

# Brunel Neurological Alliance

## Neurological Survey

A report on the experience of people living with neurological conditions in Bristol, North Somerset and South Gloucestershire

May 2014

## Table of Contents

1.0 Executive Summary .....	3
2.0 Introduction.....	4
3.0 Key Findings .....	6
3.1 A person centred service – care planning, information, emotional support .....	6
3.2 Early recognition, prompt diagnosis and treatment .....	10
3.3 Emergency and acute treatment.....	11
3.4 Rehabilitation .....	12
3.5 Assistive Technology/Equipment Services .....	15
3.6 Care and Support.....	16
3.7 Patient Views.....	17
4.0 Recommendations.....	19
5.0 Conclusion .....	19
Appendix 1: The Quality Requirements of the National Service Framework for Long-Term Neurological Conditions.....	20
Appendix 2: Breakdown of respondents.....	21

## Executive Summary

This report details the findings of a survey implemented by the Brunel Neurological Alliance (which covers Bristol, South Gloucestershire and North Somerset), which was completed by patients using the neurological services in the Bristol area. It is anticipated the findings will provide a source of intelligence for commissioners regarding the service requirements of neurological service users.

The National Service Framework (NSF) for long-term neurological conditions published by the Department of Health in 2005, aims to improve the delivery of neurological services to long-term neurological patients. Despite being published eight years before this survey was undertaken the NSF continues to be as useful now as it was then, in outlining a number of Quality Requirements for neurological services for this group of patients.

In general, the survey demonstrated that there is room for significant improvements in the way that neurological services are provided. The following presents an initial outline of the key-findings of the survey.

### **A person centred service** (care planning, provision of information and emotional support)

Over three-quarters of those questioned did not have a written care plan. Although 54% of respondents were given information at diagnosis on the treatment that was available, less than half remembered being given information about the conditions, and nearly 60% were given no information on the health and social care services that may be able to help. The majority did not have a keyworker, or were unaware whether they did or not.

### **Early Recognition, prompt diagnosis and treatment:**

A confirmed diagnosis was not made for over a year for 45% of the respondents to the survey.

### **Emergency and acute treatment:**

Patients admitted to hospital as an emergency felt that, in general, members of staff understood and listened to the needs of people with their condition.

### **Rehabilitation**

Whilst the majority of respondents had physiotherapy to maintain or improve functioning, in many people this was limited to a specified number of sessions. A large number of comments made related to the importance of ongoing therapy to the ability to remain independent.

### **Assistive Technology/Equipment Services**

A large majority (75%) of respondents felt that any services they needed to be as independent as possible were provided within a reasonable time.

### **Care and Support**

The level of training for carers, and the offer of an assessment of the carer's needs was generally very low (7% of carers offered training versus 57% who hadn't been; 10% of carers being offered an assessment whilst 53% had not been offered).

### **Patient views**

A wide range of views were expressed by respondents about the services and care that had been offered. These not only related to health services, but also to services offered by local authorities and charities. A disproportionate number of comments related to the importance of specialist nursing/advice, co-ordination of care, provision of information and access to therapies.

## 2.0 Introduction

A long-term neurological condition is defined as “A condition resulting from disease of, injury or damage to the body’s nervous system (i.e. the brain, spinal cord and/or their peripheral nerve connections) which will affect the individual and their family in one way or another for the rest of their life”.<sup>1</sup>

To improve the management of long-term neurological conditions, the government introduced the National Service Framework (NSF) for long-term conditions in 2005. The NSF establishes 11 quality requirements (QR) designed to improve the standards of health and social care services for neurological service users.

The quality requirements support people with long term neurological conditions and “cover treatment, care and support from diagnosis to end of life”. The first quality requirement, ‘A person centred service’ underlies the rest of the other quality requirements to ensure that the patient, their family and carers’, remain the focus of a multidiscipline team of care.

To measure the progress of the NSF; the Motor Neurone Disease Association, Parkinson’s UK, Multiple Sclerosis Society and Ataxia UK worked together, with the support of the Department of Health, to produce the ‘Quality Neurology Audit and Evaluation Tool’. This tool details ‘Evidence Based Markers’ which are broken down into measureable statements, for each of the quality requirements.

The implementation of the quality requirements is assessed through the use of these evidence based markers (EBMs). Service providers evaluate themselves against each statement, resulting in an overall score of red, amber or green for each EBM.

In response to the Neurological Commissioning Support (NCS) mid-term review of the NSF LTNCs, and the need to establish a baseline on services from a service user perspective, the Brunel Neurological Alliance conducted its own survey to assess the neurological services offered in Bristol, North Somerset and South Gloucestershire.

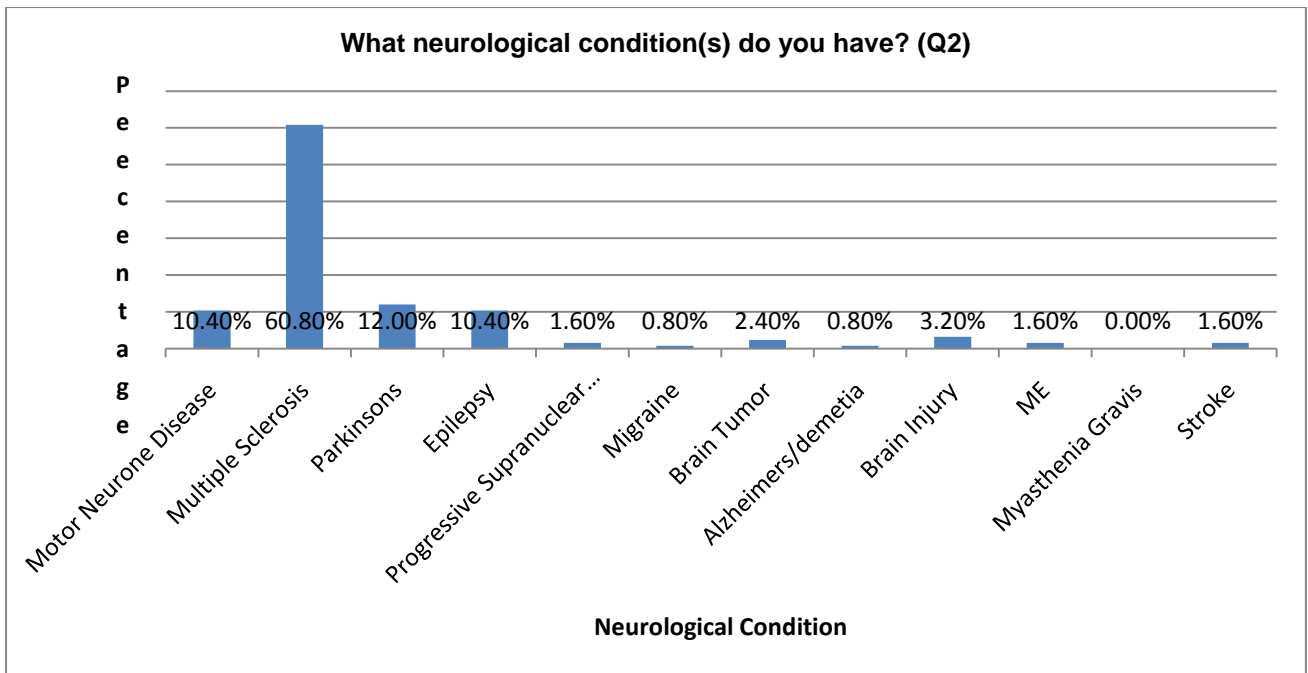
The survey questions were designed around the quality requirements of the NSF and were completed by participants using an on-line survey tool, ‘Survey Monkey’. The respondents of the survey were people diagnosed with a neurological condition and living within Bristol, North Somerset or South Gloucestershire. 139 responses were received.

**The survey was developed to understand at a local level, the effectiveness of the neurological services provided, and how well they are meeting user needs and requirements. This can be used to inform service commissioners/providers and to monitor and improve standards.**

The findings of this report will provide a significant source of information for service commissioners and will act as resource for establishing the success of the NSF requirements in shaping the delivery of the neurological services. Comparison of the findings of the survey against the NSF Quality Requirements provides an understanding of the strengths and weaknesses of the neurological services in Bristol, North Somerset and South Gloucestershire.

