

Long-term Neurological Conditions Feasibility Study *Consultation Report*

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1 INTRODUCTION

1.1 Background to the study

This report presents the first stage of a study to assess the feasibility of surveying people with long-term neurological conditions, commissioned by the Healthcare Commission and undertaken by the National Centre for Social Research between September 2006 and June 2007.

In March 2005, the Department of Health published a National Service Framework (NSF) for Long-term Conditions, with a focus on long-term neurological conditions. The NSF set out 11 quality requirements (QRs) for standards in services for neurological conditions, based on evidence from people providing and using these services, with a commitment to implement these QRs fully by 2015.

The following year, the Healthcare Commission asked the National Centre for Social Research to explore the feasibility of carrying out a survey of people with long-term neurological conditions, with a focus on the areas highlighted in the NSF and its QRs. The initial phase of research involved a consultation with people working in the field, people with long-term neurological conditions and carers. The objectives of the consultation were to establish whether it would be possible to conduct a survey of people with long-term neurological conditions, to explore priority topics to cover in such a survey, and evaluate potential methods for sampling and carrying out the survey. This report presents the findings of the consultation, and concludes with recommendations for further piloting and development work.

1.2 Research design

1.2.1 Literature review

A brief literature review was undertaken to explore previous survey work involving people with long-term conditions or their carers.

The review identified a substantial number of studies in which survey methods had been used with people with long-term neurological conditions and/or their carers. The studies identified are summarised in Appendix A. These examples confirm that people with a wide range of neurological conditions have participated actively in research, and that most of the major survey modes have been used previously in such research (paper questionnaires, face-to-face interviews, telephone surveys). The review also yielded suggestions of experts with experience of carrying out research with people with long-term neurological conditions, who could be included in the consultation phase.

1.2.2 The study sample

In-depth interviews were conducted with experts, service users and carers with experience of long-term neurological conditions.

Experts

Interviews were arranged with fourteen respondents (seven female, seven male) who had expertise around services for people with long-term neurological conditions or particular neurological conditions, covering:

- Consultants, practitioners and academics with expertise in a range of conditions (brain injury, MS, stroke, epilepsy, MND)
- Organisations for neurological advice, rehabilitation, and carers
- Central government: policy advisor; clinical advisor
- Local government/PCTs: specialist commissioning; physical disability services; social services

These respondents are referred to as 'experts' throughout this report to distinguish them from respondents commenting on their personal experience of living with or caring for someone with a neurological condition. This terminology is used for ease of reference, and is not intended to diminish the importance of service users' and carers' views, who can be viewed as experts on their conditions.

Service users and carers

Service users and carers were recruited through experts' recommendations and contacts, or through member organisations for specific conditions, particularly to ensure coverage of some of the rarer neurological conditions.

Eleven service users were recruited for interview, seven female and four male, with ages ranging from 20s to 60s. Two of the eleven interviews conducted, while providing some useful context, did not yield usable material¹; the results presented here are based on the remaining nine respondents.

Four carers were recruited for interview, two male and two female. The carers interviewed were all in older age groups, with two in their 50s and two in their 70s. Two were caring for a spouse (one husband, one wife); two were caring for their sons.

Service users and carers interviewed had experience of a range of conditions:

- Brain injury (2)
- Epilepsy (3, but 1 usable)
- Migraine (1)
- Motor neurone disease (1)
- Multiple sclerosis (3)
- Myclonus dystonia (1)
- Progressive supranuclear palsy (1)
- Spinal injury (1)
- Tourette's syndrome (1)
- Transverse myelitis (1)

¹ One service user had learning difficulties in addition to his neurological condition, so communication was difficult. For another service user, her neurological condition was very minor in comparison to other difficulties that had led her to be in residential care.

Geographical coverage

An additional aim of recruitment was to achieve a reasonable geographical representation, particularly amongst service users and carers (see Table 1.1).

Table 1.1 Geographical Profile of Respondents

Interviewees	London	South of England	North of England	Total
Experts	6	6	2	14
Service users	2	3	6	11
Carers	2	1	1	4

1.2.3 Data collection and analysis

All respondents were interviewed individually by NatCen researchers in a face-to-face format. Each interview lasted between one and one-and-a-half hours. Interviews with experts took place at the respondent's place of work. Service users and carers were interviewed mainly in their own homes, or in a few cases at a rehabilitation centre or NatCen's offices in London. The interviews were carried out between December 2006 and April 2007.

There was some variation in the topics covered in the interviews with experts and with service users and carers. Experts were asked for their views on the scope of the survey, different methodologies and potential sampling strategies, as well as the coverage of the questionnaire, focusing particularly on topics seen as a priority or missing from the NSF. Interviews with service users and carers concentrated on their personal experiences around use of services and how well their needs had been met. Please refer to the appended topic guides for more detail (Appendix B).

The interviews were tape-recorded, with the permission of respondents, and were analysed using 'Framework'. Framework is a systematic and accessible approach to qualitative data analysis developed by the Qualitative Unit at the National Centre for Social Research. The use of Framework helps to facilitate both thematic and case by case analysis and helps to ensure that all of the data is systematically included in the analysis.

2 SURVEY SCOPE AND DEFINITIONS

2.1 Introduction

In order to assess the scope of any survey of people with long-term neurological conditions, we need to define what is meant by neurological conditions and then decide whether the survey should cover the whole of this population or not.

Experts were asked about both of these issues, and this chapter outlines their views – first looking at how neurological conditions should be defined, and then looking at who the survey should and should not include.

2.2 Defining neurological conditions

Experts felt that from a health perspective, neurological conditions are well defined.

“By and large there are very clear medical conditions, and most medical professionals would know what you meant by neurological conditions”

There are, however, a few grey areas in terms of definition. The most notable one was Myalgic Encephalopathy/Chronic Fatigue Syndrome (ME/CFS). Experts who mentioned this generally felt that although it was long term, it was not a neurological condition (although it had some neurological symptoms).

One expert was unsure about primary muscular disease (e.g. Duchenne, muscular dystrophies) that tends to be treated by neurologists and can develop a neurological component. The NSF seems to include these, but whether these should be classified as neurological conditions is unclear.

Even though most neurological conditions, are from a medical point of view, fairly well defined, there is an issue around misdiagnosis, which was seen as a common problem for many neurological conditions.

“With epilepsy there is quite high misdiagnosis – both false positives and missed cases”

“Definitions of neurological conditions are reasonable, though there is a margin of error around diagnosis e.g. 10% false diagnosis of Parkinson’s”.

Some experts felt that defining neurological conditions from a purely medical perspective was not the most appropriate approach, and wanted to see a move to a social model of disability where the needs of the service user were the important element of any definition.

“Diagnosis is irrelevant – it is their needs and experiences that count”

“A needs based approach is better for service planning”

This was seen as important, as a medically defined condition could have very different impacts on different individuals.

“The reality is that once conditions go down different pathways, they have different effects on different individuals. We shouldn't exclude the effect of the condition”

This difference in how neurological conditions can be defined impacts on how records are kept. Health services (e.g. GPs, hospitals) tend to use medical definitions based on a specific diagnosis. Social care settings (e.g. Social Services) may have this specific diagnosis recorded, but assess the needs of individuals and base their service provision on these needs.

“Health services use diagnosis. Social providers may categorise differently” (Hospital consultant)

“Diagnosis is recorded at assessment, but we mainly look at range of needs that the person has” (Social Services)

In the NHS, the main coding definitions used to record diagnoses were ICD codes, READ codes and SnoMed codes.

ICD codes are commonly used in hospital settings. However, they are not seen as that accurate, and can be difficult to use.

“There are ICD codes for neurological conditions when someone has a diagnosis, but not everyone uses or applies these codes properly”

“I don't use ICD codes because they're frankly impossible to use on a day to day basis”

READ codes are used by GPs and in community health settings. As the original brief for this work did not advocate using GP records for sampling purposes, we have limited information on these and will need to do some more investigation, if there is interest in piloting a sample survey using GP records. There is a view that diagnosis is held by GPs increasingly well.

SnoMed codes are an amalgamation of ICD and READ codes, and are intended for use in the National Dataset (see Chapter 3, Section 3.2.6).

Service user and carer views on the terminology to use when referring to neurological conditions in a survey are covered in Chapter 5.

2.3 Who to include in a survey

Having discussed the general definition of neurological conditions, we asked the experts who should be included in the survey. The discussion tended to focus on the following areas:

- The types of conditions that should be included;
- The level of severity of the condition, and the impact that the condition has on people's lives;

- The recency of diagnosis;
- What ages should be included;
- Whether the survey should focus on those in contact with services;
- Specific hard to reach groups.

In this section, we look at each of these in turn and provide our recommendations at the end.

Type of condition

The NSF covers all long term neurological conditions, but it specifically mentions (and for part of its development focused on) six conditions: brain injury, spinal cord injury, multiple sclerosis, motor neurone disease, Parkinson's disease and epilepsy.

Experts felt that restricting any survey to these six conditions would be overly restrictive, and that a broader range should be covered, including some of the rarer conditions. While many felt it would be good to be very inclusive, there was an understanding that this might be difficult, and that it was more important that a wide range of conditions was covered than representing every single neurological condition.

"Probably 10-12 conditions.. not worth trying to be totally inclusive Needs and issues [of people with rare conditions] are similar enough to some people with more common conditions"

"It is important to cover the major conditions. It's not possible to include all the rare conditions, but it is important to include MND"

"Include a range of conditions as far as possible"

The NSF groups conditions into four categories.

- Sudden onset conditions, for example acquired brain injury or spinal cord injury, followed by a partial recovery.
- Intermittent and unpredictable conditions, for example epilepsy, certain types of headache or early multiple sclerosis, where relapses and remissions lead to marked variation in the care needed.
- Progressive conditions, for example motor neurone disease, Parkinson's disease or later stages of multiple sclerosis, where progressive deterioration in neurological function leads to increasing dependence on help and care from others. For some conditions (e.g. motor neurone disease) deterioration can be rapid.
- Stable neurological conditions, but with changing needs due to development or ageing, for example post-polio syndrome or cerebral palsy in adults.

Generally, these categories were seen as useful, and when talking about the range of conditions to include, a number of experts referred to making sure that conditions from each category were included.

"Make sure rapidly progressive conditions are included"

"The final category in NSF, stable but affected by ageing, have been historically badly served"

“Important to include those late [sudden] onset cases who are not going to die, but will live their natural term with their disability”

However, there is a limit to the usefulness of these groupings as there are many differences between the needs of individuals within each category.

A number of experts made the point that it was important not to select neurological conditions on the basis of prevalence, and that any sample should not go for proportional representation. This was linked to the high prevalence of people with chronic headaches or migraines. On the whole, many experts felt that this group could be excluded from the survey.

“[They] don’t pose the same health challenges as ... disabling conditions with extensive health and social service needs”

“Could exclude migraines and headaches – they won’t generally need much service support except GP”.

Some experts also mentioned that autism could be excluded from this survey, as although it was a neurological condition, it was felt that people with autism would not generally be using the sorts of neurological services that we would want to find out about.

As well as specific exclusions, there were some specific conditions that some experts felt should be included in this survey. The HCC had suggested that stroke was covered by the Older Persons’ NSF and so should not be included in this survey. However a number of experts raised the issue of young onset stroke, and one raised the issue of early onset dementia or Alzheimer’s.

“Young onset stroke is at risk of being missed if not covered here....To exclude it would be a mistake”

“HCC needs to consider its approach to early onset Alzheimer’s and young stroke”.

Severity

Linked with the issue of headaches and migraines mentioned in the previous section, there was a view that the survey should focus on people where their condition *“seriously impacts on their ability to function independently, to work and to carry out daily life”*

However, it was also felt that it was important to make sure that the survey did not miss those who were managing their condition well. These people might be difficult to access either because they may have limited contact with services, or because they may not see the point in taking part in a survey such as this.

“Should also include those with well controlled epilepsy, [who are] often not in touch with services apart from the GP”

At the other extreme, it was felt that it would be important to include those people whose condition has had a very severe impact. A number of experts suggested including people in residential or nursing homes, as they would tend to be affected more than those living in the community. However, it was acknowledged that those affected most severely (whether in residential care or not) would be the most difficult to engage in any survey.

“Those in residential or nursing care are the sub-group most likely to struggle in providing information about themselves”

Some neurological conditions are highly associated with cognitive impairment, and it will be important to address this if the survey is to be representative. For example, around 30% of people with epilepsy are also learning disabled, and experts working in this field felt it was important to include these people’s views in the survey as well.

Other neurological conditions can cause communication difficulties, and again experts felt it was important that the survey is designed to be as inclusive as possible.

Recency of diagnosis

A couple of the experts raised the issue of considering how long it was since a service user had been diagnosed with a neurological condition. Is it worth asking questions around the initial diagnosis if that took place a long time ago – are we more interested in recent service use and therefore recent diagnosis?

“Consider restricting the sample to those diagnosed relatively recently e.g. within the lifetime of the NSF”

However, a counter view is that we need to sample people at different stages, as they will be dealing with different issues and different services.

“Different sets of issues for different stages – early stages vs. late stages. I’d suggest layering the questionnaire and targeting different sections at different people”.

Contact with services

One of the focuses of the survey is likely to be the services that people have had contact with in relation to their neurological condition, and their views on the services provided.

Therefore, a few of the experts felt that it was important to select people who were in contact with services.

“This is the only rational way to do it. The Healthcare Commission is interested in services, right?”

The majority of experts felt that it was also important to make sure that the survey covered people who were not in contact with any services. This lack of contact with services could be for various reasons. Someone who is managing their condition well may not require any contact with services (except perhaps their GP). Alternatively, there may be people who tend to be excluded from services, or who don’t know how to access the services they need.

“Traumatic brain injury patients with good motor recovery but cognitive problems are often excluded from services and will be hard to reach – try to capture these”

“Risk of missing those with long-term conditions but not currently needing care, for example some time after a brain injury occurred”

“Don’t limit the survey to those recently in contact with services”

It was acknowledged that this group would be difficult to find.

“Some groups with the worst services are the hardest to get hold of”

Age

The NSF focuses on adult services, rather than children’s or older persons’ services which are covered in other NSFs.

There were mixed views about the age range that should be included in any survey. Some felt that the survey should just focus on working age adults (16-65), others felt that it should include older people as well (but perhaps cut off at 70 or 80), and a few felt it should cover children (including one expert who was interested in a specific children’s survey that would look at issue around schooling).

“Don’t limit on the basis of age. Ignoring the over 65s would skew the data”

“The NSF stops at 65, so you would have a rationale for stopping at 65 for a survey, but there are lots of reasons to not be so rigid – if someone is 67 they should still have input”

A number of the experts mentioned the importance of looking at the transition points, particularly from child to adult services, but also from adult to older people’s services.

“Transitions are a big issue. How transfer of service use works as people go from child to adult and from adult to older person. Make sure these extremes of the 16-65 group are included in the survey.”

Hard to reach groups

Hard to reach groups that were specifically mentioned included:

- Black and minority ethnic (BME) groups
- Prisoners (it was felt that other DH work was covering those in prisons, and so they did not need to be covered by this survey)
- Those in residential care (covered above)
- Those not in touch with services (covered above)

BME groups

Some work was done with black and minority ethnic groups for the development of the NSF. For some people within these communities there may be various barriers that make them less likely to engage with services. There may be language issues for people who do not have English as their first language. There may be cultural barriers, with some ethnic minority groups preferring to seek help within their own communities, and as one expert pointed out, the stigma of certain neurological conditions may be worse in some communities, which may impact on people’s ability or desire to seek support. There are also general access issues, with reported difficulties in reaching some ethnic minority groups.

