Neurological Conditions Network. Engagement exercise summary report

Public Health Agency

Health and Social Care Board

Speak out for change

Neurological Conditions Network survey

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Foreword

On behalf of the Neurological Conditions Network, I am pleased to present this report on the experiences of people living with neurological conditions and their carers.

The Neurological Conditions Network was established in recognition of the number of people living with neurological conditions and strives to ensure the best possible quality of life for those living with these conditions and their carers. To this end, it is essential that they are given the opportunity to tell their story and that we listen to these experiences.

It was with this in mind that the *Speak out for change experience survey* was developed. The survey aims to provide an opportunity for people to describe the impact neurological conditions have on their lives and is unique in its holistic focus. Throughout this process, I have had the privilege and opportunity to meet many people living with neurological conditions and their carers, and I am honoured that so many people are willing to share their experiences. These experiences and life stories are both sobering and powerful, and provide a much needed, deeper appreciation of living with a neurological condition.

This is the first time a project covering such a wide range of neurological conditions has been undertaken and, despite the diverse nature of the conditions, the life experiences shared to date have consistently revealed issues around information, choice and control, independence, and the emotional impact of neurological conditions.

This is not a one-off exercise, but the beginning of an ongoing dialogue. We recognise that this survey has not reached everyone or every condition, but we hope, through the network, to further develop the survey and create a robust communication process that allows everyone to participate and contribute towards the planning and delivery of services.

The success of this exercise would not have been possible without ongoing support from Moore Stephens Management Consultants and I would like to express sincere thanks to all those who have been involved.

Michelle Tennyson
Assistant Director Allied Health Professions and Personal and Public Involvement
Chair, Neurological Conditions Network

Background

Neurological conditions can affect people of all ages. They result from damage to the brain, spinal column or nerves caused by illness or injury and can be present from birth or begin at any time of life. There is a wide range of neurological conditions and these impact on a person's daily life in a variety of ways, depending on:

- the nature of the condition;
- the severity of the condition;
- the age of the patient at onset of the condition;
- other factors such as support and finances.

The effects of neurological conditions can result in reduced independence and impact on education, family, social relationships and a person's ability to work.

In recognition of this, the Minister for Health, Social Services and Public Safety announced the development of the Neurological Conditions Network to ensure the best possible quality of life for those living with these conditions and their carers. It is essential that their experiences are heard.

With this in mind, the network has been established in two phases. The first phase saw an ambitious engagement exercise to seek the experiences and priorities of people living with neurological conditions and their carers. A detailed list of members of the first phase of the network can be found on page 16. The information gathered through this exercise will inform phase two, the development of the final network.

This report details the background to the work, and the development and implementation of the ongoing engagement. The priority areas and recommendations, based on the first pool of results, are also outlined, as are the next steps.

Engagement

In taking forward phase one of the network, the objective was to design a mechanism that would allow ongoing engagement with people living with neurological conditions and their carers – to listen to their experiences and priorities and use the information gathered to inform service design and delivery. Consequently, the Public Health Agency and Health and Social Care Board commissioned Moore Stephens to develop such a mechanism.

The *Speak out for change experience survey* was developed using SenseMaker software, creating a survey that focuses on the impact on quality of life when living with and caring for a neurological condition. SenseMaker, a qualitative research technique, enables the capture and analysis of people's experiences and stories through carefully developed questions and then provides qualitative data.

This approach is in keeping with the Public Health Agency and Health and Social Care Board's commitment to Personal and Public Involvement in the planning and delivery of services. Listening to, talking with and supporting the involvement of those living with a neurological condition or their carers is necessary if services are to:

- be responsive and appropriate;
- be tailored to need;
- be prioritised correctly;
- acknowledge patient rights;
- recognise knowledge and expertise;
- improve levels of service satisfaction.

The survey has been promoted through websites, email, press releases and a flyer that was displayed in libraries and neurology clinics.

Assistance in completing the survey was available in four libraries across Northern Ireland, at group meetings and at neurology clinics. Visits were also arranged with service users and carers at charity support groups and in their own homes. This assistance is still available via telephone or email (028 9032 1313, neurological.conditions@hscni.net).