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<sup>1</sup> The National Service Framework for Long Term Neurological Conditions (2005)



### 3.0 Key Findings

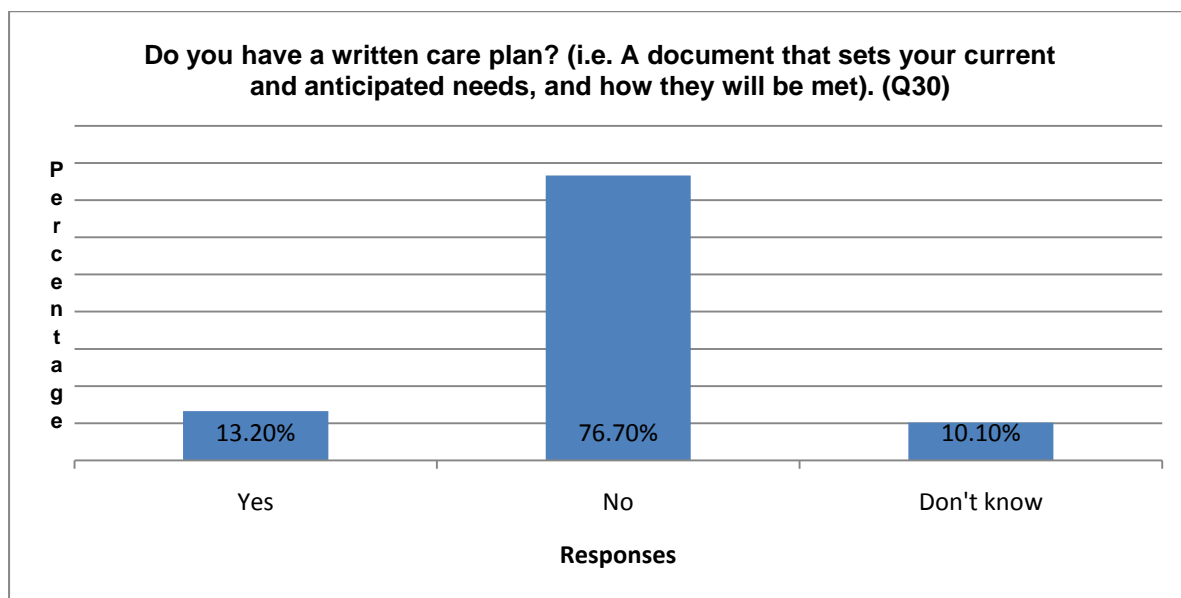
#### 3.1 A person centred service

##### 3.1.1 Care planning

Communication between interdisciplinary teams, the patient and their families/carers, is vital when composing the written care plan. Care plans should cover both current and anticipated needs, and should be regularly reviewed to ensure the patient receives the best possible care.

The NSF states that patients should be included in all decision-making about their care, and give agreement. The NCS review<sup>2</sup> of the NSF LTNCs found that many patients were unaware of the written care plan or their entitlement to an assessment of their health and social care needs, and the survey appeared to support this finding in the greater Bristol area.

An overwhelming majority of respondents to the survey (88%) did either not have a care plan or did not know whether they had one.



##### 3.1.2 Information provision

Appropriate information provision can help patients and their families deal with the diagnosis and management of their condition. Information on both health and social services is required to help patients' maintain their independence for as long as possible, and prevent unnecessary or inappropriate use of health and social care services.

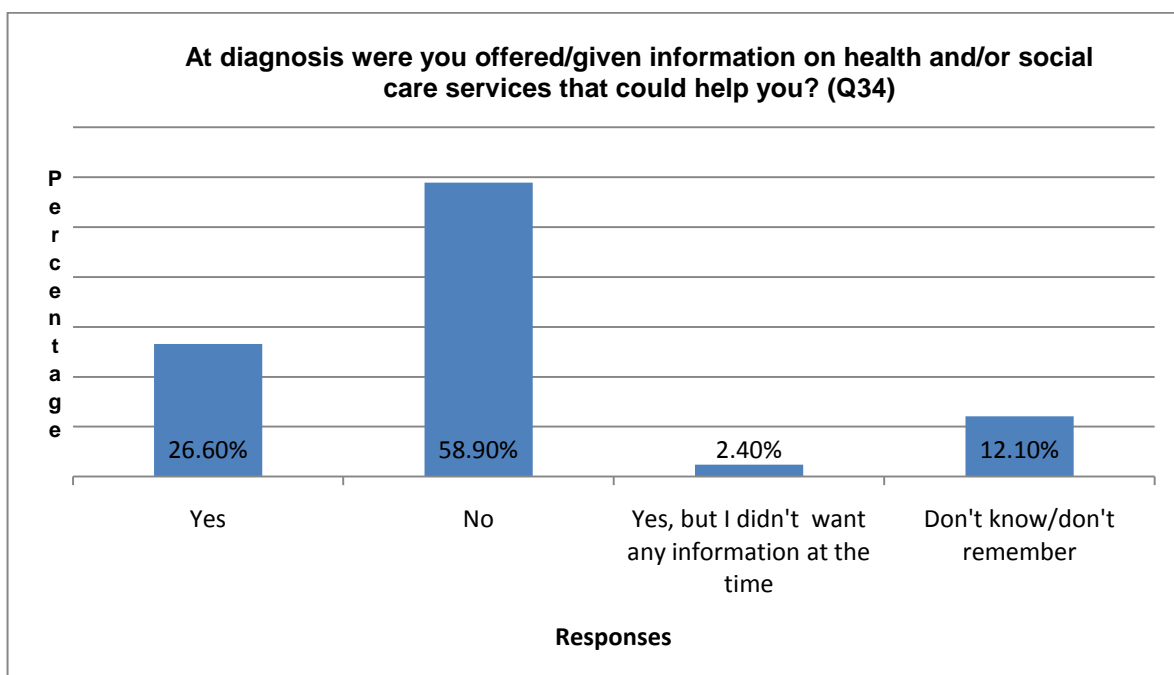
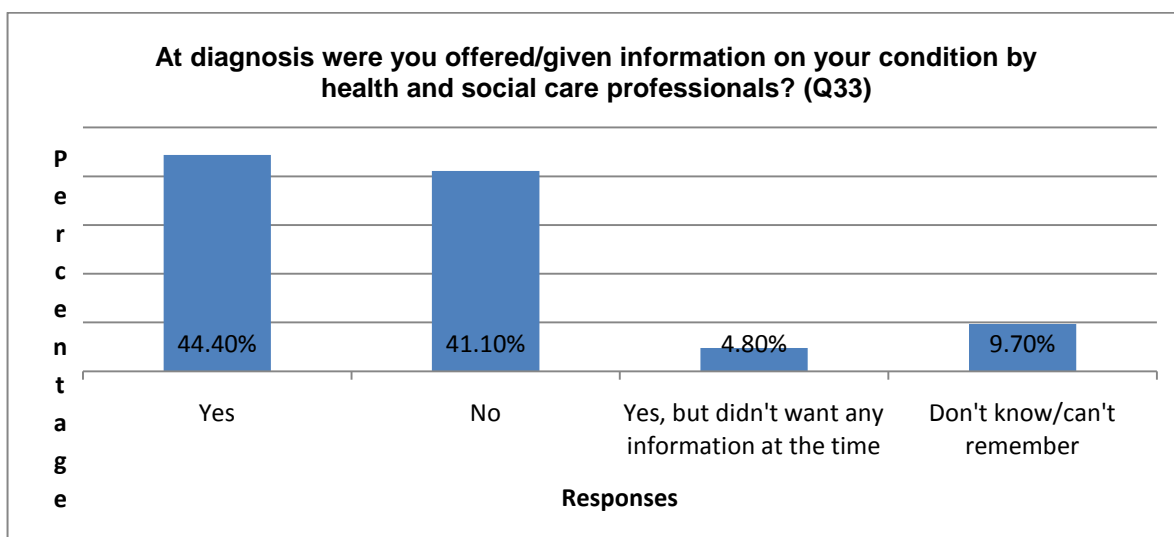
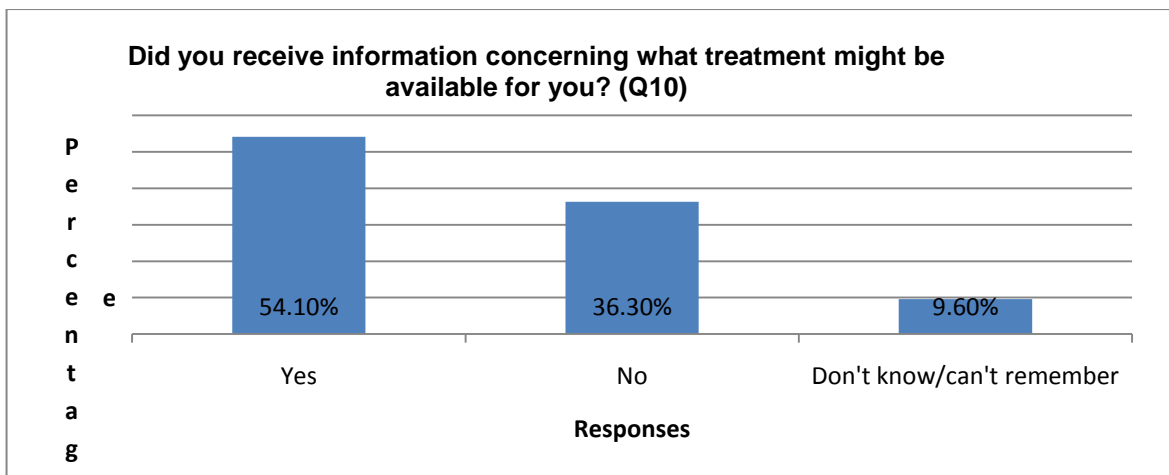
The survey showed that just over half (54%) of the respondents had received information at diagnosis about treatment options, and only 48% remember being offered information about the actual condition.

