55	37.2
To some extent	175	47.8	47	46.1	61	52.6	67	45.3
No	26	17.6	19	18.6	24	20.7	26	17.6

In terms of equipment to help with their caring role, the majority reported that they either had all the necessary equipment or did not feel they need any (Table 47). Sixteen percent (n=114) reported to either needing equipment or needing more equipment. For the respondents who reported having equipment, 664 (64.6%) reported that the equipment was very helpful, with MND (n=227, 73.2%) carers being more likely to report the equipment to be very helpful than MS (n=226, 63.8%) or PD carers (n=211, 58.0%).

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Table 47: Equipment

	EQUIPMENT TO HELP WITH CARING TASK							
	TOTAL		**MND**		**MS**		**PD**	
Responses	*N*	*%*	*n*	*%*	*N*	*%*	*n*	*%*
Yes, all equipment needed	839	46.0	252	60.7	291	41.9	296	41.5
Yes, but need more	75	10.5	64	15.4	66	9.5	75	10.5
No, but need some	39	5.5	19	4.6	36	5.2	39	5.5
No, don't need it	686	37.6	80	19.3	302	43.5	304	42.6
	IF HAVE EQUIPMENT, HOW HELPFUL IS IT?							
	TOTAL		**MND**		**MS**		**PD**	
Responses	*N*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
Very helpful	664	64.6	227	73.2	226	63.8	211	58.0
Somewhat helpful	359	34.9	83	26.8	124	35.0	152	41.8
Not helpful	5	0.5	0	0	4	1.1	1	0.3

The majority of carers did not feel that they needed any help from health or social care with care tasks including 'personal care', 'household duties', 'health care' and 'physical care' (table 47). For the remainder of the sample, a similar proportion felt that they received all the help they needed, some of the help they needed or none of the help they needed with 'personal care'. A larger number of respondents felt that they were getting none of the help they needed with 'household duties', 'health care' and 'physical care' rather than receiving all the help they needed or some of the help they needed.

Table 48: Professional help with caring tasks

	HELP FROM HEALTH OR SOCIAL CARE WITH PERSONAL CARE							
	TOTAL		**MND**		**MS**		**PD**	
Responses	*N*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
All help needed	185	10.3	51	12.3	75	11.1	59	8.3
Some of the help needed	184	10.2	58	14.0	63	9.3	63	8.9
None of the help needed	187	10.4	52	12.6	60	8.9	75	10.6
No help needed	1242	69.1	252	61.0	478	70.7	512	72.2

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Table 48 (continued): Professional help with caring tasks

	HELP FROM HEALTH OR SOCIAL CARE WITH HOUSEHOLD DUTIES							
	TOTAL		**MND**		**MS**		**PD**	
Responses	*N*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
All help needed	55	3.1	12	2.9	27	3.9	16	2.3
Some of the help needed	86	4.8	22	5.4	37	5.4	27	3.8
None of the help needed	347	19.2	81	19.9	130	18.9	136	19.3
No help needed	1315	72.9	293	71.8	495	71.8	527	74.6
	HELP FROM HEALTH OR SOCIAL CARE WITH HEALTH CARE							
	TOTAL		**MND**		**MS**		**PD**	
Responses	*N*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
All help needed	101	5.7	30	7.4	45	6.7	26	3.7
Some of the help needed	95	5.4	30	7.4	33	4.9	32	4.6
None of the help needed	183	10.3	43	10.6	63	9.4	77	11.0
No help needed	1394	78.6	302	74.6	527	78.9	565	80.7
	HELP FROM HEALTH OR SOCIAL CARE WITH PHYSICAL CARE							
	TOTAL		**MND**		**MS**		**PD**	
Responses	*N*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
All help needed	110	6.2	32	7.8	53	7.8	25	3.6
Some of the help needed	177	9.9	63	15.4	61	8.9	53	7.7
None of the help needed	266	14.9	68	16.7	88	12.9	110	15.9
No help needed	1230	69.0	245	60.0	481	70.4	504	72.8

Only a small number of carers had received any training, but the majority reported not needing any training (n=1199, 63.9%) (Table 49). However, over a fifth reported that they would like to have some training. An even smaller number reported having participated in the expert carer programme, and just over half of the carers (n=938, 50.3%) reported not being aware of this programme.

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Table 49: Carer training and carer expert programme

	RECEIVED CARER TRAINING							
	TOTAL		**MND**		**MS**		**PD**	
Responses	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
Yes, all training that was needed	85	4.5	23	5.4	37	5.2	25	3.4
Yes, to some extent	170	9.1	49	11.4	70	9.8	51	6.9
No, but would like some	422	22.5	114	26.6	146	20.5	162	22.0
No, don't need any	1199	63.9	242	56.5	459	64.5	498	67.7
	PARTICIPATED IN EXPERT CARER PROGRAMME							
	TOTAL		**MND**		**MS**		**PD**	
Responses	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
Yes	15	0.8	1	0.2	6	0.8	8	1.1
No, not aware of it	938	50.3	239	56.5	354	50.1	345	46.8
No	913	48.9	193	43.3	346	49.0	384	52.1

A total of 56.0% (n=966) of the respondents did not think that carer information is readily available. A larger number of MS carers (n=403, 62.0%) reported information not being easily available than MND (n=213, 53.3%) and PD (n=350, 51.9%) carers. The most commonly reported source of information was the neurological charity (n=893, 47.6%), particularly for MND (table 50). The specialist nurse and the consultant were the other two most commonly cited main sources of information. Nearly one fifth of the total sample did not feel they had a main source of information and the MS carers were more likely to report not having a main source of information. The average number of information sources cited was 1.7 (SD 1.3), and this was significantly higher ($p<0.001$) for MND carers (2.1 SD 1.4) than for MS (1.5 SD 1.3) and PD (1.9 SD 1.4) carers.

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Table 50: Main sources of information for carers

	TOTAL		MND		MS		PD	
Responses	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
Carers UK	115	6.1	21	4.9	46	6.5	48	6.5
CarersLine	32	1.7	8	1.9	11	1.5	13	1.8
Internet	306	16.3	60	14.0	139	19.5	107	14.5
Library	61	3.3	8	1.9	30	4.2	23	3.1
DVDs / videos	35	1.9	3	0.7	11	1.5	21	2.8
Neurological charity	893	47.6	258	60.3	286	40.2	349	47.4
Consultant neurologists	635	33.8	168	39.3	163	22.9	304	41.2
Specialist nurse	725	38.6	168	39.3	212	29.8	345	46.8
Other health or social care professional	401	21.4	166	38.8	114	16.0	121	16.4
Other	114	6.1	19	4.4	40	5.6	55	7.5
None	360	19.2	59	13.8	182	25.6	119	16.1

At the time of the survey, a total of 543 (29.7%) of the respondents were in paid full-time or part-time employment (including self-employment). The proportion of respondents in employment was the highest for MS (n=320, 45.3%), second highest for MND (109, 25.9%) and lowest in PD (n=124, 16.9%) carers. Some carers had given up work because of their caring responsibilities (n=395, 22.8%). The levels of giving up work were slightly lower for PD (n=122, 18.3%) than for MND (24.2%, n=94) and MS (26.4%, n=179).