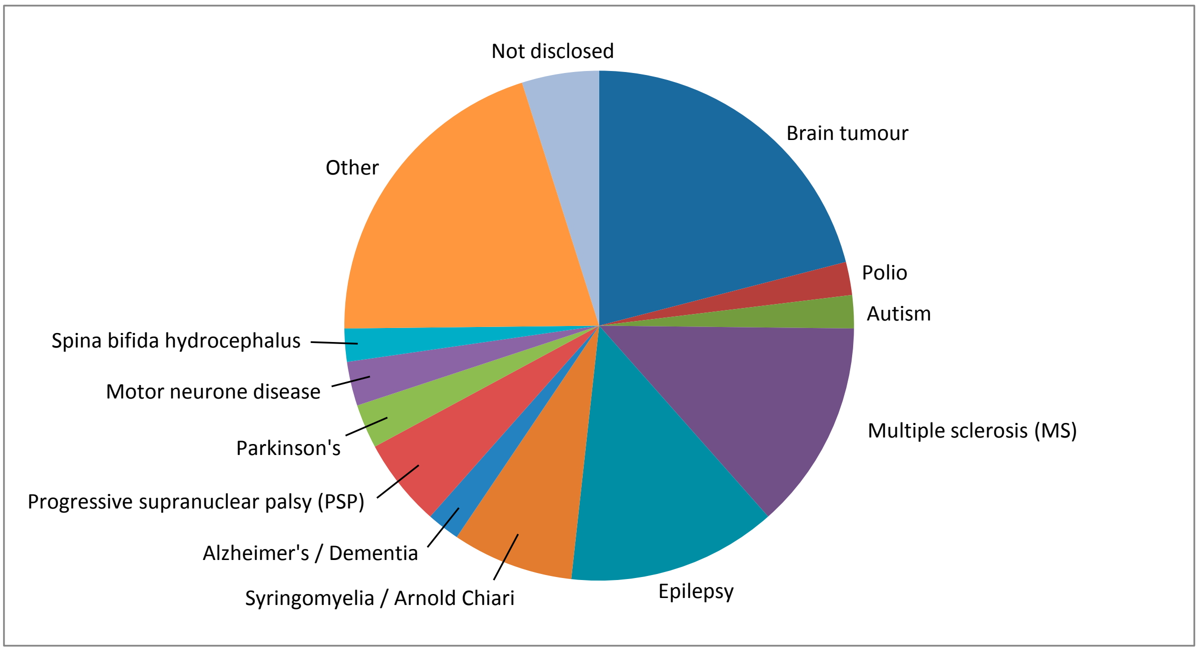
In this first pool, a total of 142 surveys were completed.

Results

Summary of conditions covered

The experiences recounted within the surveys came from people living with a wide range of conditions (some people having more than one condition) and their carers. Figure 1 illustrates the range of conditions that respondents reported in the survey.

Figure 1: Neurological conditions that survey respondents reported



Conditions included within ‘other’ were:

