



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

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CONTENTS

Foreward	iv
Executive Summary	1-7
Acknowledgements	8
How should I cite this report?	8
List of Tables	9-10
List of Figures	10-11
Appendices	11
Abbreviations	12-13
1.0 Introduction.....	14
1.1 Context and Scope.....	14
1.2 Aim and Objectives.....	15
2.0 Methodology	16
2.1 Overview.....	16
2.2 Systematic Literature Review.....	16-17
2.3 Quantitative Data Collection and Analysis.....	18
2.4 Qualitative Data Collection and Analysis.....	11
3.0 Literature Review	20
3.1 Overview.....	20-21
3.2 Policy and Practice.....	21-25
3.3 Health and Social Care Services for people with LTNCs	25-27
3.4 Service user/ Patient experience.....	21
3.5 Carers.....	29-31

3.6 End of life.....	31-32
3.7 Mental health and well-being	32-33
3.8 Transition.....	33-35
3.9 Summary of Key Findings	35-36
4.0 The Epidemiology of neurological conditions in Lincolnshire	37
4.1 Overview.....	31
4.2 Disease incidence and prevalence	41
4.2.1 Stroke.....	41-42
4.2.2 Epilepsy.....	43
4.2.3 Other neurological conditions.....	43-44
4.3 Chapter Summary.....	45
5.0 Description of Lincolnshire’s Health Services and Activity.....	46
5.1 Commissioning Arrangements and Service Provision	46
5.1.1 Clinical Commissioning Groups (CCG).....	46
5.1.2 Primary Care Services.....	46
5.1.3 Secondary and Tertiary Care Services.....	46-50
5.1.4 Community Care Services.....	50
5.1.5 Voluntary Sector Services.....	51
5.1.6 Service Activity.....	52
5.2 Hospital Activity	53
5.2.1 Hospital Admissions Data.....	53
5.2.2 Admissions Data for Lincolnshire.....	54-60
5.2.3 Hospital Episode Statistics for England – Outpatient Statistics.....	60-66
5.2.4 Compendium of neurological data on Referral to Treatment (RTT) and Admitted Pathways.....	67

5.5.5 Compendium of neurological data on Referral to Treatment (RTT) and Non-admitted Pathways.....	67
5.2.6 Costs of neurological treatment.....	63
5.2.7 Health Spend and Outcomes Tool (SPOT) Lincolnshire.....	70-71
5.3 End of life care/ Palliative care.....	72
5.4 Adult Social Care.....	73
5.5 Summary of Hospital Activity.....	73-75
6.0 Survey Response.....	76
6.1 Overview.....	76
6.2 Survey Response.....	76
6.2.1 People living with neurological conditions.....	72
6.2.2 Carers for people living with neurological conditions.....	80
6.2.3 Voluntary Sector Organisations.....	83
6.2.4 Medical/ Allied Health Professionals.....	92-98
6.3 Summary of Survey Response.....	95
7.0 Synthesis and Recommendations.....	104
7.1 Synthesis.....	104-108
7.2 Recommendations.....	108-109
8.0 References.....	110-119
9.0 Appendices.....	120
Appendix One: Survey for people living with neurological conditions	120-129
Appendix Two: Survey for carers of people living with neurological conditions.....	130-139
Appendix Three: Survey for voluntary sector organisations.....	140-147
Appendix Four: Survey for medical/ allied healthcare professionals.....	148-155

FOREWARD

This report examines epidemiological and service use data, and reports the experiences of service users and carers of people living with neurological conditions in Lincolnshire. Furthermore this report identifies gaps in current service provision, and makes practical recommendations for the improvement in experience of service users and their carers.

EXECUTIVE SUMMARY

Introduction

The Healthy Ageing Research Group (HARG) from the School of Health and Social Care at the University of Lincoln were commissioned by Lincolnshire County Council to undertake an independent health needs assessment for people living with neurological conditions in the county in September 2017. The purpose of this work is to establish the distribution of neurological conditions within the county; the level of service activity; gaps and limitations in service provision as well as examples of effective provision and good practice.

The review focuses on adults over the age of 18, and young adults transitioning into adult services, with a range of neurological conditions, including stroke. The report does not include data on people with dementia.

Aims of the report

- To review the existing literature on the epidemiology and health needs of adults living with neurological conditions, including an overview of current and existing policy and definitions of the most prominent neurological conditions;
- To describe the local epidemiology of neurological conditions and compare these data sets to other areas or localities, where possible;
- To identify and describe the current service provision and use by service users;
- To describe and review the experiences of service users with neurological conditions and their carers and identify any areas of unmet need;
- To capture the views of health and social care professionals and voluntary sector organisations about the provision of neurological care in Lincolnshire;
- To provide a synthesis of the above and make appropriate and practical recommendations.

Methodology

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

- Phase one: A systematic literature review to explore service provision for adults living with neurological conditions in the UK was conducted between September 2017 and February 2018.
- Phase two: Quantitative data were identified and extracted from a range of local and national data sets to provide information on the incidence and prevalence of neurological conditions and service activity (including number of admissions, length of stay, waiting time to treatment and bed days) within Lincolnshire. Only data that was publicly available has been used to compile this report.

Executive Summary

- Phase three: Qualitative data on the experiences of people living with neurological conditions; carers for people with neurological conditions; voluntary sector organisations and medical/ allied health professions were collected using an online survey with open-response questions.

Systematic Literature Review

Eighty articles published between 2010 and 2018 were included in the literature review. The National Service Framework (2005) for Long Term Conditions and the recommendations made by the National Audit Office (2011) are reviewed in relation to policy and practice and the complexities of commissioning and providing neurological services are discussed. National spend on healthcare services is presented, but the key focus of the literature review is on the experiences of patients and their carers.

The results of national patient experience surveys identify commonly reported problems including delays and difficulties in accessing treatment; dissatisfaction with the experience of diagnosis and difficulty in accessing information about their condition, care and treatment options (Neurological Alliance, 2017). Wide variations in access to acute and inpatient services were reported at national level (Thomas et al, 2011). Other barriers to access included lack of knowledge and understanding about neurological conditions by health care professionals; lack of access to rehabilitation, particularly in the community (Thomas et al, 2011); lack of access to equipment and poorly coordinated discharge into the community.

A considerable body of literature on the emotional and psychological effects of living with long term neurological conditions was identified. Different people deal with their neurological conditions in different ways, but as symptoms become more severe, the psychological impact can also increase (Rigby et al, 1999; Draper et al, 2013; Bergin & Mockford, 2016). Psychological support for people living with neurological conditions is therefore paramount but can be difficult to access.

The generic messages to emerge from carer research for people living with LTNCs relates to the potential for reduction in carer health and wellbeing (Hassan, 2010; Peters et al., 2013); experiences of social isolation and loneliness (Bergin and Mockford, 2016; Hassan, 2010; Peters et al., 2013); changes in relationships between the carer and the cared for person (Jones and Morris, 2013; McLaughlin et al., 2011); financial concerns (Hassan, 2010) fears for the future (McLaughlin et al., 2011; Harris, 2015) managing personal grief and loss in combination with the experiences of the cared for person (Jones and Morris, 2013; Weisser et al., 2015; McLaughlin et al., 2011); poor preparation and training for the caring role (Weisser et al., 2015; Abrahamson, 2016) and lack of recognition and support for their role (McLaughlin et al., 2011; Harris, 2015; Jones and Morris, 2013; Weisser et al., 2015).

Specific challenges have been associated with end of life care for people with neurological conditions (End of life care programme, 2010), ranging from uncertain disease trajectories and the lack of a distinct dying phase for some conditions, to the complexities of the multidisciplinary care required. Research indicates a lack of palliative care services for people with long term neurological conditions who would benefit from this (Skelly et al, 2012).

A higher prevalence of mental health conditions is seen in patients with neurological conditions (Askey-Jones et al, 2012; Bowen, 2015), but satisfaction with mental health services and support is shown to be low. A lack of psychological services, especially neuropsychology and neuropsychiatry has been widely recognised in the UK (Thomas et al. 2011; Smith et al., 2015; Agrawal, 2015).

Transitions from child to adult services have been shown to be poorly planned and the experiences of young people and their families is poor (Kirk, 2008; CSCI, 2007; Dewson et al., 2004; Cope, 2003; Dean, 2003; Heslop et al., 2002; Morris, 2002; Gibson et al., 2007; Forbes et al., 2007; Clarke et al., 2011; Cornish, 2015). Effective planning is seen as essential if deterioration and emergency admission for participants is to be avoided (Cornish, 2015).

Epidemiology

The exact number of people living with neurological conditions nationally, regionally and locally is unclear. There is a lack of consistently collected, robust data in relation all but the most commonly occurring conditions (Stroke and Epilepsy). Despite this, best efforts have been made to present the most accurate picture possible by drawing on national estimates and data relating to health care service activity.

The prevalence of stroke in Lincolnshire (2.15%) is higher than the stroke prevalence for England (1.7%) (AHPO, 2013; PHE, 2016). Stroke prevalence is highest in NHS Lincolnshire East CCG, and lowest in NHS Lincolnshire West CCG and has increased between 2005/06 and 2016/17 by 17.85% (PHE, 2016). Rates of stroke are highest in the most deprived areas of the county where we also see a higher prevalence of risk factors for stroke (e.g. hypertension, obesity, physical inactivity and smoking)

The prevalence of epilepsy is higher in three out of the four CCGs in Lincolnshire compare with prevalence in England. Epilepsy prevalence is highest in NHS Lincolnshire East CCG and lowest in NHS Lincolnshire South CCG (PHE, 2017). There is again a correlation between higher rates of disease and higher levels of deprivation.

Data on the incidence and prevalence of other neurological conditions has been estimated using national data sets and a mid-year population estimate for Lincolnshire. According to this data the conditions with the highest incidence and prevalence in the county are multiple sclerosis; Parkinson's disease; cerebral palsy; traumatic

brain injury and stroke. This data should be interpreted with caution and is likely to be an underestimate of the true level of disease.

Health services and activity

Health service use for patients with neurological conditions is highest in the NHS Lincolnshire East CCG area of the county. This pattern is consistent across inpatient admissions, day case admissions and emergency admissions to hospital (PHE, 2017). This suggests that the highest proportion of neurological conditions is experienced along the east coast strip of the county. This geographical area is characterised by higher levels of deprivation than other parts of the county.

More data on the reasons for emergency admission to hospital with a mention of a neurological condition indicate 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 (PHE, 2017). The largest number of emergency admissions however had a primary diagnosis other than a neurological condition on admission which may reflect difficulties or inaccuracies in diagnosis due to co-existing medical conditions or lack of knowledge and understanding by health care professionals. Emergency admissions account of the largest proportion of bed days and a higher total spend than for non-emergency admissions.

In 2012/13, over one million outpatients appointments were made at United Lincolnshire Hospital Trust (ULHT) for patients with neurological conditions, 67% of these were attended. The highest number of appointments were made for pain management, followed by neurology, clinical neurophysiology and neurosurgery. Patients between the ages of 40-69 have the highest number of outpatient appointments. A proportion of patients from NHS Lincolnshire East, South and South West have to travel outside of their CCG of residence for their outpatients appointments. Some are required to travel outside of the county to access services in Nottingham, Sheffield, Cambridgeshire and Peterborough (most commonly) (HSCIC, 2014).

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. The pattern is similar for outpatient care, with an average wait of 7 weeks for those referred to ULHT compared with 4.2 weeks in England (HSCIC, 2014)

It is not possible to identify the number of people in the county with neurological conditions who receive end of life care in hospitals, hospice or community settings from the available data. Data on palliative care is only available for patients who died with an underlying cause of stroke. The highest proportion of deaths from stroke

Executive Summary

in end of life care occurred in NHS Lincolnshire West CCG (7.5%), 1.1% higher than the England average (PHE, 2017).

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

Survey Response

Four groups of key stakeholders were surveyed (service users, carers, voluntary sector organisations and medical/allied health professionals) (n=84) to capture their views on the experience of and access to neurological services in Lincolnshire. All agreed that service provision does not meet demand. Specific gaps in provision were identified in relation to Neuropsychology, rehabilitation services and Neurosurgery.

There were many consistencies between the literature and experiences of those living and working in Lincolnshire. 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 perceived a lack of information about services available to support them in living with neurological conditions and 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.

The carers survey results concur with existing literature about the significant physical and psychological costs associated with the role. Many reported feeling unprepared for and unsupported in the role, and despite the good work done by voluntary sector organisations, specific support is not available for all conditions and carers general carers services within the county were ill equipped to meet the needs of those caring for people with neurological conditions.

The need for care out of the county was a focus of attention for those that responded to the voluntary sector organisations survey. Difficulties in access caused by having to make long, frequent and often expensive journeys delay diagnosis and treatment and can also exacerbate symptoms for people living with neurological conditions. Poor co-ordination of services within and between county's and the need for better training of medical and health care professionals in the recognition, management and rehabilitation of patients with neurological conditions were also highlighted

The medical/allied health care professionals who responded to the survey supported much of what patients and carers had said about variations in service availability depending on condition, limited or lack of provision for

rehabilitation and neuropsychology and long waiting times for some services. They did however highlight areas of good practice and the work of some highly skilled and dedicated clinicians. Their perspectives provided new insights into the challenges and frustrations that healthcare professionals also face in relation to the geography of the county, high caseloads and limited resources.

Synthesis

Despite gaps in the existing data and the caution that must be applied to some of the information presented here, this report 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.

Three key gaps in service provision have been identified (neuropsychology, rehabilitation and neurosurgery) along with some of the challenges faced by people living with neurological conditions, and their carers, that span the entire patient journey from diagnosis to end of life.

In drawing everything together it has been possible to make some practical recommendations that may help to improve the experience of service users and carers. Recommendations to develop a more robust evidence base have also been made. This work is essential to establish the true size and scale of neurological conditions in Lincolnshire and before a detailed review of commissioned services can be undertaken. The recommendations based on the work in this report are listed below.

Recommendations

- A more extensive primary data collection exercise needs to be undertaken to gain an accurate picture of the incidence and prevalence of neurological conditions in Lincolnshire and to establish how the county compares with the national picture. This could be achieved by a comprehensive review of GP records across all four CCGs. Until this has taken place it is not possible to determine the level of disease or need within the county.
- Any new and existing data needs to be explored to establish whether social inequalities exist for neurological conditions other than stroke and epilepsy. This would aid understanding of patterns of disease and service use and add to the existing body of knowledge within the field.
- A review of current training provided to all Health Care Professionals, particularly in primary and urgent care, needs to be undertaken in relation to recognizing and understanding neurological conditions. Due to high levels of co-morbidity in the population of neurological patients, and the frequency of non-elective care, all primary and urgent care staff need to be able to recognise and direct patients to the most appropriate services and resources, at a very minimum. This may help to reduce delays in diagnosis and treatment particularly if it is supported by clear guidelines about the recognition and management

- of neurological conditions. Raising awareness of neurological conditions could be incorporated into the 'Making Every Contact Count' initiative. Neurological conditions, like mental health and dementia should be understood by all health and social care professionals.
- A review of the reasons for emergency admissions may help to identify areas for service re-organisation and the promotion of self-care which could ultimately reduce non-elective admissions and the associated costs.
- Key gaps in service provision, specifically neurosurgery, rehabilitation and neuropsychology have been identified by this report. These need to be explored further by commissioning teams in relation to the need to balance local health and social care service developments with development of national centres of excellence for specific conditions, particularly given the geography of the county and the additional challenges that this brings.
- A review of communication between services and health care integration both within the county and across county borders needs to be undertaken to ensure that people living with neurological conditions receive continuous provision and are not allowed to 'fall through the gaps', particularly when they are repatriated to the county following care at specialist centres.
- Explore the feasibility of setting up a network of peer support groups to extend the work of existing voluntary organisations for people living with neurological conditions across the county. There is a need for widespread, easy to access practical advice and emotional support. 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 as appropriate.
- Review the support provided for carers of people with neurological conditions. The specific needs of carers for those with neurological conditions need to be expressed to the Lincolnshire Carers Service who would be ideally placed to incorporate this group into their existing provision.
- In light of the limited resource to address the gaps in service provision in the county, it is recommended that steps are taken to improve communication between the CCGs, voluntary sector organisations and patients and carers. Much could be achieved through open and transparent discussion about the challenges being faced, the possibilities of self-care and the opportunities presented by Neighbourhood Teams as outlined in the Lincolnshire Sustainability and Transformation Plan.

ACKNOWLEDGEMENTS

We would like to thank everyone who took the time and trouble to participate in this project. Particular thanks goes to all the respondents who filled in our survey, various neurological charities who enabled us to network with key individuals and provided us with useful data towards this health needs assessment. Your contributions are invaluable and we are truly grateful.

A special thank you goes to Lincolnshire County Council for providing us with the opportunity to conduct this Health Needs Assessment, and to Chris Weston and his team for their support.

Thank you.

The Evaluation Team

Healthy Ageing Research Group (HARG)

HOW SHOULD I CITE THIS REPORT?

You are free to quote from this report. In text citations should be referenced as: (Ray et al, 2018). A full citation should be referenced as: Ray, M., Sisson, K., George, T., and Scott, E. (2018) Developing a Health Needs Assessment for people living with neurological conditions in Lincolnshire. University of Lincoln.

LIST OF TABLES

Table 1. District rankings based on rank of average rank, extent of district deprivation in Lincolnshire (IMD, 2010; 2015; CLG, 2010; DCLG, 2015)

Table 2. Average rank and Average rank change per Lincolnshire Clinical Commissioning Group (IMD, 2010; 2015; CLG, 2010; DCLG, 2015)

Table 3. Lincolnshire's disease prevalence (%) per Clinical Commissioning Group (Public Health England, 2016)

Table 4. Epilepsy appointments by CCG of residence (2013/14) (Public Health England, 2017).

Table 5. Incidence and Prevalence of neurological conditions in Lincolnshire

Table 6. Inpatient admissions totals with a mention of neurological condition, age 20+ (Public Health England, 2017)

Table 7. Day case admissions totals with a mention of neurological condition, age 20+ (Public Health England, 2017)

Table 8. Emergency admissions with a mention of neurological condition, age 20+ (Public Health England, 2017)

Table 9. Emergency hospital admissions in all NHS Lincolnshire CCGs with a mention of a neurological condition, age 20+ by condition (Public Health England, 2017)

Table 10. Emergency hospital admissions under the care of a neurologist, age 20+ (totals) (Public Health England, 2017)

Table 11. Emergency hospital admissions into a neurology ward, age 20+ (totals) (Public Health England, 2017)

Table 12. Mean length of stay (LoS)in days following emergency admission with a mention of neurological condition by CCG, age 20+ (where LoS is less than 100 days) (Public Health England, 2017)

Table 13. Longest mean length of stay following emergency admission with a mention of neurological condition by condition and Clinical Commissioning Groups (CCG), age 20+ (Public Health England, 2017)

Table 14. Number of bed days for Neurological conditions in England and CCG of Treatment (2012-13)(HSCIC, 2014)

Table 15. United Lincolnshire Hospital Trust (ULHT) provider broken down by Outpatient appointment outcome, for all treatment specialities (Neurosurgery, Clinical Neuro-physiology, Pain Management and Neurology) 2012-13 (HSCIC, 2014).

Table 16. Hospital providers broken down by distinct outpatients, outpatient appointments and average number of appointments for neurological treatment specialities 2012-13 (HSCIC, 2014).

Table 17. Hospital providers broken down by all outpatient appointments, for all neurological treatment specialities, by age group 2012-13 (HSCIC, 2014)

Table 18. Hospital providers broken down by Distinct patients and number of outpatient appointments for all Neurological Treatment specialities 2012-13 (HSCIC, 2014).

Table 19. Clinical Commissioning Groups (CCG) of residence by CCG or treatment (and top 3) for all Neurological Treatment Specialities 2012-13 (HSCIC, 2014).

Table 20. Referral to Treatment (RTT) waiting times for completed admitted pathways (on an adjusted basis) for Neurology 2012-13 (HSCIC, 2014)

Table 21. Referral to Treatment (RTT) waiting times for completed Non-admitted pathways for Neurology and Neurosurgery specialties 2012-13, (HSCIC, 2014)

Table 22. Health Spend and Outcome Tool (SPOT) for Public Health and Social Care (Public Health England, 2015)

Table 23: Health Spend and Outcome Tool (SPOT) for Neurological Treatments for Epilepsy (Public Health England, 2015)

LIST OF FIGURES

Figure 1. Study flowchart of scoping review of the 'neurological conditions' literature

Figure 2. The Index of Multiple Deprivation 2015 among local authority districts based on the proportion of their neighbourhoods in the most deprived decile nationally (IMD, 2015).

Figure 3. Index Measure of Deprivation 2015 presented on Ordnance Survey data © Copyright (Lincolnshire County Council, 2015).

Figure 4. Stroke prevalence of actual recorded all ages (%) per locality in comparison to Lincolnshire and England (Public Health England and NHS HSCIC 2005/06 to 2016/17 in Lincolnshire Research Observatory 2005/06 and 2016/17).