Few carers (n=74, 14.1%) who were in paid employment reported having been given support by health or social care professionals to continue working. This level was similar in the three conditions. About a third (n=171, 31.3%) reported having reduced their working hours because of their caring tasks. This was reported more frequently by MND carers (n=51, 47.2%) than MS (n=84, 26.5%) and PD (n=36, 29.8%).

A little over half of the carers in paid employment reported that their employer knows that they are a carer (Table 51), with employers of MND carers being more likely to be aware of the caring role than employers of MS or PD carers. Some carers were given time off work to carry out caring tasks (n=202, 37.0%), or were given flexible

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work arrangements to suit their caring responsibilities (n=93, 17.0%), or flexible work arrangement 'to some extent' (n=108, 19.7%). About a quarter felt that they did not need to be given time off for caring tasks, and just under 40% felt that it was not necessary to be given flexible working arrangements.

Table 51: Carers support from and for employment

	DOES EMPLOYER KNOW THAT THEY ARE A CARER							
	TOTAL		**MND**		**MS**		**PD**	
Responses	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
Yes	304	56.3	71	67.6	164	52.2	69	57.0
No	109	20.2	13	12.4	68	21.7	28	23.1
Don't know	50	9.3	3	2.9	38	12.1	9	7.4
Self-employed	77	14.3	18	17.1	44	14.0	15	12.4
	BEEN GIVEN TIME OFF WORK TO CARRY OUT CARING TASKS							
	TOTAL		**MND**		**MS**		**PD**	
Responses	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
Yes	202	37.0	48	44.4	117	37.0	37	30.3
No	140	25.6	23	21.3	82	25.9	35	28.7
No, not needed to	134	24.5	17	15.7	80	25.3	37	30.3
No, self-employed	70	12.8	20	18.5	37	11.7	13	10.7
	BEEN GIVEN FLEXIBLE WORK ARRANGEMENTS TO SUIT CARING							
	TOTAL		**MND**		**MS**		**PD**	
Responses	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
Yes	93	17.0	24	22.0	44	13.9	25	20.3
To some extent	108	19.7	22	20.2	64	20.3	22	17.9
No, not necessary	218	39.8	34	31.2	129	40.8	55	44.7
No, but would like it	54	9.9	9	8.3	36	11.4	9	7.3
No, self-employed	75	13.7	20	18.8	43	13.6	12	9.8

As far as finances were concerned, 437 (24.0%) of carers reported receiving financial support from health and social services (Table 52). Just over 20% reported needing financial support, and a similar proportion of respondents reported not needing financial support. Approximately a third reported not to be eligible for financial

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support. A similar proportion of respondents found it very easy / easy versus difficult / very difficult to get financial support (table 51). The majority of the respondents felt that their finances had been affected 'to some extent' or 'to a large extent' because of their caring role. PD carers were less likely to report their finances having been affected 'to a large extent' in than MND and MS.

Table 52: Financial aspects of being a carer

	CURRENTLY RECEIVING FINANCIAL SUPPORT FROM HEALTH AND SOCIAL SERVICES							
	TOTAL		**MND**		**MS**		**PD**	
Responses	*N*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
Yes	437	24.0	131	31.0	149	21.7	157	22.1
No, don't need any	342	18.8	46	10.9	144	21.0	152	21.4
No, would like some	379	20.8	95	22.5	159	23.2	125	17.6
Application in process	20	1.1	10	2.4	4	0.6	6	0.8
Not eligible	642	35.3	141	33.3	230	33.5	271	38.1
	HOW EASY TO GET FINANCIAL SUPPORT							
	TOTAL		**MND**		**MS**		**PD**	
Responses	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
Very easy	45	2.5	16	3.8	18	2.6	11	1.6
Easy	268	15.0	77	18.5	88	12.9	103	14.9
Difficult	208	11.6	57	13.7	80	11.7	71	10.3
Very difficult	162	9.1	56	13.5	61	9.0	45	6.5
Did not apply	564	31.6	100	24.0	230	33.8	234	33.9
Not eligible	540	30.2	110	26.4	204	30.0	226	32.8
	EXTENT TO WHICH FINANCES HAVE BEEN AFFECTED BY CARING ROLE							
	TOTAL		**MND**		**MS**		**PD**	
Responses	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
Not at all	679	36.4	153	35.7	221	31.2	305	41.8
To some extent	829	44.4	176	41.1	317	44.8	335	46.0
To a large extent	358	19.2	99	23.1	170	24.0	89	12.2

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5.2.5.4 Health and well-being

Thirty-five percent (n=661) of the carers reported having a long-term illness or disability, with illness or disability more often reported by PD carers (n=290, 39.1%) than MND (n=138, 23.3%) and MS carers (n=233, 32.5%). The majority of the respondents (n=1454, 76.8%) had visited their GP in the last year, with only a very small number reporting not having had the time to go to their GP when necessary (Table 53). A total of 1221 (65.8%) of carers reported that their GP was aware of their caring role (Table 54). A higher proportion of MND carers (n=306, 75.2%) reported that their GP knows that they are a carer than MS (n=421, 60.1%) and PD carers (n=494, 67.3%).

Table 53: Carer GP visits in the last 12 months

	TOTAL		MND		MS		PD	
	n	*%*	*n*	*%*	*n*	*%*	*n*	*%*
Yes	1454	76.8	308	71.8	541	75.8	605	80.6
No, have not needed to	408	21.5	112	26.1	160	22.4	136	18.1
No, wanted to, but no time	28	1.5	9	2.1	9	1.3	10	1.3
Not registered with GP	4	0.2	0	0	4	0.6	0	0

Table 54: GP awareness of caring role

	TOTAL		MND		MS		PD	
	n	*%*	*n*	*%*	*n*	*%*	*n*	*%*
Yes	1221	65.8	306	75.2	421	60.1	494	67.3
No	284	15.3	56	13.3	122	17.4	106	14.4
Not sure	351	18.9	60	14.2	157	22.4	134	18.3

The majority of the sample (n=253, 68.6%) reported being able to participate in social activities 'to some extent', and about 16% were either able to participate as much as they would like to in social activities or not able to participate at all. MND carers (n=72, 22.9%) were more likely to report not being able to participate at all than MS (n=50, 14.1) or PD carers (n=60, 16.3%) (Table 55). Support to allow a break from caring was reported to be mainly given by family of friends (n=491, 47.4%), with support to taking a break being provided less frequently by health or social care

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services (table 55). About a quarter did not feel that they needed a break, and about 10% reported that they had not had a break, but felt that they needed one.