Therefore, a number of experts felt it would be important to have a strategy in place for engaging with BME groups. This could involve going through community centres, and ensuring that areas with high proportions of BME groups are included in the sample.

2.4 Issues for analysis

In the discussion around who should and should not be included in a survey of people with neurological conditions, a number of the experts mentioned factors that, in an ideal world, they would like to see any survey results broken down by. Although on a practical level, it may not be possible to break down the results to this level of detail, it is information that we should, if possible, collect during the survey.

- a) Condition
- b) NSF grouping
- c) Age of service user
- d) When diagnosed (length of time has lived with condition)
- e) Level of disability (severity)
- f) Ethnicity

“From my point of view, I would like to split by type of condition as that impacts on resource requirements”

“It would be useful to give findings by the four [NSF] categories – although spinal injury has a special set of services and could be considered separately”

Recommendations and issues for consideration

Given the consensus among experts who mentioned it, we would recommend that ME/CFS should be excluded from a survey of people with neurological conditions.

We would recommend that muscular dystrophies are included, as they appear to be within the scope of the NSF.

Sampling using a condition-based approach will be more straightforward than using needs based sampling, if the aim is to conduct a survey of people with neurological conditions, rather than of people with specific needs or disabilities.

We would recommend that the analysis of results take a needs based approach, because there are unlikely to be sufficient numbers to allow analysis by condition, and because people with the same condition can have very different needs. This approach would require the questionnaire to collect data on needs, perhaps using an existing instrument such as the postal version of the Barthel index of activities of daily living (BAI).

Sampling based on condition will mean that people who have symptoms that require them to make use of the services of interest to the survey, but who do not have a specific diagnosis will be excluded. People who have been misdiagnosed as having a neurological condition would be included in the survey, and people who have been misdiagnosed so that their neurological condition is not picked up will be excluded.

The survey should record the condition on which the service user was selected for the survey, and the condition that the service user says that they have – to allow for changes in diagnoses over time.

Recommendations and issues for consideration (cont'd)

Excluding headaches and migraines is possible, but it will be almost impossible to only exclude the less serious ones. Thus, by excluding all we will miss people who are severely affected by these. However, as the majority of headache and migraine sufferers will not be accessing or need to access the services we are interested in, we feel that this group should be excluded from the survey.

In our view the survey should be as inclusive as possible, and should not just focus on the more common neurological conditions. However, to ensure that there is coverage of rarer conditions will require a large sampling exercise. We will either need to have a large sample, so that it includes rarer conditions proportionately, or we will need to gather a large sample and then select from this sample disproportionately. How this is done will, to some extent, depend on how we find our sample.

Our initial view is that the survey should focus on people with neurological conditions who are living in the community rather than in residential or nursing homes. Although this will miss the most severely disabled, and will impact more on some conditions than others, we feel that people in residential or nursing homes would require a different focus in terms of the questions asked, and are more likely to require face-to-face interviewing by specialist trained interviewers. This could be considered as a separate survey.

It will be important to allow flexibility in terms of the mode of the survey, and in how involved carers can be to ensure that the survey does not exclude people who have communication or other cognitive difficulties that make it difficult for them to take part in a survey. (These issues are addressed further in the Chapters 4 and 6).

Whether it is possible to specifically include people from black and minority ethnic groups will depend, to some extent, on the sampling strategy adopted. Whatever approach is taken, it is important to acknowledge this issue and to ensure that areas of the country with a high proportion of their population coming from BME groups are included, or, if possible, to seek out sample sources that will ensure the inclusion of people from BME communities.

We would not advise restricting the survey on the basis of time since diagnosis, but this information should be collected as part of the context for interpreting survey findings.

The survey should focus on people of working age (16-65) as in the NSF, but we should consider the possibility of extending the age range to include older people. We recommend that 16 is kept as the minimum age. If there is interest in exploring issues around children with neurological conditions this would require a separate survey.

3 SAMPLING

3.1 Introduction

Having defined the population of interest, the next stage is to work out how to draw a representative sample of this population. Drawing a representative sample involves having access to a list where the population of interest can be easily identified and which has excellent coverage, i.e. very few members of the population are excluded.

In this chapter, we look at potential sampling frames, and their advantages and disadvantages.

3.2 Sampling frames

3.2.1 GP registers

Sampling via GPs was seen by all but one of the experts as the best approach to get comprehensive coverage.

Using GP registers was seen as providing the most inclusive sample. It was felt that, in most cases, even people who were not in contact with any services would be registered with a GP, and would have their diagnosis recorded.

"GP route would be the methodologically best route. Disease based, epidemiologically sound. The diagnoses would be reasonably good, up to date, held electronically"

"People recently diagnosed would be picked up via GP registers, but not via rehab or social services which are weighted towards the most disabled"

"GP is by far the best route – it would achieve the best cross section of the different conditions and needs, for people with epilepsy"

"Codes used by primary care are quite comprehensive on neurological conditions"

There are disadvantages to using the GP route, and some experts had concerns that we would still miss some people with neurological conditions.

"Brain injury is a problem at the milder end as people may not need to see the GP and so fall between all the services"

"There's a risk that those with multiple injuries may not have brain injury specifically recorded"

"GP records probably hold reliable enough diagnosis of major conditions like MS, but may be less reliable for some other minority conditions"

“GPs may misdiagnose, especially into mental health services e.g. Acquired Brain Injury”

The largest problem with using GP registers is the logistics of the process. Due to the relatively small number of people with neurological conditions that will be registered with each GP, especially once headaches are removed, it would be necessary to sample via a large number of GP practices.

Sampling via GPs also raises data protection issues, as GPs can be reluctant to hand over patient details for research purposes. There is also the time involved for GPs and their staff in drawing any such sample. Many, but not all, GPs will have their records computerised, but it may still be difficult to use the systems to pull off details of individuals with specific READ codes. Therefore, getting GPs to agree to take part is a challenge – and without a high proportion of co-operating GPs, the coverage of the survey will suffer.

“Logistics is the biggest problem – GP would have to pull these diagnoses on your behalf mainly from paper records”

“Disadvantages are cost, energy and the relatively small numbers picked up from any one area”

From the service user point of view, this would be an effective method of sampling. Nearly all of the service users interviewed are registered with a GP who knows their condition. A few of the service users mentioned that, in their view, the GP would not pass on the details.

“I can't see the GPs being happy putting people forward”

“Odd going through the GP though – partly confidentiality, but also GPs wouldn't want to be involved, you are using them as a post box in a sense.”

The HCC has used this route in the past for the Diabetes survey, but found that it was difficult, particularly around the data protection issues. Therefore, this method of sampling was initially discounted, and we have not spent much time evaluating it. However, our findings suggest that it would be by far the best method to ensure good coverage, and so we would suggest that some more time is spent exploring this approach. One of the main difficulties with getting GPs to participate in the Diabetes survey was the issue of whether it was necessary to obtain prior consent from patients before including them in the sample. Therefore, it would be important to explore the options around prior consent, and how best this might be obtained. This investigation would need to include discussions with the General Practitioners Committee (GMC) and the Patient Information Advisory Group (PIAG).

3.2.2 Hospital records

Hospital records could include inpatient discharge records, but should also include outpatient records (although hospitals only started holding diagnoses on outpatient records in the last couple of years). There are also records held by specialist clinics.

Many experts felt that hospital records would provide very patchy coverage of people with neurological conditions. Many neurological conditions are chronic, and so there could be limited contact with a hospital. For some neurological conditions, coverage via

hospital records could be good – for example, people with MND have specialist clinics and so nearly all people with MND would be found via hospital records. However, other conditions (e.g. MS or epilepsy) may not generally be linked into hospital based services. For some conditions (e.g. Acquired Brain Injury), people will have been in hospital initially – but once discharged, may then never go back into hospital, so it might be difficult to access those who had been living with their condition for some years.

“A reasonable number of people with epilepsy will not go through a hospital”

“These are chronic conditions, so you would only pick up a few through hospitals”

It was also suggested that the accuracy of diagnoses held by hospitals was poor, and would vary greatly from area to area.

“If a person is taken to an A&E department with a seizure, they may record seizure without sufficient detail to know if it is epilepsy or not, or they may record epilepsy when it is actually a seizure for other reasons (e.g. a reaction to medication, alcohol etc).”

“Not recommended –the quality of diagnostic registers held in hospitals varies by condition, and by area”

“Neurologists keep records, but some better than others”

There are also practical issues around how easy it would be to access hospital registers.

“It is practically difficult to get information from hospital registers [I] had to go through individual records!”

Nearly all of the service users interviewed had been discharged from hospital at some point, but in some cases this was many years ago. Some had an ongoing link with a specialist in a hospital, and some were currently outpatients. There were mixed views as to how useful this source would be, and how happy they would be to be sampled via hospital records.

“Some people with MS avoid going to hospital if at all possible, so you would miss some people”

“[Person cared for] hasn’t been in hospital for ages – not since the time of the accident [over 10 years ago]”

“Must include outpatients too or you’ll miss out patients with ongoing treatment”

“I would feel a bit taken aback to be contacted via the hospital – I would wonder what else you knew”

“I would be happy to be contacted via the hospital to take part in the survey”.

3.2.3 Specialist services

There are various specialist service providers for neurological conditions, including voluntary organisations such as Rehab UK or Headway. Experts felt that it would be difficult to tap into these as a sample source, as referral routes vary from area to area, so

it would be a time consuming approach with patchy regional coverage. For some conditions, the level of specialist service provision varies across the country. For example, there is a concentration of epilepsy services in a few specific areas, which would need to be taken into account in sampling.

There is also the problem that going via this route would mean that all the people sampled are in touch with services (which as discussed earlier, could miss those with unmet needs). It was also felt that people in touch with these sorts of services would be less likely to have been recently diagnosed, and more likely to suffer from more progressive conditions.

3.2.4 Social services

There was a general view that social services do not classify people by their condition, but by their needs. While this approach is one advocated by a number of the experts in the discussion around defining who to include in a survey, it is practically difficult to implement, as it would involve screening people with a range of needs and disabilities to assess whether they had a neurological condition. This screening would have to take place either at the service user level (using the survey as a screening instrument) or via social services staff.

"[We] can't pull reports from the system that group people by condition ... but staff at service providers would know conditions and could select people based on their condition" (Social Services)

The logistics of using social services records was also raised by a number of the experts. Records are likely to be held in different ways by different social services departments, and there may be issues around data protection that vary from area to area.

"Practical difficulty of getting data amidst bureaucracy"

"Every local authority would have a different arrangement.... As for data protection.. it would probably need to be an opt-in rather than an opt out"

"Social services occupational therapists' lists have been useful in surveys of people with MS, but the quality of records varies by area.... You still miss some people and diagnosis can be inaccurate"

There is also the issue that people in contact with social services may not be representative of all people with neurological conditions. Generally, those who are in contact with social services will be more disabled and more dependent, and this is likely to vary from area to area.

"Social services route will miss those who've got a job, got a life"

"There are great differences between boroughs in how willing they are to fund services – certain boroughs say that they don't have people with brain injury"

Two of the service users had no contact with social services, and one had only recently come into contact with them, because as she got older she needed more help. Those who were in contact felt that this could be a good route, and a couple mentioned direct payments as being a possible basis for sampling.

“Care manager and occupational therapist are the two people who’d know most about his condition” (Carer)

“[Social services] will have my address plus a lot of detail about my condition”

3.2.5 Member organisations

Nearly all of the experts mentioned the member organisations (such as the MS Society) as being a useful avenue to find people with specific conditions. Some of the organisations were seen as better and more pro-active than others, and there was felt to be some regional variation. There would also be data protection issues, with some organisations potentially asking for volunteers (i.e. using an opt in approach rather than an opt-out).

Sampling via member organisations or the Neurological Alliance would be likely to lead to an unrepresentative sample. There are likely to be differences by condition: the member organisations for some conditions will have very good coverage of people with that condition, whereas other organisations may have much more limited coverage. Where coverage is limited, there are likely to be differences between people who are members and those who are not. Thus, relying on membership lists for sampling could lead to bias.

However, it was felt that these organisations could form part of any sampling strategy, and that having them on board would definitely help response.

“The disease societies would be a perfectly good sampling frame, although there may be a selective group of those who wish to join”

“Those in touch with member organisations will generally have better support, so you can’t rely on this alone”

It was noted that if we did use this approach, we would need to make sure we took account of “interest” members, who were members, but did not have the disease. This would need to be specifically addressed on any questionnaire.

Many of the service users had been recruited via these organisations, and thus were generally positive about the idea that the membership lists could be used to sample for a survey.

“Tourette’s Association – most people with Tourette’s will be a member, it’s our only way of feeling we’ve got any support”

3.2.6 National Dataset

Four experts spoke about the National Dataset due to be ready in late 2008.

This was originally intended to extract some core data (including diagnoses) from the electronic patient record (of which there is one for every NHS patient). Although the data that DH hold will be anonymised, it will be possible to link the data with contact details, subject to data protection arrangements (such as an opt-in or opt-out).

If this dataset is set up, and works as it is meant to, then it would be an extremely useful sample source. However, there is some cynicism as to whether it will ever happen or work. Already, some scope for paper-based information is being allowed.

It is also likely that there will be very strict data protection issues surrounding the use of this database, so it may not be possible to use it as we would like to. This may be an issue that merits discussion with the Department of Health's Patient Information Advisory Group (PIAG).

However, it is worth keeping an eye on developments.

3.2.7 Others

A couple of experts and one of the service users mentioned Centres for Independent Living, which are organisations representing disabled people.

Specialist nursing and residential homes were mentioned (e.g. Leonard Cheshire homes).

One expert wondered if it would be possible to use census data, plus screening.

Use of DWP records, particularly those for Disability Living Allowance has also been mentioned, and will be followed up. However, DWP records will only cover those people who are claiming benefits, and thus may exclude people who are less severely affected by their condition.

Recommendations and issues for consideration

Although the logistics and issues surrounding the use of GP registers are problematic, this would appear to be the most effective way to sample a representative group of people with neurological conditions. Therefore, we suggest that more time should be spent considering whether it would be feasible to go down this route.

The National Dataset is worth keeping an eye on. If it works as intended it could be an ideal sample frame.

Use of DWP data also merits further investigation.

None of the other possibilities are likely to provide a representative sample on their own. Therefore, an alternative option would be to obtain a sample from a combination of sources. We would suggest hospital records, member organisations, specialist providers that can be identified in an area and possibly social services. Of course, people may be sampled more than once, so de-duplication would be necessary. This sampling would need to be done on an area by area basis, and would involve a lot of work. This approach would need careful piloting in a couple of areas to assess how feasible it would be on a larger scale, and/or which sources would be most useful to focus on for a larger scale survey.

4 SURVEY MODE

4.1 Introduction

This chapter will focus on the feasibility of using a variety of survey modes to survey people with long-term neurological conditions. Service users, experts and carers were all asked for their views on potential survey modes that could be used. The modes considered are postal self-completion questionnaires, face-to-face interviewer administered interviews (CAPI), web surveys and telephone interviews (CATI). The issue of service users who may need help completing a survey, and who could provide this help is also discussed.

4.2 Potential survey modes

4.2.1 Self-completion surveys

Self-completion surveys are often viewed as an economical and efficient mode for collecting data and have previously been the main method used in surveys carried out by NatCen for the Healthcare Commission. Service users, experts and carers were all asked for their opinions on the potential of using this method in a survey for people with long-term neurological conditions.