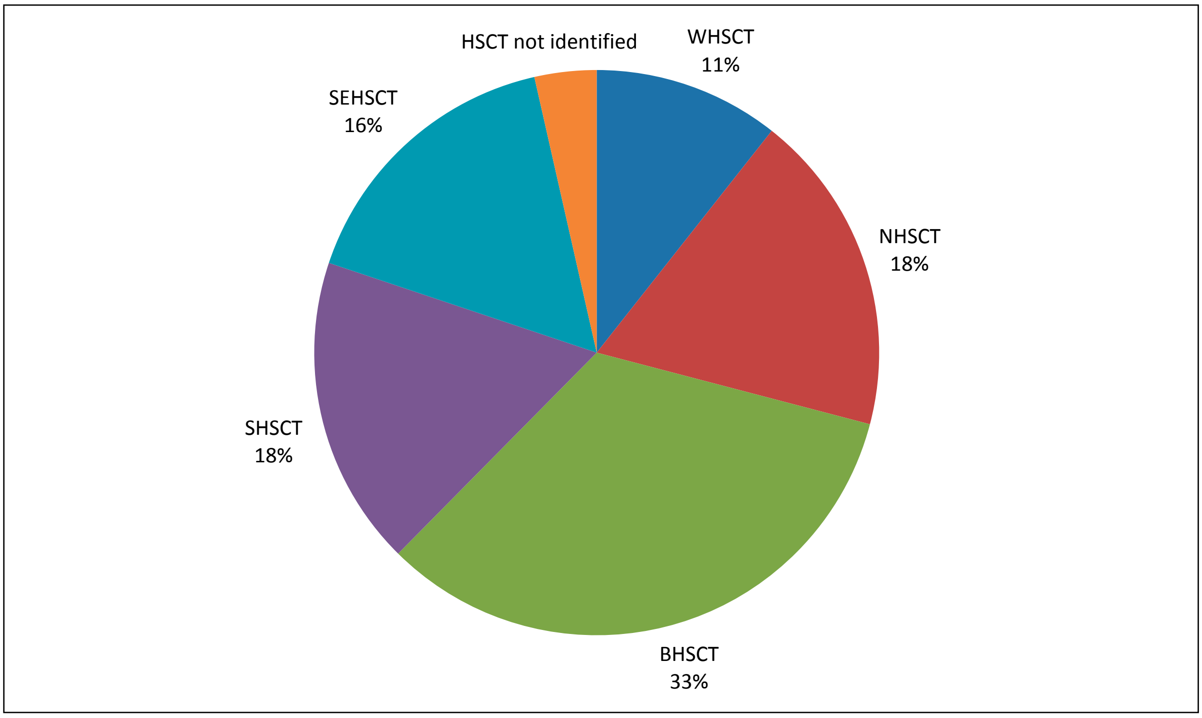
- Williams syndrome
- Angelman syndrome
- Myotonic dystrophy
- Arteriovenous malformations
- Sebaceous nevus syndrome
- Stroke
- Primary lateral sclerosis
- Brain injury
- Optical neuro
- Friedreich’s ataxia
- Muscular dystrophy

- Myoma
- Charcot-Marie-Tooth disease
- Acoustic neuroma
- Complex partial seizures
- Cerebellar atrophy
- Peripheral neuropathy
- Myalgic encephalopathy
- Chronic inflammatory demyelinating polyneuropathy
- Cerebral palsy
- Guillain-Barre syndrome
- Fibromyalgia

Location of survey respondents

The survey was distributed and promoted across Northern Ireland. Figure 2 shows the spread of responses across the region, by Health and Social Care Trust area.

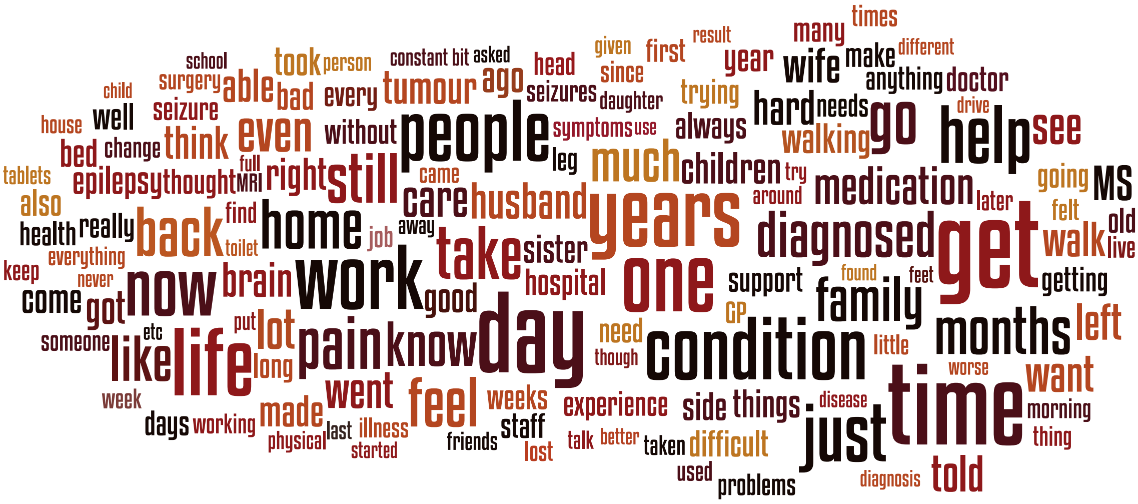
Figure 2: Distribution of survey responses, by Health and Social Care Trust (HSCT) area



The story

In completing the survey, people were asked to describe an event or experience that would help someone understand the day to day challenges they face as a person with a neurological condition or as a carer or family member.