Table 55: Carers' participation in social activities and ability to take a break from caring

	ABLE TO PARTICIPATE IN SOCIAL ACTIVITIES							
	TOTAL		**MND**		**MS**		**PD**	
Responses	*N*	*%*	*n*	*%*	*n*	*%*	*N*	*%*
As much as I would like	167	16.1	46	14.6	65	18.3	167	16.1
To some extent	253	68.6	197	62.5	240	67.6	690	66.4
Not at all	60	16.3	72	22.9	50	14.1	60	16.3
	SUPPORT THAT HAS ALLOWED BREAK FROM CARING							
	TOTAL		**MND**		**MS**		**PD**	
Responses	*N*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
Day care facility	134	12.9	40	12.8	26	7.3	68	18.5
Residential / nursing home care	97	9.4	19	6.1	35	9.9	43	11.7
Carers organisations	78	7.5	24	7.7	17	4.8	37	10.1
Care vouchers	14	1.4	6	1.9	4	1.1	4	1.1
Paid carer	152	14.7	39	12.5	68	19.2	45	12.2
Hospice	59	5.7	43	13.7	10	2.8	6	1.6
Volunteer from other sources	30	2.9	10	3.2	8	2.3	12	3.3
Family or friends	491	47.4	156	49.8	161	45.4	174	47.3
Other	40	3.9	7	2.2	17	4.8	16	4.3
None, but would like a break	111	10.7	29	9.3	33	9.3	49	13.3
None, not needed a break	252	24.3	76	24.3	90	25.4	86	23.4

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5.2.5.5 Relationships between carer health status and experiences of health and social care

Relationships were examined between carers' health and aspects of their reports of services. For those who had received a carer assessment, a summed score of problems was created. Problems with the carer assessment were significantly related to carer health status, specifically for the carers' MCS scores in the total sample and amongst carers of an individual with either MS or PD (Table 56). A second summed score recorded the number of problems reported with obtaining help from services for caring tasks. Carers reporting more problems obtaining help with caring tasks had significantly poorer PCS, MCS and CSI scores, both in the total sample and for each of the three conditions.

Table 56: Relationship between carers' problems in relation to services and health status (adjusted for age, gender, length of time as a carer, and time spent caring)

Physical Health Status (PCS)												
Quality of the carer assessment (carers who have had an assessment)												
Score	**TOTAL**			**MND**			**MS**			**PD**		
	N	Mean	SE	N	Mean	SE	N	Mean	SE	N	Mean	SE
0	82	46.11	1.46	22	41.88	2.88	24	50.25	3.25	36	42.06	2.93
1	139	48.90	1.22	38	49.95	2.10	52	50.16	2.62	49	42.60	2.89
2	47	46.70	1.82	13	45.79	3.59	14	51.47	3.68	20	40.09	3.48
3	25	45.21	2.47	9	47.85	4.22	9	40.59	4.29	7	43.97	5.29
Help with caring tasks												
Score	**TOTAL *****			**MND *****			**MS ***			**PD *****		
	N	Mean	SE	N	Mean	SE	N	Mean	SE	N	Mean	SE
0	976	49.13	0.41	192	49.63	0.89	397	48.72	0.82	378	47.09	0.84
1	167	46.58	0.85	39	44.87	1.76	76	47.71	1.37	52	44.19	1.63
2	105	46.48	1.07	35	47.16	1.83	28	45.26	2.13	42	44.11	1.79
3	66	43.02	1.34	18	40.72	2.53	26	44.45	2.17	22	40.40	2.46
4	151	44.42	0.91	41	45.60	1.72	53	43.93	1.58	57	41.33	1.62
Mental Health Status (MCS)												

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Table 56 (continued): Relationship between carers' problems in relation to services and health status (adjusted for age, gender, length of time as a carer, and time spent caring)

Quality of the carer assessment (carers who have had an assessment)												
Score	**TOTAL ****			**MND**			**MS ***			**PD ***		
	N	Mean	SE	N	Mean	SE	N	Mean	SE	N	Mean	SE
0	82	43.88	1.53	22	37.90	3.31	24	48.31	3.49	36	45.54	2.77
1	139	41.01	1.27	38	38.19	2.41	52	44.32	2.82	49	38.85	2.74
2	47	40.19	1.90	13	40.32	4.13	14	39.40	3.95	20	39.39	3.30
3	25	34.07	2.58	9	38.45	4.85	9	35.18	4.61	7	34.66	5.02
Help with caring tasks												
Score	**TOTAL *****			**MND *****			**MS *****			**PD *****		
	N	Mean	SE	N	Mean	SE	N	Mean	SE	N	Mean	SE
0	967	46.47	0.39	192	47.31	0.90	397	47.53	0.79	378	45.93	0.79
1	167	43.34	0.82	39	43.04	1.77	76	44.28	1.31	52	42.02	1.53
2	105	39.36	1.03	35	38.23	1.85	28	38.78	2.04	42	41.50	1.69
3	66	37.38	1.29	18	36.64	2.54	26	40.23	2.08	22	36.03	2.32
4	151	39.26	0.88	41	39.01	1.73	53	40.29	1.53	57	39.13	1.53
Carer burden (CSI score)												
Quality of the carer assessment (carers who have had an assessment)												
Score	**TOTAL**			**MND**			**MS**			**PD**		
	N	Mean	SE	N	Mean	SE	N	Mean	SE	N	Mean	SE
0	79	13.85	0.68	23	14.47	1.34	24	13.67	1.65	32	12.07	1.32
1	121	15.26	0.58	35	17.41	1.07	46	13.57	1.42	40	13.50	1.22
2	42	15.21	0.88	10	16.22	2.02	14	14.33	1.93	18	13.32	1.34
3	25	16.92	1.13	9	16.47	2.05	9	14.38	2.25	7	16.13	2.05
Help with caring tasks												
Score	**TOTAL *****			**MND *****			**MS *****			**PD *****		
	N	Mean	SE	N	Mean	SE	N	Mean	SE	N	Mean	SE
0	935	11.26	0.20	193	12.45	0.44	387	10.13	0.42	355	10.18	0.37
1	162	13.88	0.41	41	14.56	0.85	76	13.09	0.70	45	12.99	0.75
2	101	15.54	0.52	34	16.10	0.94	25	13.86	1.13	42	14.57	0.77
3	61	16.54	0.67	17	16.82	1.28	27	15.17	1.07	17	15.35	1.19
4	141	17.05	0.45	42	18.22	0.86	53	15.83	0.79	46	16.17	0.76

* $p \leq 0.05$** $p \leq 0.01$ *** $p \leq 0.001$

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5.2.6 Patients' and carers' health status

The relationship between patients' and carers' health status was examined (table 57). The majority of the correlations for patient and carer health status were statistically significant both for the total sample and for the individual conditions. However, the majority of correlations were weak. Some moderate and significant correlations were found mostly between carer MCS and CSI scores (for total sample and for the different conditions). Negative correlations were found between generic health status (PCS and MCS) and patient disease-specific health status, and generic health status and carer burden (CSI). This negative correlation is due to generic health status with a higher score reflecting better health, whereas a higher score on the disease-specific health status measures and the CSI indicates a less good health status.

Table 57: Correlations of patients' and carers' health status

		Carer PCS	Carer MCS	CSI
TOTAL SAMPLE	Patient PCS	0.11**	0.09**	-0.29**
	Patient MCS	0.12**	0.32**	-0.37**
MND	Patient PCS	0.13*	0.001	-0.24**
	Patient MCS	0.11	0.38**	-0.40**
	ALSAQ	-0.12*	-0.30**	0.47**
MS	Patient PCS	0.11*	0.09*	-0.28**
	Patient MCS	0.11**	0.26**	-0.37**
	MSIS	-0.12*	-0.26**	0.53**
PD	Patient PCS	0.16**	0.13**	-0.34**
	Patient MCS	0.12**	0.36**	-0.41**
	PDQ	-0.16**	-0.31**	0.56**

* p<0.05, ** p<0.01, *** p<0.001

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6 Discussion

The discussion of the results will in part be structured in terms of the Quality Requirements of the NSF for Long-Term Conditions that prompted the survey. However, the survey results do not perfectly map onto the Quality Requirements for a number of reasons. Firstly, Quality Requirements in relation to emergency and acute management (QR 3) and Early and Specialist Rehabilitation (QR 4) relate primarily to services for severe brain injury and are less relevant to the three progressive disabling conditions involved in the current survey. Secondly, it did not seem feasible or appropriate to address in any depth the issues of palliative care for individuals nearing the end of their life in our survey. Thirdly, some issues were seen by our advisory group of patients and carers as requiring greater attention than was given by the NSF, for example issues surrounding financial problems and help. Finally, some difficulties of exact mapping arise from the very broad language of much of the NSF with particular issues addressed being relevant to more one than one QR. With these caveats, the Quality Requirements are used as a loose framework for considering the results of the survey. It should be noted that it was decided that QR10, supporting family and carers, would be addressed through the questionnaire to carers. It will be separately discussed after the implications of the survey for other QRs.