Figure 5. Pyramid (iceberg) of disease (Bhopal, 2008, p.174)

Figure 6. Growth in hospital inpatient admissions and outpatient appointments for neurology compared with the NHS as a whole, 2007-08 to 2013-14 (NAO, 2015).

Figure 7. Number of distinct outpatients by CCG of residence for all Neurological Treatment Specialities by age group 2012-13 (HSCIC, 2014).

Figure 8. Number of outpatient appointments by CCG of residence for all Neurological Treatment Specialities by age group 2012-13 (HSCIC, 2014).

Figure 9. Average number of outpatient appointments per patient by CCG of residence for all Neurological Treatment Specialities by Age group 2012-13 (HSCIC, 2014).

Figure 10. Neurology Total spend, Total Elective spend and Total Non-elective spend 2014/15 (NHS England, 2016)

Figure 11. Total Spend (£000s) for neurological conditions by CCG of Residence age 20+ (Public Health England, 2016)

Figure 12. Proportion of people who died with an underlying cause of stroke across Lincolnshire's Clinical Commissioning Groups for End of Life Care Sustainability Transformation Partnership (STP) Tool (2015) (ONS Mortality Data, 2015 In Public Health England, 2017).

Figure 13. Current housing status of people living with neurological conditions.

Figure 14. Employment status of people living with neurological conditions

Figure 15. Experience of using dentist services for people living with neurological conditions.

Figure 16. Employment status of Voluntary Sector Organisations supporting people living with neurological conditions

APPENDICES

Appendix One: Survey for people living with neurological conditions

Appendix Two: Survey for carers of people living with neurological conditions

Appendix Three: Survey for Voluntary Sector Organisations

Appendix Four: Survey for Medical/ Allied Health Professionals

ABBREVIATIONS

A&E	Accident and Emergency
ALS	Amyotrophic lateral sclerosis
BSRM	British Society of Rehabilitation Medicine
CQC	Care Quality Commission
CCG	Clinical Commissioning Group
CFS	Chronic fatigue syndrome
CLG	Communities and Local Government
CNS	Central nervous system
COPD	Chronic obstructive pulmonary disease
CP	Cerebral palsy
DCLG	Department for Communities and Local Government
FAE	Final Admission Episodes
FCE	Final Consultant Episodes
GP	General Practitioner
HD	Huntingdon's disease
HSCIC	Health and Social Care Information Centre
IMD	Index Measure of Deprivation
JSNA	Joint Strategic Needs Assessment
LCC	Lincolnshire County Council
LCHS	Lincolnshire Community Health Services
LoS	Length of Stay
LRO	Lincolnshire Research Observatory
LPFT	Lincolnshire Partnership Foundation Trust
LTNC	Long Term Neurological Conditions
ME	Myalgic encephalomyelitis
MND	Motor neurone disease

Abbreviations

MS	Multiple sclerosis
MSA	Multiple systems atrophy
NAO	National Audit Office
NCPC	National Council for Palliative Care
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NSF	National Service Framework
ONS	Office for National Statistics
PHE	Public Health England
PPS	Post-polio syndrome
PSP	Progressive supranuclear palsy
QOF	Quality Outcomes Framework
RCP	Royal College of Physicians
RTT	Referral to Treatment
SCN	Strategic Clinical Network
STP	Sustainability and Transformation Partnership
TIA	Transient ischaemic attack



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Chapter 1.0

Introduction

1.0 INTRODUCTION

1.1 CONTEXT AND SCOPE

The Healthy Ageing Research Group (HARG) from the School of Health and Social Care at the University of Lincoln and has been commissioned by the Public Health Office, Lincolnshire to undertake a health needs assessment for people living with neurological conditions. The purpose of this health needs assessment is to establish the distribution of neurological conditions within the county; the level of service activity; gaps and limitations in service provision as well as examples of effective provision and good practice.

There is increasing discussion around the growing inequalities and lack of good quality evidence concerning people living with neurological conditions amongst the general population (WHO, 2006). A detailed health needs assessment of people living with neurological conditions in Lincolnshire has not been previously carried out. This report therefore seeks to address this evidence gap.

Public Health Office, Lincolnshire has commissioned this independent review to focus on adults over the age of 18 and young adults transitioning into adult services with a range of neurological conditions. These conditions are identified below;

- epilepsy
- migraines
- headaches
- Parkinson's disease (PD)
- motor neurone disease (MND)
- spinal muscular atrophy
- multiple sclerosis (MS)
- traumatic brain injury
- cerebral palsy in adults
- post-polio syndrome

The report does not include Dementia, due to the existing Lincolnshire Joint Strategy for Dementia (2014-17) which includes data on local rates of disease (LCC, 2014). It will include stroke, as the existing Joint Strategic Needs Assessment on stroke is due to be updated in 2018.

1.2 AIM AND OBJECTIVES

The aim of this assessment is to systematically assess the health needs of adults living with neurological conditions residing in the county of Lincolnshire and to identify gaps in current service provision, making practical recommendations to address the unmet need and improve the experience of those living with neurological conditions in Lincolnshire.

The main objectives of this health needs assessment are:

- To review the existing literature on the epidemiology and health needs of adults living with neurological conditions, including an overview of current and existing policy and definitions of the most prevalent neurological conditions;
- To describe the local epidemiology of neurological conditions and compare these data sets to other areas or localities, where possible;
- To identify and describe the current service provision and use by service users;
- To describe and review the experiences of service users with neurological conditions and their carers and identify any areas of unmet need;
- To capture the views of health and social care professionals and voluntary sector organisations about the provision of neurological care in Lincolnshire;
- To provide a synthesis of the above and make appropriate and practical recommendations.



Chapter 2.0

Methodology

2.0 METHODOLOGY

2.1 OVERVIEW

The scope of work, aims and objectives was approved by the Public Health Office, Lincolnshire in September 2016. The report details the mixed methods approach used which set out to integrate conclusions accumulated from a systematic literature review; quantitative statistical datasets, and qualitative surveys to construct a comprehensive picture of Lincolnshire's needs.

Section 7 of this report presents a synthesis of the identified literature and analysis conducted to provide a summary of key messages from this health needs assessments prior to a series of recommendations for commissioners of neurological conditions services in Lincolnshire to consider.

2.2 SYSTEMATIC LITERATURE REVIEW

A systematic literature review to explore service provision for adults living with neurological conditions in the UK was conducted between September 2017 and February 2018. Searches were based on keyword, title and abstract which were performed and adapted as appropriate for each of the chosen databases. The search strategy was designed in collaboration with the Public Health Office, Lincolnshire and colleagues from the from the School of Health and Social Care, University of Lincoln.

A search strategy was established and a test run was conducted before the review team agreed upon the final search strategy for a systematic literature review. The search strategy was constructed as:

Search 1: (neurological condition* OR "neurological disorder*" OR "neurological disease*");

Search 2: (United Kingdom OR UK OR Britain OR Scotland OR England OR Wales OR "Northern Ireland");

Search 3: (service provi*).

The following databases were used: Academic Search Complete; Applied Social Sciences Index and Abstracts (ASSIA), CINAHL Complete; Google Scholar; MEDLINE; PsychINFO; SCOPUS; WEB of Science (Web of Knowledge). Additionally grey literature was used including The Lancet Neurology, National Audit Office, ETHOS and NICE Guidelines. To ensure coverage of the literature, reference lists of existing reviews and retrieved articles were also screened.

The inclusion criteria for this systematic literature review were limited to published papers written in English between 2010-2017. Publications were restricted to the United Kingdom and England, Scotland, Wales and Northern Ireland only. Additionally the literature explored adults over the age of

18 and young individuals transitioning into adulthood services who are currently living with or have experienced living with neurological conditions e.g. Intermittent and Unpredictable (epilepsy, headaches, migraines); Progressive (motor neurone disease, Parkinson’s disease); Sudden onset (traumatic brain injury); and Stable with changing needs (post-polio syndrome, cerebral palsy in adults); (Department of Health, 2005; NHS England, 2017). All literature was stored on EndNote a bibliographic management software.

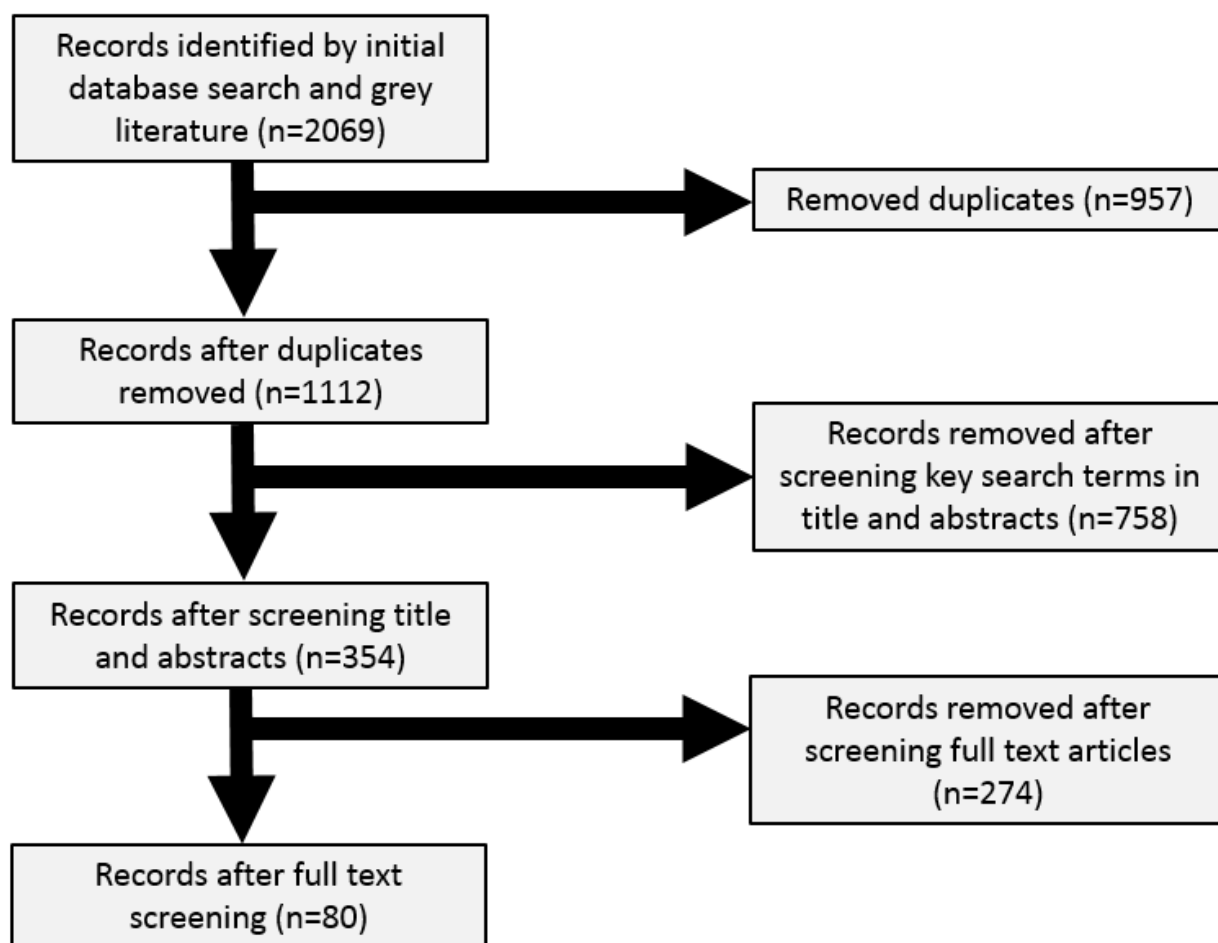


Figure 1: Study flowchart of systematic literature review of the ‘neurological conditions’ literature

Following the removal of duplicate, all titles and abstracts were independently screened by two reviewers against the inclusion and exclusion criteria. Articles that did not meet the criteria were excluded. Articles identified as potentially eligible for inclusion were obtained in full and further reviewed. The selection criteria was applied to the remaining full text articles and those not meeting the criteria were excluded. Where the independent reviewers could not reach an agreement, a third reviewer was used.

2.3 QUANTITATIVE DATA COLLECTION AND ANALYSIS

A comprehensive list of data sources were searched for information about the epidemiology of neurological conditions and health service activity in Lincolnshire. These were;

- Quality and Outcomes Framework (QOF) 2016-17 and other General Practice data (NHS Digital, 2017);
- Hospital Activity Compendium of Neurology Services – Neurological Intelligence Network for Clinical Commissioning Groups (CCGs), Sustainability and Transformation Partnerships (STPs) and England 2012-2016 (Public Health England, 2017);
- Local Health (Public Health England, 2017);
- Health and Social Care Information Centre (NHS Digital, 2017);
- Lincolnshire’s Joint Strategic Needs Assessment (JSNA);
- Lincolnshire Research Observatory (LRO);
- NHS Comparators – NHS Outcome Tool;
- Office for National Statistics (ONS);
- End of Life Care Sustainability and Transformation Partnership (STP) Tool (Public Health England, 2017);
- Spend Outcome Tool (Public Health England, 2017);
- The English Indices of Deprivation 2010 and 2015 (Department for Communities and Local Government);
- Independent, private or third sector activity data (where available).

Screening the datasets for key information was an iterative process which ceased once the review team was satisfied that no new data were being found.

Once the complete data set had been compiled, relevant information that identified either the incidence and/or prevalence of neurological conditions in Lincolnshire and health service activity were extracted. The results of this process can be found in sections 4 and 5.

2.4 QUALITATIVE DATA COLLECTION AND ANALYSIS

Surveys were created using Qualtrics, a statistical survey software, to explore the experiences of living with or supporting people living with neurological conditions in Lincolnshire. Four questionnaires were created to seek views of (See Appendix One to Four):

- People living with neurological conditions;
- Carers for people living with neurological conditions;
- Voluntary Sector Organisations supporting people living with neurological conditions;
- Medical/ Allied Healthcare Professionals supporting people living with neurological conditions.

Data collection

The questionnaire was distributed in three key ways to engage as many people as possible.

1. All key stakeholders and organisations (Neurological Alliance, Healthwatch Lincolnshire, Community Lincolnshire, Headway Lincolnshire, St Barnabas Hospice, United Lincolnshire Hospital NHS Trust (ULHT), Lincolnshire Community Health Services (LCHS), Lincolnshire Partnership NHS Foundation Trust (ULHT), Lincolnshire County Council (LCC) and district councils) were emailed the link to the surveys and encouraged to share the survey with people they knew who lived, care for or supported individuals living with neurological conditions in Lincolnshire. Approximately 100 questionnaires were sent out via email.
2. A blog page was created on the HARG website and links to this and the survey were distributed via the HARG twitter account. The stakeholders and organisations identified above were also approached via twitter to spread the survey as widely as possible.
3. Postal surveys were sent to approximately 50 people who had expressed an interest in participating in the project through voluntary sector organisations.

The questionnaires went live on 1st December 2017 and were open until 29th January 2018.

Data analysis

The data generated from the surveys was thematically analysed.



Chapter 3.0:

Literature Review

3.0 LITEATURE REVIEW

3.1 OVERVIEW

It is currently estimated that there are approximately 8 million people living in England with long-term neurological conditions (Thomas et al., 2011). It is difficult to identify precise data relating to the numbers of people living with long-term neurological conditions (LTNCs) as, at the time of writing, there is no centrally collated register of people with neurological conditions (National Audit Office, 2011). An estimated £3.3bn was spent on neurological services in the period 2012-13, with neurological services in the same period accounting for 3.5% of total NHS spending (National Audit Office, 2015). It is estimated that people with LTNCs account for 20% of acute hospital admissions and is the third most common reason for citizens to consult with a GP (Thomas et al., 2011). An average Clinical Commissioning Group (CCG) has 59,000 patients with a neurological condition. Given current limitations to data collection, it is not possible to accurately account for the annual social care spend on supporting people with neurological conditions. Nevertheless, £8.2bn was spent on social care services for adults with a physical disability in 2013-14 which included an estimated 25% of people living with neurological conditions. It is estimated that 850,000 people currently act as carers for people with LTNCs (Thomas et al., 2011). It is clear though, that those people living with LTNCs which are characterised by change, uncertainty and deterioration and which are life limiting, are highly likely to engage with multiple and complex health and care service systems. The accessibility of services, the quality of services received and the ability to provide appropriately integrated services are crucial to the experience of people with LTNCs as they navigate both their condition and the complex web of services which strive to serve them.

Neurological conditions may be defined as damage to the brain, spinal column or peripheral nerves. Some neurological conditions are life-limiting, for example, multiple-system atrophy, motor neurone disease and Huntington's disease. Many conditions may cause significant physical impairment and significantly impact on a person's ability to achieve their usual or wished for roles and responsibilities, as well as impacting on quality of life. Neurological conditions may be broadly defined in four categories:

- Intermittent and/or unpredictable, for example, epilepsy, early multiple sclerosis;
- Progressive, for example, motor neurone disease, multiple systems atrophy;
- Sudden onset, for example, acquired brain/spinal injury;
- Stable but with changing needs, for example, cerebral palsy in adults, post-polio Syndrome.

While these categories serve as a useful heuristic, it is worth highlighting its limitations. For example, it does not take account of the potential complexities of interacting co-existing, long term conditions, the impact of life course inequalities on the experience of LTNCs, variations in individual illness experience and the structural and individual circumstances of a person living with LTNCs.

The purpose of this literature review is to provide a context to the health needs assessment project commissioned by the Public Health Office, Lincolnshire. The review systematically identified research which was relevant to the terms of reference in the health needs assessment (see Section 2.2). The review considers the health and care current arrangements for people living with long term neurological conditions (LTNCs); the experience of service users living with LTNCs and those people who support them as informal carers; the effectiveness of services in meeting the needs of people with LTNCs at the end of life and to promote mental health and wellbeing of people living with LTNCs. The review concludes with summary of key findings reflecting the current national picture of neurological services.

3.2 POLICY AND PRACTICE

The National Service Framework (NSF) (2005) for long-term conditions focussed on neurological conditions and was developed around 11 quality requirements which strived to, 'put the individual at the heart of care and to provide a service that is efficient, supportive and appropriate from diagnosis to the end of life' (DH, 2005). The NSF was underpinned by a philosophy which first, expected people living with LTNCs to be able to live as independently as possible. In order to achieve this aim, as well as supporting quality of life, the NSF recognised the importance of people with LTNCs being able to access prompt advice and support from practitioners with relevant neurological expertise (DH, 2005).

Progress in implementing the NSF has been slow, reinforced by there being no specific arrangements in place to monitor how commissioners implemented the framework (NAO, 2011). Arguably, it has been difficult to accurately evaluate and assess the impact of the quality requirements because there were no defined intermediate targets, no defined central monitoring and the mid-point review was cancelled by Government (NAO, 2011; Neurological Alliance, 2015). Crucially too, the NSF was launched with an absence of base line data against which to measure progress in achieving the quality requirements. Evidence suggests that quality of care for people living with LTNCs has worsened since the NSF was published (NAO, 2011). For example, a review by the Royal College of Physicians (RCP) of people with multiple sclerosis (MS) (2011) concluded that there had not been any significant improvements in many aspects of services for people living with MS since 2008. Significant problems with service delivery and access included:

Literature Review

- Varying quality in diagnostic processes;
- Quality of advice and information given to people living with MS and carers is poor;
- Ongoing care remains fragmented and lacking coordination;
- There is poor access to specialist neurological support following emergency admission to hospital.

The major review of progress by the NAO (2011) identified a number of systemic challenges underpinned by a 'perverse incentive' to engage with a cycle of 'referral-discharge-referral', which did little to support continuity of care. Systemic challenges highlighted:

- Lack of reliable data about the prevalence and demand for a service;
- Poor knowledge about specific neurological conditions amongst health professionals;
- Poor access and availability of good-quality information people living with LTNCs and their supporters/carers;
- Little coordination between health and social care;
- Weak commissioning practice;
- A shortage of skilled workforce (NAO, 2011).

The NAO (2011) subsequently made six key recommendations to address the challenges they identified:

- The Department of Health (DH) needs to be clear and transparent in who is accountable for delivering new strategies, between itself, the NHS Commissioning Board and local commissioners. Additionally, the DH, given its overall responsibility for health and social care policy, needs to show how, under these arrangements Parliament will be able to monitor whether value for money has been delivered. Furthermore, the DH needs to establish, as part of its wider information strategy, clear baselines and common information standards to enable robust performance management of providers by local commissioners, local commissioners by the NHS Commissioning Board and the Commissioning Board by itself. This includes identifying good practice in delivering joined-up services for people with long-term conditions. These standards should further take into account the requirements of the regulators including Monitor and the Care Quality Commission (CQC).
- The DH needs to understand whether spending on neurological services has been effective, particularly, why neurological spending significantly increased in real terms; why emergency admissions and readmissions have increased and the extent to which the interrelationship between health and social care spending and services is the cause; the causes of the variation

Literature Review

- in emergency admissions across Primary Care Trusts; and the costs and benefits of different service delivery models and their impact on overall 'system' costs, with a specific emphasis on cost-benefit realisation.
- Local commissioners should require hospital trusts to ensure all neurologists, at the point of diagnosis, give patients information packs about their condition, including contact details for local and national services and charitable organisations.
- Local commissioners should work with local providers to make sure that patients have a personal care plan for health and social services, with a single professional in charge of coordinating an individual's care; furthermore, given the evidence about the positive impact of specialist nurses on patient care, make sure that caseloads for specialist nurses are not greater than those recommended by the National Institute for Health and Clinical Excellence (NICE).
- People admitted to hospitals as an emergency are usually cared for by health professionals without neurological knowledge and experience. The NHS and NICE should highlight to hospital trust management the importance of health professionals understanding the needs of people with neurological conditions.
- Perverse performance incentives result in a cycle of referral–discharge–referral and undermine continuity of care. The NHS Commissioning Board should review the 'new to follow-up' ratio performance measure so that it does not cause perverse patterns of service delivery, creating unnecessary obstacles for people with long-term conditions when accessing care.