The collection of stories gathered through the survey were entered into Wordle software to generate a ‘word cloud’. This cloud shows words that were frequently used within the stories, while the size of the word indicates how frequently it was used.



As illustrated by the word cloud, the most frequently used words within the 142 stories focused on the following themes:

- Time (day, time, years, life, months, now, long, still).
- Everyday life (home, work, family).
- The condition (medication, diagnosed, care, pain).
- Action (go, get, take, help).
- Human aspect (people, children, daughter, wife).

Interpreting the story

After describing their experience, people were asked to self-interpret its meaning using a series of questions. This information was presented to the Network at an analysis workshop in May 2011 for discussion and interpretation of the patterns.

Interpretation of the patterns focused on what the information shows for the sample population, raising questions but avoiding universal conclusions.

Recommendations

Four priority areas emerged from the analysis and interpretation of patterns:

1. A lack of clear and accurate information, and difficulties in diagnosis.
2. How people experience control and choice – this impacts in particular on their ability to self-manage and on the focus of a patient-centred service.
3. Impact on day-to-day living and independence (‘what makes you, you?’) – if independence and the aspects of daily living such as finance, employment, social life, ability to get out and about deteriorate, it increases inequalities.
4. Emotional and psychological impact on individuals with a neurological condition and their families – in particular, the support that people can access for processing the emotions (anxiety, stress, fear, frustration, isolation, loss and vulnerability) associated with living with a neurological condition.

In consideration of these priority areas, the following actions are recommended:

Undertake an audit of care plans

Completing an audit of care plans to identify the extent to which individuals have choice and control over their care and treatment.

Define care pathways

Defining care pathways would play an important part in ensuring integration of services and would provide individuals with an understanding of the care, treatment and support available.

Support people to become expert patients

Expert patients are defined as people living with a long-term health condition who are able to take more control over their health by understanding and managing their condition. We recommend supporting people with neurological conditions to become expert patients, so that they create partnerships with health professionals, choose self-management and develop control of their care and treatment, particularly when the effects of the condition impact on communication.

Review how enhanced support is integrated with professional care and treatment

Peer support groups and charities provide a wide range of assistance for people with a neurological condition and their families and carers. We recommend integrating the support from these organisations within a defined care pathway, providing opportunities for ‘wraparound’ support for individuals and their families.

Service teams

In order to manage care pathways and fully implement the recommendations within Health and Social Care, we propose that neurological conditions are prioritised within one (or more) of the Health and Social Care Board’s service teams.

Linking with the Social Security Agency

Linking with the Social Security Agency to raise awareness of benefit entitlement and increase the understanding of what financial support is available to those with a neurological condition and their carers.

Linking with public transport providers

Linking with public transport providers to explore the possibility of enabling ease of access to public transport (including the provision of free travel for those with long-term neurological conditions), so that individuals can maintain their independence and access the support services available to them.

Linking with the Department for Employment and Learning

Linking with the Department for Employment and Learning to generate discussion about possible options (such as training/re-training) for those living with a neurological condition and their carers to remain in employment for as long as possible. This would support independence and impact on the financial difficulties faced by many families.

Providing counselling and emotional support

Providing emotional support to carers and family members, in addition to the provision of mental health and wellbeing support for individuals with a neurological condition. Improving the mental health of carers and family members will enable them to support their loved ones through the neurological condition.

Ongoing engagement with individuals and carers

Engagement works best when it's in the context of a trusted relationship. While SenseMaker is an efficient way of capturing information (as a tool), we recommend using trusted individuals to collect the experiences of service users and carers.

Engagement with Health and Social Care professionals

We recommend that consideration is given to:

- engaging with Health and Social Care professionals, such as consultants and allied health professionals;
- involving them in the process of engagement;
- feeding back on these results.

Adding to the knowledge base in relation to people with neurological conditions

Continued use of a number of engagement tools, including SenseMaker, would build a dynamic knowledge base about the issues facing individuals living with neurological conditions, and their carers, which would inform decision-making and planning.

SenseMaker as a tool can deliver rich information that highlights issues such as people's experiences and what people need. We recommend that the experience survey continues to be used as a tool for engaging with people living with a neurological condition, and their carers.

In addition, to ensure that we hear about the experiences of children living with neurological conditions and children who care for others with such conditions, we recommend that the children's survey we have developed is piloted, evaluated and rolled-out on a wider basis. This will require collaboration with speech and language specialists to link the experience survey with communication aids used by those with complex communication needs. This will ensure that the experiences across the population can be understood and articulated.