The current emphasis on self-management and self-care within the current NHS as a way of reducing inappropriate hospital admissions and use of services makes these findings even more surprising.

Responses included:

“.....more information available on the condition for family and friends”

<sup>2</sup> Neurological Commissioning Support: Halfway through – Are we halfway there? A midterm review of the National Service Framework for Long Term Neurological Conditions



One way of ensuring that patients with neurological conditions receive the right information and advice at the right time in order for them to self-manage their condition is to ensure that each person is allocated a named keyworker from diagnosis.

For some conditions, this may be a specialist nurse or therapist; for others it may be a locally-based health professional within a community team (eg. therapist, community matron).

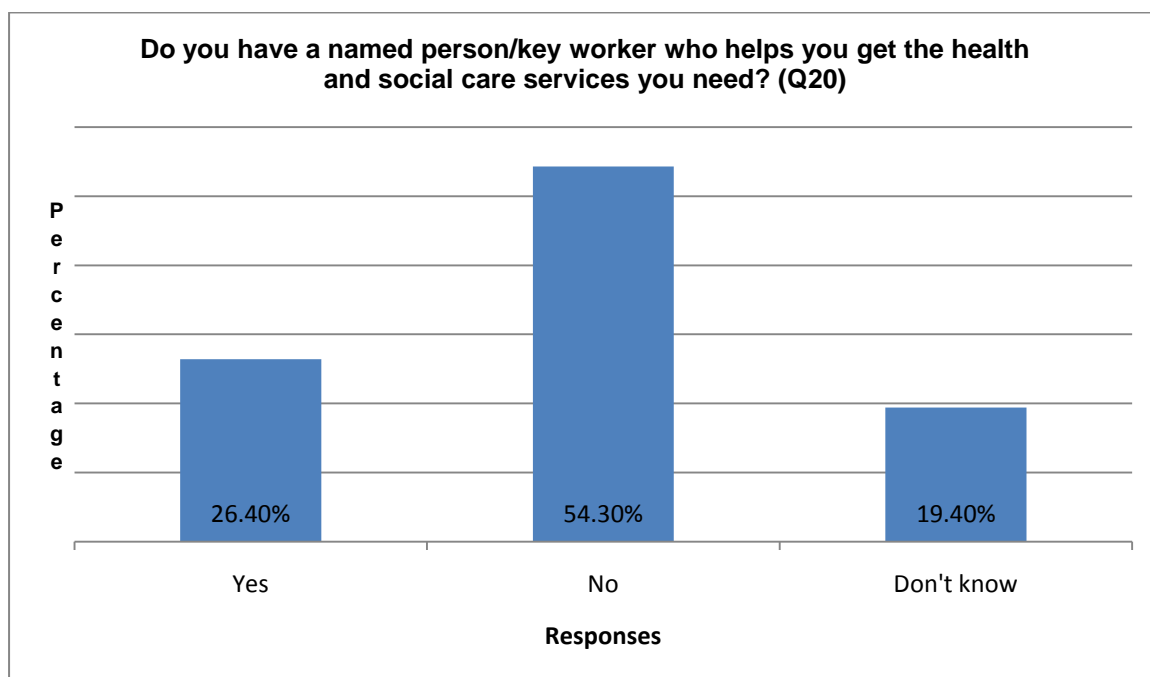
The survey showed that 78% of respondents either didn't have a keyworker or didn't know whether they had one.

In addition, a named keyworker can provide information about self-referral pathways and access to treatments. This can result in patients being unaware of which services to which they may be entitled and which help them to self-manage their condition.

The main key workers whom patients obtained information from were a specialist nurse/co-ordinator (46%) and GP (43%).

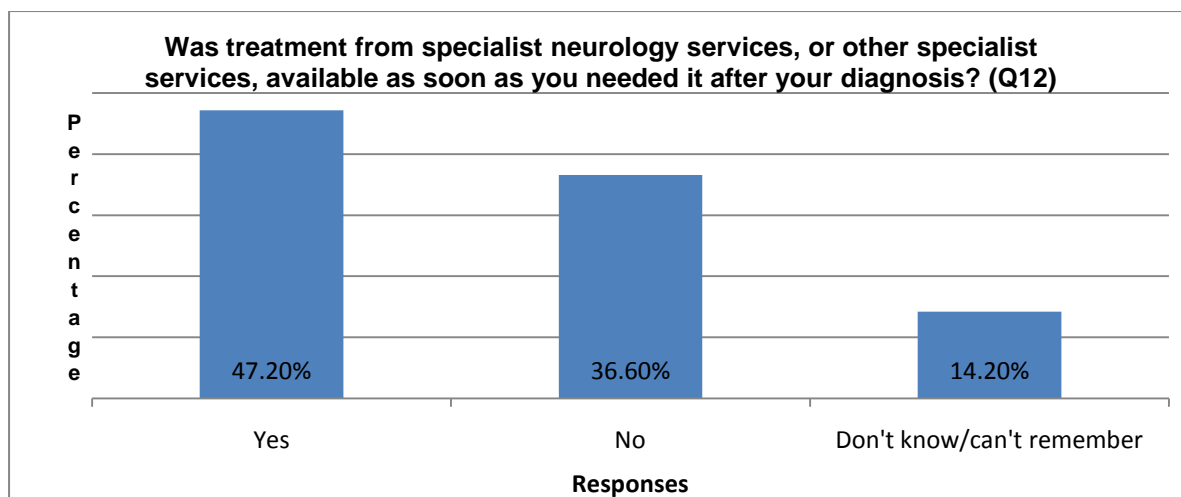
When asked what should change to improve the service, there were a number of comments about the value of specialist nurses and therapists, eg:

- "More epilepsy specialist nurses would be a great help"
- A specialist nurse to whom you could discuss problems in between treatments would be of great help."

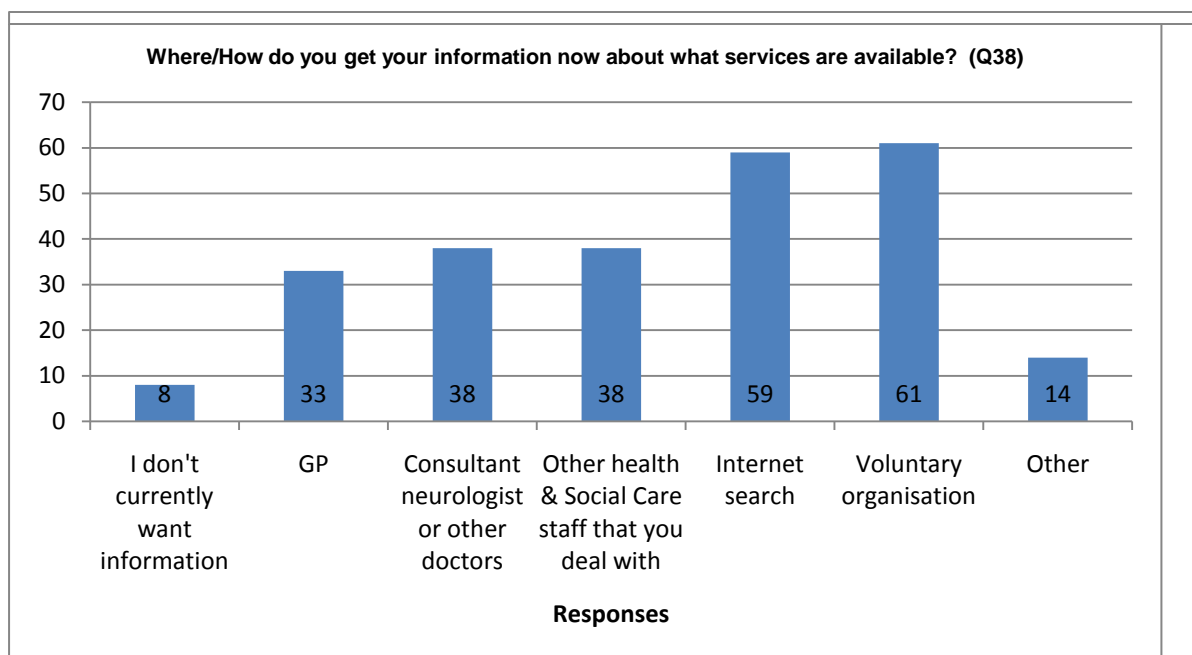


Poor information provision about available treatments makes it difficult to access services at the right time. However, 47% of respondents stated that treatment was available from specialist neurology services as soon as it was needed after diagnosis, whilst 14% didn't know/couldn't remember.