Service users generally felt that a self-completion questionnaire would be “fine” for them to complete although they may need help filling it in. However, the feasibility study may have over-sampled those who would have little difficulty completing a self-completion questionnaire. As we asked for people to volunteer themselves to participate, perhaps these service users were amongst the more physically and cognitively able. A few service users pointed out that it would be difficult for other people with long-term neurological conditions and it could therefore limit response rates.

“OK if you can use your hands”

“I could try and fill it in myself but I might need somebody to help with the writing”

“This would be fine now, but it would have been difficult at the beginning of the condition as I had trouble writing”

“May be an issue for some”

Similarly, a few experts considered a self-completion questionnaire to be a good option for some service users but for others, particularly those in the later stages of a neurological condition, it may be more problematic.

“Certainly an option for some...some struggle with complex forms or concentration”

“Sensible approach...problematic for later stages of MND, Parkinson’s”

“Some will be able to manage this, some won’t”

A number of service users reported that they would be able to ask a carer, friend or partner for help with completing a paper questionnaire. However, a number of issues around the involvement of a carer to help with completing the survey were highlighted by service users, carers and experts. These are discussed in Section 4.3.

A couple of service users and a carer remarked that they would like free text boxes to be incorporated into the questionnaire as service users felt that they *“don’t always fit into the boxes”*. However, a few service users mentioned that the questionnaire would need to be clear and easy to follow.

“Make questions guided, channelled, not too open”

Similarly, an expert suggested that the questionnaire shouldn’t necessarily include free-text boxes as this would make analysis difficult.

A number of experts felt that the self-completion questionnaire would be a good starting point but that a big group of people with long-term neurological conditions would be overlooked if this was the only method used.

Experts recommended that follow-up letters, phone calls or face-to-face interviews should be issued if a questionnaire is not returned. However, it was pointed out during the expert interviews that some people with neurological conditions may have severe communication difficulties, which would make it extremely difficult for them to participate in a survey via any method.

4.2.2 Face-to-face interviews

Face-to-face interviews, where the questionnaire is administered by an interviewer, was the favoured method for collecting information from people with long-term neurological conditions amongst service users, carers and experts.

“Best option...this would be an insight into their life”

“Easier to say rather than ticking boxes on paper”

“I like the body language and being able to see the person and ask questions”

“Doing interview administered would be best”

“Broadly, this group would prefer face-to-face interviews”

“Allows possibilities for more complex routing to address specific issues relevant to each condition”

Some experts felt that face-to-face interviews would extract “richer” information from those with cognitive difficulties and may be the only option for those who are unable to complete a paper survey (although some experts, service users and carers thought that there would be a subgroup of people with communication difficulties who would be unable to participate in a face-to-face interview). One expert also mentioned that this

method *“empowers people – people like to talk”* while a service user felt that this method would best enable her to express her opinion.

As one expert pointed out, face-to-face interviews are also beneficial when compared with telephone surveys, as interviewers are able to recognise if a respondent is becoming tired and would like to take a break, which would be much more difficult if the survey was administered by phone. Similarly, in regards to a self-completion questionnaire the ability for respondents to control their own pace would clearly be beneficial – particularly for service users who become tired easily or find it difficult to concentrate for long periods of time. This is an important consideration for people with long-term neurological conditions.

Flexibility of interviewers was highlighted as an important consideration if the face-to-face method is chosen. For example, one service user who experiences migraines emphasised that she may have to cancel an interview at short notice if she had a migraine. Another service user reported that if he was having a bad day and *“feeling ugly”* he would prefer not to be visited by an interviewer.

However, similarly to the self-completion option, a few of the experts and carers that we spoke to felt that service users may still require assistance from somebody else – for example, a carer or *“independent advocate”*. This is discussed in more depth in Section 4.3.

Other negative aspects of face-to-face interviews raised by the service users that we consulted included concern about *“bad chemistry with the interviewer”*; having people in the house might not be very easy for some respondents and the gender of the interviewer could also potentially be a problem.

4.2.3 Web and telephone surveys

Web and telephone surveys were not viewed as viable stand-alone options by service users, carers or experts but were positively received as follow-up methods for respondents who find it difficult to complete a self-completion questionnaire or take part in a face-to-face interview.

“The easiest mode for the survey will vary for different people in different situations and even on different days, in better or worst state)”

Most service users felt that web surveys were preferable to phone surveys, while experts emphasised that neither would be suitable as the only survey method and service users reported that they would like to be presented with a *choice* of how to complete the survey.

“A web survey is probably the best option. There are a lot of aides for computers that allow people to type who can’t write...best option for people with limited movement”

“Web could be good to have as an option”

“It’s best to give as many options as possible”

A couple of respondents also proposed that the self-completion questionnaire could be sent to respondents as an email attachment. Several service users highlighted that there are currently a number of aides for computers that could assist respondents with

completing an emailed Microsoft Word document. However, this would most likely entail respondents contacting the Operations department to request a questionnaire is emailed to them, as email addresses are unlikely to be included in the chosen sampling frame. In the past, similar methods – where respondents need to request the facilities to use a certain mode, be they a paper questionnaire or an e-mail attachment – have produced low response rates. Bearing in mind the low cost impact, however, this should be considered as an additional option for some service users.

Negative aspects of web surveys as a stand alone option were that they would limit response as they exclude people who do not have internet access; respondents may not “get as much out of it”; and they would be more likely to be taken up by those who are functioning well.

In regards to a telephone survey, carers generally thought that the people they care for would find it difficult to talk on the phone, while some service users mentioned that for them it would be “ok” but for other service users it might be the easiest method, particularly if they had telephone headsets. However, amongst service users, phone surveys were the least preferred method of data collection. Reasons for this included negative experience of completing phone surveys in the past; difficulty maintaining concentration on the phone; difficulties holding the phone and speech difficulties making it harder to talk on the telephone.

4.3 Involvement of carers in interviews with service users

In some cases, a service user with a neurological condition may be unable to take part in a survey without some help. Respondents were asked for their views on who is best placed to provide this help.

Some experts felt that “*some form of carer*” could help.

“The covering letter could read something like “If you cannot read or have problems understanding or filling this in, and have someone who provides care for you, it is fine for them to fill it in; if so can they please identify themselves and their role”

“Start with the client, but a proxy interview is OK if the client is unable to participate”

However, a number of the experts felt that this approach could have an impact on how people would answer certain questions.

“There can be issues interviewing users alongside carers, depending on the questions”

“Difficulty if there are questions in the survey relating to a known carer, you need to be aware of the potential bias in these responses”

To avoid this, some experts suggested making use of “independent advocates”.

“Maybe use an independent third party who is an expert in communication. Maybe the Neurological Society have people who could help – or the local societies”

However, this would be difficult to organise, and one expert felt that despite the problems, asking for help from known carers would be the most effective approach, and is the method he uses in his own surveys.

"There are issues around assuming the carer's comments are a valid report of the patient's experience, but the bias risk is outweighed by getting some information from each patient".

Service users were asked whether they would need any help with a self-completion survey, and who could best provide this. Some felt they would need help, and while some respondents would feel comfortable asking their close relatives or paid carers to help them with a survey, others mentioned that it might not be appropriate for certain topics. Most of the service users interviewed for this study expressed a preference for a survey mode that they could participate in without help.

"I could get my carer to help – go through the questions together and tick the choices. [Would you be happy with this?] Depends what the questions are .. could be some topics that are less easy – but generally it would be alright"

"I would be able to get my husband to help – but I would rather do it myself"

"I would try to fill it in myself, but I might need somebody to help with the writing, I don't mind who"

The four carers interviewed all felt that the person they cared for would need some help with a survey, but some were aware of the impact that they could have on the answers.

"My son would need help to fill in a survey by himself I'd be happy to do this, but might be better if a carer at his school did it as he could be more of himself with the answers."

The carers felt that in some situations the answers given by the person they cared for would not provide an accurate view of their situation, and so carer input would be needed to get more valid results.

"He doesn't accept how ill he is"

"It would be probably unreadable, and definitely not true!"

"He would fill it in and send it back, and wouldn't wait for help. So you would need to tell them to discuss this with someone they trust."

4.4 Practical considerations

Length of survey

Some service users felt that if the survey was relevant to them and their condition then they would not be overly concerned about the length of the survey. However, for other service users the length was highlighted as one of the deciding factors of their participation. A number of experts and a handful of service users mentioned that a longer survey could be a barrier to taking part for some service users.

"Anything is ok within reason...as long as it's agreed beforehand so I know what to expect; or know that's too long, and opt out"

The general consensus was that half an hour for a postal self-completion, phone or web survey would be appropriate, while for a face-to-face survey an hour was viewed as the maximum length.

Timing of interview/phone survey

The preferred timing of the interview varied somewhat, dependent on whether interviewees were working and when would be most convenient for them. A few service users felt that it would be best to be visited or telephoned by an interviewer during the day but avoiding first thing in the morning while one respondent said that he focuses best later at night. Interviewers at NatCen are generally flexible in this respect and would try to arrange the interview for a time that would suit respondents within reason.

Location of interview

Convenience was of utmost importance to many service users; if a survey was inconvenient for interviewees to complete then this would be a major barrier to response. Most service users would prefer a face-to-face interview to be completed at their home, although for a couple of service users security was seen as an issue.

For others, an interview at their home would be less convenient. As one expert pointed out.

“Home life can be very tricky for these people...it could be difficult or stressful to arrange a home interview”

As an alternative, one service user mentioned that it would be easier for him if the questionnaire or interview was administered at his rehabilitation centre where somebody would be able to provide assistance with completing the survey.

Incentives

None of the service users that we spoke to mentioned a financial incentive as being important in their decision of whether to participate in the survey. A service user with motor neurone disease suggested the £15 voucher that was offered for the feasibility study could be seen as slightly patronising.

“For people with neurological conditions, the last thing on their minds is a bloody voucher!”

The most important incentive for most service users was hoping that some improvements to their services could be made as an outcome of their participation.

“Knowing that it would be of benefit to people with my condition”

“I hope it will help others with epilepsy in the future”

However, one expert discussed how the survey could raise service users' expectations, which presents an ethical dilemma. He suggested clarifying in the advance letter for the survey that we are asking respondents about their experiences of how the services serve them at present, and that we are not promising any changes.

Service users were also keen that they should be informed at the beginning of the survey about the content and length of the survey, how the information that they provide will be

utilised and the reason that they have been chosen to take part. This is all information that service users felt would encourage them to participate.

As with a number of other surveys that NatCen carry out, this information could all be included in the advance letter that is sent to potential respondents a couple of weeks prior to an interview, or the covering letter attached to the self-completion questionnaire. Service users considered this method of initial contact to be the most appropriate.

Availability of contact details

Phone numbers and email addresses may not be available through some sampling routes. If respondents would prefer to complete the survey via email, internet or telephone, we may need to ask respondents to provide us with additional contact details.

Recommendations and issues for consideration

It will be important to make it as easy as possible for people to take part with limited help. This may require a variety of modes.

Face-to-face interviews were the preferred survey method for service users, carers and experts.

It should be noted that using face-to-face interviews will have cost implications and will be difficult to manage if the sample is not concentrated in a small number of geographical areas.

Self-completion questionnaires were generally well received, particularly if respondents are provided with the option of completing an emailed or web survey instead.

However, self-completion methods would make it difficult to monitor the reasons for non-response. Thus we could involuntarily exclude certain groups of people, for example those with severe cognitive or physical difficulties. Any pilot survey would need to address this, perhaps by following up people who do not respond to a self-completion survey to find out why they did not respond.

Considerations will need to be given to the intended use and outcomes of a survey that can be mentioned in an advance letter without raising false hopes.

It will, as in all surveys, also be important to know who was present during the interview. This would be more difficult to monitor with self-completion questionnaires, compared to face-to-face interviews.

If people do need help, we should allow them to choose who helps. Ideally, we would have specialist interviewers skilled at the sort of communication skills that might be needed – but this would be difficult to organise nationally, and costly.

The survey should include space to record whether respondents had help with completing it, and who provided the help.

5 SURVEY COVERAGE

5.1 Introduction

A key objective of the consultation was to explore priority topics and issues to cover in a survey of people with neurological conditions. This was approached somewhat differently in the expert interviews and in interviews with service users and carers.

Since all experts included in the consultation were aware of the NSF and its role in prompting the current study, the QR themes were used as a framework for discussion of key issues to cover in a survey. In particular, experts were asked for priority topics amongst the eleven QRs, as well as any topics seen as missing from the NSF. The broad themes covered by the QRs are listed in Table 5.1 for reference. Interviews with service users and carers were structured around their personal experiences and use of services and the extent to which they felt their needs had been met (or the needs of the person they cared for, as appropriate). Whilst some service users and carers were familiar with the NSF themes and made reference to these, it was not explicitly used as a framework for discussion, but issues raised in the interviews are discussed under the appropriate QR themes in this chapter where relevant.

Table 5.1 Quality requirements from the NSF for Long-term Conditions

QR1	A person-centred service
QR2	Early recognition, prompt diagnosis and treatment
QR3	Emergency and acute management
QR4	Early and specialist rehabilitation
QR5	Community rehabilitation and support
QR6	Vocational rehabilitation
QR7	Providing equipment and accommodation
QR8	Providing personal care and support
QR9	Palliative care
QR10	Supporting family and carers
QR11	Caring for people with neurological conditions in hospital or other health and social care settings

Both the expert and service user/carer interviews brought out issues covered by each of the NSF Quality Requirements (QRs), with the exception of QR9 (palliative care). This is not seen as a priority for the survey, and may be covered elsewhere. It was felt that the survey should attempt to reflect the remaining QRs, to a greater or lesser extent. Experts' general views on covering the NSF and QRs within a survey are discussed in Section 5.2 of this chapter. Priority issues within the QRs are discussed in the Section 5.3.

A number of further themes arose in the interviews that were seen as important to consider for a survey of people with neurological conditions, but which are not covered specifically or in sufficient detail within the QRs. These include priority topics identified by experts as missing from the NSF, as well as concerns from service users and carers that do not fit easily into the QR themes. These areas are summarised in Section 5.4 of this

chapter. Section 5.5 considers other information that could usefully be collected within the survey to provide context on service users' condition and needs, and their care situation, when interpreting the survey findings, including standard instruments recommended by experts. Finally, Section 5.6 considers appropriate terminology for use in a survey, based on comments from all groups. Themes and issues to consider for a survey are highlighted in bold for ease of reference.

5.2 Expert comments on survey coverage in relation to the NSF

Some experts commented more broadly on the coverage and level of the NSF with respect to designing a survey. These views are discussed in this section, before moving on to consider in detail priority themes within and beyond the QRs.

Several experts emphasised the importance of reflecting all areas from the NSF within the survey, as the **QRs are differentially important for people with different conditions or different needs**. For example, for people with brain injury a key issue is ongoing access to rehabilitation, whereas for other conditions early diagnosis and treatment is more important. This does imply, however, that a single survey for people with long-term neurological conditions (ie, without extensive routing or modules for different conditions) would inevitably include some questions that are irrelevant to some respondents. It was suggested that this could be a potential cause for offence to some respondents, for example when asking about rehabilitation for people with a rapidly progressing terminal illness such as motor neurone disease. The problem of inappropriate questions is greater if a postal survey is used than with other survey modes, which allow for 'transparent' routing such that respondents are not presented with questions that are known to be inappropriate to them due to their earlier response.