Next steps

This was the first exercise carried out with the aim of understanding the quality of life needs and priorities across such a range of conditions. While this survey has not been able to reach everyone, its success in determining shared priorities across a range of conditions lays a foundation for ongoing engagement, which can then be developed to include people with more complex communication needs, children living with neurological conditions and children who care for others with such conditions.

The issues highlighted in the experience survey affect people's health and wellbeing in the broadest sense. Indeed, these reveal a significant holistic impact on quality of life. These issues, therefore, cannot be viewed as falling only within the sphere of the 'health service'.

These shared priorities established the need to bring together all relevant stakeholders in order to begin the development of an action plan and ensure these recommendations are taken into account in service design and delivery across a wide range of organisations. This will be achieved through a workshop, hosted by the Neurological Conditions Network and attended by key stakeholders such as:

- people living with neurological conditions and their carers;
- consultants;
- allied health professionals;
- specialist nurses;
- key community and voluntary sector partners;
- the Department of Health, Social Services and Public Safety;
- other relevant departments.

This collaborative working should enable the development of an action plan that goes some way in addressing the issues raised through the engagement process.

If you wish to read the report in full, please go to:
www.publichealth.hscni.net/ncnsurvey

Alternatively, you can contact: neurological.conditions@hscni.net

Should you require this summary report in an alternative format, we are happy to consider any requests. Please contact: neurological.conditions@hscni.net

Membership of the Neurological Conditions Network

- Michelle Tennyson, Public Health Agency (Chair)
- Martin Quinn, Public Health Agency
- Julie Mawhinney, Public Health Agency
- Veronica Gillen, Health and Social Care Board
- Teresa Magirr, Health and Social Care Board
- Stephen Long, Belfast Health and Social Care Trust
- Sandra McCarry, Belfast Health and Social Care Trust
- Aiden Dawson, Belfast Health and Social Care Trust
- Kieran Drayne, South Eastern Health and Social Care Trust
- Carolyn Agnew, Southern Health and Social Care Trust
- Hazel Baird, Northern Health and Social Care Trust
- Patricia Gordon, Multiple Scelorosis Society, representing Long-Term Conditions Alliance Northern Ireland
- Morina Clarke, Epilepsy Action, representing Northern Ireland Neurological Charities Alliance
- Nicola Moore, Parkinson's UK, representing Northern Ireland Neurological Charities Alliance
- Christine Collins, Huntington's Disease Association Northern Ireland, representing Northern Ireland Neurological Charities Alliance
- Richard Dixon, Patient Client Council
- Tom Robinson, Department of Health, Social Services and Public Safety
- Helen Ferguson, Carers Northern Ireland
- John McCormick, Carers Northern Ireland

Glossary

Audit: A process of measuring practice against standards and then improving practice.

Care pathways: A sequence of care services linked together for people who move from one professional to another, or one place to another, in the course of their care.

Engagement: The process of meeting and inviting discussion with people and communities who use health and social care services.

Health inequalities: The variation in health standards across different sections of the population and different geographical areas.

Holistic: All aspects of people's needs – psychological, physical and social.

Neurological condition: Illness that results from damage to the brain, spinal column or nerves. Some neurological conditions can develop at any stage in life, while others can be present from birth.

Personal and Public Involvement (PPI): The process of involving the public and those who use health and social care services in the planning and delivery of future services. PPI provides people and communities with an opportunity to influence the direction of health and social care services relevant to them.

Qualitative: Investigating the 'why' and 'how' of decision making, not just 'what', 'where' and 'when'. Smaller, focused samples are needed more often than large samples.

Quantitative: Systematic investigation by statistical, mathematical or other measurable techniques.

Quality of life: The general wellbeing of individuals and societies. Standard indicators of quality of life include not only wealth and employment, but also the built environment, physical and mental health, education, recreation and leisure time, and social belonging.

Self-management: The process by which patients with a chronic condition, disability or disease can effectively take care of themselves.

Service teams: Twelve teams that ensure our regional commissioning intentions across key themes are clear, appropriate and affordable. Each team is formally appointed and reports to a programme board.

HSC Public Health Agency

HSC Health and Social Care Board

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