The recommendations that a national lead for neurological conditions was achieved and a lead appointed. However, the role was terminated in 2016 and alternative arrangements were put in place via strategic clinical networks (SCN). Their aim is to work in partnership with commissioners to support decision-making, strategic service planning and to promote improvement in experience for people living with LTNCs and their carers.

Commissioning and providing neurological services are acknowledged to be a complex process, not least because responsibilities are split across clinical commissioning groups (CCG's), specialist commissioning, the acute sector, community services, primary care, specialist neurology centres and social care. Successful reviews of neurological services (e.g. NAO, 2011, 2015; NA, 2014, 2015) suggest too, a need to encourage and support innovative practice and service development and to provide effective leadership in neurological services. Key priorities for Neuroscience Strategic Clinical Networks (NSCNs) are to: map funding responsibilities for services e.g. NHS England and or CCGs; raise the profile of neurological services; measure the impact of neurological presentations on acute

services; identify best practice in integrated pathways; identify areas for service improvement and free up capacity in service systems via service redesign; improve patient related outcomes and the experience of care (NSCN, 2015). The East Midlands NSCN (2017) is reported to be focusing on improvements in neurological rehabilitation, including preventive services, and in developing commissioning guidance and 'an exemplar service specification' for commissioners.

Each region is responsible for deciding how its NSCN's should be developed and staffed and the NA (2015) have recently identified concerns about a fall in network activity with less focus on neurology, which they linked to reductions in funding and staffing shortages (NA, 2015). Nevertheless, there is considerable support of NSCN's and a recognition of their potential value in effecting positive change in service development and delivery for people living with LTNCs (NAO, 2015; NA, 2015; Association of British Neurologists, 2014).

The NAO (2011) recommendation to mandate joint health and social care commissioning of neurological conditions in its commissioning outcomes framework was not agreed on the grounds that it was not government policy to approve specific local work (NAO, 2015). Evidence and information on the extent and outcome of joint commissioning practice remains sparse (Neurological Alliance, 2016). A further recommendation that every person with a LTNC be offered a personalised care plan covering health and social care presumably aimed to promote an integrated approach to care for people with LTNCs. A report by the Neurological Alliance (2017) suggested that 85% of the sample did not have a care plan or had not been offered a care plan. Arguably, there is little in place to encourage local action in this area given that the recommendation was not reflected in NHS England's clinical commission group outcomes indicator set (NHS Digital, 2018).

The final NAO recommendation was that NICE was to develop a generic quality standard for neurological conditions. A number of quality standards have been developed and at the time of writing, the quality standard relating to generic LTNCs, due January 2018, has not been published.

Public Health England (PHE) and NHS England sponsor a joint intelligence network for neurology. This draws together and analyses data on neurological conditions from health and care systems and produces resources with the aim of improving services and outcomes in neurological services (PHE, 2017). This guidance is intended for commissioners, public health professionals and people involved in planning and provision of services for people with neurological conditions. NHS England (2016) also commissioned Thames Valley Strategic Clinical Network in 2015 to lead a national clinical programme of work. The objective was to stimulate the delivery of person centred, coordinated care and to encourage the adoption of community-based care models in order to improve the lives of people living

with long-term neurological conditions. This has led to a transformation guide for commissioners which sets out the case for change and provides information and evidence around new models of care.

These initiatives are potentially of considerable significance in raising the profile of neurological conditions and services, not least because for example, the NHS Outcomes Framework (2015/2016) has only one indicator for neurological conditions which relates to unplanned hospitalisation for people with asthma, diabetes and epilepsy in under 19s. Similarly, there are no indicators relating specifically to neurological conditions in the Adult Social Care Outcomes Framework (ASCOF, 2017).

More recently, the Neurological Alliance Manifesto (2017) has identified four key priority areas for people living with LTNCs:

1. Access to specialist care across the progress of the condition to include end of life in all settings (home, community, hospital, hospice);
2. Improved awareness of neurological conditions in primary care, accompanied by the ability to recognise symptoms and confidently refer; reliably signpost people to other forms and sources of support;
3. To ensure that treatment decisions for people with complex and rare neurological conditions are made in partnership with the person living with the condition, their families and supporters; decision should not be made purely on the basis of cost;
4. Make mental health and wellbeing for people living with LTNCs a national priority.

3.3 HEALTH AND SOCIAL CARE SERVICES FOR PEOPLE WITH LTNCs

The National Audit Office (2010, 2011, 2015) provides a valuable source of data and evidence relevant to the organisation of delivery of health and social care services for people with LTNCs. Overall, health spending on neurological services has increased faster than overall NHS spending, accounting for £3.3 billion spent on neurological services in the period 2012-13. 3.5% of the NHS budget was spent on neurological services, an increase from 3.1% in the period 2010-11. Hospital activity has continued to grow. Between the periods 2010-11 and 2013-14, the NAO (2015) reported an increase in neurological outpatient appointments of 17.4% (from 1,462,497 to 1,716,628). Growth in hospital in-patient admissions has slowed to 3.6% between 2010-11 and 2013-14 compared to 14.6% in the previous 3 years (NAO, 2015); hospital admissions overall increased by 3.8%.

It is difficult to confidently present data on the social care spend on people living with LTNCs as data of this level of specificity is not collected, and adults using social care are defined by disability and need, rather than specific conditions (NAO, 2015). The Neurological Alliance (NA) have estimated that

25% of people between 16 and 64 with a long-term and chronic disability have a neurological condition (Neurological Alliance, 2003, 2017). It is clear that central government funding of social care has reduced year-on-year since 2010, falling in real terms by 16% between 2009-10 and 2013 (NAO, 2015; Kings Fund, 2017; ADASS, 2015). The number of adults with a physical disability receiving social care services has significantly reduced since 2010, falling from 1.2 million in 2009-10 to 0.8 million people in 2013-14 (NAO, 2015; Kings Fund, 2017; ADASS, 2015). This has been reinforced by Local Authorities managing budgets by increasing eligibility criteria thresholds. The implications of cuts to social care budgets are significant and include: additional pressures on health care services including delayed discharge (Kings Fund, 2017); additional pressures on unpaid carers (Carers UK, 2015), growth in the numbers of people living with unmet needs (Kings Fund, 2016), and a significant growth in the numbers of people who are self-funding (Baxter and Glendinning, 2015). Timely transfer of acute neurological admissions from Accident and Emergency and onto specialist wards is identified as problematic in some areas (Thomas et al., 2011). There is also variation in access to in-patient rehabilitative services.

The GP Patient Survey (2015) showed that 65% of respondents with a neurological condition reported that they definitely, or to some extent, had enough support from local services and overall satisfaction with social care services for people with a physical disability suggested that 63% of respondents were extremely or very satisfied with the support they received (GP Patient Survey, 2015). A recent patient experience survey (Neurological Alliance, 2015) reported a mixed picture of patient experience of their ongoing care and treatment; 46% of participants rated their care and treatment as excellent or good but 26% rated it as of little or no help; delays and problems in accessing treatment were reported by 58% of respondents. The Neurological Alliance's, 'Falling Short' report (2017) surveyed 7048 people living with LTNCs across England. This report found that 42% of participants saw their GP five or more times before seeing a neurological specialist; 52% of participants felt that their diagnosis had been effectively and sensitively communicated and 41% were either dissatisfied with the way their diagnosis was communicated or felt that it could have been improved upon. A significant number of participants (45% and 46% respectively) experienced difficulties with the information they were given about their condition and their care and treatment options.

Research consistently demonstrates wide variation in access to acute and in-patient neurology services. Transfer delays, reinforced by limited capacity, from Accident and Emergency to specialist units has been highlighted (Thomas et al., 2011). The Association of British Neurologists (2014) undertook a survey testing performance against a number of quality standards which highlighted significant variation in access to neurology services. For example, adults admitted to acute medical

Literature Review

units with an acute neurological concern should have access to a daily consultation by a neurology specialist (direct or remote). The survey found that in the top quarter (highest performing) of sites, a neurological review was available on 89% of days on average, whereas in the bottom quarter of sites, it was only available on 17% of days on average. Access to urgent CT and MRI imaging services, seven days a week, 24 hours a day, is also a critical component of acute care. In respect of MRI scanning, this standard was achieved in fewer than a third of sites. Evidence that the availability of rehabilitation is variable has also been cited, despite claims that rehabilitation services are in line with NICE guidelines (Thomas et al., 2011). Poor understanding and low priority given to specific conditions, such as Parkinson's disease, has been consistently reported (Hasson et al., 2010; McLaughlin et al., 2011; Peters et al., 2013; Skelly et al., 2012).

Barriers to optimal health care for patients with LTNCs in-patient and in the community, include: difficulties accessing services (O'Brien et al., 2012; Bernard et al., 2012; Hewer, 2013; Methley et al., 2015); lack of specialist knowledge about neurological conditions, exacerbated if the conditions in question are rarely encountered (Skelly et al., 2012; Miller et al., 2011; NA, 2016; Aubelluck, 2012; Foley et al., 2012; Draper et al., 2013; Smith et al., 2015); lack of awareness of the needs of people living with LTNCs (Hasson et al., 2010; Thomas et al., 2011; Coole et al., 2013); variable practice in a flagging system to alert health teams to a patient's neurological condition (Skelly et al., 2012; Smith et al., 2015); lack of confidence in timeliness and accuracy of medication for specific conditions (Skelly et al., 2012); lack of rehabilitation facilities, lack of neurological rehabilitation specialists and challenges in supporting people in the community (Thomas et al., 2011). Research has pointed to shortages in specialist practitioners such as speech and language therapists for people living with Parkinson's Disease. Miller et al., (2011) suggest fewer than 40% of people with Parkinson's disease have access to Speech and Language Therapists, despite the likelihood of experiencing communication and swallowing difficulties. Other specialist interventions in rehabilitation services should include psychological assessment to enhance and support coping strategies and assessment of family care and support (Gallacher et al., 2013). Access to essential equipment including eligibility for wheelchairs and communication aids has also been reported to be poorly understood in some areas (NSF, 2005; Turner-Stokes et al., 2011). Overall, problems with poorly coordinated discharges, with inadequate preparation for managing in the community have been consistently reported (Gallacher et al., 2013).

Of course, people living with LTNCs may also experience other long-term conditions. Research by Thomas, Davis and Peel (2011) has suggested that service users often felt that their neurological condition was ignored or overlooked when they were admitted to hospital, impacting on their independence, mobility and dignity.

3.4 SERVICE USER/ PATIENT EXPERIENCE

There is a considerable body of research detailing the emotional, psychological and cognitive wellbeing of people living with LTNCs such as motor neurone disease (MND), Huntington's disease (HD) and multiple systems atrophy (MSA) (McLaughlin et al., 2011; Foley et al., 2012; Draper et al., 2013; Harris, 2015; Bergin and Mockford, 2016). The rapid progression of these disorders means that individuals have to continually adapt to change (Draper et al., 2013) and dealing with the demands and difficulties that result from physical change and deterioration (Lazarus and Folkman, 1984). Variability in individual capacity to cope with these conditions is evident with some people appearing to cope well and others suffering significant psychological distress (Draper et al., 2013; Foley et al., 2013; Bergin and Mockford, 2016). The increasing severity of symptoms as conditions such as MND worsen can negatively impact on psychological wellbeing. Diminishing physical ability and complex symptoms and management strategies can lead to increased isolation, anxiety and embarrassment about their condition (Rigby et al., 1999). People living with complex and rare neurological conditions such as MSA, and their carers and families, experience huge physical, emotional and psychological challenges. People living with MND have described their condition as degrading, humiliating and cruel (Harris, 2015) as they are faced with a shortened life span, loss of future, uncertainty and, as their condition progresses, increasingly invasive treatment options (for example, PEG feeding) which further remove individuals from 'normality' (Draper et al., 2013). It is therefore, of paramount importance that neurological and palliative care services offer psychological support that is accessible and tailored to each patient in line with their beliefs and illness representation (Draper et al., 2013; Helder et al., 2002).

People living with complex neurological conditions struggle to access information about their condition, and information may be generic rather than specific and experienced as unhelpful, irrelevant and frightening (Draper et al., 2013; NA, 2017; 2015; Methley et al., 2015).

A similar finding is consistently reported for people who have experienced more 'common' neurological events or disorders. For example, Gallacher et al., (2013) in a systematic review of the experience of younger people with strokes found that people they frequently encountered significant barriers to getting information, that the timing of information was often problematic or that the information given was difficult to understand or process. Personal challenges associated with stroke including feeling and being 'different' which impacted on confidence in engaging in public places and spaces and affected personal relationships (Gallacher et al., 2013). Similar findings are reported with other neurological conditions including, Multiple Sclerosis (Mullan et al., 2011; Peters et al., 2013; Methley et al., 2015).

The reported lack of professional knowledge and understanding can often be experienced by people living with LTNCs as professionals lacking understanding and empathy and giving as a result, poor support (Draper et al., 2011; Aubeeluck et al., 2012; Methley et al., 2015; Abrahamson et al., 2016). Paternalistic approaches and system centred decisions from health and care professionals have been reported in a systematic review of the experience of people who have had strokes and overall, patients are not adequately consulted or included in treatment decisions or asked about their personal aspirations, goals and concerns (Gallacher et al., 2013; Lawrence, 2012). The importance of a holistic assessment of need is a very well-rehearsed argument, consistently identified in research as a barrier to effective care, support and treatment (Gallacher et al., 2013; Lawrence 2012; Abrahamson et al., 2016).

It appears that if there are poor interactions between patients and health professionals, they can interfere with the development of trusting relationships, which in turn worsens communication and prevents patients gaining the knowledge they need for the recovery process (Gallacher et al., 2013).

The challenge of managing the complexities and demands of multiple care / health providers and interacting with a variety of services e.g. care at home is consistently reported (Gallacher et al., 2013; Methley et al., 2015). The challenge of managing successive visits from carers, health care professionals and other practitioners into a person's home and its impact on personal space is rarely discussed. Moreover, for people with complex and life-limiting LTNCs, as their condition worsens, adaptations to their home, combined with an influx of 'medical' equipment and aids is inevitable.

3.5 CARERS

It is estimated that 850,000 people currently act as unpaid carers for people with LTNCs and in common with many other unpaid carers, are often unaware of the duty for Local Authorities to offer them an assessment in their own right (Thomas, Davis and Peel, 2011). Carer research points to a number of similarities in respect of the experience of providing care for people with LTNCs regardless of their role. Nevertheless, there is arguably a need to consider the specific circumstances and requirements of carers providing support for people with specific conditions, often rare, and characterised by complexity, deterioration and which are life limiting, such as, Huntington's disease (Aubeeluck et al., 2012).

An unpaid caring role is often assumed for spouses, long-term partners and parents of people with LTNCs. This role may develop gradually, over time or it may become a lived reality for people following a sudden and unexpected event such as a brain/spinal injury. Research consistently points to carers feeling ill equipped to take on a role which often requires complex moving and handling, medical

interventions and the need to cope with complex communication needs, emotional and psychological implications of the person as well as their own emotional needs and grief associated with the diagnosis or event (for example, Thomas, Davis and Peel, 2011; Draper et al., 2013; Abrahamson et al., 2016).

Best practice for families affected by LTNCs suggests a comprehensive assessment including for carers (Weisser et al., 2015). In a qualitative study of people affected by spinal injury, the researchers highlighted that whole family support should be underpinned by single point of contact, combined with joint health and social service planning (Abrahamson et al., 2016). A single point of contact could provide the opportunity for a named link worker as an ongoing point of contact, ideally placed to facilitate and coordinate integrated care (Abrahamson et al., 2016).

The importance of ongoing emotional support for carers affected by LTNCs is highlighted in research. For example, people who care for a person with an acquired brain injury are likely to have to cope with the emotional aftermath of the incident, the challenge of learning to provide care and the need to manage a number of transitions during the rehabilitation and recovery process (Abrahamson et al., 2016). Existing research suggests that family care givers of people with life limiting LTNCs face a number of unique challenges and problems linked to the complex nature of the illness (Aubeeluck, 2012; National End of Life Care Programme, 2010). For example, Aubeeluck et al., (2012) examined the caregiver role in relation to people living with Huntington's disease (HD) and highlighted the need to recognise that carers are likely to need continuous support in order to reduce the caregiver burden associated with caring for someone with HD. Such support is often not available and a consistent message in respect of HD and a range of other LTNCs is that carers are critical of the lack of services available to them. This is particularly notable when caregiving is regarded as intensive or 'relentless' (e.g. Shakespeare and Anderson; 1993; Draper et al., 2013; Hassan, 2010) and where the emotional implications of caring for someone who will die of their condition, are not appropriately recognised or supported.

The practical aspects of caregiving can be demanding and create isolation, loss and loneliness as carers struggle to manage the demands of caregiving and potentially other family pressures, leaving little time for themselves and neglecting their own wellbeing in order to achieve the caring role (Kessler, 2009; Aubeeluck, 2012; Bergin and Mockford, 2016, Peters et al., 2013). The maintenance of carer health is clearly crucial if unpaid carers are to manage the demands and emotional strain of their loved one's condition, especially if the condition is one which will deteriorate and is life limiting. Moreover, carers may be older spouses who are also affected by long-term conditions and illness and whose role is not delimited by geographical separation and is likely to be reinforced by a sense of spousal duty and responsibility (e.g. Hassan, 2010). Increasingly, palliative care is carried out at home which can

place huge burdens on unpaid carers who are expected to carry out complex, specialist tasks (Bergin and Motford, 2016). The importance of appropriate support is critical to enable carers to both achieve the role ascribed to them and to enhance the possibility of them being in good mental and physical health (Gomes et al., 2011).

The generic messages to emerge from carer research for people living with LTNCs relates to the potential for reduction in carer health and wellbeing (Hassan, 2010; Peters et al., 2013); experiences of social isolation and loneliness (Bergin and Mockford, 2016; Hassan, 2010; Peters et al., 2013); changes in relationships between the carer and the cared for person (Jones and Morris, 2013; McLaughlin et al., 2011); financial concerns (Hassan, 2010) fears for the future (McLaughlin et al., 2011; Harris, 2015) managing personal grief and loss in combination with the experiences of the cared for person (Jones and Morris, 2013; Weisser et al., 2015; McLaughlin et al., 2011); poor preparation and training for the caring role (Weisser et al., 2015; Abrahamson, 2016) and lack of recognition and support for their role (McLaughlin et al., 2011; Harris, 2015; Jones and Morris, 2013; Weisser et al., 2015).

3.6 END OF LIFE

The National End of Life Care Programme (2010) highlight specific challenges associated with end of life care for people with complex and advanced LTNCs. These include: the illness trajectory and course including prolonged and uncertain disease trajectories; the need for complex multidisciplinary care; specialist treatment; neuro-psychiatric problems; variability of neurological conditions; working with people with rapidly advancing neurological conditions; people with LTNCs who have other complex, long-term conditions. The lack of a distinct dying phase in conditions such as MND makes a committed approach to integrated end of life care all the more important (Wilson et al., 2014).

The National Service Framework (2005) identifies the importance of providing support and care for people living with LTNCs through the entirety of their condition and to include end of life care. For people living with LTNCs which are life limiting, or for which curative treatment is not an option, palliative care should be an integral part of the support offered from diagnosis (Aoun et al., 2011; All Party Parliamentary Group, 2013). Early access to palliative care has been demonstrated to limit potentially prolonged and complex grief (Aoun et al., 2011) as well as offering tailored, person-centred support to the person with a life limiting LTNCs and their family members (O'Brien et al., 2012; Aubeeluck et al., 2012). Yet, findings suggest that discussions about end of life care are being left later than is appropriate, for example, with people living with MND (Harris, 2013). Service limitations such as the absence of 24-hour care can diminish the opportunity for people to achieve their preferred

place of death and lack of confidence and training in some care settings, such as residential care, can lead to people with advanced LTNCs being admitted to hospital inappropriately, in their last hours of life (DH, 2005; Draper et al., 2013; Foley et al., 2012). Moreover, research points to lack of availability of palliative care for people living with LTNCs who would benefit from palliative approaches to care (for example, people with Parkinson's disease) (Skelly et al., 2012; Skelly et al., 2015).

