



Swindon and Wiltshire Neurological Users Survey Report 2012



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Report produced by MND Association
Arti Patel

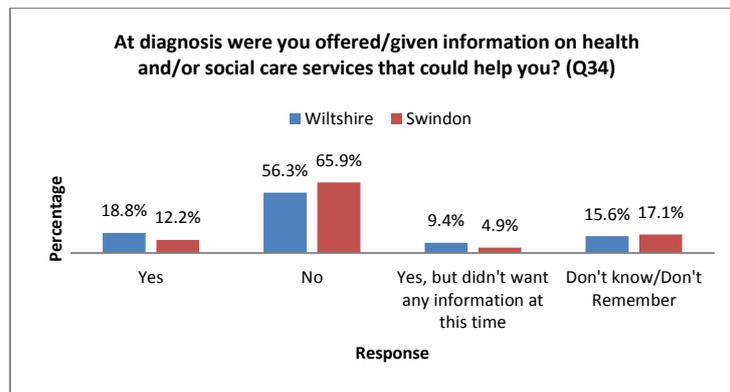


Executive Summary

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. The quality requirements set out in the NSF identify ways to improve the management of long-term neurological conditions.

This report details the findings of a survey implemented by the Swindon and Wiltshire Neurological Alliance (SWNA), which was completed by patients using the neurological services in Swindon and Wiltshire. It is anticipated the findings will provide a source of intelligence for commissioners regarding the service requirements of neurological service users.

The findings reveal low levels of awareness amongst patients about long-term neurological conditions, and the accessibility of services. When patients were asked about information provision in relation to health and social care services, over half of the respondents in each area answered that they did not receive any information at diagnosis regarding services that could help (see graph below). This could be improved to provide the same level of access to high-quality neurology services, to all patients across Wiltshire and Swindon.



The following presents an initial outline of the key-findings of the survey.

- **A person centred service:**
 - Specifies the range and incidence of neurological conditions.
- **Care Planning:**
 - Awareness and implementation of the written care plan by patients was poor.
- **Information Provision:**
 - Most patients do not receive any/enough information about their condition and how to access services to manage it. Many patients also did not have a single point of contact for information or advice.
- **Early Recognition, prompt diagnosis and treatment:**
 - The majority of patients received a definite diagnosis in under 12 months, however many patients waited over year for a confirmed diagnosis.
- **Emotional Support:**
 - The provision of counselling/emotional support to patients and their families was inadequate.

- **Emergency and acute treatment:**
 - Patients admitted to hospital as an emergency not concerning their neurological condition reported a low level of neurological support.
- **Rehabilitation:**
 - Access to community or vocational rehabilitation services was limited.
- **Assistive Technology/Equipment Services:**
 - Equipment provision was generally positive across both areas.
- **Care and Support:**
 - Support for carers' of patients with neurological conditions was minimal, with many carers not receiving any education or training to care for their loved ones.
- **Patient views:**
 - A view of services from the patients' perspective highlights the areas that require improvement, and areas doing well.

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”.¹

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. Service providers evaluate themselves against each statement, resulting in an overall score of red, amber or green for each evidence-based marker (EBM).

In response to the Neurological Commissioning Support (NCS) mid-term review of the NSF LTNC’s, the SWNA conducted their own survey to assess the neurological services offered in Swindon and Wiltshire.

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 neurological patients from Swindon and Wiltshire. 100 responses were received, 50 from each area.

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.