An important issue in survey design will therefore be to balance the need to cover key issues of interest in the NSF and more widely, against the desire to make the survey as relevant as possible to all those completing it. In fact, experts noted that the NSF intentionally **focuses on broad themes** to capture as far as possible cross-cutting issues relevant to people with a range of neurological conditions. But as a result, it may be difficult to translate the QRs into specific survey questions. The NSF **does not provide a mapping of specific services** that can be 'reasonably expected' at each stage for each condition, on which to base a detailed survey of service provision. Several experts suggested that a more suitable approach, both in terms of assessing the NSF and in terms of relevance to service users, would be to **base the survey on service users' needs**, and how well they were met, rather than asking about specific types of services and professionals involved in individuals' care.

5.3 Themes covered by the NSF Quality Requirements

Quality requirement 1: A person-centred service

Integration and co-ordination of multidisciplinary services was a key issue for carers, and was also mentioned by some experts and service users. There is a perceived need for closer **partnership** – between the various service providers involved, and with the service users and their carers. Specific areas of concern included:

- closer integration of **health and social services**;
- integration with services offered by the **voluntary sector**, such as Headway;
- coherence between **specialist/expert advice** and **local service provision**;

- better planning of **transitions** between different phases of care – from child to adult services, from adult to older people’s services, from rehabilitation to independent living etc
- closer consultation with **service users and carers** in planning appropriate care.

“The NHS provide some things, in a box; social services provide some things, in a box; voluntary sector provides some things in a box. That’s no use. We do much better when we work together.” (Carer)

“Transitions are a big issue. How the transfer of service use works as people go from child to adult and from adult to older person.” (Expert)

“Tourette’s has to be dealt with at a tertiary level. But then professionals in hospitals can’t just ignore what’s said at this tertiary level, they should try to understand.” (Carer)

Care plans should be jointly negotiated, with service users and carers **informed and involved in decisions**. A **care co-ordinator** or **key worker** should be appointed in all cases to co-ordinate information and inputs, and make sure services are provided as planned or as needed; this is particularly important to ease the burden on carers.

“We needed a key worker...and a proper, cohesive, coherent, modern care plan. I think the problem was it was incoherent, because of the number of people involved. People weren’t accountable, there weren’t dates that people had to do things by.” (Carer)

“Would be good if there was a “road plan” of the journey to expect with MND... how the disease might progress, options for this in care plan, what different professionals should be doing. (Service user)

Quality requirement 2: Early recognition, prompt diagnosis and treatment

Early diagnosis can depend on a GP’s recognition of neurological symptoms and appropriate referral, so **professional knowledge** of neurological conditions is important. In fact service users and carers raised this as a key issue for all professionals who work with neurological conditions, including social services, physio/speech language therapists, and specialist consultants (and other care settings, covered by QR11). In particular, rarer conditions may be encountered only once in a career, so it is also important that professionals are **able to admit the limits of their knowledge** – and be willing to research a condition further or refer a patient for a second opinion. Experts also mentioned the problem of **misdiagnosis** for some neurological conditions.

Sensitivity around diagnosis is very important – understanding the potential shock of the diagnosis, the importance of having somebody present for **support**, the need for **confidentiality**, offering the opportunity to **ask questions** once the initial shock has sunk in. **Clarity** is also very important – service users described situations of being left to deduce their diagnosis from unclear remarks, or returning home without a clear understanding of what the condition was and what the implications were, or what would happen next. Nearly all respondents mentioned the importance of being given **written information** at diagnosis or soon after, to digest slowly once the shock of diagnosis sinks in, and to share with family and others. Service users commented extensively on **professional qualities and approaches** that are helpful or otherwise when diagnosing and caring for people with neurological conditions, and on the types of **information and advice** that would be helpful; these are discussed in more detail in Sections 5.4.1 and 5.4.4.

“I would have liked more support from the consultant at first – ideally a follow-up appointment after being told, so I could go away and think about it and assimilate it and then see him again to discuss.” (Service user)

“I got the right diagnosis when I was about 17. The neurologist said he’d send me some literature, but I never received any. I didn’t know how to spell the name and didn’t have regular check ups, so I didn’t really know what was going on... [A few years later] I did a lot of research on the internet and eventually found out again what it was – then everything fell into place.” (Service user)

After diagnosis, GPs are often the “gatekeepers” to **accessing specialist services**, which again depends on the GP’s awareness of the condition, and “*knowing what is out there*” – as well as being **willing to explore options**. Experts suggested the survey should ask about access to services, whether appropriate input was provided that **met service users’ needs, how easy it was to access, and how long it took to access**; but also whether there are services that service users have **not been able to access**. Treatment is not a relevant concept for all conditions, but where applicable service users spoke about the importance of being **involved in decisions** and understanding the **implications of treatment**; and also stressed that **quality of life** should be taken into consideration. For example, when prescribing epilepsy medication **side effects** must be considered alongside seizure control. **Cost** is also seen as limiting the choices offered to some service users, with service provision and quality something of a “**postcode lottery**”.

Geographical proximity of treatment is mentioned in QR2, but was found to be an important factor in provision of all types of care, so is covered separately alongside considerations of mobility.

Quality requirement 3: Emergency and acute management

Fewer comments were made on emergency and acute care than for the other QRs – for some it was not a relevant topic, for others it was not a clear memory, particularly for service users with head injury, who are a particular focus for QR3. **Carers may be better placed to comment on QR3**: one carer mentioned that the initial intensive care around his son’s brain injury had been “excellent”. Some people with **epilepsy** may require acute emergency admission; experts with experience in epilepsy care suggested this would be important context to include in a survey.

Quality requirement 4: Early and specialist rehabilitation

One carer and one service user commented on inpatient rehabilitation. For the carer, inpatient rehabilitation had been provided for three months after initial intensive care for his son’s brain injury, but the problem had been **transition into the community**, with no **discharge plan** or information or contact with social services provided. For the service user, the problem had been around **initial referral to specialist rehabilitation**. After diagnosis with a rare and disabling neurological condition, she remained in the local hospital for two years before being transferred to a specialist spinal unit, apparently because “*nobody knew what to do with me*”. **Professional knowledge** and **timeliness** are again important themes within this phase of care. In terms of the specialist rehabilitation itself, the crucial aspect for this service user was being taught **confidence and skills to live independently**, as well as **ongoing contact** with the unit.

Quality requirement 5: Community rehabilitation and support

Community rehabilitation was a key issue for some of the experts and carers interviewed. There was a particular concern amongst those with experience of head injury that service

users are able to access and **re-access** rehabilitation in the **longer term**, to **support their changing needs**: it is important that service users or carers feel able to access further support if needed in future. More generally there was a concern about ensuring service users have the skills and support they need to **live in the community**, and whether there is enough **understanding of neurological conditions** in the broader community (e.g. police, school) as well as social services and local healthcare professionals.

Further important aspects of community support are discussed elsewhere in this chapter. These include the availability of suitable housing options, vocational and educational rehabilitation, and opportunities for those not able to work, and other factors relating to independent living that arise throughout the QRs.

Quality requirement 6: Vocational rehabilitation

A range of concerns were raised about vocational rehabilitation, including:

- **availability** of vocational rehabilitation where appropriate, including **sheltered work environments**
- **sensitivity** and again **awareness of neurological conditions** amongst those involved, e.g. JobCentre staff
- people with neurological conditions being offered vocational rehabilitation where **inappropriate** (e.g. MND)
- what options exist for people who are **not able to work** – access to other opportunities?
- importance of **involving carers in rehabilitation**, e.g. so vocational skills learnt can be practised and used in home life as well
- **advice** for people considering their options around employment, e.g. whether to stop working, reduce hours or change career
- access to **legal advice** around disability rights, discrimination, whether obliged to inform an employer when diagnosed with a neurological condition (e.g. epilepsy)

Education is also fundamental to people's experiences around **community support** and **independent living**, for conditions affecting people in childhood or adolescence. Service users and carers spoke about the importance of **providing education within the local community** rather than excluding or segregating people with neurological conditions. The **availability and location of residential schooling** is vitally important for some young people with complex needs (e.g. behavioural disorders alongside a neurological condition), and for their families.

"We were actually seeking [residential schooling] as a positive thing for our son... to help him with independence. As he couldn't go and stay with anyone else, he was always with us."

Quality requirement 7: Providing equipment and accommodation

Availability and timeliness of equipment and adaptations to accommodation are important topics to cover in a survey. Service users and carers discussed a range of equipment that helped them to live with neurological conditions. The range is probably too wide to cover specifically in a survey, but can more appropriately be defined in a survey in terms of needs. Key considerations raised include whether service users are **assessed** for and **offered** equipment and adaptations which meet their needs; whether provided **when needed**; whether they have had to purchase equipment (e.g. due to **lack of external funding**, poor **quality or choice** of equipment provided, long **waiting time** etc); and whether they feel confident that equipment will be available in future in case of

changing needs. There is also a perceived need for **information and advice** on appropriate equipment to buy if funded equipment is not available.

“Being able to access better information about what services/equipment you could pay for yourself, not just being told nothing is available.” (Service user)

Experts were particularly concerned about the **availability of suitable housing options.** There was a feeling that equipment and housing adaptations are given greater attention both in the NSF and in practice, but the survey should also consider needs and support for more fundamental changes in living arrangements, e.g. **needing to move to a single storey home**, or availability of **supported accommodation** (discussed further in QR8 below). Several carers and service users reported needing to move home or undertake extensive adaptations to accommodate physical disabilities, and highlighted the often **huge financial cost** of this. There is a need for **planning advice** to help service users and carers decide how best to prepare for current and future needs, particularly when taking significant financial decisions around housing or equipment.

“Housing can be the largest obstacle to improving patients’ experience on discharge from rehab.” (Expert)

Quality requirement 8: Providing personal care and support

Providing **options to support independent living in the community** was seen as extremely important, particularly amongst carers and experts. Issues raised included housing options, **supported living, residential care** and **respite care** of acceptable quality and proximity to home (covered further in Section 5.4.3 and Chapter 6); facilitating the **transition** between inpatient care to independent living; links to rehabilitation and the need to **teach basic life skills** and provide **structured activities.** The parental carers interviewed both stressed the importance of offering supported living options for service users’ **independence**, rather than relying indefinitely on **parental care.** It is vital that the caring situation be **reviewed** often.

Service users and carers also complained about the **huge administrative burden** of organising care through Direct Payments, and the hassle of worrying about funding for various aspects of their care. An elderly carer complained of being *“tired of always having to fight for everything from social services”*; a service user diagnosed with a terminal illness spoke of his resentment at having to spend so much time worrying about budgets and organising carer payment, employer liability insurance, tax and national insurance returns – *“and this is for disabled people to pay carers to look after them!”*.

Quality requirement 10: Supporting family and carers

Chapter 6 gives details of specific issues of importance to carers that might be covered in a separate survey for carers. But the involvement and wellbeing of family and carers is also an important concern for many service users, and should be considered as part of a survey of service users’ experiences as well as carers’ experiences.

Issues raised within the service user interviews included: concern over whether family and carers are given enough **practical and emotional support**; whether they have enough **information** about the condition to understand the service users’ needs and limitations; arrangement of **payment for friends acting as carers**; and **advice on benefits** to ease the financial burden on family carers. Specific issues around **children** were also mentioned, including the need for extra help with **childcare** as a result of the condition, and

availability of this; and any particular support around helping children to understand their condition, e.g. **family therapy** or counselling.

A particular issue raised in the expert interviews was the relationship between the carer and service user with respect to health and social care: **how family or carers' involvement is negotiated** between the service user, carer and professionals, and whether and how permission is given by the service user for carer(s) or family to have access to confidential information about the patient, and to have a role in decisions about the patient's treatment and care.

Quality requirement 11: Caring for people with neurological conditions in hospital or other health and social care settings

Lack of understanding of the needs of people with neurological conditions emerged as a particular cause for concern amongst carers and service users with bad experiences or reports of hospital treatment for non-neurological conditions, which a survey could usefully draw attention to. Hospital staff need to be aware, and **listen to patients and family**, about what ongoing care is needed with respect to the neurological condition – particularly around **personal hygiene, feeding and mobility**. Respondents spoke of “people coming out of hospital a lot worse than when they went in” – and a fear or even avoidance of hospitals.

“Staff [at non-specialist hospitals] can cope with the other medical conditions, but they can't cope with the neurological condition as well. They don't understand the needs of people with neurological conditions.” (Carer)

[When in hospital for gastrointestinal problems]:

“marvellous health care, but no idea of how to handle the neurological problem” (Carer)

5.4 Further themes for consideration

5.4.1 Information and advice

Service users and carers would like:

- **Written information about the condition** which they can refer to after the initial diagnosis
- **Opportunity to discuss the condition with specialists after initial diagnosis**, once coped with the initial shock, including advice on the likely impact on daily life and how to manage this
- **Information about prognosis** and how needs are likely to change – **and what services are likely to be provided** – to help service users and carers plan for the future, including making financial decisions
- **Early contact with social services**, and **advice about benefits** that service users and carers may be eligible to apply for (e.g. Disability Living Allowance, Carers Allowance, Blue Badge to help with mobility)
- **Contact details for member organisations** and local support groups

“Would be good if there was a “road plan” of the journey to expect with MND... what'll be provided, to know what to plan for, be one step ahead... whether I'll need money, have to sell the house” (Service user)

5.4.2 Quality of life and emotional needs

There was consensus amongst comments from service users, carers and experts that the survey should include **considerations of wellbeing beyond service provision**.

Service users spoke about the **emotional impact** of being diagnosed with the condition, or living with the condition, or side effects of medication. It is important that service users' emotional wellbeing and needs are recognised and taken into account by professionals, and **emotional or psychological support offered** when appropriate. Many respondents mentioned the importance of "having someone to talk to", which might be a partner, family, friends or professionals. The **social network** of the service user should therefore be considered (within care planning, and within this survey) though this does not necessarily replace the need for professional counselling. **Member organisations** also play an important role in support and advice – in particular, the **opportunity to talk to other people with the condition** can be very valuable when coming to grips with the diagnosis and understanding how to live with the condition.

Experts also highlighted the **importance of assessing quality of life and wellbeing** beyond specific considerations of health and social care as part of a survey. Suggestions for the types of questions that could be incorporated to assess quality of life included **spending time with friends**, feeling **accepted by the community**, active **involvement** in something (employment, leisure, day centre activities etc) rather than just being looked after. Carers confirmed the importance of **social contact** and **structured activity** as central to the success of external care options and independent living arrangements. One "exhausted" carer had felt unable to accept the respite care offered by social services for these reasons.

"With the respite home [through social services], he never moved out of his room for three weeks. He hated every minute of it." (Carer)

5.4.3 Mobility, proximity, accessibility

Mobility is an important factor both in providing services that meet people's needs, and in allowing people to live independently with neurological conditions.

Service users and experts recognised the **ability to drive** as a "major factor" in living independently and being able to get on with life. Service users valued the support they had received around mobility – in one case obtaining a motorbility car, but more commonly through obtaining a **Blue Badge**, which allows service users or their carers to park in more accessible places. This is another benefit which service users and carers would like to be made aware of at an early stage.

A key issue for some carers and service users was the **geographical proximity** of services offered. Whilst QR2 mentions "treatment as close to home as possible", the issues raised around mobility suggest that **travel distances** and **accessibility** need to be considered for all services offered to people with neurological conditions. For example, one carer was offered care for her son at a national centre of expertise in London on a weekday residential basis, but travelling several hours with her son twice a week was not feasible because of his violent behaviour. One disabled service user had been referred to a gym for physiotherapy, but found the nearest car park was a mile away.