The National End of Life Care Programme (2010) developed an end of life care strategy aimed at supporting all health and social care staff to have the knowledge, skills and attitudes to deliver care at the end of life. The strategy argued that, 'a cultural shift in attitude and behaviour related to end of life care must be achieved within the health and social care workforce' (National End of Life Care programme, 2011: 31). End of life care for people working with people with LTNCs should include opportunities to engage with continuing professional development (CPD) about specific neurological conditions and working with people with advanced neurological conditions.

Research examining end of life care for people with advanced LTNCs highlights a number of core themes to best practice: coordination of services and effective integration where relevant (Jackson et al., 2011); personalised approaches to end of life care (Draper et al., 2013); keeping the dignity and respect of the person with an advanced LTNCs at the forefront of all aspects of care (National End of Life Care Programme, 2011; Draper et al., 2013); personalised care planning, including ACP's (Fitzpatrick et al., 2013) support in preferred place of care (National End of Life Care Programme, 2011); care which is culturally appropriate and sensitive (Whitehead, 2012); bereavement support (Whitehead, 2012).

3.7 MENTAL HEALTH AND WELL-BEING

The Neurological Alliance survey (2017) highlighted that 53% of respondents living with LTNCs also reported living with at least one other co-morbid condition, mental health conditions, including anxiety and depression, were among the most frequently cited. For some people, a mental health condition can be a clinical symptom of their condition, whereas for other people, mental health needs can be associated with the experience of diagnosis or a sudden neurological event and coming to terms with the aftermath (Abrahamson et al., 2016; Agrawal, 2015; Askey-Jones, 2012). Mental health needs associated with long term physical symptoms are associated with poorer health outcomes and lower levels of quality of life (Naylor et al., 2012). Neurological disorders often have a high prevalence of mental health problems and there is a close relationship between mental and physical wellbeing (Askey-Jones et al., 2012; Bowen, 2015). Increased levels of disability associated with advanced neurological conditions, associated with complex mental health needs greatly adds to carer stress and

is a significant cause of admission to residential care for people with advanced LTNCs (Aubeeluck et al., 2012; Gallacher et al., 2013). Levels of satisfaction in the Neurological Alliance survey in relation to mental health services and sources of support were very low; 63% of participants indicated that they were unsatisfied with information on sources of emotional support and only 5% of the sample believed the mental health services and support they received was 'excellent' (Neurological Alliance, 2017).

Other research exploring the mental health needs of people living with LTNCs has consistently pointed to the lack of psychological services and the underdevelopment and under provision of neuropsychiatry services (Thomas et al. 2011; Smith et al., 2015; Agrawal, 2015). There is considerable variability in the quality, range and spread of mental health services responding to people with LTNCs (Agrawal, 2015) and poor recognition of the mental health needs of people with complex neurological conditions, for example, MS (e.g. Askey-Jones, 2012).

3.8 TRANSITION

Care Act Guidance (DH, 2014, p: 302) confirms that timely, person-centred transition planning is essential to help young people and their families prepare for adulthood. Of course, transitioning to adulthood implies potential changes in a young person's education, potential employment, care and health services and housing which take place alongside other developmental changes associated with physical, social and emotional development. This can have huge implications for a young person's self-image, identity, relationships, security and aspirations for the future. Despite a wealth of research evidence, including Department of Health guidelines (2005), NICE guidelines (2016), a Social Care Institute for Excellence (SCIE) evidence based resources (2014), highlighting best practice in planning the transition from child to adult services, evidence suggests that, despite examples of exemplary practice, in general, transitions are poorly planned and crucially, the experience from the perspective of the young person and their families, is poor (Kirk, 2008; CSCI, 2007; Dewson et al., 2004; Cope, 2003; Dean, 2003; Heslop et al., 2002; Morris, 2002; Gibson et al., 2007; Forbes et al., 2007; Clarke et al., 2011; Cornish, 2015). A CQC (2015) report found parents and young people caught up in unacceptable arguments between children and adult health and care services, that the experience of transition planning was patchy and often confusing, with a lack of information and support causing additional distress and stress to young people and their families. Abbott's (2012) study of young men living with MD found that all of the young men had finished full time education, had no work, had very restricted social lives and were heavily dependent upon their families for care and interaction. The study reported a stark absence of formal transition planning as required by the Care Act and families

and young people described their overall experience as problematic.

Interviews by the CQC (2015) with young people and families about their transition experience found that a number of key factors contributed significantly to a positive experience:

- Having consistent staff members who knew about their conditions and the young person's history;
- Providing adolescent clinics (adolescence is defined as ages 10-19);
- Good communication with young people, their parents and each other;
- Providing good information about what to expect.

Care Act guidance highlights that effective transition planning must be underpinned by the 'wellbeing principle' so that assessment and planning are based around individual need, wishes and outcomes. The guidance makes the point that '...looked-after children, young people with disabilities, and carers are often among the groups of people with the lowest life chances' (Department of Health, 2014, p: 303). Cornish (2015) summarises key messages from research which indicates that transition planning should happen over years and address three phases:

1. Timely preparation started within child and adolescent services;
2. Managed and coordinated transfers between child and adolescence services and adult services;
3. Continuous developmentally appropriate support from adult services.

Cornish goes on to argue that effective transition planning will ultimately save money by supporting young people to stay in work or education and support their ability to manage their conditions, but will also encourage young people not to disengage from services and to continue to attend and engage with health and support services which will prevent deterioration and reduce for example, unplanned emergency admissions to hospital.

Guidelines for children and young people around transition planning highlight the importance of improved multi-agency commissioning as crucial in planning better transition services (e.g. Clarke et al., 2011) and that commissioning practice must be based on listening and learning from young people and their families. The CQC (2015) highlights the importance of existing good practice (for example, DH, 2008, NICE, 2016) are used to support commissioning practice and service development and delivery. Multi-agency planning should reflect the spectrum of relevant professionals and services, including a more proactive and involved presence of General Practitioners (CQC, 2015, NICE 2016). Crucially, the CQC (2015) and NICE (2016) highlight the importance of recognising that adolescence/

young adulthood should be recognised within the health service as an important developmental phase which is responded to and planned for as such.

3.9 SUMMARY OF KEY FINDINGS

This literature review suggests a number of consistent findings pertinent to people living with LTNCs, regardless of their condition. These are summarised below and will be used to contextualise findings from the local HNA data.

- The importance of developing active and coherent strategies to seek out and identify people living with neurological conditions; this relates to all aspects of health care as well as ideally, making more visible people living with LTNCs in social care data;
- The development of clear guidelines about the recognition and management of neurological conditions for people in hospital regardless of the reason for admission to hospital;
- Access to appropriately skilled and qualified therapists and clinicians at all stages of the person's illness trajectory, in-patient and in the community;
- Balancing local health and care service developments with development of national centres of excellence for specific neurological conditions;
- Challenging and addressing the implications and impact of life course inequalities in health experienced by people with neurological conditions;
- Developing cohesive partnerships and appropriate integration between disciplines involved in neurological conditions;
- Developing specialist knowledge of specific conditions. This may involve targeting specific practitioners to develop specialist knowledge and should include developing sensitivity and understanding of the impact of neurological conditions on a family's life – especially conditions which are sudden and unexpected with significant ramifications for care and rehabilitation or conditions which are deteriorating, complex and life limiting;
- Developing local strategic plans underpinning how neurological services should be developed and investing appropriately in neurological services to reflect current and projected need;
- Develop integrated commissioning, joint strategic planning and service coordination for end of life care for people living with LTNCs;
- Commissioners may also need to consider the needs of young adults with neurological conditions; Children with complex conditions are now surviving into adulthood with a range of conditions and needs;
- The need for greater investment in social care funding and a long-term social care funding strategy;

Literature Review

- Priority given to Carers including meaningful assessments and support including training and advice;
- Access to tailored and timely advice and support and clear and easy signposting to other sources of support and advice.



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Chapter 4.0:

**The Epidemiology of
Neurological Conditions
in Lincolnshire**

4.0 THE EPIDEMIOLOGY OF NEUROLOGICAL CONDITIONS IN LINCOLNSHIRE

4.1 OVERVIEW

Lincolnshire, the second largest county in England, is a sparsely populated county, predominantly rural with pockets of urban communities. It is one of 9 counties in the East Midlands and encompasses seven local authorities. Lincolnshire is comprised of four NHS Clinical Commissioning Groups (CCGs); NHS Lincolnshire West CCG, NHS Lincolnshire East CCG, NHS South West Lincolnshire CCG and NHS South Lincolnshire CCG.

Between 2012 and 2017, the county experienced a 4.61% increase in population (PHE, 2017), which was higher than the 3.59% increase in the population of England during the same period. The greatest increases in population numbers have been seen in the over 65 age group (ONS, 2011) and in NHS Lincolnshire South CCG (ONS 2013, 2016). It is expected that the population of Lincolnshire will increase by another 3.15% between 2015 and 2020 (PHE, 2017).

In 2015, life expectancy for men was 80.2 years and 83.5 years for women while the life expectancy was 79.4 and 83.1 respectively. The population comprises a small percentage of people from ethnic minority groups (2.2% compared with 13.2% in England as a whole (PHE 2017)).

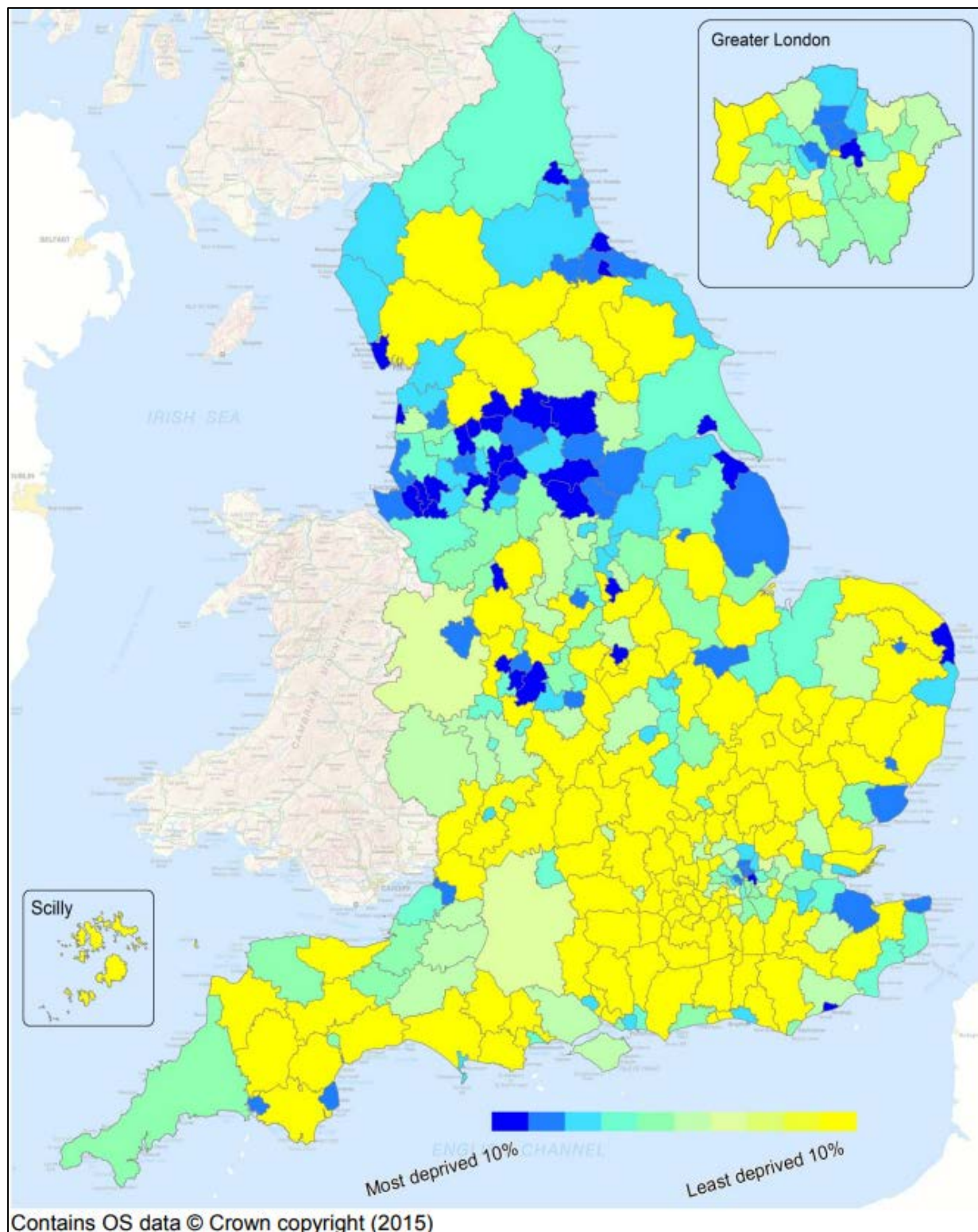


Figure 2: The Index of Multiple Deprivation 2015 among local authority districts based on the proportion of their neighbourhoods in the most deprived decile nationally (IMD, 2015).

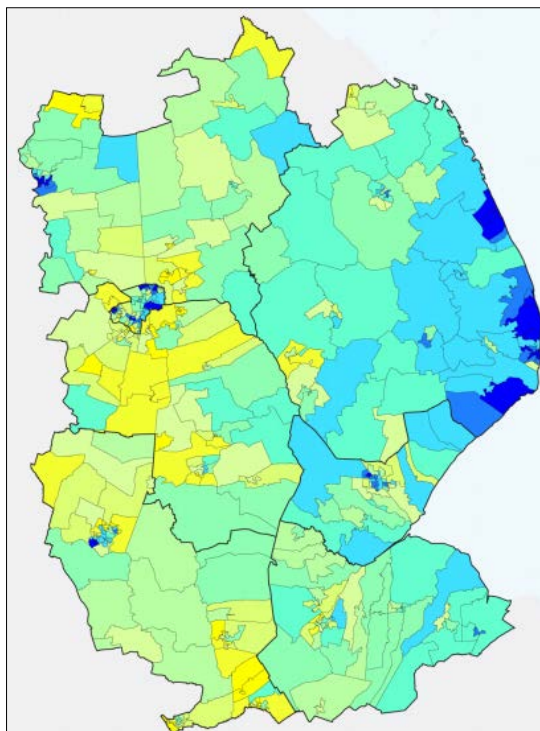


Figure 3: Index Measure of Deprivation 2015 presented on Ordnance Survey data © Copyright (Department for Communities and Local Government, 2015).

Lincolnshire is in the top 20-40% most deprived counties in England (IMD, 2015). The East Coast strip of the county is the most deprived area, with Skegness and Mablethorpe being among the 10% most deprived of neighbourhoods nationally (IMD, 2015; Department for Communities and Local Government, 2015). These areas fall within NHS Lincolnshire East CCG. The urban areas (Lincoln, Grantham and Boston) also experience relatively higher levels of deprivation compared to the rest of the county. Lincoln and East Lindsey have the highest proportion of people living in the most deprived areas, 31.9% and 29.8% respectively, which is considerably higher than in other parts of the county and indicates significant deprivation.

Table 1: District rankings based on rank of average rank, extent of district deprivation in Lincolnshire (IMD, 2010; 2015; CLG, 2010; DCLG, 2015)

District	East Lindsey	Lincoln	Boston	South Holland	West Lindsey	South Kesteven	North Kesteven
Persons living in most deprived areas IMD 2010 (%)	22.0	29.8	16.7	1.1	9.4	3.7	0.1
Persons living in most deprived areas IMD 2015 (%)	29.8	31.9	19.6	2.1	13.1	4.6	0.3
Change from IMD 2010	7.8	2.1	2.9	1.0	3.7	0.9	0.2

The Epidemiology of Neurological Conditions in Lincolnshire

When the data on deprivation are reported by CCG, NHS Lincolnshire East has the highest average deprivation score followed by NHS Lincolnshire West CCG. NHS Lincolnshire South CCG has the lowest.

Table 2: Average rank and Average rank change per Lincolnshire Clinical Commissioning Group (IMD, 2010; 2015; CLG, 2010; DCLG, 2015)

CCG	NHS Lincolnshire East CCG	NHS Lincolnshire West CCG	NHS South West Lincolnshire CCG	NHS South Lincolnshire CCG
IMD 2010 Average Rank	23.8	19.83	15.13	12.99
IMD 2015 Average Rank	26.33	20.68	16.36	14.95
Average Rank Change	2.53	0.85	1.23	1.96

Note: Clinical Commissioning Groups were not formed until 1st April 2013 however an average deprivation score based on IMD 2010 has been created. Average Rank Change IMD 2010 and IMD 2015.

Lincolnshire has marginally lower employment rates than the East Midlands and England. Approximately 17.5% of households in the county are workless (ONS, 2017).

The rural nature of the county and its position on the East Coast are compounded by poor transport networks. The county has no motorways and only approximately 41 miles of dual carriageway. The rail networks are also limited. Grantham sits on the East Coast main line, but only 9 of the 22 largest towns in Lincolnshire have a railway station. Despite this, passenger numbers are reportedly rising (Lincolnshire Local Transport Plan, 2013).

4.2 DISEASE INCIDENCE AND PREVALENCE

Data on the incidence and prevalence of neurological conditions in Lincolnshire are largely absent. The information that is accessible relates to Stroke and Epilepsy, two of the most common neurological conditions, and this is summarised below.

4.2.1 STROKE

The prevalence of stroke in Lincolnshire across all four CCGs is higher than the prevalence for England. In England, the prevalence is estimated to be 1.7% of the total population, whereas in Lincolnshire it is estimated to be 2.15% (PHE, 2016). Prevalence is highest in NHS Lincolnshire East CCG and lowest in NHS Lincolnshire West CCG.

The prevalence of known risk factors for Stroke (hypertension, overweight/obesity, physical inactivity and smoking) (Stroke Association, 2018) is also higher in Lincolnshire than in England, which may help to explain the pattern of stroke prevalence (Cox et al., 2006; Chen et al., 2014). Rates of stroke are highest in the most deprived areas of the county.

Table 3: Lincolnshire's disease prevalence (%) per Clinical Commissioning Group (Public Health England, 2016)

Estimated Prevalence	Period	England	NHS Lincolnshire East CCG	NHS Lincolnshire West CCG	NHS South West Lincolnshire CCG	NHS South Lincolnshire CCG
Stroke	2011/12	1.7	2.5	1.9	2.2	2.0
Hypertension (16+)	2014/15	23.6	29.1	24	27.4	27.7
Adults classified as overweight or obese	2012/14	64.6	72.4	67.1	69.8	71.6
Physically inactive adults	2014	27.7	29.1	29.3	24.8	28.8
Self-reported occasional/regular smokers (aged 18+)	2016	16.4	18.3	16.5	15.4	16.3

Note: Red indicates significantly worse than England average; yellow indicates similar but no significant difference between England average; green indicates significantly better than England average.

The Epidemiology of Neurological Conditions in Lincolnshire

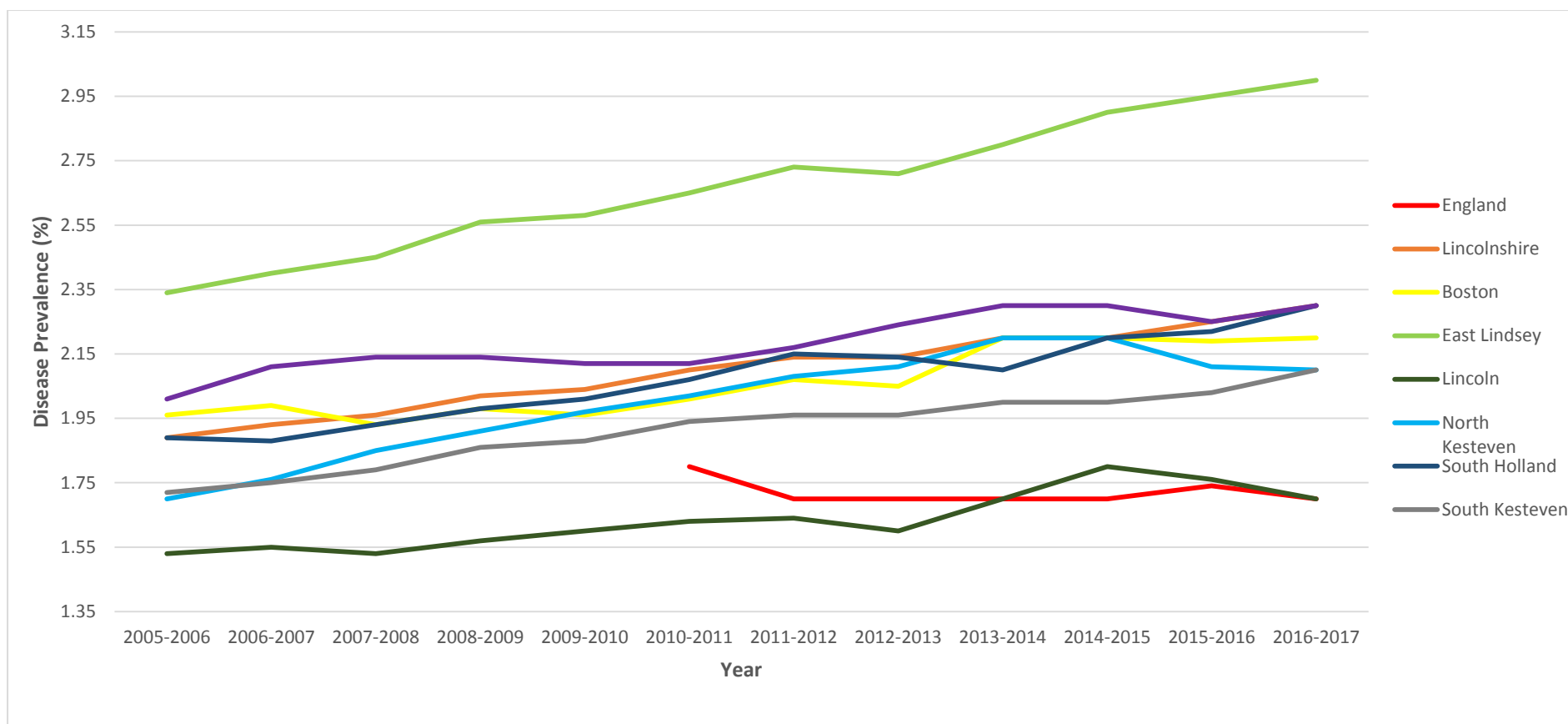


Figure 4: Stroke prevalence of actual recorded all ages (%) per locality in comparison to Lincolnshire and England (Public Health England 2016 and NHS HSCIC 2005/06 to 2016/17 in Lincolnshire Research Observatory, 2018).