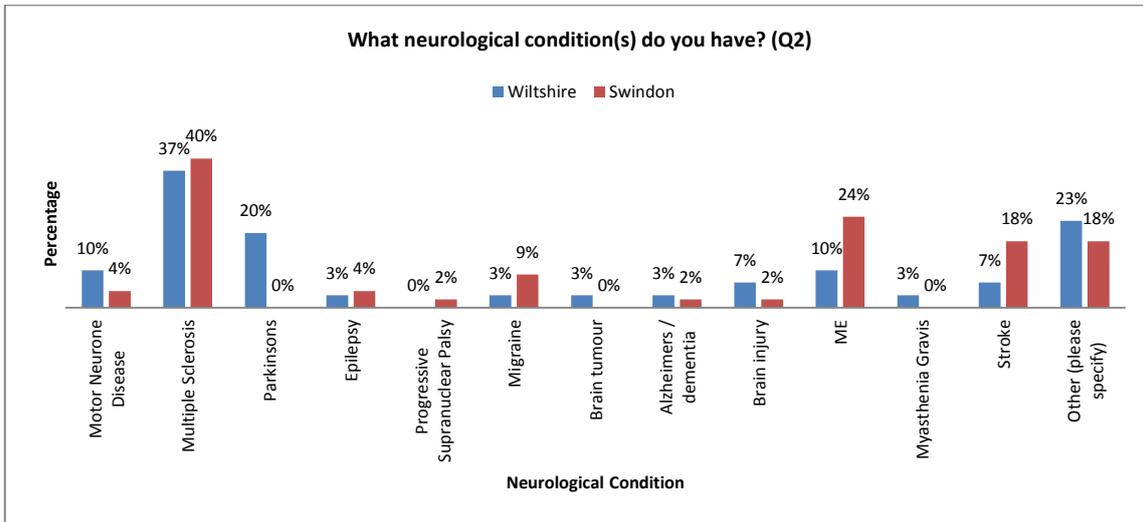
The findings of this report will provide a significant source of information for service commissioners and will act as resource for establishing the success of the NSF requirements in shaping the delivery of the neurological services. Comparison of the findings of the survey against the NSF QRs provides an understanding of the strengths and weaknesses of the neurological services in Swindon and Wiltshire.

¹ The National Service Framework for Long Term Neurological Conditions (2005)

Key Findings

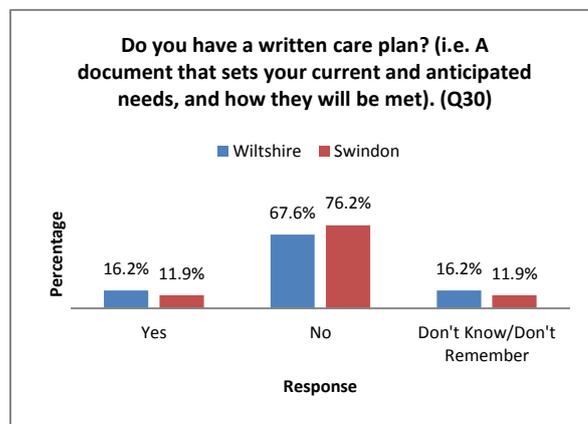
A person centred service

One of the important aims of this study is to establish the range of neurological conditions and the approximate number of patients with these conditions. This intelligence can help commissioners to commission more effectively to meet patient needs. The graph below shows the prevalence of a range of neurological conditions in Swindon and Wiltshire.



Care planning

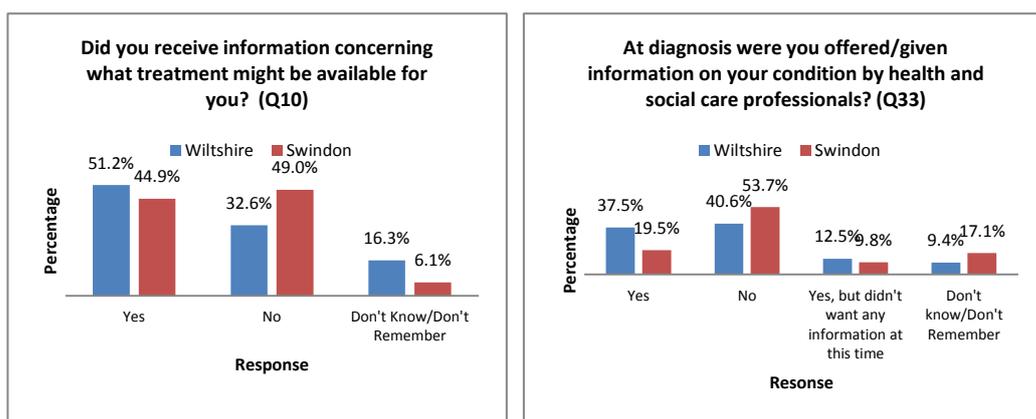
Communication between interdisciplinary teams, the patient and their families/carers', is vital when composing the written care plan. This plan covers both current and anticipated needs, and is to be regularly reviewed to ensure the patient receives the best possible care. An overwhelming majority of patients in both areas did not have a written care plan (Wiltshire 67.6%, Swindon 76.2%). However, the EBMs require the inclusion (and agreement) of the patient in all decisions. The NCS review² of 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. An explanation of the results could be that the patients are not aware that such a plan exists.



