



# Summary Report: July 2018



## A Health Needs Assessment for people living with neurological conditions in Lincolnshire

### INTRODUCTION

The Healthy Ageing Research Group (HARG) is a group of researchers within the School of Health and Social Care at the University of Lincoln. In September 2017 we were asked by Lincolnshire County Council to undertake an independent health needs assessment for people living with neurological conditions in the county. A health needs assessment is a way in reviewing the current resources available to meeting the needs of a specific population. This report is a summary of the work. Please email Thomas George for the full report (email: [tgeorge@lincoln.ac.uk](mailto:tgeorge@lincoln.ac.uk) or phone: 01522 837496).

The review looked at adults over the age of 18, and young adults moving into adult services. It covered a range of neurological conditions, including stroke, epilepsy, Parkinson's and multiple sclerosis, among others. Lincolnshire County Council had previously undertaken a separate review looking at the needs of people with dementia, so dementia was not included within this study.

### AIMS OF THE REPORT

When planning this health needs assessment, we aimed to:

- Establish how many people in Lincolnshire are affected by neurological conditions, and how this compares with other parts of the UK;
- Review what we already know about the needs of people with neurological conditions;
- Explore what current services exist to meet the needs of people with neurological conditions;
- Understand the views of service users, their carers, voluntary groups and healthcare professionals on neurological services;
- Identify examples of good practice in services, but also see if any needs were not being met;
- Make recommendations to those who plan and deliver healthcare locally.

## METHODOLOGY

The research to inform this report was carried out in three key phases.

- Phase one: We conducted a scoping review of previously published research on services for adults living with neurological conditions in the UK.
- Phase two: We analysed information from local and national data sets to explore how many people in Lincolnshire were affected by different neurological conditions and what services they used (for example, we looked at data on hospital admissions and waiting times).
- Phase three: We asked people living with neurological conditions, carers for people with neurological conditions, voluntary sector organisations and healthcare professions to complete a questionnaire to tell us about their perceptions and experiences of neurological services in Lincolnshire.

## PHASE ONE RESULTS

A scoping review is an approach which explores the literature on a particular topic area providing an opportunity to identify key concepts and gaps in the research. We looked at eighty research articles related to neurological conditions published between 2010 and 2018. We also reviewed the National Service Framework for Long Term Conditions (2005) [1] and the recommendations made by the National Audit Office (2011) [2] two key documents discussing national policy and practice on providing neurological services. We focused mainly on research that explored the experiences of people with neurological conditions and their carers.

Key findings from previous research conducted throughout the UK include:

- Patients with neurological conditions often report delays and difficulties in accessing treatment, poor experiences with diagnosis, and difficulties in accessing information [3];
- There is a lot of variation in access to services in the UK and healthcare professionals sometimes lack knowledge on neurological conditions [4];

- Living with neurological conditions can have significant emotional and psychological effects. Different people deal with their neurological conditions in different ways, but as symptoms become more severe, the psychological impact can also increase [5, 6, 7]. Psychological support for people living with neurological conditions is therefore important but difficult to access.
- Carers also experience difficulties, including social isolation and loneliness, reduced health and wellbeing, and lack of recognition and support [8 - 13,]. Becoming a carer can result in changes in relationships between the carer and the cared for person, financial concerns and fears for the future [8-11]. Carers often report that they have received poor preparation and training for the caring role [13, 14].
- End-of-life services do not always take into account the specific needs of people with neurological conditions, and this can mean some people do not have access to palliative care services that they would benefit from [15, 16].
- People with neurological conditions are at increased risk of mental health problems [17, 18]. However, there is poor access to psychological services, (especially neuropsychology and neuropsychiatry), and service users are often dissatisfied with their experiences [4, 19, 20].
- Young people and their families often have poor experiences when moving from child to adult services, and need better planning and support at this time [21-31].

## PHASE TWO RESULTS – NUMBERS OF PEOPLE LIVING WITH NEUROLOGICAL CONDITIONS IN LINCOLNSHIRE

Stroke and epilepsy are among the most commonly occurring neurological conditions in the UK, and the NHS collects figures on the number of people affected by these conditions in each clinical commissioning group (CCG). There are four clinical commissioning groups in Lincolnshire, responsible for managing health care services in the east, west, south and south-west of the county. For other neurological conditions, there are no centrally collected statistics on how many people are affected. We have drawn on national estimates and data relating to health service usage to present the most accurate picture possible.