6.1 Person-centred service (QR1)

This is by far the broadest of the Quality Requirements setting out aspirations for services in a wide range of areas. The QR for a person-centred service underpins all other QRs.

Almost the entire sample (95%) was in contact with a health professional about their neurological condition in the year before the survey. Not surprisingly they were most likely to have consulted a hospital specialist, followed by their GP, followed by a specialist nurse. Timely access is an important requirement of the NSF. A majority of the sample reported no difficulties of seeing a health or social care professional. Amongst those reporting a difficulty, it was more likely to be in relation to seeing a consultant, a specialist nurse or physiotherapist.

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At the heart of person-centred care in the NSF is an emphasis on integrated care with such an approach being the key to improving the quality of life of individuals with long-term neurological conditions. Given the importance of this central feature of services it was an important challenge to the survey to find reasonable ways of capturing respondents' experiences of integration of services. The NSF identifies two specific 'evidence-based markers of good practice for QR1' that could be reasonably explored with respondents: having a named point of contact and a named individual who coordinates services. Fifty three per cent of respondents had an assigned and named professional that they felt that they could contact. Thirty-six percent of the sample also felt that there was a single health or social care professional who coordinated their care. In addition, a third general question was asked to elicit respondents' impressions of integration. In answer to the question whether respondents felt that different health and social services work well together in relation to planning their care, an even distribution of answers across response categories resulted but with only 24 per cent replying 'yes'. The divided pattern of views is consistent with preliminary evidence of an evaluation of integration of services for long term neurological conditions that considers progress towards integration 'patchy and slow' (85).

One of the main ways in which integrated services are to be achieved is by producing a personalised care plan for each individual with a long term neurological condition. Care plans are to be offered to everyone with a long term condition with the intention that complete coverage will be achieved by 2010. The plan is an agreement between the individual with a named lead professional, identifying an agreed personal package of needs, goals and services. The sample were given a brief explanation of what was meant by a care plan and asked whether they were aware of having one. Only 22% of the sample were aware of having a care plan. However, of those who did have a care plan, three quarters felt that their care plan was kept up to date. Although there may be ambiguities as to what constitutes a care plan and varying levels of awareness of the existence of coordinated plans, it is clear that there is a major challenge to move toward all individuals being fully aware of a care plan in which they have been actively involved.

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Two more general questions elicited respondents' broader sense beyond the formalities of the care plan, of being actively involved in decisions about their care. Only 40% responded with a clear positive that they were as involved as they would like in making decisions with professionals about their care and a similar proportion felt that their wishes and preferences were clearly taken into account by professionals in planning their care. This pattern of results is consistent with the evidence of a recent survey of individuals with multiple sclerosis of whom only 54% felt that NHS staff had involved them in clinical decisions on treatment as much as they wanted (86). The NSF was not particularly prescriptive about goals in relation to shared decision making although it acknowledged that most patients would want to be involved in decisions and share responsibility with staff. Furthermore, shared decision making may be considered central to broader aspirations regarding choice and personalised services.

Successful care planning is intended to result in better recognition of patients' needs. It therefore seemed reasonable and appropriate to ask the sample whether they felt various professionals understood their needs. Given that respondents interact with a very large number of service providers, some grouping of service providers was essential. With an analysis of responses (Table 28) excluding those who chose 'not applicable', the rates of fully positive responses indicate a mixed picture with between 60% and 40% of the sample rating professionals as understanding of their needs in relation to neurological conditions; hospital consultants receiving the highest proportion of positive responses (60%) and social services the lowest (40%). The lower rate of positive responses in relation to social services is further explored with other questions in the survey, for example regarding help with personal care, and equipment and aids in the home.

The majority of the sample was currently receiving a prescribed medication for their neurological condition. A very high proportion of respondents (94%) felt they were given enough information about how and when to take their medication. The NSF cited evidence that approximately 50% of medications for long term conditions are not taken as prescribed and that patients' preferences and beliefs about medicines have a large effect on adherence to recommendations about use. Whilst the sample felt satisfactorily informed about how to take prescribed medicines, there were more

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respondents (27%) who did not feel that they received information about possible side effects. Moreover 39% of the sample felt that their medication was not adequately reviewed. The Parkinson's Disease Society identified need for regular medication review as a result of its 2007 survey of members (87). The NSF considers access to regular medication review to be good practice but does not further define 'regular'. Further issues remain to be resolved as to responsibilities in services for medication review.

The NSF was supportive of self management programmes as a way of enhancing patients' skills and confidence to cope better with their conditions. The Expert Patient Programme (EPP) was developed as specific initiative to improve the confidence and skills of individuals with long-term conditions. In the current survey only 27% of respondents felt that they had definitely been given support by health and social care professionals to develop self-management strategies. Individuals with neurological conditions have not been found to be frequent attenders of EPP (88). The programme was originally developed to support individuals with musculoskeletal conditions and may not appeal or seem so relevant to individuals with long-term conditions. There may also be a less developed evidence base for self-management interventions for neurological conditions, compared to, for example, for arthritis and diabetes. Self-management would not yet appear to be a clearly provided element of services for the neurological conditions in the current survey.

6.2 Early recognition, prompt diagnosis and treatment (QR2)

This QR requires that individuals suspected of having a neurological condition should have prompt access to specialist expertise to provide accurate diagnosis and treatment. It was unclear how helpful it would be to examine this aspect of respondents' experiences given that some considerable time would have elapsed between the time of diagnosis and responding to the survey. In this survey, 65% of respondents had received their diagnosis at least 5 years prior to the survey. However, it was very clear from the qualitative interviews and advice from the patients in the Research Advisory Group that experiences surrounding diagnosis remain salient for respondents and an attempt should be made to ask about experiences of diagnosis in the survey.

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Of those who could provide an estimate, 66% reported that the time between first seeing their GP for their neurological condition and seeing a hospital specialist was less than 6 months, whereas for 34% the period was 6 months or longer. Respondents were also asked to estimate how long the period was between the first consultation with their GP and receiving a definite diagnosis from the specialist. Taking out of the denominator those who were not sure or did not feel they had a definite diagnosis, 65% of respondents reported a period of a year or less before they received a definite diagnosis and 35% reported a period of at least a year.