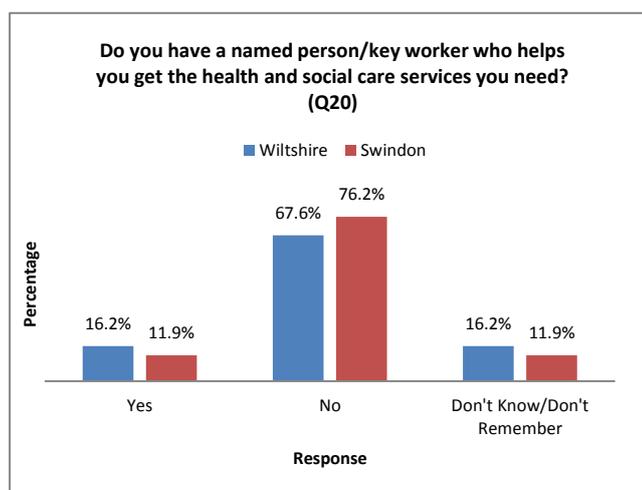
² Neurological Commissioning Support: Halfway through – Are we halfway there? A midterm review of the National Service Framework for Long Term Neurological Conditions

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. The survey established information provision regarding conditions and available treatments was better in Wiltshire compared to Swindon. The availability of information about service provision, condition management and social inclusion is vital to help the patients manage their condition and treatment.

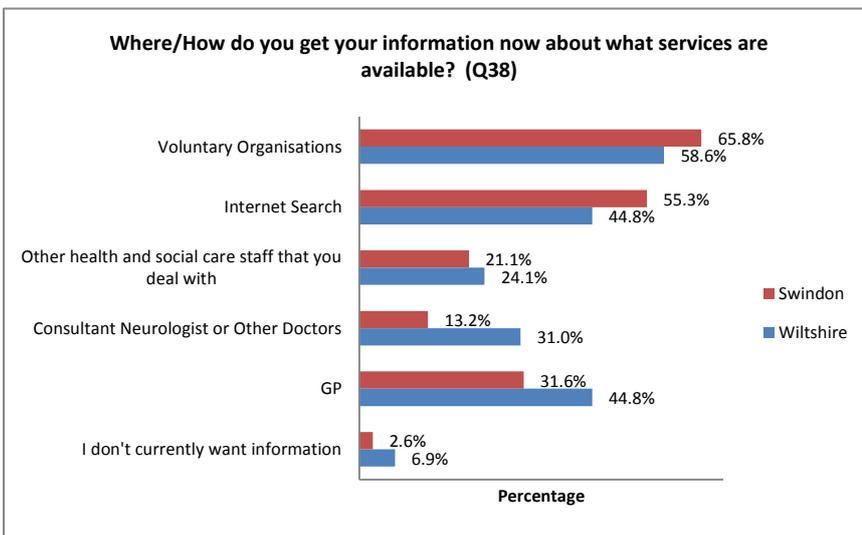
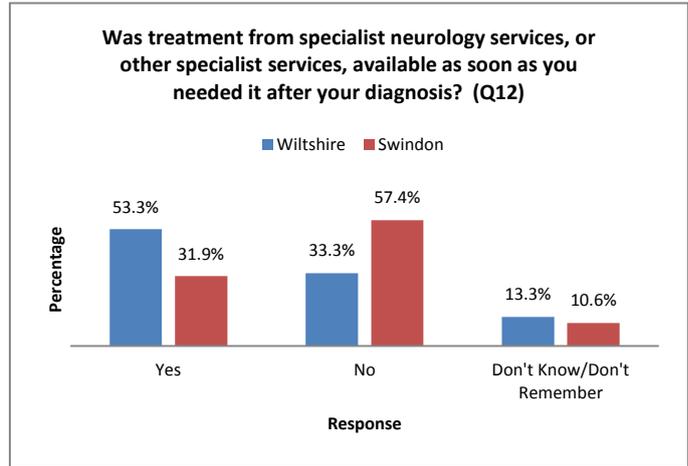