More people are found to be affected by Stroke in Lincolnshire (2.15%) than across England as a whole (1.7%) [32]. Rates of stroke are highest in NHS Lincolnshire East CCG, and lowest in NHS Lincolnshire West CCG. Between 2005/06 and 2016/17 there was a 17.85% rise in the rate of strokes [33]. The high rate of strokes in Lincolnshire, and the differences between

different parts of Lincolnshire may be linked to different rates of smoking, obesity, physical inactivity and high blood pressure, which are all known risk factors for stroke. Stroke is also more common in the more economically deprived areas of the county.

Two CCG areas in Lincolnshire also have higher average rates of Epilepsy than for England and a whole [33]. Research suggests epilepsy is more common in economically deprived areas, which may explain differences within the county.

We estimated the number of people living with neurological conditions using national data sets and a mid-year population estimate for Lincolnshire. According to this data, traumatic brain injury, Parkinson's disease, cerebral palsy and multiple sclerosis each affect over a thousand people in Lincolnshire. However, this data should be interpreted with caution and is likely to be an underestimate of the true level of disease.

## PHASE TWO RESULTS – HEALTH SERVICES AND ACTIVITY

People from the Lincolnshire East area of the county make highest use of health services related to neurological conditions. This pattern is consistent across inpatient admissions, day case admissions and emergency admissions to hospital [33], and mirrors the pattern found in terms of levels of disease.

Emergency admissions to hospital have negative impacts on patients and their carers, are more expensive than non-emergency admissions, and result in patients spending longer in hospital. We analysed data on emergency admissions to hospital where a neurological condition was mentioned in the health records. This analysis indicated that the most common reasons for emergency admission to hospital were headache and migraine; epilepsy; rare and other neurological disorders; traumatic brain and spinal injury and tumours of the nervous system [33]. However, the largest number of emergency admissions had a primary diagnosis other than a neurological condition on admission. This could be indicative of misdiagnosis on admission but it could also be because people with NC's also have other health problems. Only a very small fraction of patients admitted with a neurological condition were placed on a neurological ward and/or were under the care of a neurologist. This suggests that patients with neurological conditions receive emergency care within a range of different hospital departments, and that it is important that hospital staff outside neurology services have good knowledge and understanding of their needs.

In 2012-13, United Lincolnshire Hospitals Trust (ULHT) scheduled around 35,000 outpatient appointments for neurological specialities. The highest number of appointments were made for pain management, followed by neurology and clinical neurophysiology. In total, 47% of all neurological specialty outpatient appointments for Lincolnshire residents took place outside the CCG where the patient lived. More than 12% of neurological specialty outpatient appointments – including all neurosurgery appointments - took place out of county, most commonly in Nottingham, Sheffield, Cambridgeshire and Peterborough [34]. Accessing services out of area can result in longer travel times for patients and their carers, and requires good communication between health and social care teams from different areas, for example in arranging a suitable care plan.

Neurology patients referred to ULHT wait on average 10.7 weeks to be admitted. This is longer than the average for England of 8.5 weeks. Similarly, for outpatient care there was an average wait of 7 weeks for those referred to ULHT compared with average of 4.2 weeks in England [34].

The available data did not allow us to identify the number of people in the county with neurological conditions who receive end of life care in hospitals, hospice or community settings, except for those whose cause of death was stroke. On average in England, 6.6% of deaths in end of life care are caused by stroke. This was higher in Lincolnshire West (7.5%) and lower in Lincolnshire South West (4.3%), with the other CCGs close to the national average [33]. This suggests that there are variations in access to end of life services within the county for people who have experienced stroke.

Currently there is no available data on spending on social care for adults living with long term neurological conditions in Lincolnshire.

## PHASE THREE RESULTS – SURVEY RESPONSE

We surveyed service users, carers, voluntary sector organisations and health professionals, 84 people in total, to capture their views on the experience of and access to neurological services in Lincolnshire. All four groups agreed that service provision does not meet demand. Particular gaps in provision were identified in relation to Neuropsychology, rehabilitation services and Neurosurgery.