The prevalence of stroke in Lincolnshire increased by 17.83% between 2005/06 and 2016/17. East Lindsey District has the highest percentage increase of stroke prevalence than any other district in Lincolnshire and significantly higher than the England average from 2010/11 to 2016/17. From 2017, this data set on stroke prevalence (actual, estimated or projected indicators) will no longer be updated on the Lincolnshire Research Observatory.

4.2.2 EPILEPSY

The prevalence of epilepsy per 100,000 population (estimated by number of appointments) is higher in three out of the four CCGs in Lincolnshire when compared with the rest of England. Prevalence is highest in NHS Lincolnshire East CCG and lowest in NHS Lincolnshire South CCG. This matches with the pattern of deprivation and research indicating a social gradient in epilepsy distribution (Steer et al., 2014; Pickrell et al., 2015).

Table 4: Epilepsy appointments by CCG of residence (2013/14) (Public Health England, 2017).

Indicator	Period	England	NHS Lincolnshire East CCG	NHS Lincolnshire West CCG	NHS South West Lincolnshire CCG	NHS South Lincolnshire CCG
Recorded prevalence of epilepsy per 100,000 (18 years and over)	2012/13	780	949	860	810	722

Note: Red indicates significantly higher than England average; yellow no significant difference between England average; green indicates significantly lower than England average.

4.2.3 OTHER NEUROLOGICAL CONDITIONS

In order to present data on other neurological conditions, estimates of incidence and prevalence in Lincolnshire have had to be made using national data sets and an estimate of the size of the population in Lincolnshire. Gaps in the table exist where no data are available. The process of establishing these estimates is subject to two key flaws. Data on the national incidence and prevalence of neurological conditions have been taken from a variety of sources, dates of which range between 1991 and 2017. Where the data are older, estimates of current incidence and prevalence in Lincolnshire are likely to be less accurate. In addition, figures derived for Lincolnshire's population are based on population estimates from ONS Mid-year 2016 of 743,000. It is argued these derived figures under-estimate the actual population of Lincolnshire. Therefore the data on the incidence and prevalence of individual neurological conditions in Lincolnshire must be interpreted with caution.

The Epidemiology of Neurological Conditions in Lincolnshire

Table 5: Incidence and Prevalence of neurological conditions in Lincolnshire

Group	Condition	Incidence		Prevalence		Source
		Estimated number in UK per 100,000	Estimated number of cases in Lincolnshire	Estimated number in UK per 100,000	Estimated number of cases in Lincolnshire	
Intermittent and unpredictable	Epilepsy	51 per 100,000 (5.1 per 1,000)	379	97 per 100,000 (9.7 per 1,000)	721	Joint Epilepsy Council of UK and Ireland (2011)
	Headaches	Migraine 400 per 100,000 (1)	2972	15,000 (8,000,000)	743	(1) Steiner TJ et al., (1999) Epidemiology of migraine in England. Cephalalgia 19:305-6. (2) Olesen J and Goadsby PJ (1999) Cluster Headache and related conditions in Olesen J (Ed) Frontiers in Headache Research Vol 9.
		Cluster headache 4 per 100,000 (2)	30	100		
	Multiple sclerosis	8	59	167 per 100,000	1219	MS Society (2016)
Progressive	Parkinson's disease	26.6	198	210.1	1561	Parkinson's UK (2017) Figures from 2015
	Motor neurone disease	2	15	7	52	Motor Neurone Disease Association (2017)
	Huntingdon's disease	0.72 per 100,000 (7.2 per million)	5	12.3 per 100,000 (1.23 per million)	91	Wexler et al., (2016) Figures from 2010
	Muscular dystrophy			7.1- 11.9 (1,2)	53-88	MacMillan & Harper, 1991) (1) Hughes et al, 1996 (2)
Stable with changing needs	Cerebral palsy			186 (110,000)	1382	Scope – based on population studies
	Post-polio syndrome			Estimates range from 100-300 (120,000 approx)		Lincolnshire post-polio network
Sudden onset	Traumatic brain injury	Severe injury 10-15 Moderate injury 15-20 Mild injury 250-300 New and sustained disability amongst adults resulting from head injury 100-150	74-111 111-149 1859-2229 734-1114	228 with long term problems (135,000)	1694	Headway, the Brain Injury Association and Society of British Neurological Surgeons. Incidence figures from Powell T Head Injury – A practical guide, 1994. Winslow Press Ltd. Thornhill S and Teasdale GM et al Disability in young people and adults one year after head injury: prospective cohort study BMJ 2000; 320: 1631-1635. Prevalence estimate using data from study by McMillan T and Greenwood R Rehabilitation programmes for the brain injured adult: current practice and future options in the UK, 1991. Department of Health

4.3 CHAPTER SUMMARY

- Lincolnshire is a large, rural county with a growing and increasingly ageing population;
- There are significant social inequalities within the county, with the most deprived area along the east coast. This deprivation is compounded by poor transport networks;
- Data on the incidence and prevalence of neurological conditions in Lincolnshire are largely absent. Condition specific information is only available for stroke and epilepsy;
- The prevalence of stroke in Lincolnshire (2.15%) is higher than the stroke prevalence for England (1.7%);
- Stroke prevalence is highest in NHS Lincolnshire East CCG, and lowest in NHS Lincolnshire West CCG;
- Rates of stroke are highest in the most deprived areas of the county where we also see a higher prevalence of risk factors for stroke (e.g. hypertension, obesity, physical inactivity and smoking);
- The prevalence of stroke has increased between 2005/06 and 2016/17 by 17.85%;
- The prevalence of epilepsy is higher in three out of the four CCGs in Lincolnshire compare with prevalence in England;
- Epilepsy prevalence is highest in NHS Lincolnshire East CCG and lowest in NHS Lincolnshire South CCG. There is again a correlation between higher rates of disease and higher levels of deprivation;
- Data on the incidence and prevalence of other neurological conditions have been estimated using national data sets and a mid-year population estimate for Lincolnshire. According to these data the conditions with the highest incidence and prevalence in the county are multiple sclerosis; Parkinson's disease; cerebral palsy; traumatic brain injury and stroke. This data should be interpreted with caution and is likely to be an underestimate of the true level of disease.



Chapter 5.0

Description of Lincolnshire's Health Services and Activity

5.0 DESCRIPTION OF LINCOLNSHIRE'S HEALTH SERVICES AND ACTIVITY

5.1 COMMISSIONING ARRANGEMENTS AND SERVICE PROVISION

5.1.1 CLINICAL COMMISSIONING GROUPS (CCG)

Lincolnshire County consists of four CCGs, seven district councils and approximately 96 GP practices (NHS Digital, 2017):

- NHS Lincolnshire East CCG (29 GP practices, 128 Practitioners);
- NHS Lincolnshire West CCG (33 GP practices, 131 Practitioners);
- NHS South West Lincolnshire CCG (19 GP practices, 66 Practitioners);
- NHS South Lincolnshire CCG (15 GP practices, 84 Practitioners).

Lincolnshire Sustainability and Transformation Partnership (STP) was launched in December by NHS Lincolnshire and is a five year plan as part of a nationwide STP for NHS services (NHS England, 2016). The STP is designed to help ensure health and care services in Lincolnshire are developed around the needs of the local populations, by boosting the health and wellbeing of residents and bringing the healthcare system back into financial balance by 2021.

5.1.2 PRIMARY CARE SERVICES

There are 96 GP practices in Lincolnshire with a total of 405 Practitioners (NHS Digital, 2017). GPs are the first point of contact with health services for patients with neurological symptoms and conditions and act as the gatekeepers to secondary care services in most cases.

5.1.3 SECONDARY AND TERTIARY CARE SERVICES

Neurology Services – United Lincolnshire Hospital Trust (ULHT, 2018)

Neurology services at ULHT are organised into North and South Lincolnshire with access to Sheffield and Nottingham tertiary neuroscience centres respectively. All patients admitted to any of ULHT's hospitals (Lincoln, Boston, Grantham) have access to an inpatient neurology service throughout the entirety of their condition. Transfers or admissions to regional tertiary neuroscience centres are available for patients who may require more specialist neurological or neurosurgical care services which are not currently available in Lincolnshire County.

Description of Lincolnshire's Health Services and Activity

Currently there are 13 staff employed across the neurology department in ULHT. This includes six specialists (two consultants), multiple sclerosis nurse specialists, multiple sclerosis coordinator, four neurology secretaries and one speciality coordinator. Neurosurgical outpatient clinics are led by two consultant neurosurgeons at the Royal Hallamshire Hospital Sheffield on a fortnightly basis. Patients requiring this service therefore have to travel out of county. There is also one full time clinical multiple sclerosis (MS) nurse based in Lincoln County Hospital's neurology department at, where clinics are undertaken and monitoring and support is provided for MS patients across the County. Additionally there is also one part time specialist neuro-physiologist. The neurology department has good connections with Parkinson disease nurses under the care of the Elderly Department and with CCG employed Parkinson disease nurses within the community.

In addition, physiotherapy, occupational therapy and rehabilitation services are provided by the Rehabilitation Medicine Department. There is also a neurophysiology unit based in Lincoln County Hospital and an outreach nerve conduction service provided at Pilgrim Hospital, Boston. All ULHT hospitals have on-site radiology with Computer Tomography (CT) and Magnetic Resonance Imaging (MRI) facilities. Lincoln County Hospital also has image-link facilities with Royal Hallamshire Hospital, Sheffield and Queen's Medical Centre, Nottingham for neuroradiology reporting when services are needed.

The Neurology services are managed within the Integrated Medicine Board and headed by a clinical director. The funded consultant establishment is three days per week and supported by a further consultant who visits one day a week from Sheffield. The Neurology service is managed from Lincoln providing outpatient and ward referral services to the three main hospital sites of Lincoln, Boston and Grantham. The department also has a clinical nurse specialist (CNS) for multiple sclerosis providing follow up care and support for MS patients. The department also has two CNS for seizure disorders. According to ULHT the Trust is committed to improving the service with more specialist nurse support.

There are currently nine outpatient clinics held per week at Lincoln County Hospital, weekly all day Monday clinics held at Grantham and District Hospital and four neurology clinics per week held at the Pilgrim Hospital, Boston for patients aged 16 years or older with, or suspected of, any neurological disease.

Neurology services were temporarily closed to routine referrals from December 1st 2016 until September 1st 2017, due to being unable to extend visiting consultant services from Nottingham.

Specialist Rehabilitation Unit - Ashby Ward – United Lincolnshire Hospital Trust (ULHT, 2018)

Ashby Ward is a specialist inpatient service at Lincoln County Hospital which houses a 12 bed purpose built rehabilitation unit accepting patients with newly acquired neuro-disabilities and other forms of complex neurological disorders which require a multidisciplinary assessment and rehabilitation approach. Patients are supported to achieve their full potential for physical, cognitive, social and psychological function and quality living. Furthermore consultant outpatient clinics are also provided across a number of sites in Lincolnshire. The rehabilitation medicine community outreach service includes a dietitian, specialist nurses, occupational therapists, physiotherapists, and speech and language therapists. The teams are based at the four main hospitals providing services as either outpatients or in the patient's home.

Clinical Neurophysiology – United Lincolnshire Hospital Trust (ULHT, 2018)

Clinical Neurophysiology is based at Lincoln County Hospital's Hemswell Clinic, and referrals are accepted from all consultants, GPs and other external providers across Lincolnshire. There are services available for both adults and children and inpatients and outpatients county wide. Clinical investigations are conducted by both consultant clinical neurophysiologists and clinical physiologists, including electroencephalogram (EEG), nerve conduction studies (NCS), electromyography (EMG), visual evoked potentials (VEP) and somatosensory evoked potentials (SSEP).

Pain Management – United Lincolnshire Hospital Trust (ULHT, 2018)

The chronic pain service is consultant led and supported by advanced nurse led clinics, nurse led acupuncture clinics and physiotherapy. The pain management (PM) team consists of three chronic pain consultants, one acute pain consultant, two associate specialists, one clinical nurse specialists, two sisters, one specialist physiotherapists, two healthcare support workers, two secretaries, one waiting list clerk and a receptionist. The clinical nurse specialist has a monthly nurse led clinic at Grantham and District Hospital. Referrals are received into the department mainly from local GPs and Lincolnshire Intermediate Musculoskeletal Service (LIMSS) with some additional referrals from secondary care consultants. The range of treatment options include medicine management (pharmacology), spinal (epidural) injections, lidocaine infusions, physiotherapy, acupuncture and transcutaneous electrical nerve stimulation (TENS). The acute pain service takes referrals for inpatients in Lincoln County Hospital. It is nurse led with support from the acute pain consultant. The service involves treatment planning for patients with difficult to manage acute and chronic pain.

Description of Lincolnshire's Health Services and Activity

A chronic PM services runs at Louth County Hospital, supported by the Pilgrim Hospital, Boston. There are approximately two to three clinics and procedure sessions scheduled per week held at the Woldside unit by a pain consultant. While a range of pain treatments are available, acupuncture services are provided by two trained nurses at the Woldside unit. Patients for procedures are admitted to Fotherby Ward as day cases and treated in operating theatres.

Boston's PM team consists of three consultants, two associate specialists, one clinical nurse specialist, four junior sisters, a healthcare support worker and two secretaries. The team is both consultant led and advanced nurse led in the primary and secondary setting. The nursing team alongside the acute pain consultant also provide an acute pain service within the secondary care setting at the Pilgrim Hospital. This service also involves pharmacology (medicines). The nursing team also monitors and provides training on patient controlled analgesia (PCA) and Entonox (Nitrous Oxide).

Grantham's acute PM team is mainly a nurse-led service, with an associate registrar. The team provides advice and management to acute pain patients across the hospital and have close links with critical care and surgical enhanced recovery programmes which enable them to cover a wide range of specialities including elective general surgery and orthopaedic procedures. Grantham also has two outpatient clinics per week with support from Lincoln and Boston acute pain team referrals for patients listed for elective surgery, following routine visits to the ward via care/ anaesthetic colleagues and a bleep system. While a range of PM options are available, PM nurses also provide acupuncture services in the department on a Friday.

There are currently nine outpatient clinics held per week at Lincoln County Hospital, weekly all day Monday clinics held at Grantham and District Hospital and four neurology clinics per week held at the Pilgrim Hospital, Boston for patients aged 16 years or older with, or suspected of, any neurological disease.

Chronic fatigue syndrome/ Myalgic encephalomyelopathy (CFS/ ME) – Lincolnshire Partnership Foundation Trust (LPFT, 2018)

Chronic fatigue syndrome/ Myalgic encephalomyelopathy (CFS/ ME) services are therapy led services delivered by Lincolnshire Partnership Foundation Trust (LPFT) who are currently receiving 5-10 referrals per week (LPFT, 2013). Domiciliary services to severe and very severe sufferers are also offered. The majority of mild-moderate sufferers are being offered CFS/ ME rehabilitation groups. LPFT offers support and advice to employers/ occupational health and schools and universities.

The Laurels Neurological Rehabilitation Centre – Christchurch Group

The Laurels Neurological Rehabilitation Centre, a Headway approved provider (2016/18), opened in 2014 and provides specialist community-based transitional rehabilitation in North-East Lincoln. The centre offers accommodation for 12 residents including 11 single en-suite rooms and one studio apartment and includes a garden, training kitchen, therapy room and wheelchair accessibility on all floors including a lift. The Laurels is situated two miles from Lincoln County Hospital and there is easy access to local amenities, occupational and education resources, social and leisure activities and GP practices. The Laurels is within walking distance of the city centre and Lincoln College where residents can use the hydrotherapy pool for their rehabilitation. A lead consultant works at the Laurels and is supported by an interdisciplinary team of rehabilitation medicine consultants, neurologists, a neuropsychiatrist, neuropsychologists, physiotherapists, speech and language therapists and occupational therapists. Additionally further support is also provided by experienced rehabilitation and therapy assistants.

5.1.4 COMMUNITY CARE SERVICES

Lincolnshire's Integrated Neighbourhood Teams

Individuals living with a wide range of long term conditions, for example neurological conditions, can be referred or case transferred into Lincolnshire's Integrated Neighbourhood Teams (LCHS, 2013; LCHS, 2018).

Lincolnshire's Integrated Neighbourhood Teams consist of a multidisciplinary team of medical professionals, allied health professionals, healthcare support workers and support staff who support people in the local community who require healthcare. The team may also include specialist practitioners, clinicians and district nurses e.g. specialist Parkinson's nurse. Given Lincolnshire's Integrated Neighbourhood Teams is still in its infancy, it is somewhat difficult to conclude the scope and scale of this multidisciplinary team in supporting individuals with a range of, at times, complex long term neurological conditions (George et al., 2017).

5.1.5 VOLUNTARY SECTOR SERVICES

Voluntary Sector Services in Lincolnshire include:

- **Headway Lincolnshire** is a charitable organisation which provides support, guidance, understanding and signposting to individuals, family members and carers affected by an Acquired Brain Injury in the County of Lincolnshire;
- **St Barnabas Hospice** is a charitable organisation providing palliative and end-of-life care to adults living with life-limiting or terminal illness in Lincolnshire;
- **Sue Ryder Hospice** provide person-centred hospice and neurological care for people facing frightening, life changing diagnoses, including medical, emotional and practical support;
- **Lincolnshire and Nottinghamshire Air Ambulance Charitable Trust** is a charitable organisation which has a dedicated Helicopter Emergency Medical Service which flies on average 3 missions per day, 365 days of the year.
- **Parkinson's UK** (Lincoln Branch) is a research and support charity that aims to improve the quality of life for people affected by Parkinson's disease and find a cure for the condition. Branches offer information and support to local people with Parkinson's disease including family and carers.
- **Huntingdon's Disease Association** (Lincolnshire) is a support charity that aims to improve the quality of life for people affected by Huntingdon's disease. Branches and support groups are run by volunteers and offer a mixture of social activities, information sessions, fundraising and awareness raising.
- **Myaware** (Lincoln) is a research and support charity dedicated solely to the care and support of people affected by myasthenia. Branches and support groups offer opportunities through support groups for people living with myasthenia and their families, fundraising and awareness raising.
- **Stroke Association** are the UK's leading stroke charity, delivering stroke services across the country, campaigning, investing in research and fundraising.
- **MS Society** (Lincolnshire) a research and support charity dedicated to people living with MS. Branches and support groups offer opportunities for people living with MS and their families, fundraising and awareness raising.

5.1.6 SERVICE ACTIVITY

Although it has been difficult to obtain comprehensive data on the number of people living with neurological conditions in Lincolnshire, more information is available on the use of hospital services (including number of admissions, length of stay (LOS) and bed days) by people with neurological conditions. These data only capture the proportion of the population who are engaged with health services. It is likely that the proportion of people with symptoms of neurological conditions living in the county is higher, as illustrated by the concept of the healthcare iceberg.