5.4.4 Professional qualities and approaches

When talking about their personal experiences of services, service users and carers provided rich insights into qualities and approaches that are, or would be, particularly helpful in professionals working with neurological conditions. These included:

- **Professional knowledge** about neurological conditions (already mentioned in the sections above, but an overarching theme throughout the interviews);
- Treats service user with **dignity and respect** (also identified by experts as a key theme from the NSF);
- Good **personal skills**, makes eye contact, **speaks clearly and directly** to the service user (including children), particularly around “breaking the news” (see QR2);
- **Listens** to the service user, **takes them seriously** (including children), shows **belief** in their symptoms;
- Not too proud to **admit limits of their knowledge** or abilities, research the condition further or refer for a second opinion;
- **Explains** what they’re doing and why, willing to **answer questions**
- Willing to **discuss options** for treatment or rehabilitation if appropriate, involves service user in decisions;
- Can be **contacted** when help or advice is needed in future, or arranges regular **follow-up** appointments.

“[Expert neurologist] was the first person I spoke to that actually believed what I was saying” (Service user)

5.5 Additional survey information

Experts made a number of suggestions around additional contextual information that should be collected in a survey; and if possible, that they would like to see survey results broken down by.

Demographic information

- Age
- Gender
- Ethnicity

Details of condition

- Condition (as reported by service user)
- Length of time since diagnosed with condition
- Some assessment of level of need or disability
- Details of care provided

Standard instruments

Experts also provided suggestions of standard instruments that might be appropriate to assess service users’ level of need or disability. In particular, the Barthel ADL Index was recommended as a widely used assessment of dependency in activities of daily living. It assesses respondents’ ability to care for themselves through 10 basic questions, and is appropriate for use in self-completion questionnaires.

Other suggestions included the Carers' and Users' Expectations of Services (CUES) Assessment, a community outcome measure developed by Stillwell et al (1998), and the Brain Injury Community Rehabilitation Outcome-39 (BICRO-39).

5.6 Terminology

All respondents were asked for their views on the terms "long-term neurological conditions", "service user" and "carer", to explore whether these terms were familiar and felt to be appropriate, and consider any preferred alternatives.

Referring to long-term neurological conditions

Some of the service users and carers interviewed saw themselves or the person they cared for as having a long-term neurological condition, and were familiar with this term as well as the specific diagnostic label for their condition. Others were more familiar with the diagnostic label only. It was suggested that the survey should list specific conditions to illustrate what's meant by "Neurological Conditions".

One carer did not feel comfortable describing brain injury as a long-term neurological condition, as he felt that after the initial phase it was not a medical problem. He preferred the term "life long condition".

Referring to people with long-term neurological conditions

Interviewees were asked for their views on acceptable terms to use when referring to people with neurological conditions (as this full phrase may not always fit easily within the wording of survey questions).

"Service user" was seen as an appropriate term to use in the survey, by people with neurological conditions and by carers. It is not ideal, for some. A disadvantage is that it does not distinguish people with neurological conditions, as everyone uses services; but is generally seen as "OK" and "the best term we have at the moment".

Stronger views were expressed on the terms that should not be used. "User" (as opposed to "service user") is not appropriate. Several people mentioned their dislike of being talked about as a "patient", or referred to by their disability - e.g. "the MS". There were mixed views on terms like "customer", "client", "consumer" - while one interviewee preferred these terms, others disliked this type of reference as it "implies you have a choice".

Referring to carers

"Carer" is a generally recognised term amongst service users, carers and those working with neurological conditions.

Some service users pointed out the distinction between paid and unpaid carers; one viewed the term "carer" as referring to someone who is unpaid and provides support, and uses the term "Personal Assistant" to refer to paid carers. An alternative phrase to catch both relatives and paid carers, suggested by an interviewee with experience in running similar surveys, is "someone who cares for you".

The term "carer" was least acceptable when describing a husband-wife relationship. In particular, both service users and carers mentioned that they saw their partner or themselves simply as a husband, with no need for a particular term to reflect the support

provided within the relationship. For these interviewees, “carer” was viewed as a term used by other people.

"As far as I'm concerned I'm her husband, but they call me a carer."

Recommendations and issues for consideration

Survey questions should be based around service users’ needs where possible, and how well they were met, as well as asking about specific types of services and professionals involved in individuals’ care.

Respondents have raised an extensive and varied list of issues that could be covered in a survey of people with neurological conditions. The amount of information that can be collected in a survey will depend on the chosen survey mode.

It is recommended that some aspects of each QR, except QR9, be covered in the survey; the discussion here provides some suggestions on relevant issues to cover within each QR, but HCC will also have views on the most important information to collect.

The additional themes raised in this consultation should be given serious consideration for coverage in a survey alongside QR topics.

Overarching themes that cut across the NSF but should be reflected in the survey include independent living, professional qualities, information, ongoing support and transitions; key themes that may not be captured by the NSF include quality of life and financial considerations.

Additional information collected in a survey should include age, gender, ethnicity, and details of the condition and any care provided.

Standard assessments of disability of need should be investigated further for possible inclusion in a survey. Consideration will need to be given to the length of standard instruments, whether appropriate for the selected survey mode, and their relevance to respondents with a range of conditions.

Recommendations for terminology

The official term “Long-term Neurological Conditions” can be used for a survey title, but a list of examples should be given to illustrate the types of condition this includes.

The survey may be best introduced as a survey of “people with long-term neurological conditions”, but as a more concise reference within the survey it is acceptable to use the term “service user”.

When referring to carers, the phrase “someone who cares for you” may better capture the range of people providing care. It is worth using this phrase when introducing the topic or when identifying appropriate help for proxy survey completion. But “carer” is generally a recognised term and can be used as a more concise reference within the survey.

6 CARERS SURVEY

6.1 Introduction

One of the Quality Requirements in the NSF relates specifically to carers, and their needs. Therefore, one of the issues that was investigated as part of this feasibility study was whether there should be a separate survey of carers.

In this chapter we look at who carers are, whether there is interest in a separate survey, how this could be done and what such a survey could cover.

6.2 Definitions of carers

When defining carers, experts mentioned the following factors as being relevant:

- Paid vs. unpaid carers
- Amount and type of care provided

Paid vs. unpaid

Unpaid carers tend to be close relatives (often spouses, parents or children), and are often what the term “carer” conjures up.

“A family member or friend who cares for them in order for them to live independently”

Paid carers, commonly called Personal Assistants, often provide help alongside that of unpaid carers. One expert made the point that “carers tend to be close relatives, or paid carers: you rarely find unpaid friends as carers”.

When one service user was diagnosed, a close friend had moved in to help him with day to day tasks. They were then viewed as a couple by social services, and his benefits were cut, as she had a job. She therefore moved out and is now paid via direct payments to help him. This scenario may help to explain why close friends are rarely unpaid, live-in carers.

Among service users, this distinction between carers and Personal Assistants seems common, but a number of service users did not like the term “carer” even though they understood what it meant.

“The term carer is a bit of a problem, personal assistant is better – but they are paid. However, some people would not see their husband, for example, as their carer.”

“My partner and I hate the term carer, but we do differentiate between a PA and a carer – a carer is unpaid and provides support, but I wouldn’t call my partner a carer”

Section 5.6 considers appropriate terminology for use in a survey.

Amount and type of care

Carers can provide a range of care, and this will depend on the needs of the person they are caring for. Some carers will have to provide full-time care, while others may provide care for fewer hours a week, and for certain activities, because the person they care for can do more for themselves.

The age and employment situation of the carer will also affect the amount and type of care given, and the need for additional paid care.

"The role differs depending on whether the carer is providing personal care versus looking after social or organisational aspects" (Expert)

"Carers for the cognitively impaired and the incontinent tend to have the most stress!" (Expert)

6.3 Caring arrangements of service users

A variety of caring arrangements were reported by service users and carers interviewed.

Almost all those interviewed had some support through their family (husband, wife, parents) or friends. Depending on the needs of the service user, this ranged from largely emotional support, *"just being there"*, or being ready to help during difficult phases (e.g. migraine, epileptic seizures), through to full-time care. Some family carers had reduced their working hours or took time off work on an ad hoc basis to provide care when needed, while others had resigned or retired from paid work altogether. This might be because the person they care for needs, or began to need, full-time care; carers may provide this themselves because they prefer to, or because external care was not funded, or not acceptable.

"I gave up paid work nine years ago to make sure [my wife] was going to get the right care, as opposed to some of the care she hadn't been getting."

People reported using paid carers or Personal Assistants (PAs) to supplement the support provided through family – either at times when a family carer was not available, or to provide different kinds of help, such as personal hygiene.

Several people mentioned using Direct Payments from social services to pay for external care. This attracted both positive and negative comments – on the one hand allowing control and choice over one's care, but on the other hand involving a huge administrative burden. In particular, one service user diagnosed with a terminal illness resented the amount of time and mental effort involved in meeting the bureaucratic requirements of carer employment.

6.4 Survey of carers

The NSF has a Quality Requirement (QR10) that relates specifically to carers, and their needs. Therefore, there has been some discussion of whether a separate survey of carers should be conducted.

Most experts felt that it would be useful (but not necessarily essential) to have a specific survey for carers that covered issues relating to them rather than to the service user.

“Yes, their experiences are very different”

“The carer and the user are not a package – they are separate individuals”

“Carers are involved along the whole care pathway – and will have valid views, but a different perspective to users that will add richness and depth”

Carers were keen on the idea.

“I’d welcome this, actually. It would be nice to be asked what my views are.”

“Yes, that would be worth doing – but you’ll find that nobody has the help they need”

6.5 Sampling carers

The most straightforward way to conduct a survey of carers would be to identify carers via a sample of service users. Identifying a specific sample of carers, especially those caring for someone with a neurological condition, would be difficult.

However, as one expert pointed out, this approach via service users could have problems:

“Don’t contact carers via the person being cared for. The relationship can be very delicate, and people with some conditions might not acknowledge that they have a carer.”

Among service users, there is the issue of who they see as their carer – and so who they would suggest should take part in any “carer” survey. The language used will be important to make sure the right people are involved – this is discussed in Section 5.6.

6.6 Carers survey mode

The carers that we consulted were asked about potential survey methods: postal self-completion questionnaires, face-to-face interviewer administered interviews (CAPI), web surveys and telephone interviews (CATI).

For most carers, all methods were feasible although face-to-face and self-completion questionnaires were the favoured modes. A few of the experts that we spoke to were carrying out surveys for which they sent postal self-completion surveys to service users and carers. One expert pointed out that self-completion questionnaires would allow the carer time to look up information about services that they or the service user had been in contact with, which may help carers to complete the questionnaire more accurately.

For carers, space for free text comments was again important.

“Including space for free text comments is very important, for patients and for a carers survey” (Expert)

However, as one carer pointed out, it shouldn't be assumed that all carers can write, which is something that needs to be considered.

“I have a friend who cares for his wife fantastically, but is no longer able to write”

Additionally, face-to-face interviews were well received as the primary survey method while telephone interviews were viewed as an acceptable alternative or follow-up method for carers. One of the experts that we spoke to was utilising telephone surveys as a follow-up method for carers and felt it had *“worked well”*.

There were varying views in terms of the length of the survey. For one carer the length of the survey would not be an issue if it was for the Healthcare Commission as it is *“important to feed back to them”*. Meanwhile another carer felt that an hour would be a reasonable length for a survey and she would be disinclined to take part if the survey was too long. Carers also felt that they would want to know that the survey is *“worth doing”*, which reflects the view amongst service users.

6.7 Carers survey content

6.7.1 Priority themes for a carers survey

As shown in the topic guide (Appendix B), carers were asked to comment in the interviews both on the experiences of the service users that they care for, and also about their own experiences. The first part of each interview focused around provision of services and how well service users' needs had been met; these views are included alongside those of service users and experts in Chapter 5.

The following section presents themes emerging from carers' comments on their own experiences, including their **needs as a carer**, and the **types of support** they receive or would like to receive. Themes and issues to consider for a survey are highlighted in bold. These should be considered alongside those in Chapter 5 from service users and experts around QR10, if there is interest in undertaking a separate survey for carers.

Emotional needs and support

Carers spoke about being **exhausted** through caring, both through the physical and mental demands of caring, and the difficulty of **getting proper rest** when providing 24 hour care. The need for respite care is discussed below; but carers also expressed a general need to **feel that “support” is available**.

Carers spoke about the importance of being able to **access professional advice** around caring when needed, including out-of-hours contact; but also of just having **someone to talk to** about the demands and frustrations of being a full-time carer. As with service users, the **support network** of the carer should be considered by those involved in caring for the service user, and **counselling** should be offered where appropriate. **Member organisations** again play an important role – carers appreciated the opportunity to talk to other carers and professionals with experience of the condition. In particular, some organisations (e.g. Tourette's Association, PSP Association) offer access to professional advice by phone, which is highly valued by carers.

"Tourette's Association... [is] our only way of feeling we've got any support" (Carer)

*"It's knowing there's somebody there at the other end of the phone if you need them"
(Carer)*

Asking for help, being offered help

A particular issue emerging in the carer interviews is the reluctance of some carers to ask for help. Carers spoke of feeling that they should be able to cope, wanting to manage everything themselves, being too proud to ask for help; and often not seeking help until they became desperate (even suicidal), or were persuaded to accept help by a professional treating the person they care for. There is therefore an important role for **professionals in contact with service users** to be aware of the emotional wellbeing and needs of carers, and to **actively encourage and help to arrange support for carers** where needed – whether counselling, respite, assistance from an external carer, or other support.

"It creeps up on you – you start off thinking, "I can cope". But you don't realise how much you are coping." (Carer)

"It took a lot to ask for help" (Carer)

Respite care

There is clearly a huge need amongst some carers for respite care as a relief from the pressures of full-time caring, or in some cases a need for full-time residential care. However, there is a perceived **lack of acceptable funded options** for residential care, or places for residential schooling. As discussed in Chapter 5, there is a concern about the quality of life in residential care homes funded by social services, particularly around structured activities and social contact, to the extent that one very tired carer felt unable to accept this option for her husband. Practicalities and geographical proximity also sometimes prevent carers accepting much needed residential care. As mentioned above, pride is also an issue, and carers may need to be encouraged to use respite care as an acceptable part of caring. It is therefore important to consider in a survey not only whether carers have been **offered respite care** if needed, but also whether it was offered in an **acceptable and workable manner**.

"[With respite] I'd get a decent night's sleep. You know... it's tiredness more than anything, that gets to you." (Carer)

"I hesitate to use the word respite care – because it suggests that you're parking someone away for your own convenience." (Carer)

Life outside caring

Other than respite care, carers talked about the need for **time for themselves**, and with **other family members** – particularly when parents are caring for a young person with neurological conditions alongside looking after other children. One carer spoke of a sibling support group that had worked very well for her younger son; it would be worth including questions on **family support** in a carers survey, as an additional aspect of QR10. Carers also spoke about having to **give up working**, and the lack of mentally stimulating pursuits outside caring. One carer who had given up paid work to make sure his wife received the right care had sought challenging volunteer work *"just to keep myself going"*. It may be interesting to assess in a survey whether carers have left employment to provide care, and why (e.g. prefer to provide care themselves, or dissatisfaction with

external care provided); and whether carers have time for themselves outside caring. Standard instruments may cover some of these issues.