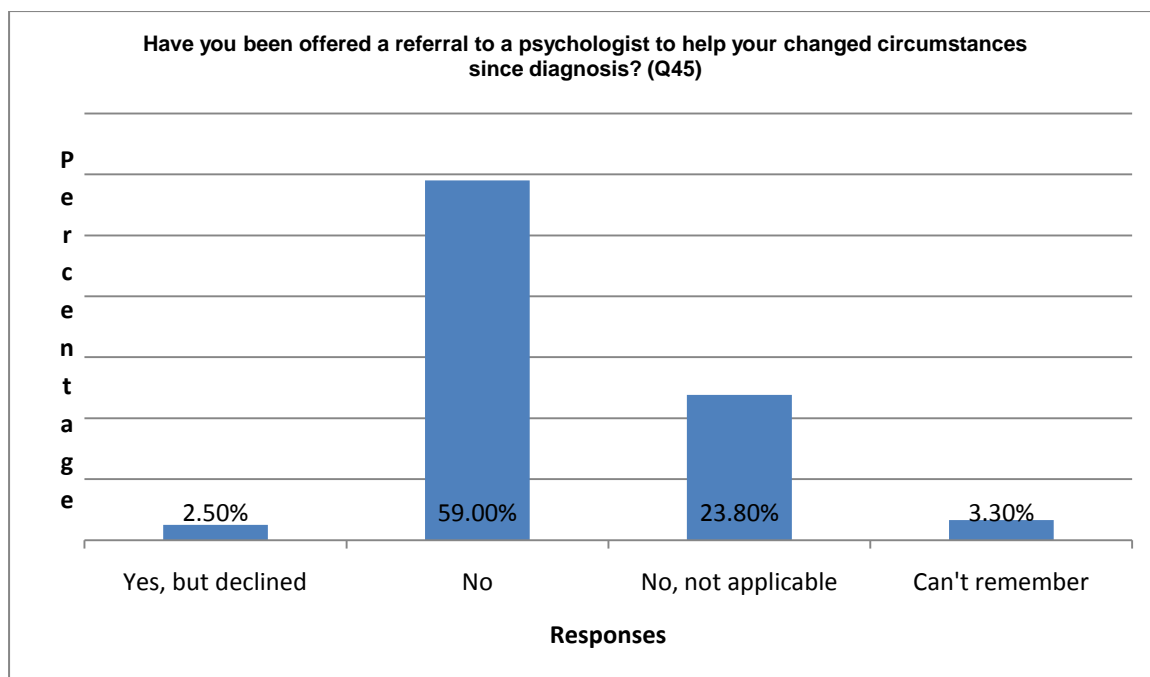
When patients were asked where/how they obtained information about services, over half responded that they used voluntary organisations. This was followed by internet searches and then GP's. However, at diagnosis, many reported they were not given any information regarding voluntary organisations from whom they could obtain advice, support or information on services.



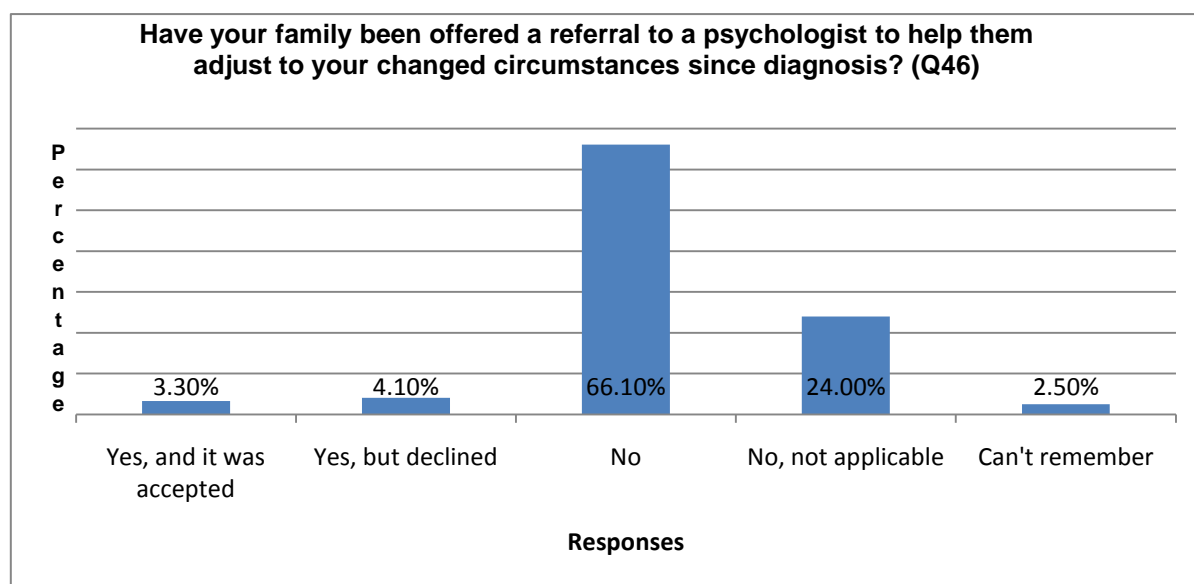
The other main sources of information were specialist nurses and the MS Therapy Centre at Bradley Stoke (for respondents with MS).

### 3.1.3 Emotional Support

The survey found that the emotional needs of patients and their carers'/families had not been considered, this confirms the findings of the NCS review. A new diagnosis induces a significant change in family and personal circumstances.

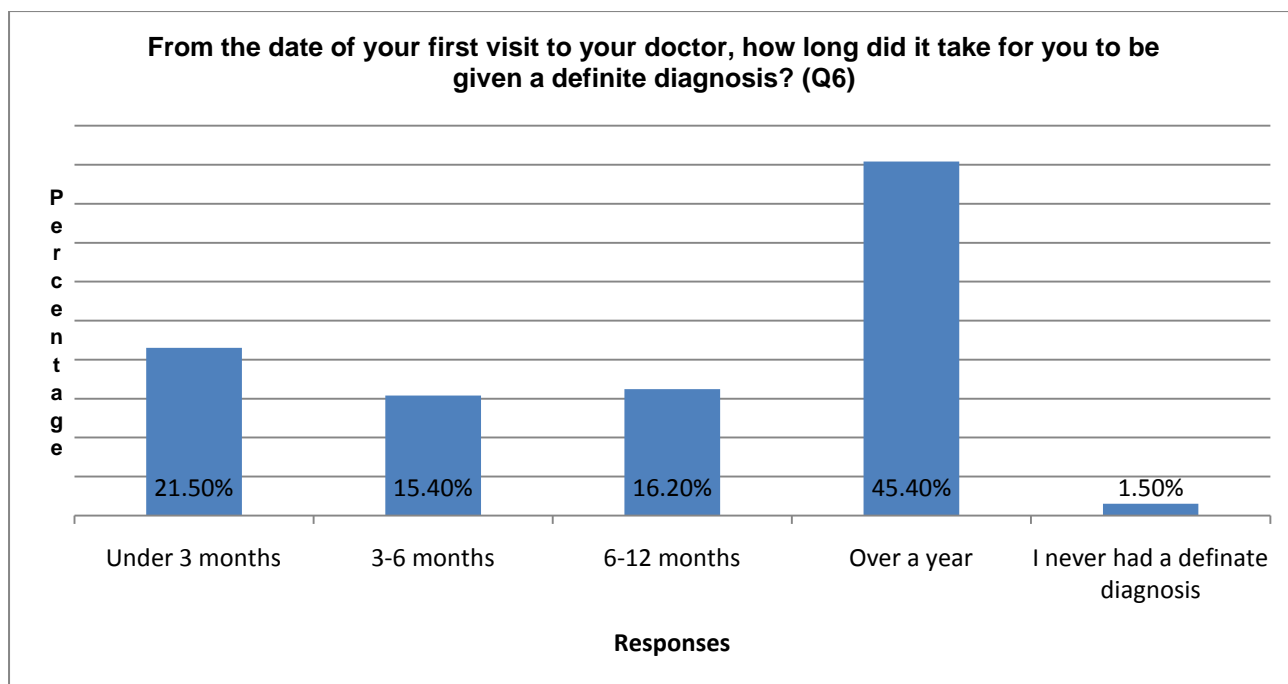


There was also a lack of a support for their families. Only 7% were offered a referral to a psychologist, and 66% were not. The remainder either couldn't remember or the offer of a referral was not applicable to their circumstances. For many families, the diagnosis will also signal a change in **their** circumstances, with the possibility of increased caring responsibilities, attendance at hospital appointment and a change in the financial status of the family. For all these reasons, the offer of psychological support can be very important.



### 3.2 Early recognition, prompt diagnosis and treatment

The graph below shows the approximate time for definite diagnosis. 45% had to wait over a year from the date for their first visit to a doctor. Whilst some delay may be unavoidable (for example in the case of progressive neurological conditions), and undue delay may miss opportunities for early interventions, lifestyle and self-management advice, and also minimise anxiety for the individual and their family.