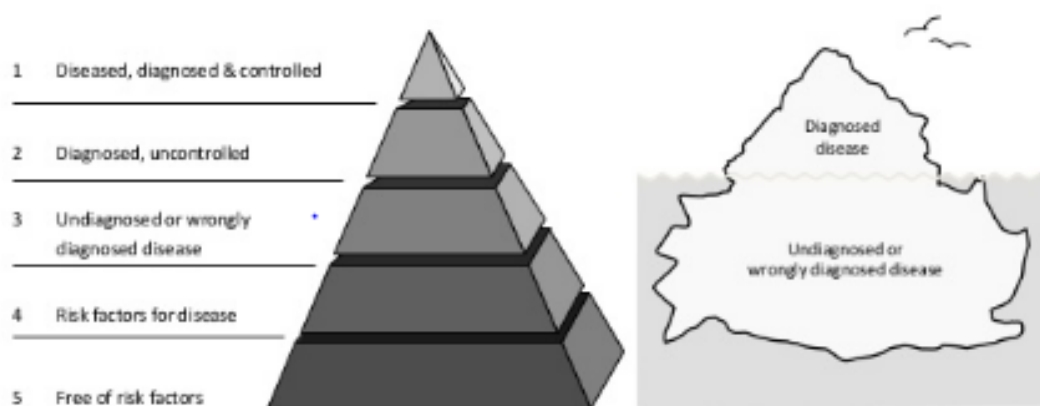


Figure 5: Pyramid (iceberg) of disease (Bhopal, 2008, p.174)

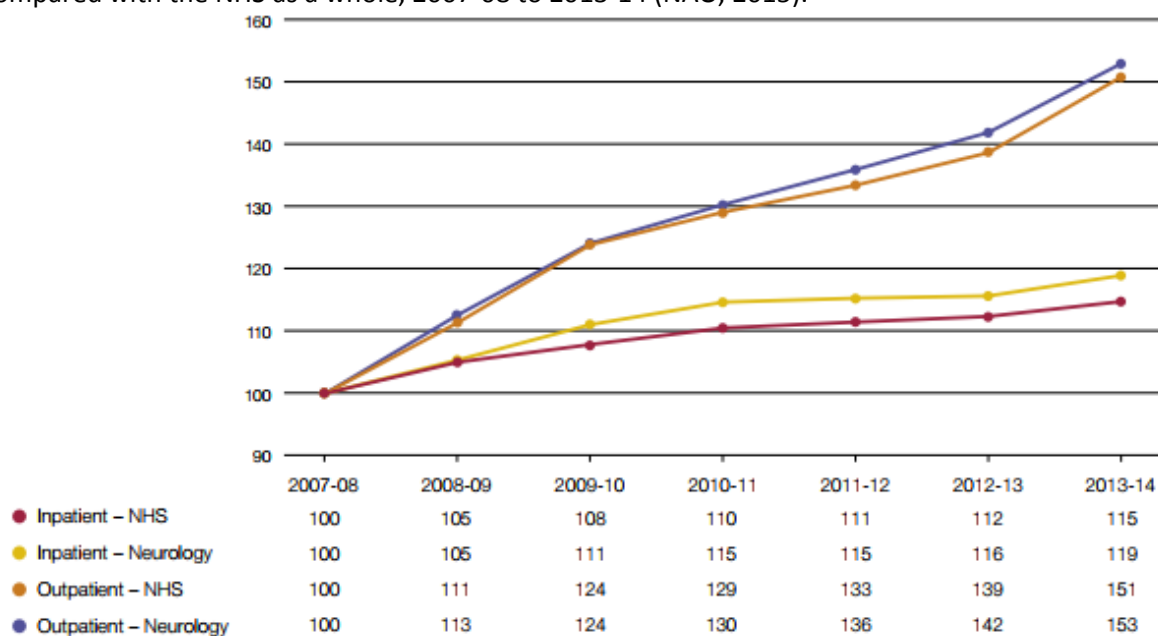
5.2 HOSPITAL ACTIVITY

5.2.1 HOSPITAL ADMISSIONS DATA

According to the National Audit Office £3.3bn was spent in 2012/13 on neurological services, equating to approximately 3.5% of the total annual NHS spend (NAO, 2015). There has been an increasing upward trend in neurological deaths since 2001, 39% increase in annual deaths compared to 6% decrease in all-cause deaths. People living with neurological conditions have the lowest health-related quality of life (EQ5D) of any long term conditions. £750 million was spent on urgent and emergency care including admission to hospital with a 3.6% growth in emergency admissions year on year (NHS England, 2017).

To set the data for Lincolnshire in context, it is useful to first look at the patterns and trends in England as a whole. In England, the number of neurology inpatient admissions and outpatient appointments rose steadily between 2007-08 and 2013-15 (NAO, 2015). Data on patients suffering from dementia, stroke, migraine and headache have been excluded from the inpatient data, therefore the actual level of service activity is likely to be higher than indicated here.

Figure 6: Growth in hospital inpatient admissions and outpatient appointments for neurology compared with the NHS as a whole, 2007-08 to 2013-14 (NAO, 2015).



Notes:

1. Inpatient activity is based on Public Health England’s definition of adult neurological conditions – Public Health England, *Defining adult neurological conditions: National Neurology Intelligence Network technical briefing*, March 2015.
2. Public health England’s definition of neurological conditions does not include dementia and stroke. In addition, for inpatient activity we have excluded headache and migraine.
3. Inpatient activity is based on neurology featuring in one of the top three diagnostic codes. Outpatient activity is based on the treatment specialty the patient was treated under.
4. Index (2007-08 = 100)

5.2.2 LINCOLNSHIRE ADMISSIONS DATA

Table 6: Inpatient admissions totals with a mention of neurological condition, age 20+ (Public Health England, 2017)

Clinical Commissioning Group (CCG)	2012/13	2013/14	2014/15	2015/16
NHS Lincolnshire East CCG	3,748	4,054	3,877	3,730
NHS Lincolnshire West CCG	2,898	3,144	2,889	2,962
NHS Lincolnshire South CCG	2,122	2,151	2,087	2,042
NHS Lincolnshire South West CCG	1,733	1,688	1,489	1,457
Total	10,501	11,037	10,342	10,191

The data show that the number of inpatient admissions with a mention of neurological condition is highest in NHS Lincolnshire East CCG across all four years. It is not overly clear from the data whether inpatient admissions is referring to elective or emergency admissions. Unlike the data for England, the number of inpatient admissions has fluctuated in recent years, showing a slight peak in 2013/14 and then decreasing since. There were fewer inpatient admissions in 2015/16 than in 2012/13 across three of the four CCG areas, with NHS Lincolnshire West being the exception.

Table 7: Day case admissions totals with a mention of neurological condition, age 20+ (Public Health England, 2017)

Clinical Commissioning Group (CCG)	2012/13	2013/14	2014/15	2015/16
NHS Lincolnshire East CCG	1,313	1,405	1,625	1,595
NHS Lincolnshire West CCG	1,099	1,296	1,322	1,441
NHS Lincolnshire South CCG	832	872	1,048	1,120
NHS Lincolnshire South West CCG	670	642	747	802
Total	3,914	3,615	4,742	4,958

As with the data for inpatient admissions, the data for day case admissions with a mention of neurological condition indicates higher numbers of admissions in NHS Lincolnshire East CCG. The lowest number of day case admissions has occurred consistently in NHS Lincolnshire South West CCG. Interestingly, the data over time show a different pattern, with a drop in day case admissions in 2013/14 and an increase since this point. The number of day case admissions with a mention of neurological condition has increased by over 1000 admissions in the four year period between 2012/13 and 2015/16. This may be a direct result of demand for services, or due to greater service provision becoming available.

Table 8: Emergency admissions with a mention of neurological condition, age 20+ (Public Health England, 2017)

Clinical Commissioning Group (CCG)	2012/13	2013/14	2014/15	2015/16
NHS Lincolnshire East CCG	2,908	3,156	3,011	2,915
NHS Lincolnshire West CCG	2,345	2,509	2,251	2,326
NHS Lincolnshire South CCG	1,336	1,273	1,112	1,127
NHS Lincolnshire South West CCG	1,665	1,685	1,635	1,624
Total	8,254	8,623	8,009	7,992

According to this data set, the number of emergency admissions with a mention of neurological condition is again higher in NHS Lincolnshire East CCG than in the other areas of the county. Like the data for inpatient admissions, the number of emergency admissions peaked in 2013/14 and has since declined. These data suggest the number of emergency admissions in Lincolnshire is lower than the level of inpatient admissions overall, however it should be acknowledged that dementia and stroke have not been included here.

Table 9: Emergency hospital admissions in all NHS Lincolnshire CCGs with a mention of a neurological condition, age 20+ by condition (Public Health England, 2017).

Primary diagnosis on admission episode	2012/13	2013/14	2014/15	2015/16
Ataxia	0	0	0	0
Central nervous system infections	80	84	96	83
Cranial nerve disorders	72	74	80	93
Development disorders	0	0	0	21
Epilepsy	718	622	544	605
Functional Disorders	7	6	0	0
Headaches and migraine	909	801	805	844
Motor neurone disease/ Spinal muscular atrophy	0	6	6	0
Multiple sclerosis and inflammatory disorders	58	61	61	21
Neuromuscular disorders	57	34	51	61
Parkinsonism/ other Extrapyrmidal disorders/Tic disorder	96	68	87	90
Peripheral nerve disorders	21	29	31	17
Rare and other neurological disorders	273	224	225	215
Sleep disorders	0	0	0	0
Spondylotic myelopathy and Radiculopathy	69	98	64	90
Traumatic brain and spine injury	205	261	259	255
Tumours of the nervous system	127	162	148	141
Other primary diagnosis on admission	5,521	6,051	5,514	5,410

*0 values represent either zero cases or suppressed values.

The data above show that the most common reasons for emergency admission to hospital with a mention of neurological condition across Lincolnshire are;

- Headache and migraine
- Epilepsy
- Rare and other neurological disorders
- Traumatic brain and spine injury
- Tumours of the nervous system (Public Health England, 2017)

Description of Lincolnshire's Health Services and Activity

The category of 'other primary diagnosis on admission' accounts for by far the largest proportion of all emergency admissions with a mention of neurological conditions. There could be several reasons for this. It may be the case that neurological conditions co-exist with other health problems which lead to symptoms which are considered to be the primary reason for admission. Alternatively, it could be that neurological conditions are difficult to diagnose in urgent care settings and the primary diagnosis is something other than a neurological condition.

Table 10: Emergency hospital admissions under the care of a neurologist, age 20+ (totals) (Public Health England, 2017)

Clinical Commissioning Group (CCG)	2012/13	2013/14	2014/15	2015/16
NHS Lincolnshire East CCG	20	16	12	8
NHS Lincolnshire West CCG	12	12	*	11
NHS Lincolnshire South CCG	*	16	9	7
NHS Lincolnshire South West CCG	8	10	15	*
Total number of emergency admissions under the care of a neurologist	40	54	36	26
Total number of emergency hospital admissions with a mention of neurological condition	8,254	8,623	8,009	7,992
% of emergency admissions under the care of a neurologist	0.48%	0.62%	0.45%	0.33%

Whilst both the total number and percentage of emergency admissions under the care of a neurologist peaked in 2013/14, the numbers have remained low during the period of data collection shown above. This may be indicative of difficulties in diagnosis and allocation to an appropriate consultant on emergency admission, as suggested by previous data, or it may be that neurologist care was not available at the point of admission. Patients are being allocated to the care of medical professionals from other fields of practice.

Table 11: Emergency hospital admissions into a neurology ward, age 20+ (totals) (Public Health England, 2017)

Clinical Commissioning Group (CCG)	2012/13	2013/14	2014/15	2015/16
NHS Lincolnshire East CCG	9	13	11	*
NHS Lincolnshire West CCG	12	8	*	*
NHS Lincolnshire South CCG	*	13	9	7
NHS Lincolnshire South West CCG	8	10	13	*
Total number of emergency admissions into a neurology ward	29	44	33	7
Total number of emergency hospital admissions with a mention of neurological condition	8,254	8,623	8,009	7,992
% of emergency admissions into a neurology ward	0.35%	0.51%	0.37%	0.90%

The total number of emergency hospital admissions into a neurology ward has fallen considerably between 2012/13 and 2015/16. This may be due to a reduction in the availability of emergency neurology beds within the county. These data very clearly highlight the fact that the majority of emergency hospital admissions with a mention of neurological condition result in admission to a ward other than neurology. Patients are therefore likely being cared for in a number of other areas of the hospital. This is consistent with the picture in terms of emergency admission under the care of a neurologist and also the data which indicate that the largest number of emergency admissions have a primary diagnosis other than a neurological condition on admission. As previously stated, it is not possible to deduce whether this is because other symptoms are masking neurological symptoms or whether neurological conditions are being misdiagnosed.

Table 12: Mean length of stay (LoS) in days following emergency admission with a mention of neurological condition by CCG, age 20+ (where LoS is less than 100 days) (Public Health England, 2017)

Clinical Commissioning Groups (CCG)	2012/13	2013/14	2014/15	2015/16
NHS Lincolnshire East CCG	8.96	7.9	8.25	8.41
NHS Lincolnshire West CCG	7.85	7.91	8.43	8.25
NHS Lincolnshire South CCG	9.31	8.59	8.92	9.28
NHS Lincolnshire South West CCG	8.74	8.19	8.15	8.07

The mean length of stay in days following emergency admission with a mention of neurological condition has not fluctuated much between the four CCGs or over the four year period reported here. NHS Lincolnshire South CCG seems to have a slightly longer mean length of stay than the other CCGs, but the difference is small. This table does however hide significant variation in length of stay reported by condition. The three conditions resulting in the longest mean length of stay by CCG are reported in the table below.

Table 13: Longest mean length of stay following emergency admission with a mention of neurological condition by condition and Clinical Commissioning Groups (CCG), age 20+ (Public Health England, 2017)

Clinical Commissioning Groups (CCG)	Date	Neurological condition	Mean length of stay (days)
NHS Lincolnshire East CCG	2012/13	Central nervous system infections	17.85
		Function disorders	16.38
		Neuromuscular diseases	15.89
	2013/14	Multiple sclerosis and inflammatory diseases	17.39
		Parkinsonism and other Extrapyrmidal disorders/Tic disorders	12.65
		Tumours of the nervous system	11.67
	2014/15	Central nervous system infections	14.96
		Development disorders	13.29
		Tumours of the nervous system	12.37
	2015/16	Tumours of the nervous system	15.15
		Functional disorders	12.83
Central nervous system infections		10.9	

Clinical Commissioning Groups (CCG)	Date	Neurological condition	Mean length of stay (days)
NHS Lincolnshire West CCG	2012/13	Parkinsonism and other Extrapyrmidal disorders/Tic disorders	18.32
		Neuromuscular diseases	12.14
		Rare and other neurological diseases	11.49
	2013/14	Central nervous system infections	18.19
		Multiple sclerosis and inflammatory disorders	11.44
		Tumours of the nervous system	10.86
	2014/15	Motor neurone disease	18.71
		Traumatic brain and spine injury	13.47
		Rare and other neurological disorders	12.68
	2015/16	Multiple sclerosis and inflammatory disorders	25.67
		Parkinsonism and other Extrapyrmidal disorders/Tic disorders	16.59
Traumatic brain and spinal injury		11.32	

Description of Lincolnshire's Health Services and Activity

Clinical Commissioning Groups (CCG)	Date	Neurological condition	Mean length of stay (days)
NHS Lincolnshire South West CCG	2012/13	Multiple sclerosis and inflammatory disorders	28.57
		Parkinsonism and other Extrapyrmidal disorders/Tic disorders	21.8
		Central nervous system infections	16.64
	2013/14	Parkinsonism and other Extrapyrmidal disorders/Tic disorders	16.91
		Central nervous system infections	12.93
		Tumours of the nervous system	10.33
	2014/15	Central nervous system infections	15.42
		Rare and other neurological diseases	14.45
		Traumatic brain and spinal injuries	13.66
	2015/16	Central nervous system infections	17.78
		Rare and other neurological disorders	13.31
		Parkinsonism and other Extrapyrmidal disorders/Tic disorders	13.15

Clinical Commissioning Groups (CCG)	Date	Neurological condition	Mean length of stay (days)
NHS Lincolnshire South CCG	2012/13	Neuromuscular diseases	17.36
		Parkinsonism and other Extrapyrmidal disorders/Tic disorders	13.69
		Central nervous system infections	10.42
	2013/14	Multiple sclerosis and inflammatory disorders	18.46
		Motor neurone disease and Spinal muscular atrophy	15.14
		Spondylotic myelopathy and Radiculopathy	12.79
	2014/15	Parkinsonism and other Extrapyrmidal disorders/Tic disorders	23.13
		Traumatic brain and spinal injury	11.56
		Tumours of the nervous system	10.66
	2015/16	Parkinsonism and other Extrapyrmidal disorders/Tic disorders	23.19
		Spondylotic myelopathy and Radiculopathy	16.83
		Neuromuscular diseases	16.71

There are no consistent patterns across time, or by CCG, however, the neurological conditions that feature most frequently in the top three by year and CCG are central nervous system infections; Parkinsonism and other Extrapyrmidal disorders/Tic disorders and Tumours of the nervous system.

Table 14: Number of bed days for Neurological conditions in England and CCG of Treatment (2012-13) (HSCIC, 2014)

CCG Description	Total bed days		Elective bed days		Emergency bed days	
	Mention	Primary	Mention	Primary	Mention	Primary
England	11,135,560	4,428,983	1,287,567	611,677	8,598,442	3,120,189
NHS Lincolnshire East CCG	53,356	19,454	1,190	155	47,851	16,708
NHS Lincolnshire West CCG	56,523	20,678	2,915	1,498	52,240	18,174
NHS Lincolnshire South CCG	2,448	538	87	.	2,252	468
NHS Lincolnshire South West CCG	14,888	5,272	1,092	588	13,500	4,446

The data above on recorded bed days for neurological conditions from the Lincolnshire CCGs show that the largest proportion of bed days result from emergency admissions. This is the pattern both nationally and within Lincolnshire. Within the county, NHS Lincolnshire West and East CCG account for the largest proportion of bed days and NHS Lincolnshire South the smallest proportion. This data does not include bed days as a result of Stroke.

5.2.3 HOSPITAL EPISODE STATISTICS FOR ENGLAND – OUTPATIENT STATISTICS

Table 15: United Lincolnshire Hospital Trust (ULHT) provider broken down by Outpatient appointment outcome, for all treatment specialities (Neurosurgery, Clinical Neuro-physiology, Pain Management and Neurology) 2012-13 (HSCIC, 2014).

Description	All outpatient appointments					
	Attended	Did Not Attend	Patient cancelled	Hospital cancelled	Unknown	Total
Treatment Total	674,856	59,066	113,591	153,059	345	1,000,917
Neurosurgery	-	-	-	10	-	10
Clinical Neuro-physiology	3,503	311	842	191	1	4,848
Pain Management	11,794	1,427	3,231	3,013	2	19,467
Neurology	7,231	896	1,468	1,730	-	11,325

According to HSCIC (2014), in 2012-13, 674, 856 outpatient appointments were attended (67.42%) out of the 1,000,917 appointments made at by ULHT. 5.9% of patients 'did not attend', 11.13% 'cancelled' their appointments, and 15.29% had their appointments cancelled by the hospital. United Lincolnshire Hospitals Trust (ULHT) makes up approximately 1% of the total number of outpatient appointments in England. There is no provision for neurosurgery in Lincolnshire, patients therefore attend appointments outside of the county.

Description of Lincolnshire's Health Services and Activity

Table 16: Hospital providers broken down by distinct outpatients, outpatient appointments and average number of appointments for neurological treatment specialities 2012-13 (HSCIC, 2014).

Description		Neurological Treatment Specialities			
		Neurosurgery	Pain Management	Neurology	Clinical Neuro-physiology
England	Distinct Patients	101,434	193,392	284,477	35,834
	Outpatient appointments	345,892	905,778	1,447,471	134,088
	Average number of appointments	3.4	4.7	5.1	3.7
United Lincolnshire Hospital NHS Trust	Distinct Patients	10	3,479	2,860	1,032
	Outpatient appointments	7,218	8,946	17,704	2,686
	Average number of appointments	1.0	5.6	4.0	4.7

ULHT treated a total of 7381 distinct neurological patients, 1.2% of the total distinct patients treated in England. More distinct patients are treated in Pain Management, in comparison to Neurology, Clinical Neuro-physiology and Neurosurgery respectively. The average number of outpatient appointments per patient is considerably higher for Pain Management Treatment and Clinical Neuro-physiology in ULHT than the England average in comparison to Neurology and Neurosurgery.

Description of Lincolnshire's Health Services and Activity

Table 17: Hospital providers broken down by all outpatient appointments, for all neurological treatment specialities, by age group 2012-13 (HSCIC, 2014)

Description	Number of Outpatient appointments (age group)									Total
	16-19	20-29	30-39	40-49	50-59	60-69	70-79	80+	Other / Unknown	
England	57,778	245,837	366,639	571,773	550,944	486,428	359,605	161,254	32,971	2,833,229
United Lincolnshire Hospital NHS Trust	649	2,570	3,936	7,388	6,597	6,573	4,989	2,456	492	35,650
BMI The Lincoln Hospital		*	*	13	*	11	9	*	-	45

The number of outpatient appointments for neurological treatments was highest for individuals in the 40 – 49; 50 – 59 and 60 – 69 age groups in 2012-13 in ULHT and England. Values were suppressed for BMI The Lincoln Hospital due to low numbers. The number of outpatients appointments peaks between the ages of 40-49 which is of interest considering neurological conditions are often associated with ageing (Kowalska, 2017). A more detailed exploration of the data in this age group would help further understand service use patterns and types of neurological conditions being experienced in the county.

Table 18: Hospital providers broken down by Distinct patients and number of outpatient appointments for all Neurological Treatment specialities 2012-13 (HSCIC, 2014).