The experiences of those living and working in Lincolnshire were often similar to what was reported in previous national research. Service users and carers expressed frustration with a perceived lack of knowledge and understanding of neurological conditions by primary and urgent care health professionals, which leads to delays in referral, diagnosis and the onset of treatment. They also felt that there was a lack of information about services available to support them in living with neurological conditions. They highlighted problems associated with transfer from one service, or part of a service, to another because of organisations not communicating effectively and using different policies and processes. This is particularly problematic for those who have to travel out of the county for treatment.

Carers' views were consistent with national research about the significant physical and psychological costs associated with being a carer. Many reported feeling unprepared for and unsupported in the role. Despite the good work done by voluntary sector organisations, specific support is not available for all conditions. General carers services within the county were not always well equipped to meet the needs of those caring for people with neurological conditions.

Voluntary sector organisations highlighted the problem of people often needing to access services out of county. Having to make long, frequent and often expensive journeys to access care could delay diagnosis and treatment and can also exacerbate symptoms for people living with neurological conditions. Voluntary organisations also highlighted poor co-ordination of services within and between counties and suggested that there was a need for better training of medical and health care professionals in the recognition, management and rehabilitation of patients with neurological conditions.

The health care professionals who responded to the survey supported much of what patients and carers had said about variations in service availability, limited provision for rehabilitation and neuropsychology and long waiting times for some services. They also highlighted areas of good practice and the work of some highly skilled and dedicated clinicians. They explained the challenges and frustrations that they faced in providing services, given the rural geography of the county, high caseloads and limited resources.

## SUMMARY

There are some gaps in the existing data on neurological needs within Lincolnshire. The results of this review do therefore need to be interpreted cautiously. Overall, however, our research has highlighted patterns of disease and service use which indicate neurological conditions affect more people living in the East of Lincolnshire than elsewhere in the county. In addition, patients in many parts of the county access services at some distance from their home.

We have identified three key gaps in specialist service provision (neuropsychology, rehabilitation and neurosurgery). We have also identified that people living with neurological conditions and their carers often also experience challenges in accessing other services, and that there can be problems with links between services.

Based on our findings, we have made some practical recommendations that may help to improve the experience of service users and carers. A summary of the recommendations based on our review are listed below.

## RECOMMENDATIONS

- There is a need for better data on the number of people affected by neurological conditions in Lincolnshire, and what services they need to access. This could be achieved by analysing GP records in the county.
- There is a need for a better understanding of how neurological conditions link to wider issues such as social inequality. We suggest that this should be taken into account in future data analysis. This would help researchers and health commissioners better understand who may be at particular risk of neurological conditions, and plan services to meet their needs.
- People in Lincolnshire with neurological conditions often have other health needs too. Professionals in all health services need suitable training to ensure they are able to work sensitively with people with neurological conditions, recognise their needs, and signpost them to appropriate services. This may help to reduce delays in diagnosis and treatment. One possible option to achieve this would be to incorporate awareness of neurological conditions within the 'Making Every Contact Count' initiative.
- A review of the reasons for emergency admissions may help to identify changes that would help avoid emergency admissions. This could include changes to non-urgent

services to help prevent problems, and better support for people in managing their health needs.

- There are gaps in local service provision for neurosurgery, rehabilitation and neuropsychology. Health commissioners should consider carefully the balance between developing national centres of excellence for specific conditions, and the potential difficulties for patients in accessing services, particularly in a rural county like Lincolnshire.
- There should be a review of how services inside the county and outside the county communicate with each other, to ensure that people living with neurological conditions receive continuous provision and are not allowed to 'fall through the gaps' between services. This is especially the case when patients have been receiving specialist care outside the county, but then transfer to community services.
- There is a need for widespread, easy to access practical advice and emotional support. Commissioners should consider setting up a network of peer support groups to extend and support the work of existing voluntary organisations for people living with neurological conditions across the county. Information about neurological conditions and services available should also be added to the training for Care Navigators so that they can actively signpost patients and carers to appropriate services.
- Carers for people with neurological conditions have specific needs. We suggest that there should be further discussion with carer support services in the county regarding the needs of carers for people with neurological conditions, and how they could develop services to better meet the needs of this group.
- We all know that the NHS and social care services are facing substantial resource challenges at the moment. Better communication between health organisations, voluntary sector organisations, patient and carers could help to ensure everyone understands the challenges being faced, and help identify changes that could improve services: for example, better support for service users in managing their own needs, and ensuring that neurological conditions are taken into account when planning other local health initiatives, such as the development of Neighbourhood Teams.



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