“Everyone needs a break.” (Carer)

“Well I’ve forgotten what a normal life is like, haven’t I?” (Carer)

Life after caring

It is important for carers, and service users, to know that arrangements are in place to take care of a service user when their carers are no longer able to. As noted elsewhere, social services should not be over-reliant on parental or other family care where it exists, but should offer options for independent living; and should not assume that carers will cope, or that they will ask for help when they are struggling. Pride is often at play, as parents or partners feel they should be able to cope. Carers become old, or exhausted, and patients’ conditions deteriorate; it is important that caring arrangements are reviewed regularly, and carers feel able and encouraged to ask for help when they need it.

*“Whatever needs doing, I’ll do it. And I will continue to do it as long as I can.”
(Carer, 70s)*

“We are getting older – what happens [to our son] when we die? This is a problem for a lot of carers of brain injured people.” (Carer, 70s)

Information and advice

As with service users, availability of information and particularly advice is a key issue for carers. Being provided with **written information** on the condition and prognosis is important for **carers’ own understanding** of the condition and the person they care for, as well as allowing them to **plan how to provide appropriate care and support**. The financial implications of caring for someone with a neurological condition can be massive: carers would appreciate early advice to help with **financial decisions** around housing and equipment, and information about **benefits** available to the service user and themselves. Again, this information is needed at an early but appropriate stage, as diagnosis can also be a huge shock for the family and take time to come to terms with. The issues raised in Chapter 5 under QR7 are particularly relevant for carers as well.

“You need a drip feed of information, as it is difficult to take in initially” (Carer)

Professional qualities and approach

Most of the approaches discussed in Chapter 5 are relevant to professionals when working with both service users and carers. Some professional qualities were discussed specifically with reference to carers:

- **Involves the carer** in decisions about care, and in the care itself (e.g. rehabilitation)
- **Listens** to the carer, gives them the chance to **ask questions**
- Appreciates what’s involved in being a full time carer, concerned about the **carer’s needs**, proactive in arranging **support for carer** (e.g. respite, counselling, paid carer)
- Shows **belief** in the carer, confidence in their capabilities as a carer or parent

6.7.2 Additional survey information

On the basis of discussion with experts and carers, various pieces of additional information should be collected in a carers survey to provide context around the caring situation and help to interpret survey responses.

Demographic information (carer)

- Age
- Gender
- Ethnicity
- Employment status

Details of person cared for

- Relationship to person they care for
- Condition

Details of care provided

- Whether living with person they care for
- Type and amount of care provided (hours per week)
- How long been providing care
- Whether any paid care provided

Standard instruments

Experts again mentioned standard instruments that might be considered for inclusion in a survey of carers. Suggestions included carer sections of the CUES assessment and BICRO-39 mentioned in Chapter 5; and some standard measure of psychological wellbeing such as the General Health Questionnaire (GHQ), “to get a feel for how bad it is for them”.

Recommendations for a carers survey

We would recommend that serious consideration is given to conducting a separate survey of carers.

Finding carers separately to service users would be very difficult, so any survey of carers would, from a pragmatic point of view, need to be based on those caring for a sample of service users that we identify.

One option would be to request carers’ contact details from service users and contact them directly with a follow-up survey. This approach may present ethical issues, and would need to be investigated further.

Alternatively, a questionnaire for carers could be sent or given (depending on the mode) to all service users selected for a survey, asking if there is someone that provides care for them, to pass it on.

If we are interested in unpaid carers, we would need to make this clear to service users.

Recommendations for a carers survey (cont'd)

No particular problems are anticipated with using self-completion for a carers survey. We envisage that a carers survey would be considerably shorter than the survey for service users.

Recommendations for survey content

Issues identified as being important to carers are wide ranging, and show less correspondence to the NSF areas than those important to service users. A carers survey would require substantial development of questions beyond those for service users.

Overarching themes again include information, professional qualities, emotional needs and ongoing support. Further areas include appropriate involvement of carers by professionals, consideration of carers' needs, and provision of external care options.

Additional information collected in a survey of carers should include details of the carer and care provided, as well as details of the person they care for and their condition. Standard instruments should be investigated further for possible inclusion in a survey of carers.

7 RECOMMENDATIONS FOR A SURVEY AND NEXT STEPS

7.1 Recommendations for a survey

This section draws together the recommendations that have been made in the various chapters of this report.

7.1.1 Who should be included

- We would recommend that ME/CFS should be excluded from a survey of people with neurological conditions.
- We would also recommend excluding headaches and migraines, as the majority of headache and migraine sufferers will not be accessing or need to access the services of most interest. However, it should be noted that by excluding these we will miss people who are severely affected by the condition.
- We would recommend that muscular dystrophies are included, as they appear to be within the scope of the NSF. We would also suggest that young stroke and early onset dementia are included in this survey (by setting an age criteria for sampling, for example including anyone with these conditions who falls within the age criteria specified for the survey – see below).
- In our view the survey should be as inclusive as possible (given sampling practicalities), and should not just focus on the more common neurological conditions. However, we would also suggest that the current survey should focus on people with neurological conditions who are living in the community rather than in residential or nursing homes.
- We would not advise restricting the survey on the basis of time since diagnosis, but this information should be collected as context for interpreting survey findings.
- The survey should focus on people of working age (16-65) as in the NSF, but we should consider the possibility of extending the age range to include older people. We recommend that 16 is kept as the minimum age. If there is interest in exploring issues around children with neurological conditions this would require a separate survey.

7.1.2 Sampling issues

- Sampling using a condition-based approach will be more straightforward than using needs based sampling – although there are weaknesses to this approach (see Chapter 2). To draw a sample relevant to this survey, a sampling frame would need to contain information on condition, age and contact details.
- Although the logistics and issues surrounding the use of GP registers are problematic, this would appear to be the most effective way to sample a representative group of people with neurological conditions. Therefore, we suggest that more time should be

spent considering whether it would be feasible to go down this route. Use of DWP data also merits further investigation.

- The National Dataset is worth keeping an eye on: if it works as intended it could be an ideal sample frame.
- None of the other possibilities are likely to provide a representative sample on their own. Therefore, an alternative option would be to obtain sample from a range of sources: we would suggest hospital records, member organisations, specialist providers that can be identified in an area and possibly social services. Such an approach would need careful piloting in a couple of areas to assess how feasible it would be on a larger scale, and/or which sources would be most useful to focus on for a larger scale survey.
- Whatever sampling approach is taken, it is important to try to ensure that the sample represents people from black and minority ethnic groups.

7.1.3 Survey mode

- It is important to allow flexibility in terms of the mode of the survey, and in how involved carers can be, to ensure that the survey does not exclude people who have communication or other cognitive difficulties that make it difficult for them to take part in a survey.
- Face-to-face interviews were the preferred survey method for service users, carers and experts. A face to face approach would allow more information to be collected during an interview than self completion methods would, and would also allow more filtering, so that the questions could be more specific to the needs and condition of each respondent.
- This would be an expensive approach and would require the sample to be clustered into assignments that are cost effective for interviewers to cover. This level of clustering will be difficult, as people with neurological conditions are only a small proportion of the population and are thus unlikely to be found in sufficient numbers in small geographical areas.
- Self-completion questionnaires were generally well received, particularly if respondents are provided with the option of completing an e-mailed or web survey alongside this. However, self-completion methods would make it difficult to monitor the reasons for non-response and could exclude certain groups of people, for example those with severe cognitive or physical difficulties. The amount of information that could be collected would be limited both in terms of length and specificity.
- Ideally, we would have specialist interviewers skilled at the sort of communication skills that might be needed who could assist where help is needed – but this would be difficult to organise. Therefore, if people do need help completing the survey (whatever the mode), we should allow them to choose who helps them (e.g. a carer, a personal assistant, someone at a service provider). If help is provided, we will need to record this, and who provided the help.

7.1.4 Survey content

- Survey questions should be based around service users' needs where possible, and how well they were met, as well as asking about specific types of services and professionals involved in individuals' care.
- It is recommended that some aspects of each QR, except QR9, be covered in the survey; Chapter 5 provides some suggestions on relevant issues to cover within each QR, but HCC will also have views on the most important information to collect.
- We would recommend that some of the additional themes raised in this consultation should be given serious consideration for coverage in a survey alongside QR topics.
- Overarching themes that cut across the NSF but should be reflected in the survey include independent living, professional qualities, information, ongoing support and transitions; key themes that may not be captured by the NSF include quality of life and financial considerations.
- Additional information to collect in a survey includes age, gender, ethnicity, and details of the condition (diagnosis and impact of condition).
- There are a number of standard questionnaire instruments that merit further investigation for inclusion (see Section 5.5).

7.1.5 Survey terminology

- The official term "Long-term Neurological Conditions" can be used for a survey title, but a list of examples should be given to illustrate the types of condition this includes
- The survey may be best introduced as a survey of "people with long-term neurological conditions", but as a more concise reference within the survey it is acceptable to use the term "service user"
- When referring to carers, the phrase "someone who cares for you" may better capture the range of people providing care. It is worth using this phrase when introducing the topic or when identifying appropriate help for proxy survey completion. But "carer" is generally a recognised term and can be used as a more concise reference within the survey.

7.1.6 Carers survey

- We would recommend that serious consideration is given to conducting a separate survey of carers, that is linked to a survey of service users. Finding carers separately to service users would be very difficult, so it makes sense to identify those caring for a sample of service users that we identify.
- If we are interested in unpaid carers, we would need to make this clear to service users, and ask them if there was someone appropriate who we could contact to follow up with a separate survey. This approach may present ethical issues, which would need to be investigated.
- A more pragmatic approach could be to send/give a questionnaire for carers to all service users selected for a survey, asking them to pass it on.

- We recommend that a self-completion questionnaire be used for a carers survey.
- Additional questionnaire development would be required beyond that undertaken for service users, to reflect the range of issues identified as a priority for carers; though we envisage that a carers survey would be considerably shorter than the survey for service users.
- Priority areas to cover in a carers survey include information, professional qualities, emotional needs and ongoing support, as well as appropriate involvement of carers, consideration of carers' needs, and provision of external care options.
- Additional information collected in a survey of carers should include details of the carer and care provided, as well as details of the person they care for and their condition. Standard instruments should be investigated further for possible inclusion.

7.2 Next Steps

To test out our recommendations, and to assess how well such a survey would work in practice, the next stage will be to pilot a survey of people with neurological conditions (perhaps in just a couple of areas) in order to test:

- Whether we can find a feasible sampling method, that will be practical to use for a larger scale survey and that provides a representative sample
- Which mode will be most effective (in information, coverage and cost terms)
- The questionnaire
- How easy it is to “piggy back” a carers survey onto a service user survey.

The design of this pilot stage will be produced in consultation with the Healthcare Commission. In this section we propose some ideas about how this pilot might be conducted, and some of the issues that we believe merit further investigation.

7.2.1 Sampling

We recommended that the idea of sampling through GP registers is investigated further. This approach has been used before, and is problematic – mainly due to the many data protection issues that arise. We would like to discuss this further with the Healthcare Commission, and possibly with GPs or their professional bodies, to see if this approach is worth considering. In particular, the issue of prior consent from sample members and how this could be obtained in a practical way would need to be addressed. This issue could be discussed with the General Practitioners Committee (GPC) and the Patient Information Advosry Group (PIAG).

If this approach is not possible, then we feel that it will be necessary to sample from a combination of sources in an area. We suggest including hospital records, specialist service provider records, local societies membership records and possibly Social Services. To pilot this approach, we would identify at least two areas (size to be agreed – possibly PCTs), and would attempt to access a sample from the relevant sources. This would involve identifying the relevant sources in any area and then approaching them. There may be logistical or data protection issues relating to these sources, and the pilot would allow us to identify these. Any sample produced would need to be combined, and de-

duplicated. This will allow us to see the level of overlap, and whether the different sources are contributing significantly to the sample coverage.

7.2.2 Survey mode

The design of the questionnaire will depend, to a great extent, on the survey mode that is adopted. A face-to-face interview would be the ideal approach – this was service users' preferred method, it would allow better coverage among those who are more severely disabled by their condition, and would allow a longer interview that could be tailored according to the needs of each individual.

However, such a survey would be expensive, as it would be difficult to cluster a sample of people with neurological conditions into areas which are cost-effective for interviewers to work in.

Therefore, a pragmatic approach is to use a self-completion survey that is posted out in paper form, but with options for respondents to complete a web version, or to request a Word version that they can complete and e-mail back.

Ideally, for the pilot, we would follow up some non-respondents to the self-completion questionnaire with a face-to-face interview, to find out why they did not respond (to assess whether this survey mode discriminates against those more severely affected by their condition). However, this may not be possible, due to the ethical issues around recontacting non-respondents.

Another option would be to have face-to-face interviewers placing (at least some of the) self-completion questionnaires, and so identifying respondents where this mode would not be practical.

7.2.3 Questionnaire design

Having identified the topics that should be covered, the next stage will be to design a questionnaire, and test it thoroughly using cognitive interviewing. There is a team at Oxford, lead by Professor Ray Fitzpatrick, which is working on developing a survey of people with neurological conditions for the Department of Health. This team has put a lot of time and effort into developing a self-completion questionnaire that focuses on questions around the NSF, and which is designed to be completed by people with MS, Parkinson's and MND. We recommend collaborating with that team, so that the questionnaire designed for the HCC survey builds upon work already done and does not reinvent the wheel. We have arranged to meet the team in Oxford to discuss how best to work together as the two projects progress. One important aspect of a collaborative approach should be to look at how the two surveys can be presented as complementary to the service user community.

Following design and testing, the final questionnaire would be tried out on the sample gathered in the areas where we conduct the pilot.

7.2.4 Carers survey

If it was decided to also pilot a survey of carers, this would need to be developed and tested alongside the survey of service users.

7.2.5 Ethical approval

The pilot study will require ethical approval from the National Research Ethics Service (NRES). This needs to be considered in any timetable for the pilot.

APPENDIX A LITERATURE REVIEW

The literature review considered previous studies using non-passive research methods with patients with long-term neurological conditions, and/or their carers. A summary of the studies reviewed is shown below.