This early period leading up to diagnosis was also examined in a large scale survey of patients with Parkinson's disease (87) which suggested that more recently diagnosed patients are seen more promptly by the neurologist than those diagnosed ten years or more prior to the PDS survey, with 87% of respondents waiting three months or less from being referred to actually seeing the specialist. Our survey addresses a slightly different issue, the overall period of being seen and assessed by the GP for what eventually emerges as a neurological condition without seeing a specialist. For a third of the sample this period was six months or longer. It is impossible to say to what extent any of the long waiting times reported were unnecessary given the complex ways in which neurological symptoms appear and are presented and difficulties for GPs of determining when to refer. GPs typically have small numbers of patients with conditions such as MS or MND on their practice list so that experience may be harder to gain in appropriately recognising and managing symptoms. Ways of addressing any under-referral or late referral for neurological symptoms include improved training of GPs and use of telehealth; however, as in many other aspects of services for neurological conditions, good evidence for such interventions is lacking in the NSF or the update reviews informing the current survey.

Given the great significance of a diagnosis and potentially distressing responses to its receipt, it is understandable that the NICE Guidelines for MS (53) recommend that patients receive a further appointment, ideally with the same doctor. It is noteworthy that nearly one third of the sample (table 20) reported that they did not have such a follow-up appointment but would have liked one. This may be related to the finding that the majority of respondents felt they had not received all the information that they wanted at the time of diagnosis.

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6.3 Community rehabilitation and support (QR5)

This QR is intended to enable and support people with long term neurological conditions to lead a full life in the community. To some extent the boundaries between this QR and person-centred service (QR 1) and providing personal care and support (QR 8) are difficult to determine, particularly viewed from questions that can be addressed through a survey. Thus, some aspects of community rehabilitation and support have already been discussed under person-centred care (QR1) and some topics are considered later in relation to personal care and support (QR8). An additional challenge was that the concept of rehabilitation (and specific examples of rehabilitation received) was not very familiar either to participants in the qualitative interviews or to the patients who were members of the Research Advisory Group. The term 'rehabilitation' was seldom used and it proved difficult to find more accessible ways of describing experiences from services that may have been intended to rehabilitate. The survey results only indirectly inform regarding experiences of community rehabilitation. Aspects of vocational rehabilitation are separately discussed in relation to QR 6, Vocational Rehabilitation, below.

As already noted, respondents were in contact with a diverse range of service providers in the year before the survey, most commonly the hospital specialist, the GP and the specialist nurse (Figure 2). The only service providers commonly described as having been difficult to access when the respondent wanted to were the hospital consultant (11%), the specialist nurse (8%) and the physiotherapist (7%). There is some evidence supportive of effectiveness of physiotherapy interventions for MS and PD (89;90) and it is this service that seemed most problematic of rehabilitation services for the sample to access.

Mention has already been made of the low proportion of respondents who report help with self-management. Respondents were also asked about help received from services in relation to nutrition. It needs to be acknowledged that nutrition may play distinct and different roles in the management of the three conditions. Nevertheless nutrition is identified as a responsibility in guidelines for rehabilitation for neurological conditions (91). It is interesting that whilst half the sample felt no need for help or support with nutrition, the remaining half were almost equally divided

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between respondents who received this form of support (24%) and who did not and would have liked such support.

Providing social care support is referred to in relation to this QR and QR 8 (Providing personal care and support). Evidence from the survey is discussed here. Respondents were asked about whether they been offered help from health and social services in two areas, housework and personal care (dressing, washing, eating). In relation to housework, the vast majority (79%) either did not feel they needed help or received help from other sources. Of the remaining respondents, just over half (52%) had not been offered help from services and would have liked it. Similarly, in relation to personal care, 76% of the sample either did not feel they needed help or received help from other sources. Of the remaining respondents, 16% had not been offered help and would have liked help.

The survey by Parkinson's Disease Society addresses some similar issues of personal care in its survey (87). About a fifth of their sample were receiving help from formal services for housework (22%) and personal care (such as dressing, bathing) (21%). The PDS were surprised with the low proportions (9% and 5% respectively) who said they did not receive the service and needed it. They speculate that this may be because informal carers provide this form of support or respondents are unaware of the existence of support from formal services. It would seem that access and uptake of these aspects of care is uneven with many individuals with long term conditions receiving personal care from services but a significant minority needing and not receiving support.

A minority of the sample may have received some rehabilitation as part of hospital admission. Fifteen per cent of respondents reported being admitted to hospital specifically for their neurological condition in the twelve months prior to the survey. Of this group, 59% felt their needs in relation to their neurological condition were met; the remainder feeling needs were not met at all or only to some extent.

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6.4 Vocational rehabilitation (QR6)

In QR 6, the goal is stated to enable people with long-term neurological conditions to work. It was decided that respondents would be asked about their experiences in this area if they had worked in a three year period prior to the survey, longer time periods being harder to remember. Less than a quarter (23%) of the sample had been in paid employment in this period. Only a minority had received any formal support from services to help them to stay in work, specifically receiving an assessment of how their neurological condition affects work (20% of those who had worked), and smaller proportions receiving support for work from an occupational therapist, or receiving specific guidance about staying in work or restarting work. A few respondents said they wanted support in relation to these items. It is possible that this is due to lack of awareness of such services. It is worth noting that examples of good practice cited for this QR tend to focus on specific groups such as individuals recovering from brain injury. Late onset of other neurological conditions may not encourage development of more generic services. Further research is being conducted into vocational rehabilitation services for neurological conditions under the current research initiative because services are considered under-developed.

6.5 Equipment and accommodation (QR7)

This QR sets the goal to provide individuals with long term neurological conditions with appropriate equipment and adaptations to their accommodation to support independence and choice.

Respondents were asked about 20 different types of equipment that they might need, specifically being asked whether they had any difficulties in obtaining any of the equipment from health or social services. Eighty per cent of the sample either did not need to get the equipment form health or social services or reported no difficulties in obtaining equipment. No items seemed to cause problems for many respondents. Forty nine per cent of the sample reported modifications to their current accommodation arising from their neurological condition. Of this group of respondents, 12% reported not receiving financial support that they needed from services for modifications to accommodation. The survey by the Parkinson's Disease

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Society (87) reported that one in ten respondents had needed but not received professional advice about housing adaptations. The Neurological Alliance (http://www.neural.org.uk/living-with-a-neurological-condition/services#whatservices) point out that currently aids, equipment and adaptations for the home are provided by a range of different sources, rather than through one point of contact. The current survey seems to indicate that for the majority of respondents obtaining equipment is not a major problem. Issues such as timeliness, flexibility and ease of use of equipment were considerably beyond the scope of this broadly focused survey to explore. For example, patients (both in the interviews and RAG members) reported buying items themselves because they did not know that the equipment is available on the NHS or because they felt it might take too long to get the equipment through the NHS/ social services. Some patients also said they bought their own equipment as they could afford to do so. These issues are probably too complex to explore in a broadly focused survey, and this may be an area for future, more specific, research.

6.6 Providing personal care and support (QR8)

This QR is concerned with the goal of ensuring that individuals with long-term neurological conditions are able to choose where and how they live. Responses to questions about help received with personal care have already been discussed in relation to community rehabilitation and support. The sample was also asked about being offered respite care (Table 33). Three quarters of the sample did not need consider that they needed respite care. Nine per cent of respondents had been offered and used respite care and a similar proportion (10%) had not been offered respite care and would have liked some.