This can be provided by a named person/key worker, however over 50% of respondents in both areas did not have a single named person/key worker for advice and information. For many patients, a named person/support nurse is often the sole source of advice and information. There was also a lack of knowledge surrounding the self-referral pathways and access to treatments. The NCS review in 2010 also found that patients did not have a single point of contact for information. This can result in patients being unaware of which services they are entitled to. The main key workers whom patients obtained information from were; a specialist nurse/co-ordinator and GP. When patients’ were asked about key services that should be available, but were not provided, one patient stated, **“One key worker for all initial contacts (Health and Social Services)”**.



Neurological Users Survey Report

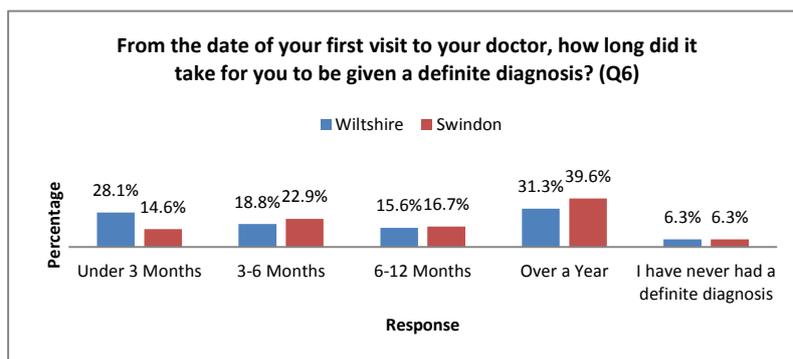
Poor information provision about available treatments makes it difficult to access services at the right time. This may hinder the prompt availability of specialist treatment after diagnosis. 53.3% of survey respondents in Wiltshire received treatment straight after diagnosis compared to 31.9% in Swindon (57.4% in Swindon reported not having treatment available as soon as required after diagnosis). One patient thought there should be, **“Better information about what is available and how to get access”** when asked for their opinion about how they feel service provision should change.



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 which they could obtain advice, support or information on services.

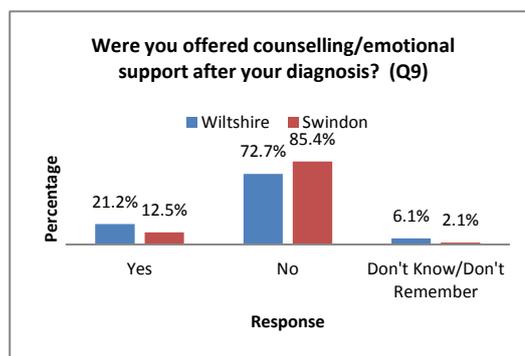
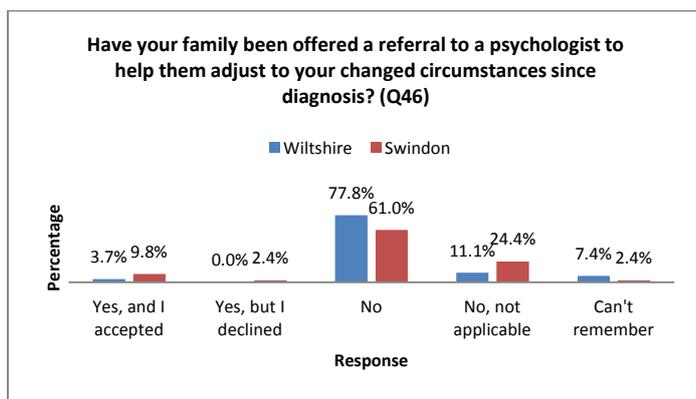
Early recognition, prompt diagnosis and treatment

The graph below shows the approximate time for definite diagnosis. The majority of patients had to wait over a year for a confirmed diagnosis. In Wiltshire, 28.1% received a diagnosis in under 3 months, compared to 31.3% who waited over a year. When compared against Swindon where 14.6% received a diagnosis in less than 3 months compared to 39.6% who waited over a year. The need for recognition and diagnosis of neurological conditions is essential for reduced anxiety of the patients and their families, and prompt access to treatment. However some conditions may be very difficult to diagnose, therefore it is critical that patients with suspected LTNCs are referred to a specialist team/centre for an assessment and that pathways (and awareness of them) are in place for this to occur.