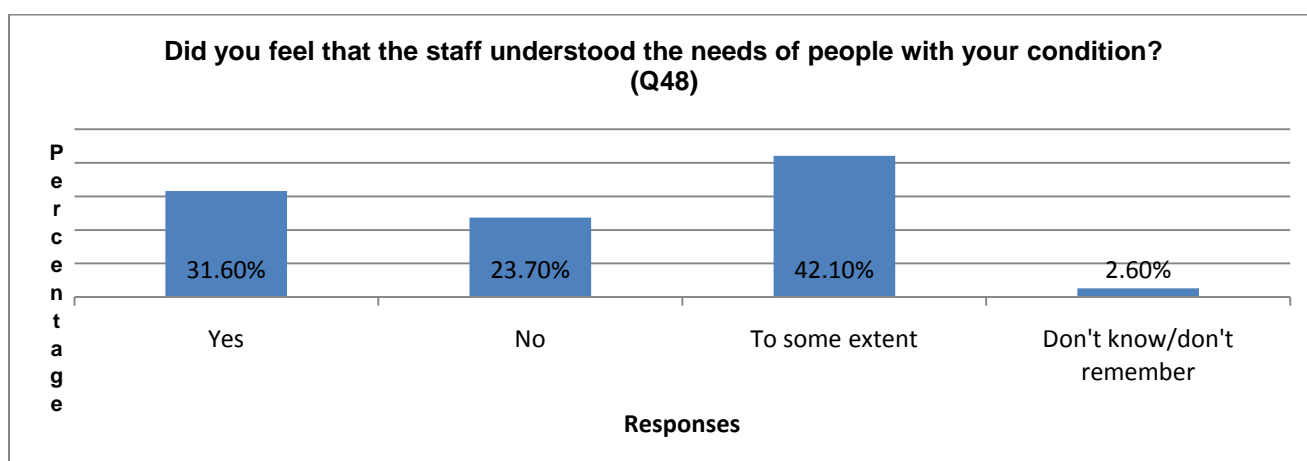


### 3.3 Emergency and acute treatment

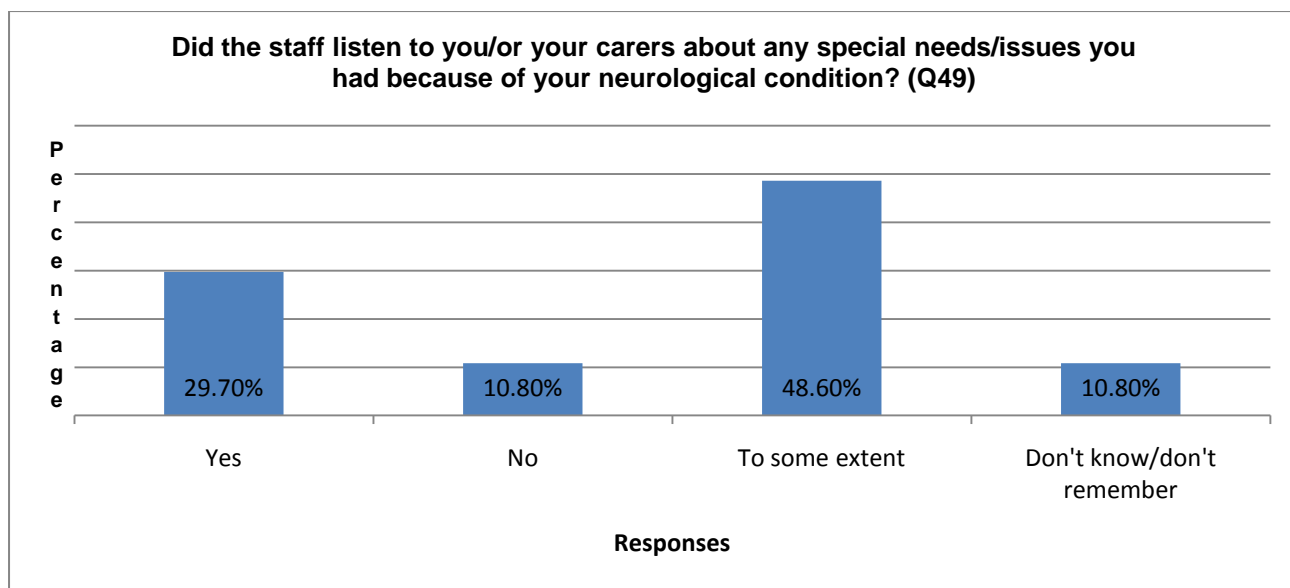
Patients with a neurological condition, who are admitted to hospital in an emergency, require attention to their neurological condition, as well as their emergency situation.

Patients who were admitted to hospital as an emergency, because of their neurological condition, reported an overall satisfactory level of care. 74% stated that the staff understood, or mostly understood, the needs of their condition.

The NCS report also found that people with neurological conditions admitted to A+E were not receiving ongoing neurological care.<sup>3</sup> Some felt their neurological condition was disregarded and there was no input from specialist neurology staff. Many neurological patients have regular medication regimes which need to be maintained to continue management of the condition. Failure to provide this can lead to further complications leading to longer hospital stays and unnecessary costs.



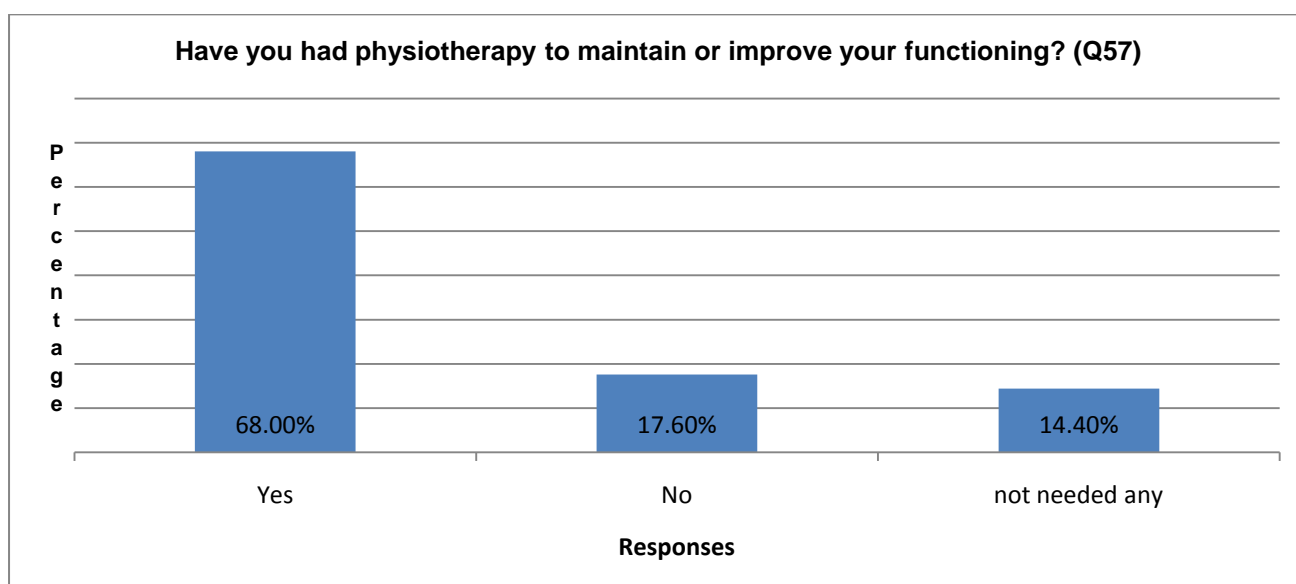
<sup>3</sup> Neurological Commissioning Support: Halfway through – Are we halfway there? A midterm review of the National Service Framework for Long Term Neurological Conditions (Page 32)

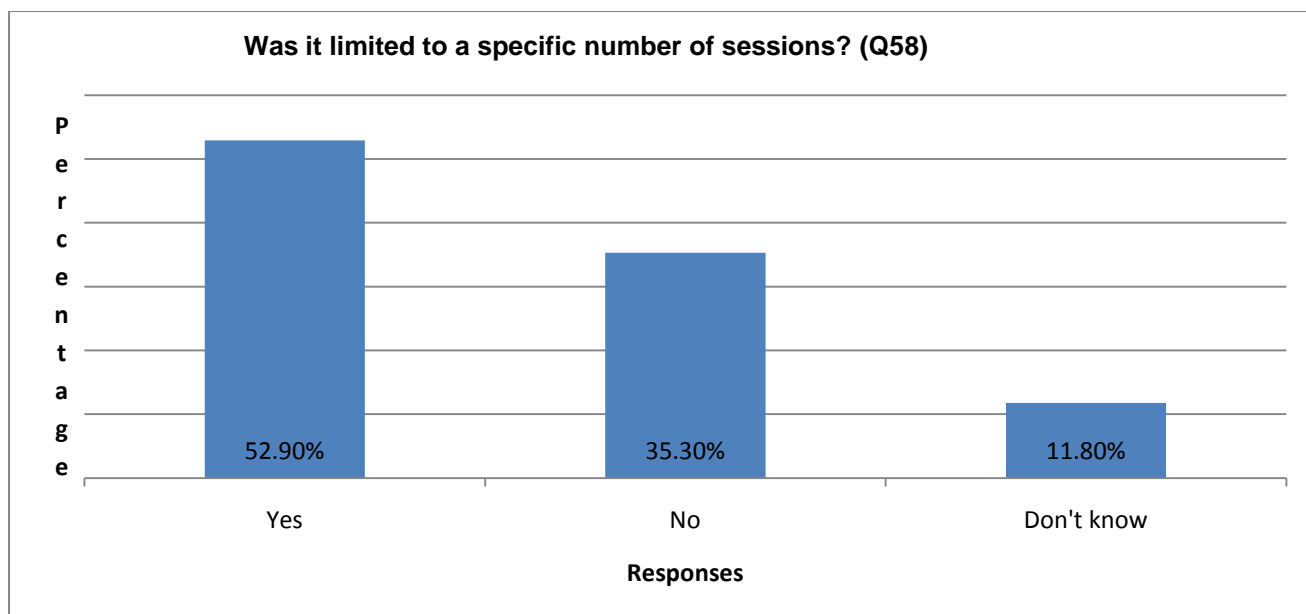


### 3.4 Rehabilitation

The effective management of a neurological condition requires timely access to rehabilitation services such as physiotherapy and speech therapy. Prompt rehabilitation improves the prospect of independent living and reduces re-admissions. There are many issues surrounding the awareness and accessibility of services, as well as limits to the number of sessions, e.g. physiotherapy sessions are often limited to 6 sessions per patient. 53% of patients received a limited number of physiotherapy sessions.