Description	Number of appointments per patient										All distinct patients
	1	2	3	4	5	6	7	8	9	10 or more	
England	277,184	104,218	55,341	34,693	23,874	17,495	13,640	10,769	8,661	69,262	615,137
United Lincolnshire Hospital NHS Trust	2,905	1,234	751	464	356	247	193	162	142	927	7,381

In terms of the number of outpatient appointments per patient for all neurological treatment specialities the pattern in both England and ULHT is U shaped. The greatest number of patients required one or two outpatient appointments, these may reflect more acute conditions. The number of appointments then steadily declines before rising again the in 10 or more category. This may be representative of patients with ongoing conditions who require ongoing care and monitoring by health care professionals.

Description of Lincolnshire's Health Services and Activity

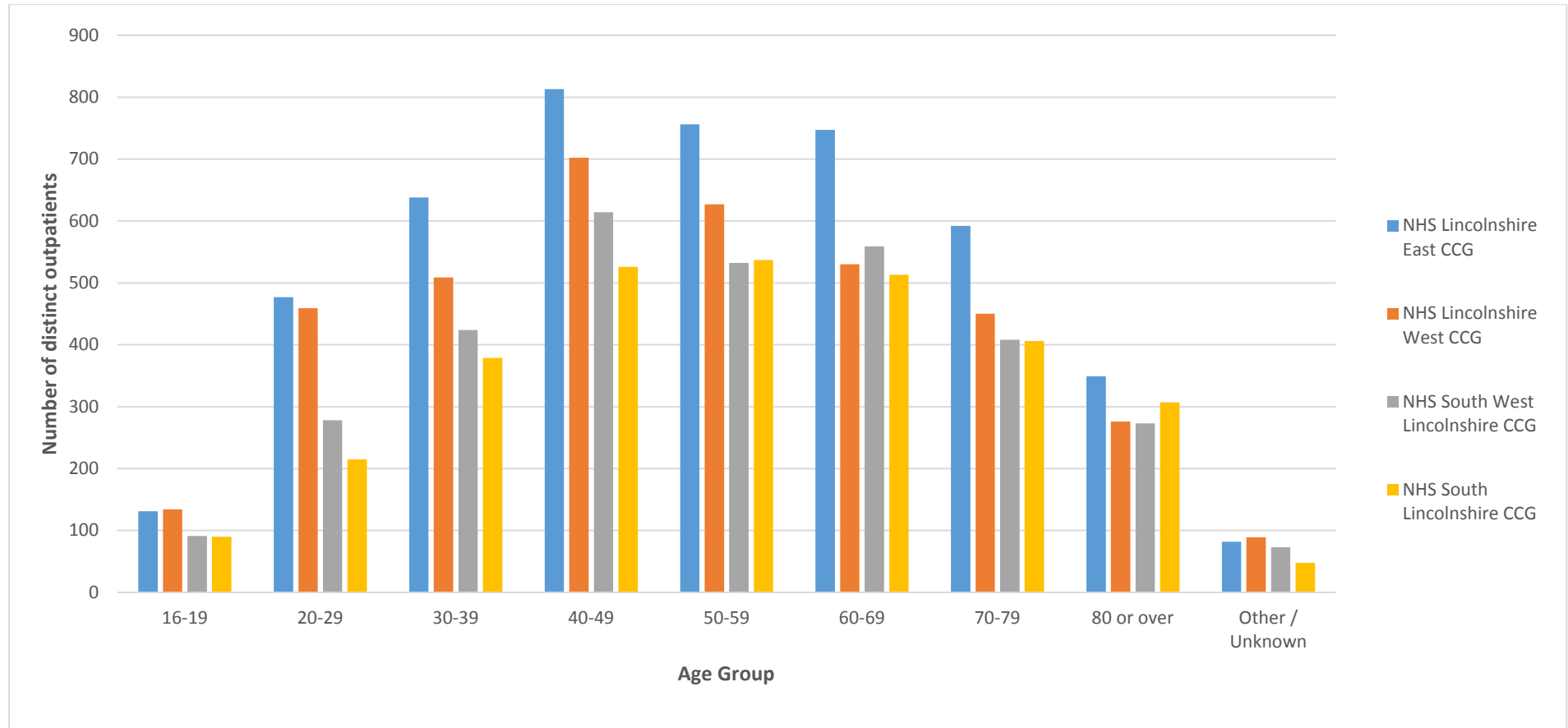


Figure 7: Number of distinct outpatients by CCG of residence for all Neurological Treatment Specialities by age group 2012-13 (HSCIC, 2014).

Across all age groups, patients from NHS Lincolnshire East CCG account for the highest number of distinct outpatients. The data again indicate that the highest number of distinct outpatient occurs with patients aged between 40 and 69. This suggests that the burden of neurological disease in Lincolnshire is greatest between the ages of 40 and 69.

Description of Lincolnshire's Health Services and Activity

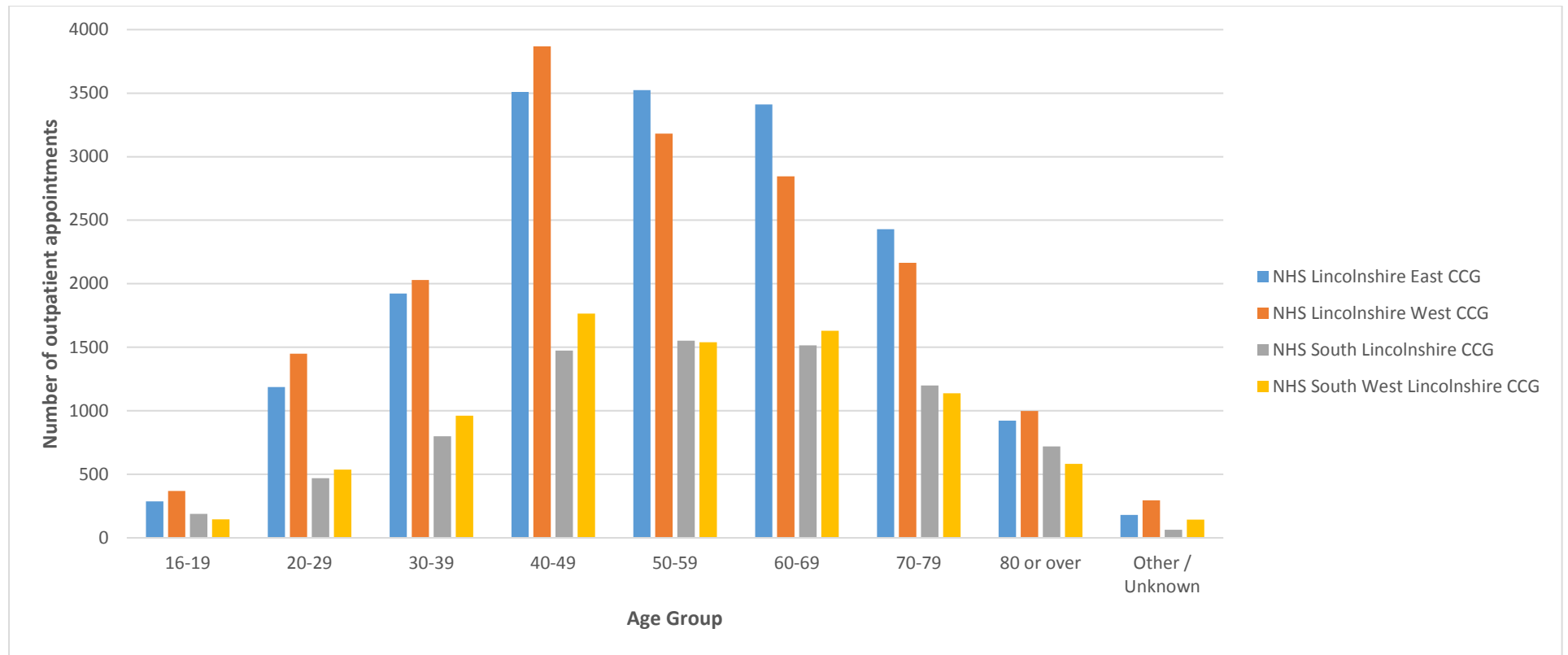


Figure 8: Number of outpatient appointments by CCG of residence for all Neurological Treatment Specialities by age group 2012-13 (HSCIC, 2014).

It is evident from this dataset that the number of outpatient appointments for neurological treatments was significantly higher for individuals in the 40 – 49; 50 – 59 and 60 – 69 age group for all Lincolnshire CCGs, with patients from NHS Lincolnshire East and West CCGs accounting for significantly higher numbers of outpatients appointments than NHS Lincolnshire South and South West CCGs.

Patients from NHS Lincolnshire East and West CCG attend on average a greater number of appointments than patients from NHS Lincolnshire South and South West. The highest average number of appointments is for adults aged between 40 – 79 years, as illustrated below.

Description of Lincolnshire's Health Services and Activity

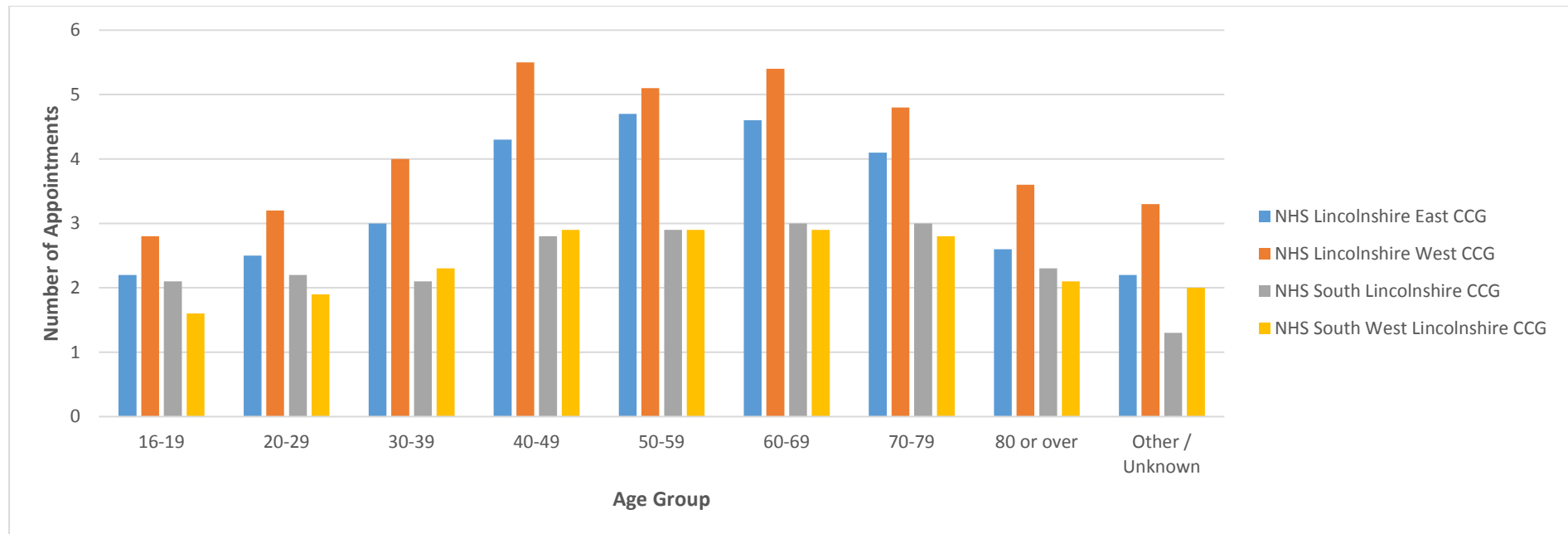


Figure 9: Average number of outpatient appointments per patient by CCG of residence for all Neurological Treatment Specialities by Age group 2012-13 (HSCIC, 2014).

To set this data in context, the average number of outpatients appointments for all Lincolnshire CCGs is equal to (NHS Lincolnshire West CCG) or less than the average of all England CCGs (approximately 4.6 appointments per person) (HSCIC, 2014)

Care 'out of county'

Not all patients with neurological conditions in Lincolnshire are able to receive their treatment in their CCG of residence. A proportion of patients from NHS Lincolnshire East CCG (40.36%); NHS Lincolnshire South CCG (8.39) and NHS Lincolnshire South West CCG (64.34%) are required to travel outside of their CCG for treatment. Whilst this may be within the county, some patients are required to travel beyond the county to access services in Nottingham, Sheffield, Cambridgeshire

and Peterborough. There may be significant costs associated with travelling to appointments and significant time requirements due to poor public transport provision within the county.

Table 19: Clinical Commissioning Groups (CCG) of residence by CCG or treatment (and top 3) for all Neurological Treatment Specialities 2012-13 (HSCIC, 2014).

				Top 3 CCG areas where patients had their Outpatients appointments					
CCG Name	CCG of residence	CCG of treatment	NET import / export	CCG Name (1)	Number (1)	CCG Name (2)	Number (2)	CCG Name (3)	Number (3)
NHS Lincolnshire East CCG	17,372	10,361	-7,011	NHS Lincolnshire East CCG	8,475	NHS Lincolnshire West CCG	5,074	NHS Nottingham City CCG	866
NHS Lincolnshire West CCG	17,201	21,964	4,763	NHS Lincolnshire West CCG	13,332	NHS Sheffield CCG	1,145	NHS Nottingham City CCG	726
NHS South Lincolnshire CCG	7,982	7,312	- 670	NHS South Lincolnshire CCG	2,597	NHS Cambridgeshire and Peterborough CCG	2,479	NHS Lincolnshire East CCG	1,052
NHS South West Lincolnshire CCG	8,440	3,010	- 5,430	NHS South West Lincolnshire CCG	2,711	NHS Lincolnshire West CCG	2,470	NHS Nottingham City CCG	1,276

5.2.4 COMPENDIUM OF NEUROLOGICAL DATA ON REFERRAL TO TREATMENT (RTT) AND ADMITTED PATHWAYS

Table 20: Referral to Treatment (RTT) waiting times for completed admitted pathways (on an adjusted basis) for Neurology 2012-13 (HSCIC, 2014)

Provider Name	All treatment functions						
	Average (median) waiting time (in weeks)	% within 18 weeks	95th percentile waiting time (in weeks)	Total number of completed pathways (all)	Total number of completed pathways (with a known clock start)	Total (with a known clock start) within 18 weeks	Percentage with a known clock start within 18 weeks
England	8.5	92.0	21.6	3,327,101	3,322,429	3,057,580	92%
United Lincolnshire Hospitals NHS Trust	10.7	90.0	21.3	25,827	25,827	23,466	91%
Lincolnshire Partnership Foundation Trust	No data	No data	No data	No data	No data	No data	No data

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. Ninety per cent of participants are admitted within the recommended 18 weeks, 2 % lower than the England average. There were no known data available for Lincolnshire Partnership Foundation Trust (LPFT) as this is primarily a community based service.

5.2.5 COMPENDIUM OF NEUROLOGICAL DATA ON REFERRAL TO TREATMENT (RTT) AND NON-ADMITTED PATHWAYS

Table 21: Referral to Treatment (RTT) waiting times for completed Non-admitted pathways for Neurology and Neurosurgery specialties 2012-13, (HSCIC, 2014)

Provider Name	All treatment functions						
	Average (median) waiting time (in weeks)	% within 18 weeks	95th percentile waiting time (in weeks)	Total number of completed pathways (all)	Total number of completed pathways (with a known clock start)	Total (with a known clock start) within 18 weeks	Percentage with a known clock start within 18 weeks
England	4.2	97.6%	15.8	10,174,403	10,165,173	9,918,027	97.6%
United Lincolnshire Hospitals NHS Trust	7.0	95.1%	17.9	88,941	88,941	84,585	95.1%
Lincolnshire Partnership Foundation Trust	-	-	-	-	-	-	-

Neurology patients referred to ULHT wait and average of seven weeks to receive treatment via non-admitted pathways, this is longer than the average wait time in England (4.2 weeks). The percentage of people seen within 18 weeks is high (95.1%) but still lower than the equivalent data for England (97.6%). Patients in Lincolnshire are waiting longer for referral to treatment on admitted and non-admitted pathways than neurology patients in England on average.

5.2.6 COSTS OF NEUROLOGICAL TREATMENT

Total spend on neurological conditions in Lincolnshire is highest in NHS Lincolnshire East CCG which corresponds with the higher levels of service activity seen. The costs of non-elective treatment are significantly higher than the costs of elective treatment across all four CCGs. This reflects the higher number of emergency admissions and may be related to the unpredictable onset and progression of many neurological conditions.

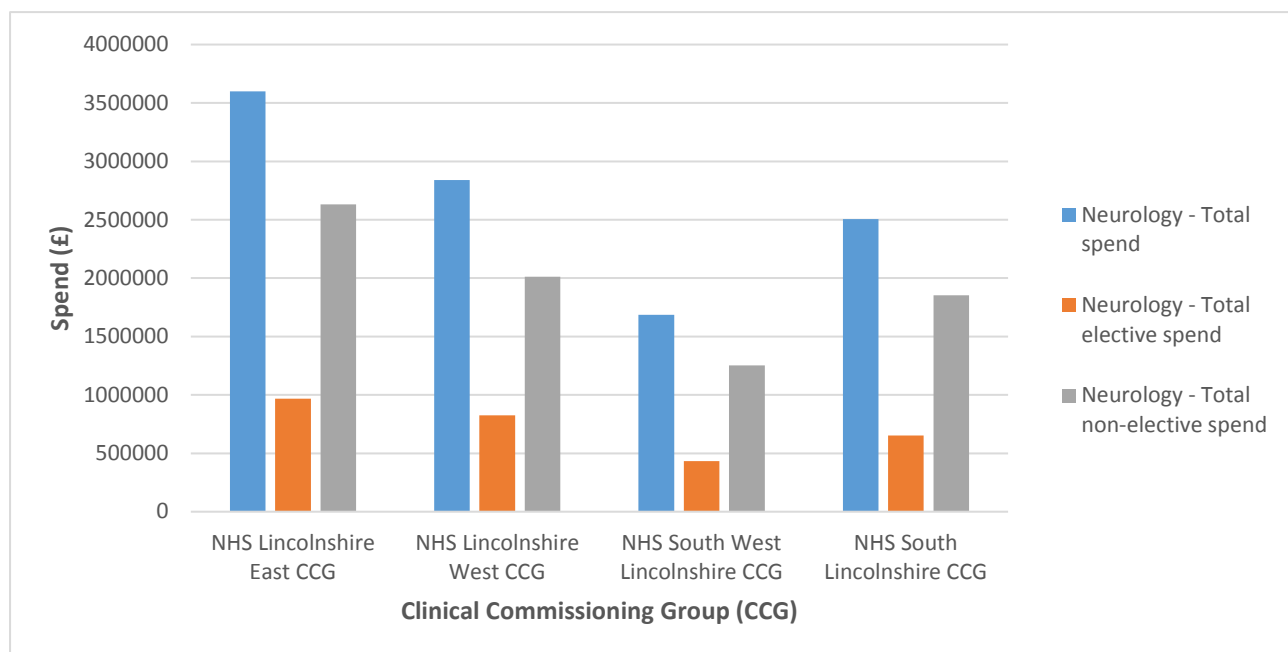


Figure 10: Neurology Total spend, Total Elective spend and Total Non-elective spend 2014/15 (NHS England, 2016)

The data by condition reveal an interesting picture.

The non-elective spend is higher across all four CCGs for the following conditions;

- Epilepsy
- Tumours of the nervous system
- Traumatic brain and spinal injuries
- Headaches and migraines (NHS England, 2016).

The elective spend is higher across all four CCGs for;

- Functional disorders
- Chronic pain

Description of Lincolnshire's Health Services and Activity

The pattern of spending by CCG is mixed for;

- Motor neurone disease and spinal muscular atrophy
- Multiple sclerosis and inflammatory disorders
- Parkinsonism and other extrapyramidal disorders
- Neuromuscular disorders

The data by Clinical Commissioning Group reinforces what we see in terms of patterns of service use, with highest spend in either NHS Lincolnshire East CCG or NHS Lincolnshire West CCG. There are differences between the two in terms of the conditions where spend is highest.

Total spend is highest in NHS Lincolnshire East CCG for;

- Epilepsy
- Tumours of the nervous system
- Motor neurone disease and spinal muscular atrophy
- Parkinsonism or Parkinson's disease
- Neuromuscular disease
- Functional disorders
- Traumatic brain and spinal injury
- Chronic pain

Total spend is highest in NHS Lincolnshire West CCG for;

- Multiple sclerosis and inflammation disorders
- Headaches and migraines (NHS England, 2016)

This may indicate that prevalence of these neurological conditions is highest in these areas of the county. It again corresponds with earlier data showing that disease burden is highest in the area of the county covered by NHS Lincolnshire East CCG.

5.2.7 HEALTH SPEND AND OUTCOMES TOOL (SPOT) LINCOLNSHIRE

According to Public Health England (2015) spending in Lincolnshire for Public Health and Adult Social Care per head was significantly lower than the England spending during 2015, 32.81% and 16.73% respectively.