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. One patient quoted, **“Support at times when living with a degenerative condition gets the better of you emotionally”**. 85.4% (Swindon) and 72.7% (Wiltshire) of respondents were not offered counselling/emotional support after their diagnosis. There was also a lack of a support for their families, e.g. 61% (Swindon) and 77.8% (Wiltshire) were not offered a referral to a psychological to assist with the adjustment to the changed circumstances after diagnosis. This essential service is valued by patients and can facilitate communication between the patients and their family/carer. Therefore it is important patients and their families are offered counselling/emotional support to help adapt to the new situation.



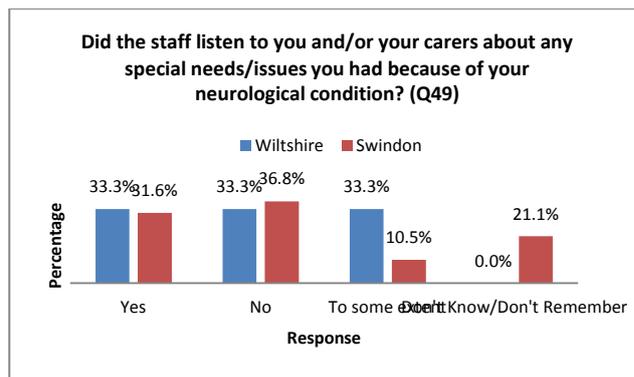
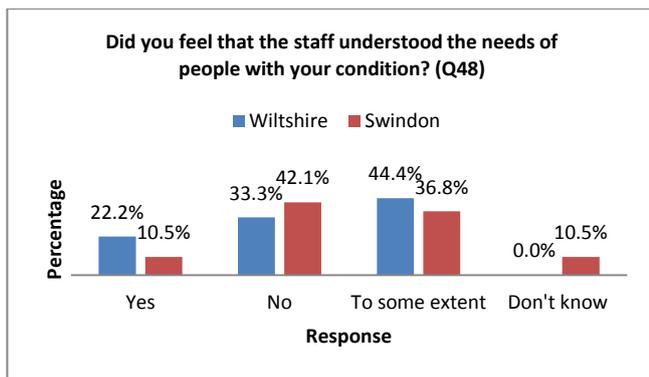
Emergency and acute treatment

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. However, when admitted as an emergency case for a problem not concerning their neurological condition, some patients' reported that they were not provided with on-going neurological care. The graph below shows the majority of patients (42.1%) in Swindon who were admitted to A+E with a problem not concerning their neurological condition did not feel that the staff understood the needs of their neurological condition. One patient suffering from fibromyalgia chronic fatigue reported the following situation when admitted to hospital: **“I dislocated my hand, none of the ambulance or hospital pain relief worked because of the oversensitivity Fibromyalgia sufferers have, and only one nurse over this period knew this, but still could provide no relief”**.

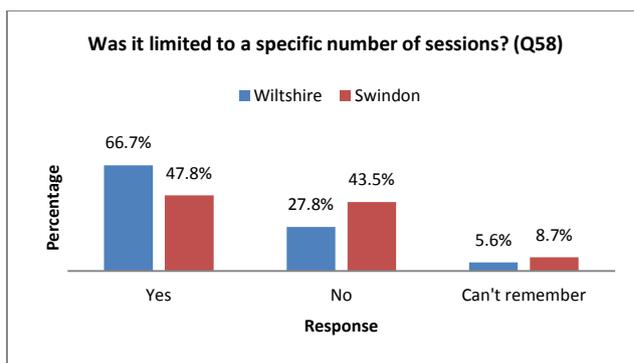
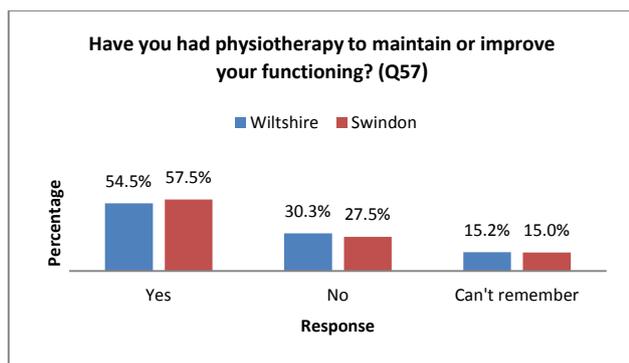
The NCS report also found that people with neurological conditions admitted to A+E were not receiving on-going neurological care.³ Some felt their neurological condition was disregarded and there was no input from specialist neurology staff. Many neurological patients have regular medication regimes that 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.