Three quarters of the sample described themselves as in receipt of financial support such as disability allowance in relation to their neurological condition. Only 6% reported not having received financial support but wanting such support.

Only a small number of respondents indicated that they experienced problems in accessing respite care and obtaining financial support, such as disability allowance. Nevertheless, neurological conditions clearly impacted on respondents' finances. Almost three quarters of the sample felt their personal finances had been negatively

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affected to some extent or a large extent by their neurological condition. Similarly, the PDS Survey (87) report one third of the sample 'just getting by' financially.

6.7 Palliative care (QR9)

It was not thought likely that the current survey would reach respondents in receipt of palliative care. There was also a concern shared by the research team and the Research Advisory Group that an extended section of questions about palliative care would be distressing to a sample likely to have more positive health status. Only one question was included: whether respondents had been offered hospice care. As predicted, 92% had not been offered hospice care and did not consider that they needed it. However 4% did report being offered and using hospice care and 3% were not offered hospice care and would have liked to be offered it.

6.8 Caring for people with neurological conditions in hospital or other health and social care settings (QR11)

QR11 requires that individuals with neurological conditions should receive appropriate care for their neurological condition when receiving hospital or other forms of care for other problems. Admissions to hospital for the neurological condition have already been discussed above (QR5 Community Rehabilitation and Support). In relation to hospital admission unrelated to their neurological condition, 20% reported that they had been in hospital in the previous twelve month period. It is striking that in this group, 28% felt that needs in relation to their neurological condition were met 'to some extent' and 26% felt that their needs had not been met. The NSF suggests a variety of ways in which this broad and difficult problem might be addressed, ranging from getting care managers to ensure that patients' neurological conditions are appropriately made known when patients are admitted to in-patient care, through to strengthening access to specialist neurological expertise in non-neurological hospital services.

6.9 Health-related quality of life and experience of services

The SF-12v2 results show that health-related quality of life was worse than normative data of the general adult population, for the sample as a whole and also for all three

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neurological conditions. While both Physical Component Scale (PCS) and Mental Component Scales (MCS) scores were worse than normative data, the differences were far greater for the PCS. This evidence is consistent with another UK study using SF-36 to compare individuals with MS or PD with normative data (92). Riazi and colleagues found that both scores were poorer for both neurological conditions across all dimensions of SF-36 but differences were less for mental health.

In order to examine the relationship between health-related quality of life and experiences of services in the sample, a number of service problem scores were created (described above in methods) summing the number of problems or negative experiences respondents reported for a number of different areas of services. Analyses were then performed to examine whether there were differences in SF-12v2 scores for respondents reporting varying numbers of problems or negative experiences with services, adjusting for age, gender and duration of time with a neurological condition. The results consistently show that individuals experiencing more problems or negative experiences with services had poorer health-related quality of life scores for both dimensions of SF-12v2. This pattern is also fairly consistent across the three neurological conditions.

Similar analyses conducted between experiences of services with the three condition-specific health-related quality of life instruments for the three separate conditions were very consistent with the pattern of results from SF-12v2. Poorer reports of service experience were consistently associated with poorer health-related quality of life assessed with condition-specific measures, controlling for age, gender and time since the condition had been diagnosed.

Other studies have found similar associations between health status or health-related quality of life and patient experience of services (93-95). It is difficult to determine the causal direction between variables. Poorer experience of services may negatively impact upon health-related quality of life. However, there are several mechanisms whereby poorer health-related quality of life could result in poorer experience of services. Furthermore, other variables, for example, cognitive biases or depression, might also be responsible for the observed associations with no direct causal link between them.

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In policy terms, whilst it may not be possible to unravel causal connections it is clear that poorer experiences of services and poorer health-related quality of life are closely and consistently associated across the three neurological conditions. It is highly likely that efforts to improve services along the lines set out by the NSF will result in improved quality of life. At the very least targeting the specific areas of services high-lighted by the NSF quality requirements, and identified by the current survey as less well progressed, will also target those individuals with neurological conditions reporting poorer health-related quality of life.

6.10 Carers

The NSF (QR 10) requires that carers of individuals with long-term conditions should have appropriate support and services both in their role as carers and in their own right. It refers to the Carers Act 2004 being implemented in 2005, and requiring that local authorities inform carers of their right to an assessment. A National Strategy for Carers (1999) (96) high-lighted the needs of carers as a priority. Additional emphasis on the needs of carers were provided by Our Health Our Care Our Say (2007) (63) and the New Deal for Carers (2008) (97) and the setting up of a Standing Commission for Carers to monitor and advise in relation to the national strategy. Following a review of the National Strategy on Carers, a more recent policy document, Carers at the heart of 21st-century families and communities (2008) (98), sets out a more detailed short term and long term vision for the future care and support of carers. Some aspects of the vision are not expected to be in place until 2018. Amongst the more immediate commitments, over the period 2008-11, are provision of more breaks for carers funded from public money, pilots to improve support from the NHS to carers, public funds to enable carers to combine paid work and caring and improvements from services in their provision of emotional support to carers. The current survey of carers took place when these policy commitments were only just being expressed and at the earliest stages of being implemented.

Carers in the current survey were more often women except in the case of individuals with multiple sclerosis where the majority of carers were men. They typically described themselves as having been a carer for more than five years, although for a somewhat shorter period for carers of MND. For the majority caring tasks required twenty hours or more a week, and majorities of carers reported regularly carrying out

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personal care (such as dressing and washing), physical care (such as moving or lifting), household tasks (such as cleaning and shopping), and health-care (such as administering medications or other treatments).

Carers were asked about whether services were aware of their caring role. Although a majority felt their GP was aware of their role as carer, 34% either felt the GP did not know or were unsure. In current policies, the GP has a key role in mobilising services and support for carers and an important focus of current pilots in the NHS is to improve GPs' awareness of and role in supporting carers. To date GPs involvement in the care of carers has been somewhat limited and reactive (99).

It is a goal of the NSF that, because of the growing availability of alternative sources of care in addition to themselves, carers should be able to choose how much caring they do rather than being constrained or obliged to fulfil caring tasks. However fewer than half the sample of carers had ever had a discussion about the amount of caring they undertook. The carer assessment is a specific mechanism whereby carers' needs are identified, discussed and addressed by social services and carers have specific entitlements to an assessment. Having been given a brief explanation of a carer assessment, only 21% of respondents reported having received one. However 44% felt they did not need one. Twenty three per cent had not received an assessment and would have like one, a similar proportion to the number who had received an assessment. Some caution is required; for example, 12% were unsure whether they had had a carer assessment. Nevertheless it would appear that assessments are still unevenly made available to carers.

The NSF makes recommendations about how the care assessment should be delivered, for example, providing a specific contact person and providing a written report. A majority of those who received a care assessment were given a specified contact person and 45% received a written plan. Asked to judge the value of their care plan, of the group who did receive a carer assessment only one third found it definitely helpful. Other research has high-lighted the limited impact of the carer assessment arising from, for example, professionals concerns not to raise carers' expectations of services (100). It is noticeable that, in this sample, there did not appear to be very high levels of expectations about help that might be obtained from services. Two thirds to three quarters of the sample described themselves as not

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needing help with various caring tasks, ranging from dressing and washing to lifting, moving the person cared for. On the other hand between 10% and 19% described themselves as having received none of the help they needed for various caring tasks.