CONDITION	PATIENTS or CARERS	RESEARCHER(S)	RELEVANT DETAILS OF STUDY
A) STUDIES OF KEY INTEREST			
Parkinson's, multiple sclerosis, motor neurone disease; cerebral palsy	P & C	Ray Fitzpatrick, Oxford: current proposal within DH long-term neurological conditions research initiative ²	Proposes to assess health status, needs, access and experiences of services for patients and carers, focusing on Parkinson's, MS, MND (& cerebral palsy), using qualitative interviews for survey development
Brain injury	P & C	Lynne-Turner Stokes, Northwick Park Hospital, London - ongoing work for DH ³	Aims to assess experiences of people who care for patients with acquired brain injury. Using postal questionnaire for carers and patients, with options for telephone or face-to-face interview if required. Pilot phase validates postal & phone methods against interview data for same carers. NB Sampling via rehabilitation services network register (access to over 1200 patients), may be extended to voluntary membership groups
Multiple Sclerosis	P	NHS 2006 (Derick Wade, Oxford) ⁴	National survey of NHS services for people with multiple sclerosis included 674 MS patients' response to postal questionnaire on service use, satisfaction with support, access etc. Did not audit social service use but noted this as an area for future attention. NB Sampling - study notes lack of accessible register of MS patients to use as sampling frame; relied on postal survey to known patients, with a 30% response rate

² <http://www.sdo.lshtm.ac.uk/sdo1232006.html>

³ http://212.188.234.56/newgenNRR/ASP/printDocument.asp?docID=N0515124650&xsl=Print_NRR_pubproj.xsl

⁴ <http://www.rcplondon.ac.uk/pubs/contents/700f3a0e-32ed-463f-be05-191494875e15.pdf>

CONDITION	PATIENTS or CARERS	RESEARCHER(S)	RELEVANT DETAILS OF STUDY
B) OTHER STUDIES OF INTEREST (A to Z by condition)			
Charcot-Marie-Tooth disease	P	Angela Arnold et al (2005), Royal Free Hospital, London ⁵	Interviewed 14 adult patients with CMT based around an informal questionnaire on psychosocial issues – experiences of first symptoms, diagnosis, disability, genetic counselling
Charcot-Marie-Tooth disease	P	MacMillan & Harper (1992), Cardiff	Study included a subjective perception of disability from CMT patients
Chronic fatigue syndrome	P	Moss-Morris & Chandler (2003), NZ	49 CFS patients completed the Illness Perception Questionnaire-Revised and 36-SF – found more negative views about symptoms and impact on lives than arthritis patients (similar disability level but clearly defined)
Head injury	P & C	Kneafsey & Gawthorpe (2004), Manchester ⁶	Reviews studies exploring impact of head injury on patients' and families' lives and range of support needed
Huntingdon's disease	P & C	Jacopini et al (2000), Rome ⁷	Ad hoc questionnaire used to analyse experience of home assistance for individuals with HD and their families
Migraine & other headache	P	Bekkelund & Salvesen (2002), Norway ⁸	Questionnaire of patient satisfaction with specialist consultation NB Sampling via neurological outpatient clinics (Norway)
Migraine	P	Turner (2005), UK ⁹	Results of the 'Migraine Experience' survey, a pan-European survey of the impact of migraine on the lives of over 2,000 sufferers
Motor Neurone Disease	P & C	Crispin Jenkinson, Ray Fitzpatrick, Oxford ¹⁰	Patient and carer experiences of health care services for MND

⁵ http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=pubmed&cmd=Retrieve&dopt=AbstractPlus&list_uids=16047093&query_hl=2&itool=pubmed_docsum

⁶ http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=pubmed&cmd=Retrieve&dopt=AbstractPlus&list_uids=15189413&query_hl=20&itool=pubmed_DocSum

⁷ http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=pubmed&cmd=Retrieve&dopt=AbstractPlus&list_uids=11293303&query_hl=20&itool=pubmed_DocSum

⁸ http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=12389752&dopt=Abstract

⁹ <http://www.medicalnewstoday.com/medicalnews.php?newsid=30900>

¹⁰ http://www.publichealth.ox.ac.uk/units/huru/activities/copy_of_patient

CONDITION	PATIENTS or CARERS	RESEARCHER(S)	RELEVANT DETAILS OF STUDY
B) OTHER STUDIES OF INTEREST (A to Z by condition)			
Multiple Sclerosis	P	Isaksson & Ahlstrom (2006), Sweden ¹¹	Content analysis of qualitative interviews with 61 MS patients on their experiences of initial symptoms & diagnosis
Multiple Sclerosis	P & C	Khan et al (2006) – including Lynne Turner-Stokes – Melbourne ¹²	Comparison of perceptions of MS patients, carers and doctors using structured interviews (open questionnaires and standardized assessments). NB Sampling via a tertiary hospital database of 101 MS patients living at home (also provided disease data).
Multiple Sclerosis	P	Rothwell et al (1997), Edinburgh ¹³	Asked opinions of 42 MS patients to prioritise which domains of health are most important to consider in future clinical trials. NB Sampling via consecutive patients at neurology outpatient clinic or rehabilitation ward
Myasthenia gravis	P	Padua et al (2002), Rome ¹⁴	Development and validation of the Myasthenia Gravis Questionnaire (MGQ), a patient-derived outcome measure for MG: based partly on items proposed by patients with MG, & edited through further testing
Myasthenia gravis	P	Rostedt et al (2006), Sweden ¹⁵	Tested reproducibility of MGQ on clinically stable Swedish MG patients
Parkinson's disease	P	Dodel et al (1998), Munich ¹⁶	40 PD patients required to document all items of health care provision over a 3 month period! (for calculation of medical costs) NB Sampling via neurological outpatient clinic and patients of 2 neurologists

¹¹ http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?itool=abstractplus&db=pubmed&cmd=Retrieve&dopt=abstractplus&list_uids=16924998

¹² http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=pubmed&cmd=Retrieve&dopt=AbstractPlus&list_uids=16609318&query_hl=20&itool=pubmed_docsum

¹³ http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?itool=abstractplus&db=pubmed&cmd=Retrieve&dopt=abstractplus&list_uids=9169401

¹⁴ http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?itool=abstractplus&db=pubmed&cmd=Retrieve&dopt=abstractplus&list_uids=12235493

¹⁵ http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=pubmed&cmd=Retrieve&dopt=AbstractPlus&list_uids=16816904&query_hl=16&itool=pubmed_docsum

¹⁶ http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=pubmed&cmd=Retrieve&dopt=AbstractPlus&list_uids=10186468&query_hl=20&itool=pubmed_DocSum

CONDITION	PATIENTS or CARERS	RESEARCHER(S)	RELEVANT DETAILS OF STUDY
B) OTHER STUDIES OF INTEREST (A to Z by condition)			
Stroke	P	Parker, Dewey & The Total Study Group (2000), Nottingham ¹⁷	Assessment of postal questionnaire response amongst stroke patients. Qnaire sent to 440 stroke patients as outcome assessment, incl standard assessment scales. High initial response rate of 60%; increased to 85% through postal and telephone reminders. Telephone follow-up effective for incomplete response. Both potential sources of NR bias. Sampling via hospital stroke centres.
Stroke	P & C	Prof Ann Ashburn and colleagues, Southampton and Bournemouth ¹⁸	Research programme focuses on rehabilitation and recovery after stroke, personal experiences of stroke to understand the views of patients and carers. NB Sampling through patients in hospital acute stroke unit & rehabilitation centre (over 400 patients involved)
Stroke	P & C	Profs House & Hewison, Leeds Uni ¹⁹	Developing measures of patients' and carers' perception of care; qualitative study exploring meanings of continuity of care for patients and their carers; interviews with patients and carers to test feasibility and acceptability of producing case-specific care plans following stroke.
Stroke	P	Sturm et al (2002), Australia ²⁰	Interviewed 93 patients three months after stroke to validate the Assessment of Quality of Life (AQOL) instrument for stroke community NB Sampling via follow up to community-based stroke incidence study
Stroke (young patients)	P	Hamedani et al, Yale	Open-ended interviews with 40 young stroke patients to develop a QOL instrument for young stroke patients; assessed validity & reliability of instrument with a further 71 patients, one year after stroke

¹⁷ <http://ije.oxfordjournals.org/cgi/content/full/29/6/1065#T4>

¹⁸ <http://www.stroke.soton.ac.uk/research.htm>

¹⁹ <http://www.leeds.ac.uk/medicine/psychiatry/research/strokecont.htm>

²⁰ http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?itool=abstractplus&db=pubmed&cmd=Retrieve&dopt=abstractplus&list_uids=12468787

CONDITION	PATIENTS or CARERS	RESEARCHER(S)	RELEVANT DETAILS OF STUDY
B) OTHER STUDIES OF INTEREST (A to Z by condition)			
Various neurological conditions	P	Ray Fitzpatrick & A Hopkins (1983), Oxford ²¹	Study of patients attending neurological outpatient clinic (cf Sampling) found patient satisfaction surveys do not fully capture patient concerns
Various neurological conditions	P	Barnes & Skeil (1996), Newcastle ²²	Questionnaire seeking patient views and preferences on format of neurological rehabilitation clinic. NB Sampling – sent to all new outpatients attending a multidisciplinary rehabilitation centre
Various long-term conditions	P	Sara Corben & Rebecca Rosen (2005), Kings Fund, UK ²³	Reviews patients' perceptions about managing their own long-term conditions, identifies how health and social care providers can support them (NB focus is not on neurological conditions)
Research with seriously ill patients	P	Davies et al (1998), St Barts Hospital, London ²⁴	Reflections on whether research interviews with seriously ill patients cause distress or interfere in management (based on cancer patients)

²¹ http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=10265564&dopt=Abstract

²² http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=pubmed&cmd=Retrieve&dopt=AbstractPlus&list_uids=8730542&query_hl=20&itool=pubmed_DocSum

²³ <http://www.kingsfund.org.uk/resources/publications/selfmanagement.html>

²⁴ http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=pubmed&cmd=Retrieve&dopt=AbstractPlus&list_uids=9819729&query_hl=20&itool=pubmed_DocSum

APPENDIX B TOPIC GUIDE COVERAGE

Topic Guide Coverage – Experts

Long-term Neurological Conditions Survey, Feasibility Study

Expert Interview Topic Guide

Context:

The Healthcare Commission has asked us to carry out a feasibility study into whether a survey of people with long-term neurological conditions could be carried out and, if so, what the best methods are for doing this. This study would focus on both the health and social care of people with such conditions.

They have asked us to consider national and NHS Trust based surveys, all healthcare settings, different types of long-term neurological conditions, service users and carers.

General:

- Talking to a range of experts – fairly unstructured, although there are key areas we want to cover in this discussion
- Confidential – no comments attributed to any individual
- Check if OK to tape record (just for research use, saves taking so many notes, easier to analyse, any transcripts will be anonymised etc)
- Will take about an hour

A. BACKGROUND INFORMATION ABOUT RESPONDENT

- Current position and length of service
- Previous experience/roles
- Knowledge of and involvement in long-term neurological conditions
- Expertise in any particular condition(s)?
- Current/previous involvement in any groups relating to specific conditions or service users

B. DEFINITIONS

Objective of this section: To discuss the definition of long-term neurological conditions (we will talk later about how we might identify and sample people with such conditions, and which conditions should be included in a survey)

Are all neurological conditions sufficiently defined, e.g. by ICD codes? Are these used for diagnosis?

How would people with the condition be likely to define their condition?

Are any conditions particularly problematic in terms of definition and diagnosis (e.g. ME? Migraine?)

Any useful distinctions / groupings that are commonly used?

e.g. broad categories in NSF – with suggested implications for service use:
BUT DON'T LEAD TOO MUCH ON THIS

- Sudden-onset conditions (followed by partial recovery)
[e.g. acquired brain injury or spinal cord injury]
- Intermittent & unpredictable conditions (relapses & remissions mean service needs vary)
[e.g. epilepsy, headache, early multiple sclerosis]
- Progressive conditions (deterioration means increasing dependence on care)
[e.g. motor neurone disease, Parkinson's disease, later multiple sclerosis]
- Stable neurological conditions, with needs changing only due to ageing
[e.g. cerebral palsy in adults, post-polio syndrome]

Agree with these groupings? Any other important distinctions to make?

(NB Implications for who to include = discussed in section D below)

C. SAMPLING FRAME

Objective of this section: To find out whether data is collected about people with long-term neurological conditions in such a way that we could contact, for example, a random sample of people either at NHS Trust level or nationally

Where should we look to find a sampling frame?

- Primary Care
- Acute hospital care
- Specialist neurological clinics (including rehabilitation centres)
- Social Care, Social Services
- Anywhere else we could get a sample?

Think about each in terms of:

- National or local surveys
- Who we include or exclude as a result of choosing each method
- Whether there is consistency geographically
 - (e.g. specialist services may be concentrated in centres – accessibility to these?)
- Practical considerations
- Ethical considerations
- Data protection considerations
- Can we sample service users and/or carers

Are there people with certain neurological conditions who we would always **exclude**? Any way to define this cut-off?

Are diagnoses (and patient details) about different types of neurological conditions held in different places?

e.g. GP practices, hospitals, specialist clinics or facilities etc.

Consider sampling through specialist clinics: is this likely to miss any particular groups, e.g. some conditions which do not generally involve use of clinics?

Consider sampling through social services (e.g. on basis of social needs rather than medical diagnosis) – issues with this?

Data protection: who owns the data, what are possible access restrictions, limitations on direct contact/need for opt-in or opt-out with particular information sources?

Separate sample of carers? Or select service users, but proxy interview with carers if necessary?

D. WHO SHOULD BE INCLUDED?

Objective of this section: To consider who we should be surveying and to think of whether there are priority groups in terms of survey coverage

HCC will exclude Alz & Dementia, & stroke, from the study as they're covered separately. Beyond this we want to think about groups to focus on.

Think about different types of neurological condition, by type, by severity. Should we include them? Why?

Reasons to exclude – e.g. conditions associated with severe cognitive, communicative, emotional problems that would make survey problematic; conditions that are too broad or difficult to define (e.g. migraine, ME); other reasons or conditions to exclude?

Are there **priority conditions** in terms of healthcare or social provision? For example,

- high prevalence conditions²⁵
- conditions associated with particular healthcare needs or problems; or particular social care needs
- conditions for which there has been no previous research of this sort
- people with conditions who are likely to be able to take part in survey (e.g. cognitive and motor function relatively intact?)
- hard-to-reach groups (e.g. those with communication difficulties, or with more severe conditions, that may have excluded them from previous studies)

Think about people in terms of use of healthcare services, and social services – should we include people as a priority because they use specialist neurological services²⁶, or acute hospital services, or social services for care and rehabilitation – are some of these user groups more important to talk to?

Think about age of people – children, adolescents, adults, people aged over 65. (Some neurological conditions are more strongly associated with onset or progression at particular ages – what are the key trends to consider here? e.g. Parkinson's and Alzheimer's amongst older people; consider other progressive conditions e.g. MND or MS, or those where needs change with age, e.g. cerebral palsy²⁷. Do some conditions tend to limit lifespan? What are the implications for priority age group(s) to cover?

Think about hard-to-reach groups, and whether there are particular issues here:

BMEs? Any others?

Any other reasons for including or excluding people?

Issues around including carers only, user only or both?

²⁵ Migraine & ME >1 million in UK; Alzheimer's/dementia, epilepsy, stroke, brain injury, Parkinson's, Cerebral palsy >100k in UK; Multiple sclerosis, muscular dystrophy, narcolepsy, Tourette's, neurofibromatosis >10k in UK; Huntingdon's, Ataxia, Motor neurone disease >1k in UK

²⁶ cf NSF p12 on DoH designation of certain elements of neurological services as 'specialised': includes neurology, neurosurgery, rehabilitation for adults with brain injury and complex disability

²⁷ cf NSF p9 classification of LT neurological conditions by: sudden-onset; intermittent and unpredictable; progressive; stable but with changing needs due to ageing or development.

E. WHICH SURVEY METHODS SHOULD WE USE?

Objective of this section: To discuss the types of methods we could use for the survey. Note that all the previous HCC surveys carried out were mailed self-completion. Is this likely to be an unsuitable method for people with some types of neurological condition?

Think about which methods we should consider using:

Postal self-completion – is this an option by itself for any users?

Face-to-face with service users – if so, where?

Telephone with service users – if so, identifying phone numbers?

Other modes (internet)? Selection and self completion at primary/secondary health care settings)

Mixed modes

How well can we predict on the basis of type of neurological condition whether a person is likely to be willing & able to take part in the survey, or whether a carer should be surveyed? Are there situations when it would be worth including both (if feasible)

Who do we exclude by using each method?

Should we use a separate method for user and carers?