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



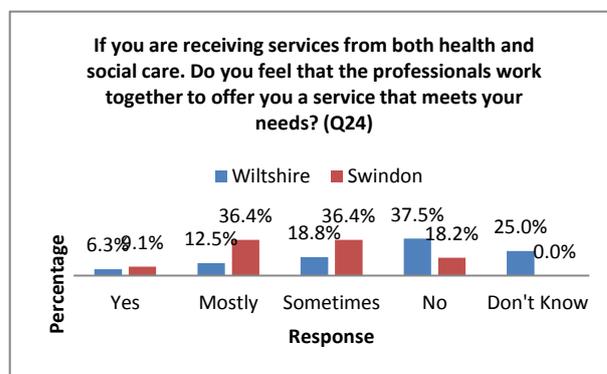
Rehabilitation

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 may reduce 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. 66.7% (Wiltshire) and 47.8% (Swindon) of patients received a limited number of physiotherapy sessions. One patient resorted to paying privately for further physiotherapy treatment, as the NHS service was limited to six sessions.



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.

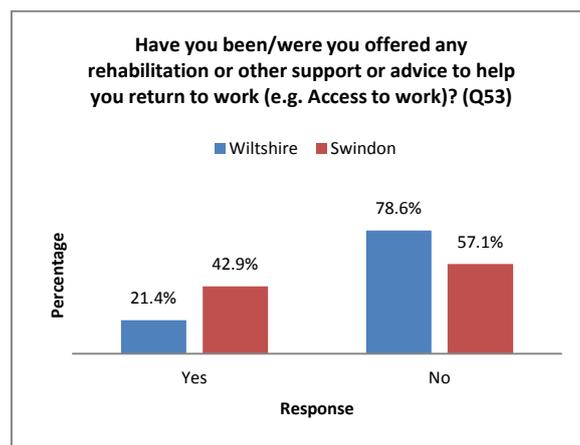
The co-ordination of both health and social care is important to provide long-term services to help patients maintain their independence at home. The attitude of some patients suggests that better communication and co-ordination between services is required. 37.5% of respondents in Wiltshire felt that health and social care professionals do not work together to provide a service that meets their needs, whilst 36.4% of respondents in Swindon felt this occurs occasionally.



When invited to give examples of ways in which service provision could be improved, one patient in the survey wanted better communication between professionals **“Improved Communication...Improved attitude of joint working by service, recognition that the user knows what they need (to a degree)”**. 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.⁴ 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. When asked about what they value most about the services they use, one patient stated, **“...being able to attend the specialist MND Care Centre at JR Oxford”**. The prospect of meeting other patients with the same condition can be invaluable to patients who wish to 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.