A large number of respondents (46%) felt that health and social services had provided them with equipment to help with caring tasks. Sixteen per cent felt they were in need of equipment to support their caring tasks.

Respondents were asked about other forms of support. Small numbers of respondents had received breaks from caring that may have arisen through formal services; more often breaks were made possible informally through family or friends. Eleven per cent described themselves as not having had a break from any source and needing one. Specific funding has now been made available to provide breaks for carers since the current survey was conducted. This should mean that suitable breaks are more readily available than was the case at the time of our survey.

Information for carers is supposed to be readily available; a majority did not feel that information for carers was easily available. Caring with Confidence was initiated around the time of the current survey – a programme to provide carers with knowledge and skills in relation to caring tasks. The survey did ask about participation in the programme; 1% had participated but it would not be appropriate to judge the programme from this data because of the timing of the survey. Respondents were asked more generally about training for caring tasks. Five per cent maintained that they had received the training they needed. However a much larger number 23% felt they needed some training and had not received any.

Carers were asked some general questions about their experiences of health and social care professionals in relation to caring. Asked about being as involved in planning the care recipients' care as much as wanted, a majority of those who felt the question applicable answered only 'to some extent' or 'no'. Over one third of respondents did not feel their knowledge and experience as carers was recognised and valued.

Overall the very clear, strong and consistent policies over recent years to prioritise carers' needs are very striking, although timelines to implement policies have been long-term. Policies have been broad and have identified the wide range of forms of care and support that may be relevant. There is much evidence from the current

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survey of carers receiving specific services although significant numbers reporting themselves in need of services but not receiving them. It will be very important to see to what extent Carers at the heart of 21st-century families and communities (2008) (98) will further improve services to support carers.

As found in other studies, the health of carers was lower than population norms or non-carers (101;102). In terms of SF-12v2 scores, physical health was a little lower than norms for the instrument but mental health was much poorer. As with patients, a number of pragmatic scores were produced of problems with services experienced by carers and higher problem scores were associated with poorer health status.

As noted in other studies of long-term neurological conditions (103), there were modest but significant correlations between the health status of patients and that of their carer. The strongest association was found between poorer mental health on the part of the individual with a long-term condition with poorer mental health reported by the carer. The evidence of relationships between care recipients and the health and well-being of carers is complex. In a meta-analysis of the evidence the strength of the impact of care recipients' problems upon their carers' health was not consistent or very strong (104). There is specific evidence in relation to long-term neurological conditions indicating that the care recipients' health negatively effects carers' health status (105;106). This body of evidence is helpful in suggesting that, whilst the distinct and different needs of patient and carer need to be separately addressed, effective support may well positively impact on both patient and carer.

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7 Conclusions

The NSF for Long-Term Neurological Conditions, published in 2005 was one of a series of policy documents setting out standards for services for different areas of healthcare. It differed in a number of important respects from preceding NSFs placing greater emphasis on broader goals and outcomes, rather than specific quantitative processes, drawing more strongly on the inputs and preferences of users of services and drawing on a broader evidence base of evidence and methods of assessing evidence than the 'goal-standard emphasis upon sources such as RCTs central to previous NSFs (107). A ten year time period was identified for health and social care services to respond to and implement the NSF taking account of local circumstances. Given the distinctive form of the NSF, with its emphasis upon users' views and values and its reliance on a broader range of observational evidence, it was appropriate that one element of the research programme initiated by the Department of Health should be a survey of experiences of services of individuals with selected long-term conditions and of their carers.

Rather than address the full range of neurological conditions, an unrealistic goal within one study, it was decided to focus on three neurological conditions, motor neurone disease, multiple sclerosis and Parkinson's disease, that were an important numerical sub-group of all neurological conditions considered by the NSF with sufficient features of their condition similar to warrant a common approach. From the outset it was clear that the current study had to address several key methodological challenges. The first and most difficult to address was how to obtain a sample of respondents that would sufficiently represent the population of individuals with the three conditions. Options considered for sampling frames included hospital records, GP records and memberships of neurological charities. It was decided that neither hospital nor GP records would provide accurate records of relevant individuals and would also pose difficulties of feasibility of recruitment within a reasonable time-frame. Preliminary discussions with the three main relevant charities: the MND Association, MS Society and PD Society indicated their support and willingness to collaborate with the project. This collaborative approach, combined with greater likelihood of delivery resulted in recommending a sampling approach based on

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memberships of the three charities. It has to be recognised that it is impossible to estimate how the three charities' memberships would differ from the overall populations of individuals with the conditions and what biases may operate in the results of the survey. It is, for example, difficult to estimate the extent to which less disabled and less socially excluded individuals were more likely to participate.

It is of interest that the National Centre for Social Research (NatCen) began to plan a similar survey for the HealthCare Commission of a broader range of neurological conditions soon after the current project commenced. In 2009 they published the results of their consultation processes and deliberations about sampling options (108). They ruled out primary care records as being too patchy and not feasible to use. They considered charities' memberships and ruled out this mechanism, largely on grounds that memberships were likely to comprise such a low proportion of the total population that they were likely to be unrepresentative. However it is noticeable that their own discussion suggests that coverage for some charities such as MND Association might be quite high. It is also important to note that NatCen's preferred mechanism of recruitment, via hospital specialist centres, was rejected by ethics review as likely to produce unrepresentative results, so that, to date, no further progress has occurred to conduct a survey. Thus whilst fully recognising potential unknown biases in the chosen method of sampling, the current study did identify a feasible method that could be pursued in order to engage with a large number of individuals about their experiences with services.

The additional problem was that we received returned questionnaires from 49% of individuals with one of the three conditions of the whole target sample of 5209 individuals. Although an improvement on the pilot response rate, and not markedly different from response rates to other NHS health surveys, this is an additional ground for caution in interpreting the results of the survey.

The second methodological challenge was how to determine the content of the survey. The NSF is remarkably broad in its scope, covering all aspects of health and social care that might impact on neurological conditions. There were few if any precedents of survey evidence on which to draw, in determining the focus of the survey. Furthermore it was agreed that excessive length would jeopardise the response rate. Topics to be included emerged from a process described above in the methods

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section, working form content analysis of the NSF and further research evidence post-NSF, issues identified in qualitative interviews with patients and carers and then a long iterative process of drafting items and versions of the questionnaire in discussion with the Research Advisory Group of individuals with one of the conditions and carers. The resulting survey was then piloted and further refined in the light of pilot results before reaching its final version. Whilst very broad in its coverage, most issues had to be dealt with through small numbers of items, and certain topics were not addressed at all, for example, access to appropriate transport.

They survey was conducted as a single standard survey except for the inclusion of condition-specific health-related quality of life instruments. Although condition-specific analyses were performed and reported, this discussion has focused upon experiences common to the whole sample. This is partly because of the spirit of the NSF itself, aiming to achieve broad improvements across conditions using generally applicable changes to health and social care. As discussed below, it is likely that future developments, including monitoring of improvements by the NHS are likely to be assessed in terms of broad groupings of neurological conditions because of the relatively small numbers of individuals with specific conditions at a local level. There will of course still be a vital and distinct role for charities in monitoring and evaluating services for the specific conditions that they serve.