If assistance is required, who might that be – family, informal carer, professional carer? How do we contact these people?

If we do face-to-face interviews, who would be the best people to do the interviews?

What will be the barriers to achieving a good response to such a survey?

F. QUESTIONNAIRE/INTERVIEW COVERAGE

Objective of this section: To discuss the sorts of issues that any survey of people with long term neurological conditions should be covering – what are the key information needs from point of view of users of the survey data? What are key issues that users may feel it is important to comment on?

NSF and the consultation involved brought out the following areas as being important. How important do you see each being, what are the key elements within each and are there any missing areas?

- | | |
|-----------------|--|
| Access: | Prompt, equitable referral to appropriate specialist (who understands needs; out of area if necessary etc) |
| Diagnosis | Prompt and accurate diagnosis (timing of diagnosis; timing of follow up treatment and support) |
| Information | for patients and carers at diagnosis and beyond (what should be provided, when, how) |
| Choice | involvement in decisions, aim for independent living |
| Ongoing support | Regular review of condition, access to specialist beyond diagnosis |
| Carers | Involved in decisions, their own support needs recognised |
| Rehabilitation | Access, routine assessment to ensure needs met (specialist, psychological; equipment; educational,) |
| Integration | transition between care stages, joint planning by health and social services |
| Training | awareness of needs throughout: from GP to staff in nursing homes/hospices |

Any other issues

Aspects of healthcare for people with long-term neurological conditions that are **most important to meet patient needs**, from patients' perspective/from expert perspective

Aspects of service which **most need improvement**, from patients' perspective

Differences between views of patients and professionals in critical features of quality service

Criteria by which services should be judged, from patients' perspective

Any other issues they would like to raise

G. WHICH HEALTHCARE SETTINGS SHOULD WE CONSIDER?

Linked with above: which aspects of healthcare we should cover in such a survey and any priority areas to be identified.

Who are the key healthcare professionals that people with NC see. Are there any perceived priorities here?

GP/other practice staff
Neurologists
Other specialist neurological professionals, e.g. nurses
Care co-ordinator (or case manager or community matron)
Local rehabilitation services, including vocational
Counselling and psychological support
Speech & language therapist
Neuro-physiotherapist

Others? ADD TO LIST

The NSF for long-term conditions mentions:

- Specialist services, sometimes concentrated in specialist centres
- Primary care (including all health and social care professionals in community settings)
- Hospitals accepting people with emergency and acute needs
- A&E - in particular for head injuries

“Neuro Numbers” estimates that 10%, 17% and 19% respectively of visits to A&E, GPs and hospital admissions, relate to a neurological condition

It may be difficult for us to cover all aspects of healthcare for people with neurological conditions in sufficient detail for it to provide useful feedback. We may therefore have to identify priority areas and focus in detail on these when running the survey.

Which of these should we cover, and why? Are any of these a priority?

Primary Care - GPs, practice nurses, GP out-of-hours

Acute Care - inpatient, outpatient, emergency services at acute NHS Trusts

Specialist neurological services - neurologists, specialist nurses, specialist rehabilitation centres

Social services - community rehabilitation, independent living

ANY OTHER COMMENTS GENERALLY?

Thank respondent for time!

Topic Guide Coverage – Service Users

Feasibility Study: Long-term Neurological Conditions

Service user Topic Guide

Aims and objectives of the study:

- To explore user experiences of services they have come into contact with
- To obtain views about the services provided, any perceived gaps in provision and any suggested areas for improvement
- To establish the areas of survey coverage of greatest relevance to service users
- To obtain views about the methods and survey conditions for conducting a survey amongst this population
- To explore potential sampling sources for the survey
- To explore factors affecting the ability or willingness of service users to take part in the survey

Introduction

- Introduce self & NatCen: largest independent institute specialising in social policy research; bulk of work for government departments
- The Healthcare Commission has asked us to look at the feasibility of doing a survey of people with long-term neurological conditions and, if so, what the survey should focus on – especially in terms of services provided (or not).
- We've been talking to people who provide the services (e.g. within the NHS, voluntary sector and social services), but it is very important that we also talk to people who use the services.
- Confidentiality: everything you tell us is completely confidential. It will be used purely by the research team to assist us in designing a survey.
- Recording: this interview is for you to tell us about your experience and your opinions – more like a chat. Difficult to listen and take notes so very helpful if can record our conversation. Recording will be deleted once we have made our notes.
- Any questions you would like to ask us before we begin?

A. BACKGROUND

- *Personal details*: age; whether living alone or with other people; what doing
- *Condition*: what it is; how long they have had it; how the condition has changed over time

- *Implications for daily life:*
 - how the condition affects them; what they can and cannot do
 - whether they need help with any aspect of their life: what; who provides the help (relatives, professionals etc)
 - travel/mobility problems
 - any problems around social life; whether they belong to any community groups; if so, what type of support they provide

Would now like to take them through the services that they have come into contact with since they have had the condition

B. ACCESS AND REFERRAL

- When condition first appeared
 - How first became aware
 - What they did at that stage
- Who they saw / were referred to at that stage
 - Where; ease of access
 - What treatment, help or support offered or provided
- Views about the help and support received
 - How well met their needs
 - Any gaps in provision

C. SERVICES ENCOUNTERED POST REFERRAL

Would now like to take them through what happened after that and the types of services they encountered.

Prompt for possible stages:

Diagnosis

Post diagnosis

Treatment: in or outpatient

Ongoing support & treatment

Independent living: e.g. equipment/vocational

Any other services

For each stage:

- How they accessed the service
- Who they saw
- Types of service provided
- Extent to which met their need
- Any gaps or limitation in provision
- How involved they felt in the decision-making process
- Whether relatives or carer had any input into decision-making
- Whether any financial implications of accessing the service

D. PERSPECTIVES ON USER SURVEY

Explain that we will be carrying out a survey amongst people living with (neurological) conditions like theirs. The survey has been commissioned for the Healthcare Commission who want to improve the help and support that is available. The survey would be carried out in strict confidence. We would really value their input into the sorts of things that are included in the survey.

Survey coverage

- What have been the most important issues for them about living with this condition
- What are the sorts of things about services for people with their condition that that they would want to communicate if they took part in the survey
- Whether there are any issues that might be important for people with other types of condition: reasons for their views
- Views on wording to use in a survey - what would be acceptable to them
- Talking about “long-term neurological conditions” or their specific condition
- Service users? Carers? Anything else to consider here?

Methodology

We are thinking about the best way to carry out the survey and would welcome their views about this. Describe the range of potential options :

- Self-completion (postal or interviewer administered)
- Telephone
- Via the Internet
- Face to face

For each:

- How they would they feel about the method
- Any specific problems/issues for them
- Whether they would they want any help or support to do the survey
- What type of help or support
- Who would best provide it (e.g. carer, relative, survey interviewer)
- Any issues it might be difficult to cover in survey with carer present
- Optimum length of interview using this method

Face to face only:

- Where they would want to do the survey, e.g. home, somewhere else: reasons
- Any issues around timing of the interview

Contacts

We will need to get a comprehensive list of people with different neurological conditions. There are various sources which we might approach for this:

- Via hospital discharge records
 - Via GP registers
 - Via specialist support services
 - Other
- Which of these routes would include them? (i.e. which have they been in contact with?)
 - *GP registers* – are they registered with a GP; does that GP know about their condition?
 - *Hospital discharge* – when were they last in hospital; when left, did they move around? Would most people with their condition have had hospital treatment
 - *Specialist support services*– do they use such services; would most people with their condition be in touch with the services
 - *Others* – would most people with their condition have chance of being included

Explain that we are looking at whether these service organisations could provide us with name & address of people diagnosed with neurological conditions, so we could contact them to ask if they would be willing to take part in the survey, provide information about the survey, and to give them a chance to opt out of any further contact in relation to the survey.

- How they would feel about being contacted for a survey like this as a result of contact with the service organisation?
 - Feelings about being contacted
 - What information would they want in an initial letter about the survey?
 - What would they consider when deciding whether they want to opt out?
 - How could we make opt-out easiest for them?

[NB: IF feel very strongly against their details being given to us with checking first:
How would you feel if contacted directly by the service organisation, informed about survey, asked to opt-out if you would not like your details to be passed on?]

Participation

- What would encourage them to take part in the survey, and why?
 - What would make it worthwhile for them (incentive, input into policy)?
 - What type of information they would they like?
- What would deter them and why?
- Any other issues they would like to raise?

THANK AND END

Topic Guide Coverage – Carers

Feasibility Study: Long-term Neurological Conditions

Carers Topic Guide

Aims and objectives of the study:

- To explore user experiences of services they have come into contact with
- To obtain views about the services provided, any perceived gaps in provision and any suggested areas for improvement
- To establish the areas of survey coverage of greatest relevance to service users
- To obtain views about the methods and survey conditions for conducting a survey amongst this population
- To explore potential sampling sources for the survey
- To explore factors affecting the ability or willingness of service users to take part in the survey

Introduction

- Introduce self & NatCen: largest independent institute specialising in social policy research; bulk of work for government departments
- The Healthcare Commission has asked us to look at the feasibility of doing a survey of people with long-term neurological conditions and, if so, what the survey should focus on – especially in terms of services provided (or not).
- We've been talking to people who provide the services (e.g. within the NHS, voluntary sector and social services), but it is very important that we also talk to people who use the services.
- Confidentiality: everything you tell us is completely confidential. It will be used purely by the research team to assist us in designing a survey.
- Recording: this interview is for you to tell us about your experience and your opinions – more like a chat. Difficult to listen and take notes so very helpful if can record our conversation. Recording will be deleted once we have made our notes.
- Any questions you would like to ask us before we begin?

A. BACKGROUND

- *Personal details of carer:* age; relationship to person they care for; whether live with person they care for; who (else) live with; whether caring is full time occupation; if not, what else they do

- *Personal details of person cared for:* age; condition; what it is; how long they have had it
- *Implications for daily life for person cared for:* how the condition affects them; what they can and cannot do

B. HISTORY OF SERVICE PROVISION

Briefly map what has happened to the person since they have had the condition before go on to talk about services they have encountered

- Key events; dates
- What happened

Would now like to take them through the types of services they encountered at each stage

- What services accessed at that stage
 - How accessed
 - How easy to access
- Who they saw
 - Types of service provided
 - How useful/helpful

Prompt for possible stages:

Onset of condition

Initial access and referral

Diagnosis

Post diagnosis

Treatment: in or outpatient

Ongoing support & treatment

Independent living: e.g. equipment/vocational

Any other services

C. OVERALL SATISFACTION WITH SERVICES PROVIDED

- Extent to which the person's needs have been met in terms of :
 - *Managing the condition*
 - *Medical care & treatment*
 - *Rehabilitation*
 - *Social networks*
 - *Accessing financial support*
 - *Independent living*
 - *Physical support*
 - *Emotional support*
 - *Other needs*

- At what stage was this service provided
 - Whether this was when the support was most needed
- Where have there been any gaps in provision
 - What did they need
 - Who should have provided it
- Whether the person's condition has had any financial implications: details

D. SPECIFIC SERVICES TO HELP OR SUPPORT CARER

- Nature of caring role:
 - Type of support given
 - Details of tasks involved
- Implications for daily life of carer:
 - How being a carer affects them;
 - Physical demands
 - Emotional demands
 - Impact on their life
 - Whether any financial impact
- Support for carer role:
 - Awareness of support available to carers (e.g. respite care)
 - Awareness of any financial support available
- Extent to which they are able to access the type of help they need
 - Type of help needed
 - Extent to which their needs are recognised

EXPLAIN THAT WE WANT TO DO A SURVEY OF THE VIEWS AND EXPERIENCES OF PEOPLE LIVING WITH NEUROLOGICAL CONDITIONS. ALSO WANT TO CARRY OUT A SPECIFIC SURVEY OF CARERS. WOULD LIKE TO DISCUSS EACH OF THESE IN TURN.

E. PERSPECTIVES ON USER SURVEY

The Healthcare Commission has commissioned the survey of service users in order to improve the help and support available. The survey would be carried out in strict confidence. There are likely to be three categories of service user:

- *Those who can do the survey on their own*
- *Those who can do the survey with the assistance of a carer*
- *Those who would be reliant on the carer to do the survey on their behalf*

We would really value their input into the sorts of things that are included in the survey.

Survey coverage

- In their view, what have been the most important issues for the person they care for about living with this condition
- What are the sorts of things about services for people with the condition that they would want to communicate if they took part in the survey
 - Whether there are any issues that might be important for people with other types of condition: reasons for their views
- Views on acceptable wording to use in a survey
 - Talking about “long-term neurological conditions” or their specific condition
 - Service users? Carers? Anything else to consider here?

Methodology

We are thinking about the best way to carry out the survey and would welcome their views about this. Describe the range of potential options :

- *Self-completion (postal or interviewer administered)*
- *Telephone*
- *Via the Internet*
- *Face to face*

For each:

- How they would they feel about the method
 - Would the person they care for be able to complete the survey using these methods?
- Whether the person they care for would they want any help or support to do the survey
 - What type of help or support
 - Who would best provide it (e.g. you, another carer or relative, survey interviewer)
 - Any issues around you/a carer filling in such a survey on behalf of the person they care for

Contacts

We will need to get a comprehensive list of people with different neurological conditions. There are various sources which might approach for this:

- *Via hospital discharge records*
- *Via GP registers*
- *Via specialist support services*
- *Other*
- Which of these routes would include the person they care for? (i.e. which have they been in contact with?)
 - *GP registers* – are they registered with a GP; does that GP know about their condition?
 - *Hospital discharge* – when were they last in hospital; when left, did they move around? Would most people with their condition have had hospital treatment
 - *Specialist support services*– do they use such services: which; would most people with their condition be in touch with the services
 - *Others* – would most people with their condition have chance of being included

Explain that we are looking at whether these service organisations could provide us with name & address of people diagnosed with neurological conditions, so we could contact them to ask if they would be willing to take part in the survey, provide information about the survey, and to give them a chance to opt out of any further contact in relation to the survey.

- How they would feel about the person they care for being contacted for a survey like this as a result of contact with the service organisation?
 - Feelings about being contacted
 - What information would they want in an initial letter about the survey?
 - What would they consider when deciding whether they want to opt out?
 - How could we make opt-out easiest for them?

NB: IF feel very strongly against their details being given to us with checking first:

- How would you feel if contacted directly by the service organisation, informed about survey, asked to opt-out if you would not like your details to be passed on?

F. PERSPECTIVES ON CARER SURVEY

We are also considering a separate survey of carers to look specifically at their needs and experiences.

Survey coverage

- What are the most important issues for them as a carer of someone with this condition
- What are the sorts of things about caring for people with the condition that they would want to communicate if they took part in the survey
 - Whether there are any issues that might be important for carers of people with other types of condition: reasons for their views

Methodology

Any survey of carers would probably need to start with a survey of people with LT neurological conditions, and use this to identify those that had a specific carer. Carers would then be sent a questionnaire to ask about their views

- What do they think about this approach

We are thinking about the best way to carry out the survey and would welcome their views about this. Describe the range of potential options :

- **Postal Self-completion (our preferred option)**
- Telephone (possible option)
- Via the Internet (possibly option)
- Face to face (not likely)

For each:

- How they would they feel about the method
- Optimum length of interview using this method

Participation

- What would encourage them to take part in the survey, and why
 - What would make it worthwhile for them (incentive, input into policy)
 - What type of information they would they like
- What would deter them and why
- Any other issues they would like to raise

THANK AND END