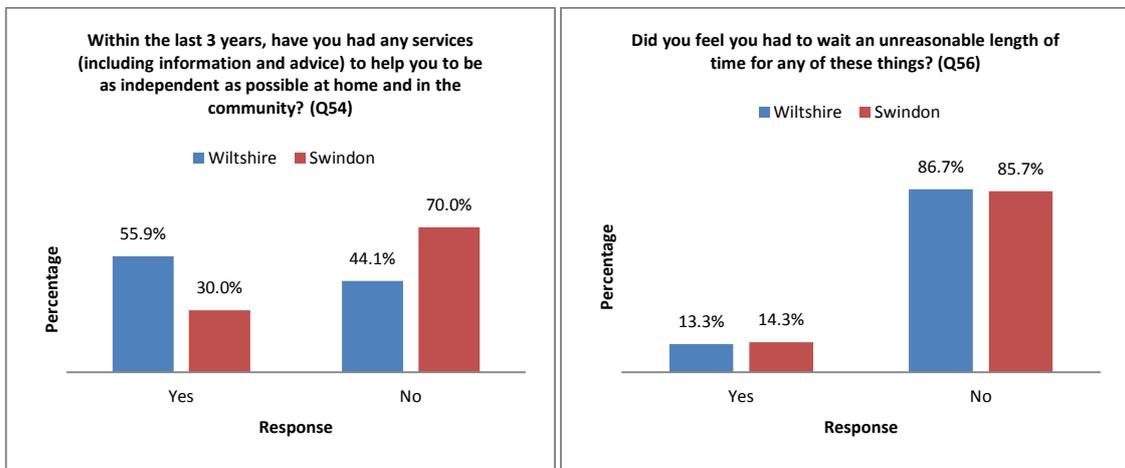
The progression of neurological conditions often leads to withdrawal from paid employment. This can affect the patients’ financial and emotional well being. The ability to work can maintain independence and improve quality of life. Many patients struggle to remain or return to work because of a lack 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 a lack of support and guidance on returning to work. E.g. 78.6% (Wiltshire) and 57.1% (Swindon) of respondents reported not receiving any support or advice about access 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. Patients’ may also need advice about leaving employment on medical grounds, pensions and family financial arrangements.



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

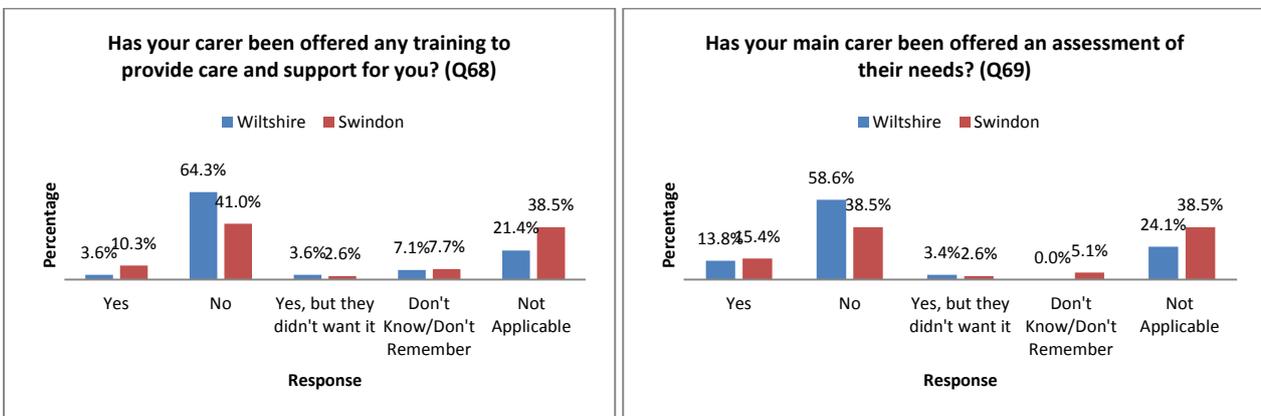
Assistive Technology/Equipment Services

The length of time taken to receive assistive technology/equipment when requested was generally good in both areas. The graph below showing question 56 shows that; 86.7% (Wiltshire)/85.7% (Swindon) 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 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.



Care and Support

Patients with neurological conditions often receive care from specialist carers and loved ones. However many 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 implement their carer duties effectively. 64.3% (Wiltshire)/41% (Swindon) of patients in the survey reported that their carer had not received any training to provide care or support.