In response to this level of service delivery, several respondents commented that they paid privately for physiotherapy. Some of the reasons given were that it was “not frequent enough” on the NHS, “long term therapy is not available on the NHS”, “was told NHS could only offer six sessions and I would need more”, and “the excellent neuro physio I have cannot provide all the physio I need.”

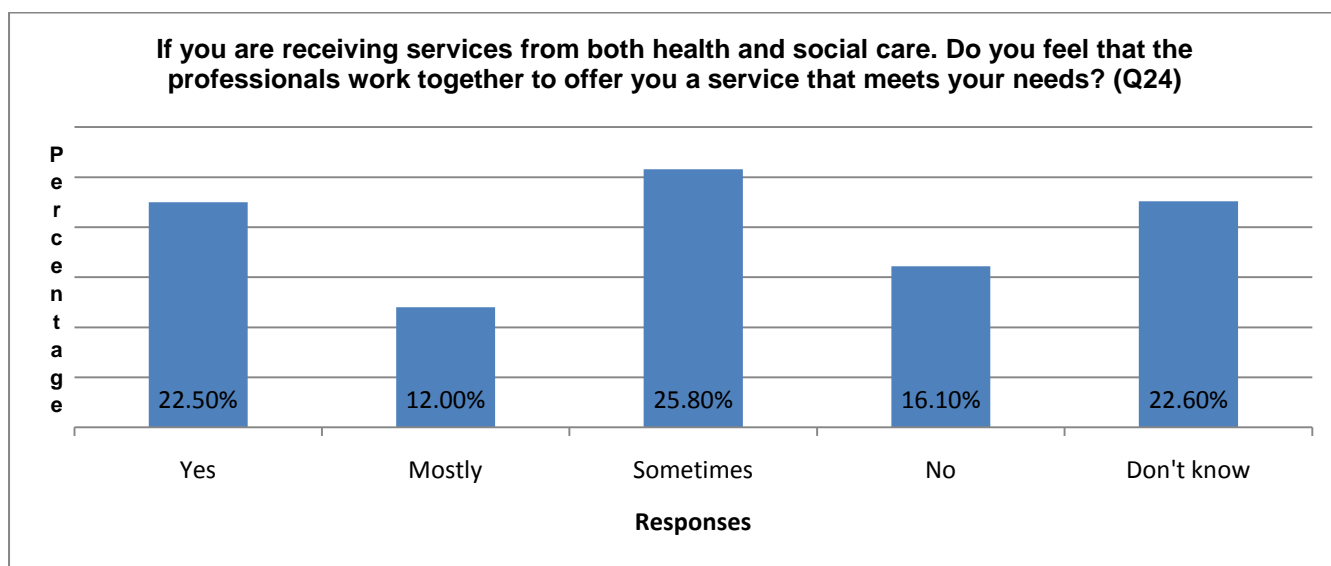




The other service which many respondents stated that they sourced privately was acupuncture and counselling.

Communication between health and social care services is essential to deliver the standard of care required by the NSF. Improving the awareness of different neurological conditions within rehabilitation teams can help to further support neurological patients, improve well-being, recovery and prevent delays in obtaining services they need.

The co-ordination of both health and social care is important to provide long-term services to help patients maintain their independence at home. The attitude of some patients suggests that better communication and co-ordination between services is required. 35% of respondents felt that health and social care professionals work (or mostly work) together in the area, whilst 42% felt that this doesn't happen or only happens 'sometimes'.

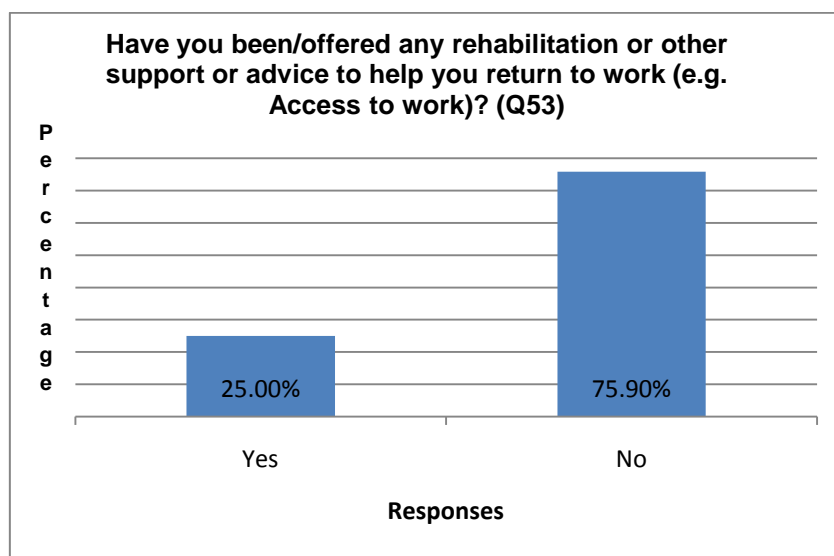


When invited to give examples of ways in which service provision could be improved, several respondents mentioned improved co-ordination and sharing of information between professionals. An expert key worker

would be best placed to co-ordinate care and resources for each patient, as well being able to provide long-term support to patients. The NCS report also supports the use of a key-worker systems and single information access points.<sup>4</sup> An increased awareness of neurological conditions amongst generic teams may improve the quality of care many patients receive at their local hospital.

Specialist centres such as the MS Centre, local Parkinson’s UK groups and the MND Care Centres are very well received by users of the service. The prospect of meeting other patients with the same condition can be invaluable to patients who wish take up the opportunity. The provision of these services increases the chances of the patients becoming more independent by having the skills to be able to manage their condition. The MND Association branches and groups and other similar organisations, often co-ordinate care and provide information and support to patients.

The progression of neurological conditions often leads to withdrawal from paid employment. This can affect the patients’ financial and emotional well-being. The ability to work can maintain independence and improve quality of life. Many patients struggle to remain or return to work because of a lack of flexibility and understanding by employers’ about the patients’ condition. This can be overcome by the provision of information and advice about rehabilitation services. The survey found that 75% of respondents to question 53 had not been offered any rehabilitation or other support or advice to help them return to work. Raising the awareness of other agencies such as Jobcentre Plus, NHS Plus and other voluntary organisations which can help rehabilitate the patients’ back into employment may significantly increase patient well-being, should they wish to return to work. Access to advice about leaving employment on medical grounds, pensions and family financial arrangements would also help to ensure that the most appropriate decisions are made at the right time for each individual.