In terms of substantive results from the survey, highlights and key findings have already been discussed. The survey indicates many aspects of services that are satisfactory for the majority of respondents. For example with regard to health services, large majorities report no important difficulties of accessing relevant health professionals and received the information they needed regarding medications. However for many other aspects of health services experience was divided with substantial numbers reporting positively about identified professionals who coordinated their care or feeling that their care was well coordinated, but many respondents being less than positive on such experiences. On certain issues, such as receiving a care plan or specific support for self management, only a small number of respondents reported receiving the relevant service.

Similarly with social services, for some topics, a large majority seemed not to have experienced a problem. For example, basic access to equipment resulted in few

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reported difficulties. For some other issues, a majority did not need a service or needed it and received it. However, a minority of respondents reported not receiving help with personal care or housework that they needed. Small numbers also reported problems in other areas such as not receiving the respite care or financial support they wanted.

Whilst it is difficult to gauge the overall significance of the positive patterns of experience by many respondents and the seriousness of problems with services reported by others, it is clear that those reporting problems with services were consistently more likely to reported poorer health-related quality of life, whether measured in general terms or in terms of more specific issues associated with their neurological condition. Whilst it is not appropriate to attempt any casual interpretation of such consistent associations, it should provide positive encouragement that targeting improvements in specific aspects of service is likely to target those individuals with poorer health-related quality of life that might be improved by services. Whilst experience of services was consistently associated with quality of life, no type of service experience was more strongly associated with health-related quality of life.

A preliminary assessment of policy making for the NSF suggests that progress towards integrated services is 'patchy and slow' (85). The authors suggest that the specific goals of the NSF for neurological conditions have suffered because of greater attention being given to other long term conditions such as diabetes and COPD that have greater impact on use of expensive acute and expensive services. The evidence of the current survey, with appropriate caution due to methodological difficulties, is that progress is substantial but also mixed. Whilst many individuals with neurological conditions experience few major problems with services, to varying degrees, others, commonly with poorer quality of life, experience limitations of services. Some policy commitments, such as the care plan, seem fundamental to any further progress in achieving the ambitious goals of the NSF. More attention will be needed not only to ensuring that they are rolled out more extensively but also that they work in terms of further facilitating integrated and effective services.

Another aspect of policy needs further effort and consideration. Although the NSF, for understandable reasons, steered clear of quantifiable indicators emphasising

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instead ultimate health outcomes, the absence of any real evidence in terms of quantifiable indicators does pose risks that services are not incentivised to improve. Epilepsy is an exception amongst long term neurological conditions in that quantitative indicators are used in the Quality and Outcomes Framework (QOF) to measure aspects services and take account of performance in reimbursement. The three conditions considered in the current survey are not a part of QOF. Efforts have been made to address the issue of measurement and monitoring to support service developments for neurological conditions. The Better Metrics Project, run by the Healthcare Commission (now the Care Quality Commission), in its last report did identify a number of ways in which experiences of individuals with long term conditions could be regularly monitored (109). However, hardly any indicators were routinely collected. The key challenge is that key indicators are rightly focused on how individuals experience services and the impact of services on quality of life. These indicators are not routinely collected and little thought has been given to date to how they might be collected across a range of conditions. A second project, commissioned by DH in the Long Term Conditions Research Initiative will address this issue. The Quality Neurology Project intends to make practical recommendations of ways in which bodies such as PCTS can regularly monitor a range of indicators including user experiences to inform progress for the goals of the NSF. Lastly, and indirectly, the pilot for PROMS in primary care, although not directly addressing conditions such as MND, MS, PD, will provide indications for the feasibility of routine collection of patients' health status via PROMs.

Other developments may help establish systems for measuring the quality of services for long term conditions. The Information Centre for Health and Social Care with the Department of Health has reported results of extensive consultation with the NHS to agree Indicators for Quality Improvement (IQI) that could be promoted throughout the NHS. One recommended indicator specifically for long-term conditions is consistent with the results of the current survey: 'People with a long-term condition feeling independent and in control of their condition.' The other recommended indicators for long-term conditions do not specifically relate to the neurological conditions focused on in the current survey and more effort would be needed to agree such indicators. Other indicators recommended for broad application, for example in any planned care could also be used with specific reference to neurological

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conditions, for example, numbers of patients who reported that they were involved as much as they wanted to be in decisions about their care and treatment.

The Department of Health has facilitated a system, Commissioning for Quality and Innovation (CQUIN), whereby NHS organisations are rewarded for achieving agreed measurable improvements in services. All NHS providers will be required to set up CQUIN systems. The significance of CQUINs is that providers will be increasingly incentivised through this system to demonstrate improved quality of services.

It is difficult to know how readily CQUIN will work for neurological conditions given that quantitative indicators are less clearly established and relate to a broad spectrum of services. Partly in recognition of the challenges of commissioning for neurological services, Neurological Commissioning Support (http://www.csupport.org.uk/) was established by three participating charities (MNDA MSS PDS) to ensure that commissioning takes account of the individuals with neurological conditions in the commissioning process. A key role is the support of local initiatives to improve commissioning for neurological services. Their website reports a small number of ongoing projects to improve commissioning of local organisations, for example working with commissioners in Wandsworth to improve care pathways for neurological conditions and support the personalisation agenda.

These different developments need to be considered together with evidence such as the current survey to inform decisions as to whether it is feasible to monitor progress toward the impressive goals set out for long term conditions especially in terms of the users' voice that was so influential in the original vision.

It might be argued that further development needs to be achieved at a national level. The work of the Information Centre in developing, by wide-ranging consultation, strategic lists of IQIs could be further developed by bodies such as Neurological Commissioning Support and the Neurological Alliance, drawing on evidence from the current survey and other data now being gathered from commissioners and providers for the mid-term review of the NSF. In the absence of very robust evidence of specific services that make a clear difference to health-related quality of life, PROMs will play an important role as broad indicators of the progress of services whilst requiring careful interpretation.

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There are suggestions for future research arising from this survey. Those charged with assessing the evidence base for the NSF argued for a wider range of evidence being required to inform recommendations (110). It was argued that methods such as randomised controlled trials (RCTs) were not necessarily the only appropriate way to evaluate services and methods such as qualitative research could provide invaluable evidence of patients' and users' experiences. This was a positive and constructive step, making it possible for recommendations in the NSF to emerge despite a lack of evidence from RCTs for some key issues. However there is a need now to build the evidence base for long term neurological conditions in terms of identifying services that work, i.e. make a difference to the quality of life of individuals with the conditions and their carers, whether such research comes from RCTs or other best forms of evaluative research design. There is extensive NIHR infrastructure to perform such studies. There are patient-reported outcome measures to address outcomes that matter to patients, although some work may still be needed to produce measures that work across neurological conditions. More thought has been given to methodological challenges needing to be addressed when evaluating complex interventions (111). Evaluative research requires partnership between patients (including the relevant charities) and health and social care professionals to identify key questions, joined by methodologists to turn questions into high quality studies. Bodies such as James Lind Alliance (http://www.lindalliance.org/) provide models of the role of users working with professionals to identify key uncertainties. There are many areas of care for individuals with long term conditions where partnerships and funded research are needed to address uncertainties. Such diverse areas as community rehabilitation, self management, care planning, support from health services for carers, could all benefit from further debate between users and providers about best service models followed by their development and then evaluation.

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