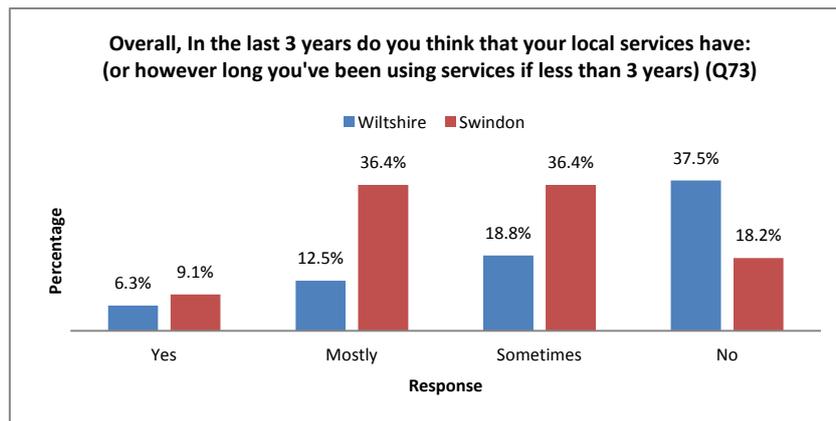


An assessment of carer needs is required so that they have a choice in their role and they can continue to support themselves, the patient and family. However in Wiltshire, 58.6% stated that their carer had not been offered an assessment of their needs. Although this figure was lower in Swindon (38.5%), 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 that 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.

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. However, the consistency of the services has remained.



Areas for improvement:

- ❖ When patients were questioned regarding areas of improvement, common topics from both areas included information provision, ***“It seems to be that it is down to the patient to find out about things and then fight to be able to go. Patients should be advised that there are options available when diagnosed”***, and better co-ordination/communication of health and social services, ***“Improved Communication. Improved attitude of joint working by services”***.
- ❖ The survey asked patients if there were any services they felt were needed that they were not receiving. The majority of answers from this open-ended question concentrated around the available and number of sessions of physiotherapy.

Areas doing well:

- ❖ Many patients valued the supportive relationship they receive from their GP and being able to converse by telephone.
 - ***“My GP has responded well to my health needs”*** (Swindon)
 - ***“My GP is my first port of call and he is very understanding about my condition which makes it easier to receive treatment”*** (Wiltshire).
- ❖ The availability of specialist services run by charity organisations such as the Oxford MND Care Centre and local MS Society and Parkinson’s UK Centres.
 - ***“Having a social services OT and a specialist nurse available to contact by phone. And being able to attend the specialist MND Care Centre at JR Oxford”.***
 - ***“...The social benefit of the MS centre...”***
 - ***“I get to meet other parky people. Thanks to the local Parkinson’s UK group. Once a year we have a Medical Forum at Salisbury Hospital where the latest research news is given us by our Health Care Professionals. Plus organised visits to local interesting place”.***

Conclusion

This survey highlights the needs of long-term neurological patients in Wiltshire and Swindon. The findings given above may appear negative, however it is apparent that some patients are able to access 100% of the services required by their needs. An improvement in some areas, e.g. information provision, would mean that patients in both Swindon and Wiltshire can receive a regular service across all areas. Although many facilities do exist, the lack of awareness and accessibility hinders the full impact of these services. There is no doubt about the value or the commitment of the health care professionals who provide these services. It is hoped this report will be used to inform commissioners for the benefit of the neurological services users and providers.

Further information

If you would like to find out more about the Swindon and Wilts Neurological Alliance please contact us through our website

www.swna.org.uk

or through

info@swna.org.uk

Appendices:

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	<p>A person-centred service 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.</p>
Quality Requirement 2	<p>Early recognition, prompt diagnosis and treatment 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.</p>
Quality Requirement 3	<p>Emergency and acute treatment 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.</p>
Quality Requirement 4	<p>Early and specialist rehabilitation 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.</p>
Quality Requirement 5	<p>Community rehabilitation and support 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.</p>
Quality Requirement 6	<p>Vocational rehabilitation 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.</p>
Quality Requirement 7	<p>Providing equipment and accommodation 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.</p>
Quality Requirement 8	<p>Providing personal care and support 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</p>
Quality Requirement 9	<p>Palliative care 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</p>
Quality Requirement 10	<p>Supporting family and carers 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.</p>
Quality Requirement 11	<p>Caring for people in hospital or in other health and social care settings 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.</p>

Table 1: The Quality Requirement of the National Service Framework for Long-Term Neurological Conditions¹

Appendix 2: Survey Summary – Swindon

(Please see attachment)

Appendix 3: Survey Summary – Wiltshire

(Please see attachment)