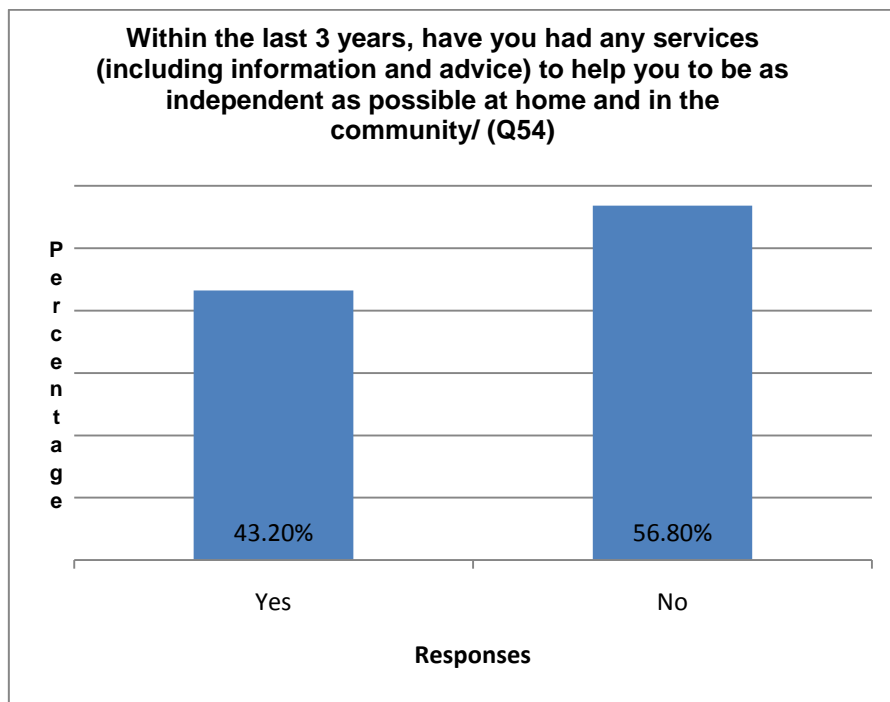


### 3.5 Assistive Technology/Equipment Services

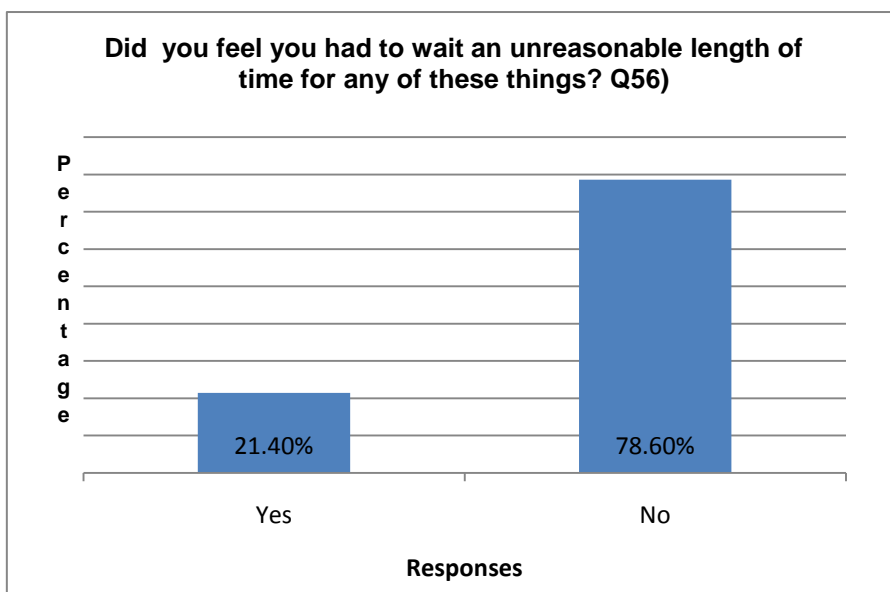
The length of time taken to receive assistive technology/equipment when requested was generally good across the whole area. The graph below showing question 56 shows that; 78.6% of patients who received equipment did not feel they had to wait an unreasonable length of time for the equipment to arrive. People with long-term neurological conditions may require assistance as their condition progresses and disability becomes more apparent. It is therefore important the appropriate equipment is provided in a timely manner to help maintain care and independence. Patients with rapidly progressing conditions, such as motor

<sup>4</sup> Neurological Commissioning Support: Halfway through – Are we halfway there? A midterm review of the National Service Framework for Long Term Neurological Conditions (Page 7)

neurone disease, should be supplied with information at an earlier stage so they are informed of what technology/equipment is available. They can then choose their preferred equipment/services before their condition becomes unmanageable. The assessment process and care planning should be co-ordinated and non-repetitive to maintain the patients' ability. Questions about adaptations to accommodation also received positive feedback with most reporting that these services were completed in a reasonable length of time.



For 78% of those saying 'yes', this was for equipment (eg. grab rails, wheelchair). Of these the majority (79%) felt that they did not have to wait an unreasonable amount of time.



Some of the comments relating to equipment provision included:

“Sometimes the ideas were there, the supply of equipment/services was sometimes very slow.” “I waited for some time after the first telephone call, but after making a second call some months later things started to move more quickly.”

“I needed grab rails around the house and although once assessed they were quick to install them it took several months to be seen.”

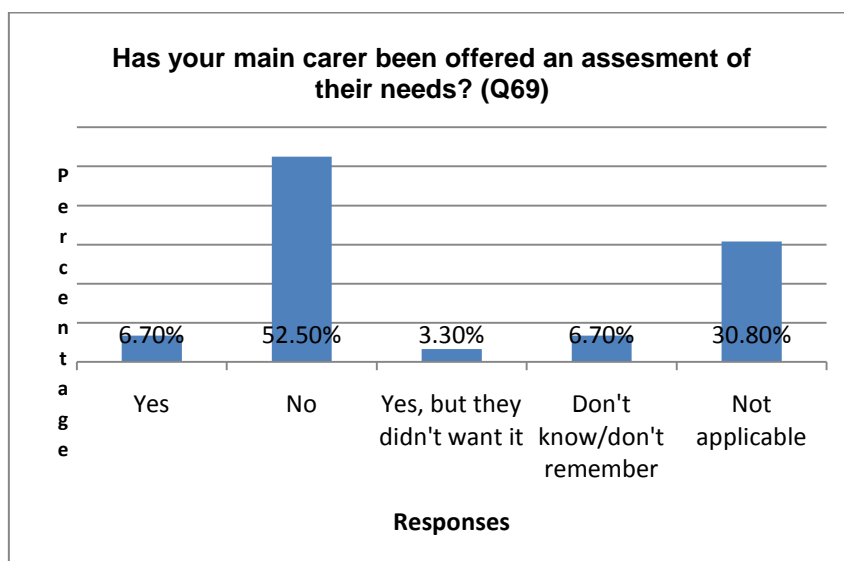
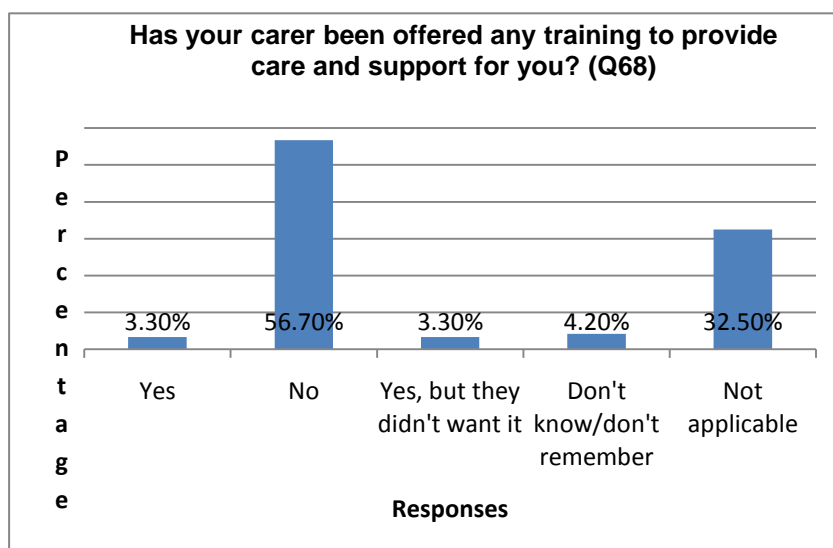
“Stairlift and bathroom alterations – one year.”

“Waiting three months for wheelchair replacement.”

“Waited five months for motorised wheelchair, then two more months before driving test to be allowed to use it outdoors.”

### 3.6 Care and Support

Patients with neurological conditions often receive care from a combination of family members and friends (‘informal carers’) and paid carers. However many informal carers are unaware of the support and training that is available to them. The involvement of carers in the decision-making process when deciding on the care of the patient is crucial so that the carer is able to work as a partner in delivering care. Many respondents to the survey reported that their carer had not received any training to provide care or support.



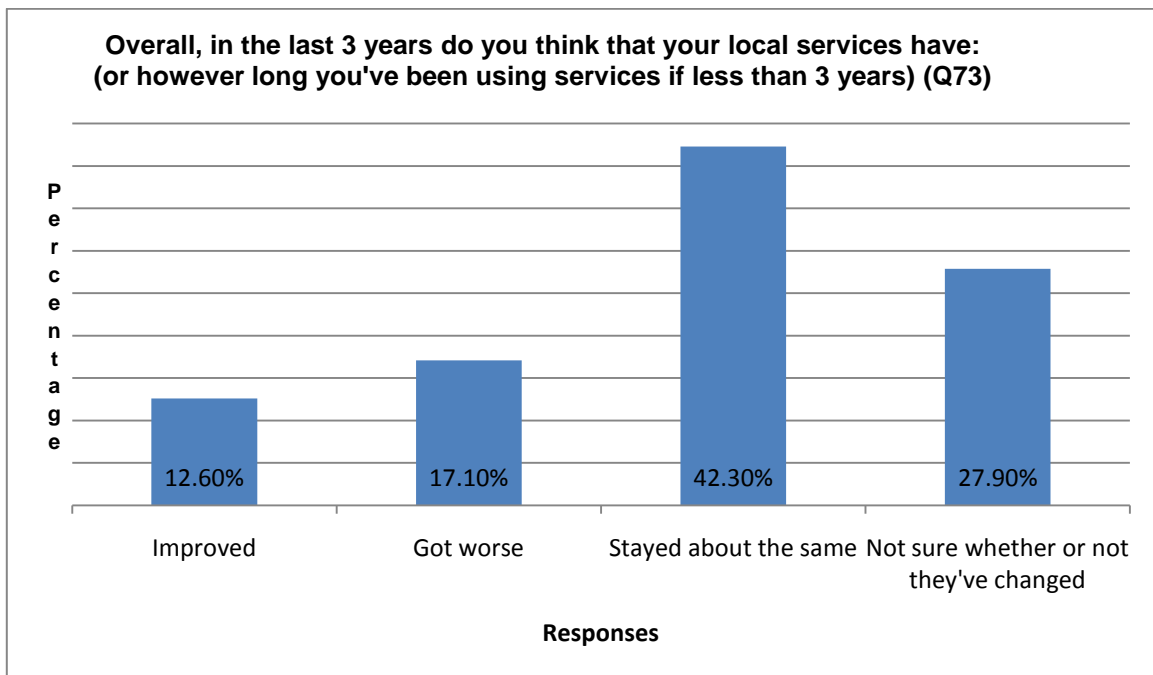


An assessment of carer needs is required so that they have a choice in their role and they can continue to support themselves, the patient and family. However, 57% stated that their carer had not been offered an assessment of their needs. An analysis of their health and social care needs is important to identify the support they need in their caring role. These assessments can shed light on the education and training requirements to help support the carer in their duties. Carers' need should be able to decide on the level of support they wish provide and be confident that they are well equipped to provide the level of care required by the patient.

The survey discovered an overwhelmingly low level of support for carers, something which confirms the NCS report findings. This report relays the fact that many carers work unsupported without any respite care and highlights a worrying trend that many healthcare professionals are unaware of the separate needs of the carer. The NCS also report that many carers are signposted to voluntary organisations for advice and support.

### 3.7 Patient Views

Feedback from patients can provide a source of information for commissioners about what services are required and help improve services for the future. This can allow the appropriate services and equipment to be commissioned to the needs of long-term neurology patients. A subjective look at the patients' view of local services shows a low level of improvement. Overall, 83% of respondents felt that services had improved, stayed the same or were unsure whether they had changed; the remaining 17% felt that services had got worse.



When asked what respondents value or like most about the services they currently use (or have used in the recent past), a range of responses were recorded.

Specialist staff and services came in for a considerable amount of praise, eg.

- “Good access to neurological consultants when needed.”
- “Easy access for advice from the Epilepsy Nurse Specialist.”
- “Availability of Parkinson’s nurse.”
- “Headway and HITU have been fantastic.”

## Brunel Neurological Alliance Survey Report

- “The MS nurse.”
- “Physiotherapy at the MS Therapy centre is absolutely and utterly vital to keep moving.”
- “The MS Therapy Centre is a Godsend and a lifeline that has altered my perception totally and helped me not to be afraid anymore.”
- “The MS Therapy Centre is indispensable to me physically and socially.”
- “My wonderful consultant neurologist.”

Also there were several comments about the accessibility of services, eg:

- “Services are local to me.”
- “I do not have to travel too far for treatment.”
- “The quickness of the treatment.”
- “Easily available.”

In answer to the question “What do you least like about the service you currently use (or have used in the recent past) – question 72, a significant number of respondents answered ‘nothing’ or ‘not applicable’.

For those who gave comments, these can broadly be split into four categories:

1. **Attitude** – “not being listened to or paid attention to”, “being talked down to”.
2. **Perceived difficult in accessing or lack of services** – “cannot seem to get in touch with my consultant”, “only see the neurologist once a year- not often enough”, “length of time between appointments”, “not always contactable, not constant and not localised enough”, “the consultant neurologist who appears not be to be very interested”, “long waits in neurology outpatients”, “the difficult for anyone with Parkinsons in North Somerset being able to make use of a Parkinsons nurse if in hospital at Bristol”, “the length of time it takes for me to get an appointment with my consultant.”
3. **Information** – “knowing what’s available,” “lack of information”
4. **Lack of continuity or co-ordination** – “fragmented care; nothing joined up”, “this week I have had five separate MND related appointments”, “not all the professional involved seem to know what has gone before, or what is currently happening”, “I have visited the hospital eight times and seen eight different doctors so have been unable to build up any rapport with doctors and also received contradicting advice.”

When respondents were asked whether there were any service that they thought should be available but which aren’t currently in place, there were a variety of responses but several relating to the following categories:

- Access to specialist nursing (Weston-super-Mare hospital specifically mentioned by several)
- Cognitive behaviour therapy/counselling
- Alternative therapies
- Access to a consultant neurologist at Weston-super-Mare hospital
- Local physiotherapy-led exercise classes
- Regular and long-term physiotherapy

It was striking (although not surprising in light of the number of respondents to the survey with MS) that there were a considerable number of comments about the MS Therapy Centre at Bradley Stoke. This clearly is a great resource for respondents, and highly prized. Three responses are included below:

“I would love for someone to come and spend some time at the Centre I go to in Bradley Stoke and discuss the benefits of everything offered there. It really will inform your debate, I promise you.”

“I am fortunate at present to be able to access subsidised physio and other therapies through charity (MS Therapy Centre). These should be available to all, and funded for all.”

“I would like to see more collaboration between NHS services and the excellent by financially struggling MS Therapy Centre, Bradley Stoke. This large new centre has much potential for extension to NHS provision of services for neurological patients.”

### 4.0 Recommendations

Brunel Neurological Alliance recommends that commissioners of health and social care services in Bristol, North Somerset and South Gloucestershire:

1. Consider the finding of this report carefully
2. Identify areas where commissioning of services for people with neurological conditions can be improved to ensure that they more closely match the needs of individuals, and to allow for more efficient use of resources
3. Work with the Neurological Alliance to improve the awareness of neurological conditions, engage more fully with people with neurological conditions and those who care for them, and promote self-management through the improved access to information and support.

### 5.0 Conclusion

This survey highlights a number of needs of people with long-term neurological patients in Bristol, North Somerset and South Gloucestershire.

It gives commissioners an opportunity to hear from a number of people who use the services and help inform the future planning and delivery of services in the areas in which they serve.

## Appendix 1: The Quality Requirements of the National Service Framework for Long-Term Neurological Conditions.

The Quality Requirements of the National Service Framework for Long-Term Neurological Conditions	
Quality Requirement 1	<b>A person-centred service</b> People with long-term neurological conditions are offered integrated assessment and planning of their health and social care needs. They are to have the information they need to make informed decisions about their care and treatment and, where appropriate, to support them to manage their condition themselves.
Quality Requirement 2	<b>Early recognition, prompt diagnosis and treatment</b> People suspected of having a neurological condition are to have prompt access to specialist neurological expertise for an accurate diagnosis and treatment as close to home as possible.
Quality Requirement 3	<b>Emergency and acute treatment</b> People needing hospital admission for a neurosurgical or neurological emergency are to be assessed and treated in a timely manner by teams with the appropriate neurological and resuscitation skills and facilities.
Quality Requirement 4	<b>Early and specialist rehabilitation</b> People with long-term neurological conditions who would benefit from rehabilitation are to receive timely, ongoing, high quality rehabilitation services in hospital or other specialist setting to meet their continuing and changing needs. When ready, they are to receive the help they need to return home for ongoing community rehabilitation and support.
Quality Requirement 5	<b>Community rehabilitation and support</b> People with long-term neurological conditions living at home are to have ongoing access to a comprehensive range of rehabilitation, advice and support to meet their continuing and changing needs, increase their independence and autonomy and help them to live as they wish.
Quality Requirement 6	<b>Vocational rehabilitation</b> People with long-term neurological conditions are to have access to appropriate vocational assessment, rehabilitation and ongoing support to enable them to find, regain or remain in work and access other occupational and educational opportunities.
Quality Requirement 7	<b>Providing equipment and accommodation</b> People with long-term neurological conditions are to receive timely, appropriate assistive technology/equipment and adaptations to accommodation to support them to live independently; help them with their care; maintain their health and improve their quality of life.
Quality Requirement 8	<b>Providing personal care and support</b> Health and social care services work together to provide care and support to enable people with long-term neurological conditions to achieve maximum choice about living independently at home
Quality Requirement 9	<b>Palliative care</b> People in the later stages of long-term neurological conditions are to receive a comprehensive range of palliative care services when they need them to control symptoms; offer pain relief and meet their needs for personal, social, psychological and spiritual support, in line with the principles of palliative care
Quality Requirement 10	<b>Supporting family and carers</b> Carers of people with long-term neurological conditions are to have access to appropriate support and services that recognise their needs both in their role as carer and in their own right.
Quality Requirement 11	<b>Caring for people in hospital or in other health and social care settings</b> People with long-term neurological conditions are to have their specific neurological needs met while receiving care for other reasons in any health or social care setting.

**Table 1: The Quality Requirement of the National Service Framework for Long-Term Neurological Conditions<sup>1</sup>**

## Appendix 2

### Breakdown of respondents

The survey was completed by 120 people with neurological conditions, who described the area in which they lived as follows:

Area of residence	Number of respondents
Bristol	44
South Gloucestershire	33
North Somerset	43

The number of respondents in each age bracket were as follows (not all respondents completed this field):

Age range	Number of respondents
18 – 30	1
31 – 50	35
51 – 65	54
Over 65	28