Table 22: Health Spend and Outcome Tool (SPOT) for Public Health and Social Care (Public Health England, 2015)

Spend	England value	Lincolnshire value
Public Health		
Public Health (RO)	£64	£43
Social Care (Adults)		
Adult Social Care	£269	£224
Service users having control over their daily life	77%	80%

According to Public Health England (2015) spending for neurological treatments specifically epilepsy across all four Lincolnshire CCGs was similar or higher than the England average, and considerably higher than the Regional average.

Table 23: Health Spend and Outcome Tool (SPOT) for Neurological Treatments for Epilepsy (Public Health England, 2015)

Area	England value	Regional Value	NHS Lincolnshire East CCG	NHS Lincolnshire West CCG	NHS South West Lincolnshire CCG	NHS South Lincolnshire CCG
Neurological (spend per head)	£53	£51	£56	£55	£57	£53
Social Needs (spend per head)	£23	£27	£55	£38	£57	£97
Other areas of spend/ condition	£233	£217	£205	£243	£157	£165
General Medical Services/ Personal Medical Services	£4	£4	£11	£8	£7	£9
Registration of patients on a drug treatment for epilepsy	0.8%	0.8%	1.0%	0.8%	0.8%	0.7%
% epilepsy and seizure free	76%	88%	99%	100%	100%	98%

Description of Lincolnshire's Health Services and Activity

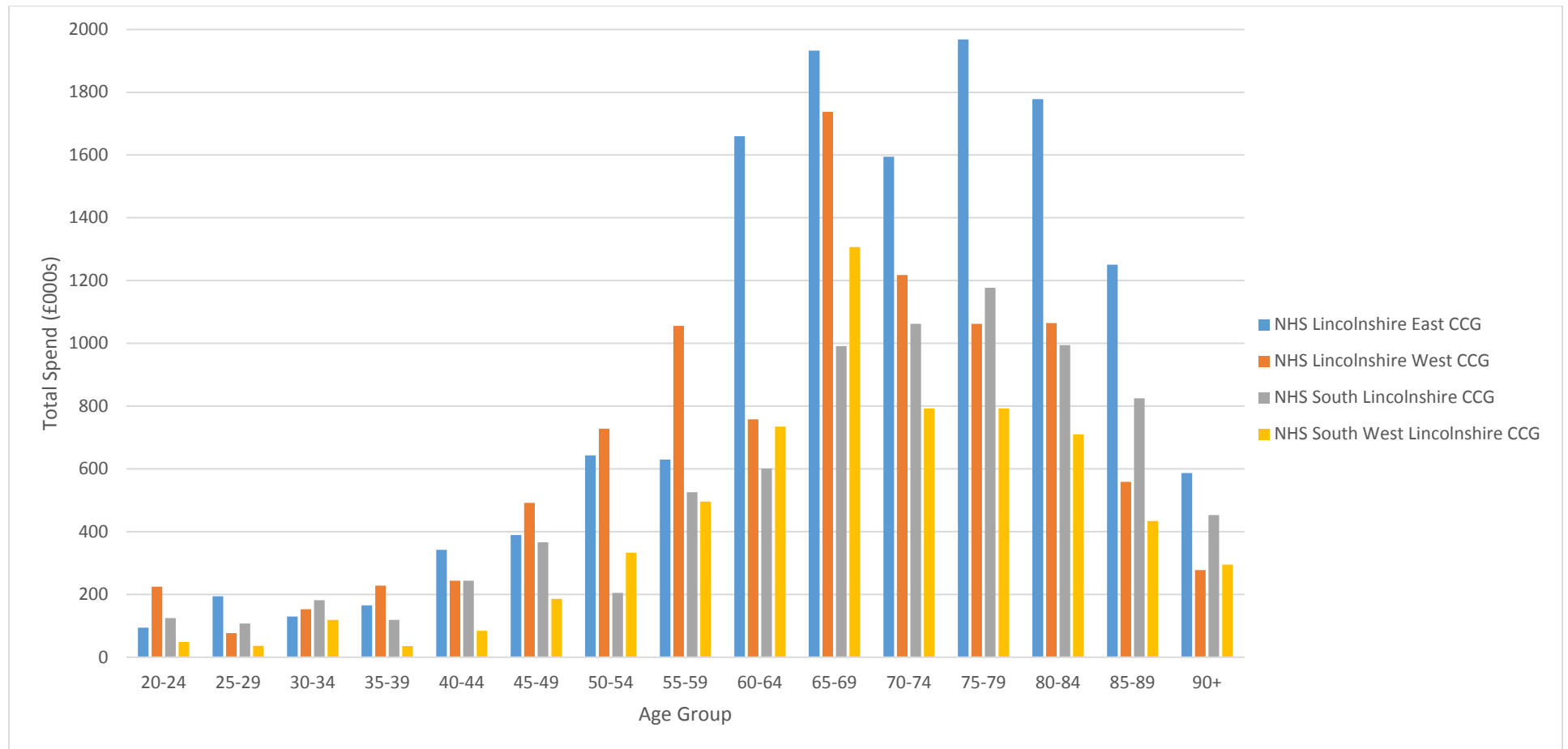


Figure 11: Total Spend (£000s) for neurological conditions by CCG of Residence age 20+ (Public Health England, 2016)

A higher total spend (£000s) for neurological conditions was reported for age groups 65-69, 70-74, 75-79 and 80-84 particularly amongst NHS Lincolnshire East CCG and NHS Lincolnshire West CCG than the other Lincolnshire CCGs (Public Health England 2016).

5.3 END OF LIFE CARE/ PALLIATIVE CARE

Palliative care services are services designed to provide support and relief towards the end stages of life. For some people this could be required for days, weeks or even months, but it is a predicted course of the condition. They can be based in hospices run by voluntary sector organisations and or provided as community services. Sources of data are mixed, as palliative care consultants can include some of their activity as Finished Consultant Episodes (FCEs) for hospital episodes; however this will not reflect the palliative care provided by a range of other professionals.

It is not possible to identify the number of people in the county with neurological conditions who receive end of life care in hospital, hospice or community settings. Data on palliative care are only available in relation to patients who died with an underlying cause of stroke.

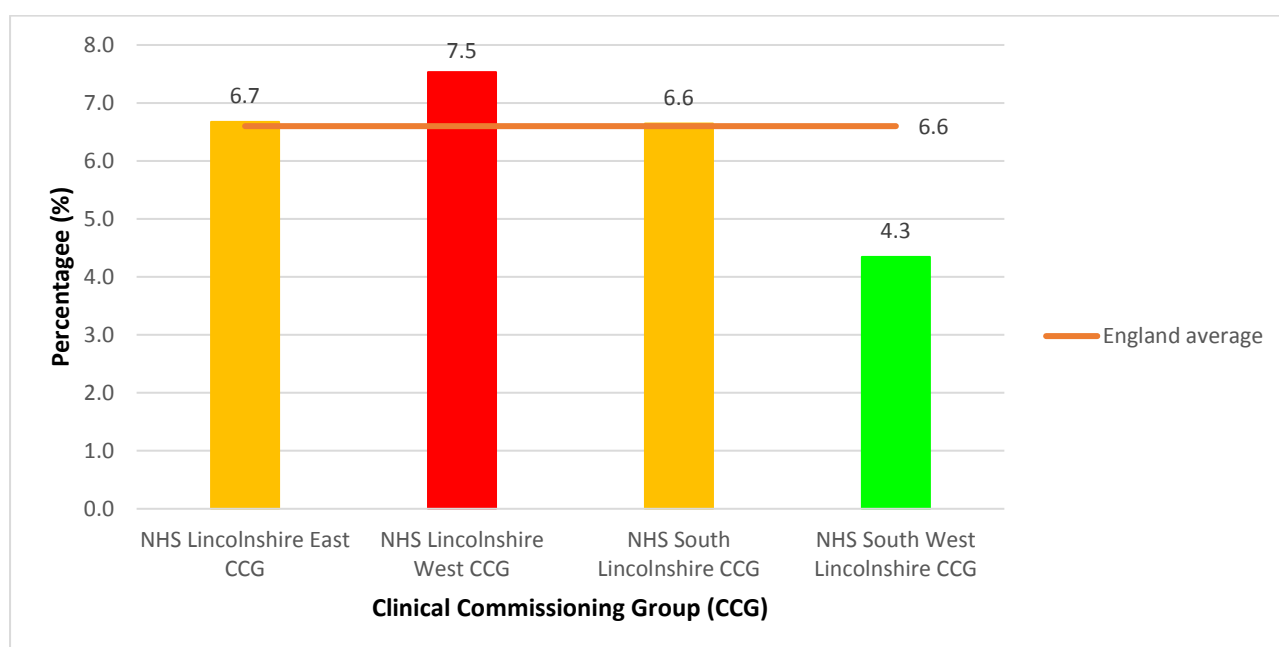


Figure 12: Proportion of people who died with an underlying cause of stroke across Lincolnshire’s Clinical Commissioning Groups for End of Life Care Sustainability Transformation Partnership (STP) Tool (2015) (ONS Mortality Data, 2015 In Public Health England, 2017).

Note: Red indicates significantly higher than England average; yellow indicates similar but no significant difference between England average; green indicates significantly lower than England average.

The highest proportion of deaths with an underlying cause of stroke (2015) occurred in NHS Lincolnshire West CCG where 7.5% of deaths in end of life care were attributed to stroke, 1.1% higher than the average for England (6.6%). Only NHS Lincolnshire South West CCG (4.3%) experienced a lower proportion of deaths with an underlying cause of stroke in end of life care than the England average. This could be explained by differences in stroke prevalence, or differences in the availability of end of life care.

5.4 ADULT SOCIAL CARE

Currently there are no data on spending on social care in England specifically for people living with long term neurological conditions (LTNCs), as adult social services are defined by disability and need rather than condition. People identified living with neurological conditions generally fall within the category of 'people with a physical disability' (ADASS, 2017). This is also the situation in Lincolnshire.

5.5 SUMMARY OF HOSPITAL ACTIVITY

Inpatient admissions

- The number of inpatient admissions with a mention of a neurological condition in Lincolnshire has fluctuated in recent years, showing a slight peak in 2013/14 and then decreasing since. This is opposite to the trend in England, where inpatient admissions have slightly risen during the corresponding period.
- Within the county, the number of inpatient admissions with a mention of neurological conditions is consistently highest in patients residing in NHS Lincolnshire East CCG.

Day case admissions

- The number of day case admissions with a mention of a neurological condition is highest in NHS Lincolnshire East CCG and lowest in NGS Lincolnshire South West CCG.
- Between 2012/13 and 2015/16 the number of day case admissions rose in all areas by 1000 admissions. This is a reversal of the pattern for inpatient admissions and may reflect a change in service delivery.

Emergency admissions

- As with inpatient and day case admissions, the number of emergency admissions with a mention of a neurological condition is higher in NHS Lincolnshire East than the other CCGs.
- The number of emergency admissions was relatively stable during the period 2012/13 to 2015/16.
- 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.
- A large number of patients admitted on emergencies have a primary diagnosis other than neurological condition on admission.

Description of Lincolnshire's Health Services and Activity

- Emergency admission under the care of a neurologist, or on to a neurology ward is very low indicating that neurological patients are being cared for elsewhere in the acute setting.

Length of stay and bed days

- The mean length of stay following emergency admission with mention of a neurological condition is between 7.9 and 9.28 days.
- NHS Lincolnshire South CCG has a slightly longer mean length of stay than other CCGs, but the difference is small.
- When length of stay is examined by condition, central nervous system infections; Parkinsonism/ Parkinson's disease and extrapyramidal disorders/Tic disorders and tumours of the nervous system result in the longest mean length of stay.
- The largest proportion of bed days for neurological conditions in both Lincolnshire and England result from emergency admissions.
- Within the county, NHS Lincolnshire West and East account for the largest proportion of total bed days, NHS Lincolnshire South accounts for the smallest proportion.

Outpatient statistics

- In 2012/13, over one million outpatients appointments were made at United Lincolnshire Hospital Trust (ULHT) for patients with neurological conditions, 67% of these were attended.
- The highest number of appointments are made for pain management, followed by neurology, clinical neurophysiology and neurosurgery.
- The average number of appointments per patient for pain management and clinical neurophysiology is higher at ULHT than the England average.
- Patients between the ages of 40-69 have the highest number of outpatients appointments. In 2012/13, service use peaked between the ages of 40 and 49.
- Across all age groups, patients from NHS Lincolnshire East CCG had the highest number of distinct outpatients appointments.
- A proportion of patients from NHS Lincolnshire East, South and South West have to travel outside of their CCG of residence for their outpatients appointments. Some are required to travel outside of the county to access services in Nottingham, Sheffield, Cambridgeshire and Peterborough (most commonly).

Referral to treatment and waiting times

- 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.
- Neurology patients referred to ULHT wait on average 7 weeks for outpatient care, compared with 4.2 weeks in England.

Costs of treatment

- Total spend on neurology is highest in NHS Lincolnshire East CCG which corresponds with the pattern of service use seen.
- The costs of non-elective treatment are significantly higher than the costs of elective treatment across the county.
- Non-elective spend is highest in relation to epilepsy; tumours of the nervous system; traumatic brain and spinal injury and migraine and headaches.
- Elective spend is highest for Functional disorders and chronic pain.
- The highest total spend is for patients between the ages of 65-84 years.

End of life care

- It is not possible to identify the number of people in the county with neurological conditions who receive end of life care in hospitals, hospice or community settings from the available data.
- Data on palliative care are only available for patients who died with an underlying cause of Stroke. The highest proportion of deaths from stroke in end of life care occurred in NHS Lincolnshire West CCG (7.5%), 1.1% higher than the England average.

Adult social care

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



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Chapter 6.0

Survey Response

6.0 SURVEY RESPONSE

6.1 OVERVIEW

In order to gain data on the experiences of those living with and caring for individuals with neurological conditions in Lincolnshire a survey was conducted. This data can help us begin to understand the level of unmet need in the county. The findings must however be interpreted with caution as the sample size is small and unlikely to be representative of the population living with neurological conditions or their carers. This should not however detract from the the experiences and insights they have shared. The views and experiences of Voluntary Sector Organisations and Medical/Allied Health Professionals and were also sought and are presented here.

6.2 SURVEY RESPONSE

An online Qualtrics survey which was distributed by email and post to all of the key stakeholders listed below. The survey response window was open from 1st December 2017 until 29th January 2018. Four individual surveys were distributed and a total of 84 responses were yielded in this time frame:

1. People living with neurological conditions (n=41)
2. Carers for people living with neurological conditions (n=19)
3. Voluntary Sector Organisations (n=11)
4. Medical/ Allied Health Professionals (n=13)

6.2.1 PEOPLE LIVING WITH NEUROLOGICAL CONDITIONS

Forty-one responses were provided by people living with neurological conditions in Lincolnshire, however not all respondents answered all questions fully. Respondents ranged from 37 years old to 81 years old. Of the 37 responses, 41% were male and 59% were female. Additionally 68% were married, 14% were single, 8% divorced, 8 % living together and 3% separated.

The majority of the sample lived in owner occupied housing (76%). We were not able to identify the CCG of residence of participants from the data collected.

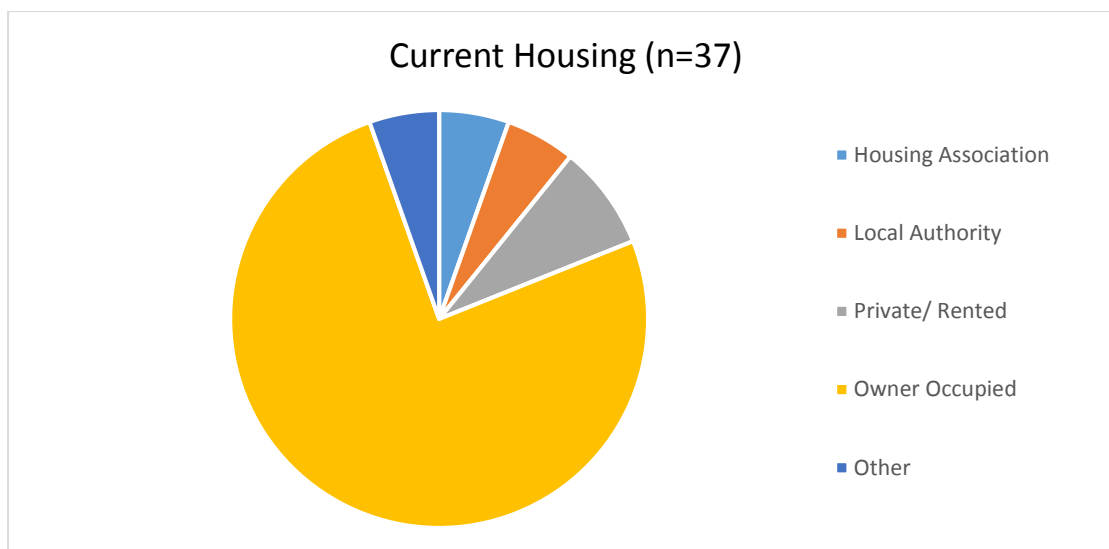


Figure 13: Current housing status of people living with neurological conditions.

Forty participants responded to the question about home adaptation, with 45% indicating that their home had been adapted to meet their needs. Adaptations included grab rails, concrete ramps, outside steps, walk in showers, wet rooms, raised toilets, raised beds, stair rail, shower seat, stair lift, pressure mattress, bath stool, NHS zimmer frame, wider doors and level access.

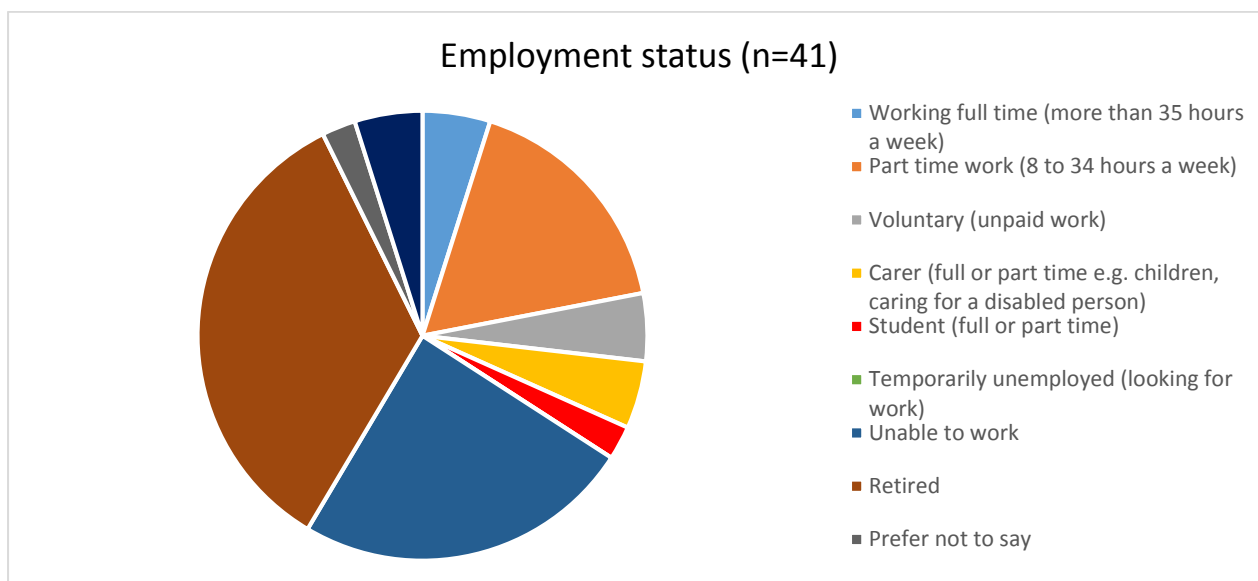


Figure 14: Employment status of people living with neurological conditions

Of the 41 responses, 5% worked full time, 17% worked part time, 5% worked voluntarily (unpaid), were a carer (full or part time) or were self employed (other). Additionally 2% were students (full time, part time), 24% were unable to work due to their neurological condition and 34% were retired.

Survey Response

The type of neurological conditions respondents (n=40) had been diagnosed with included multiple sclerosis (3%); epilepsy (5.00%), stroke (3%), Parkinson's disease (18%) and other (73%). Other neurological conditions included brain haemorrhage, subarachnoid aneurysm and burst coils, post-polio syndrome, myasthenia gravis, traumatic brain injury, frontal lobe brain damage, transient ischemic attack (TIA), dystonia, non-epileptic attack disorder (NEAT), functional disability, restless leg syndrome (RLS), migraine, neuralgia from shingles, cerebrospinal fluid leak, migraine with brain stem aura, chronic migraines, ataxia, fibromyalgia, Charcot Marie-Tooth Syndrome (CMT), cervical dystonia, hemiplegic migraine and sciatic nerve damage. The diagnosis of neurological conditions ranged from newly diagnosed around one month to 66 years.

Many of the respondents had co-existing long term health conditions including, heart disease (2%), heart attack/ angina (8%), chronic obstructive pulmonary disease (COPD)/ asthma (8%), arthritis (23%), diabetes (13%), high blood pressure/ hypertension (21%) and other (26%). Other long-term health conditions included irritable bladder, lupus, macular dystrophy, rheumatoid arthritis, visual impairment, hearing loss, memory loss, sleep apnoea (obstructive), arrhythmia, functional right sided weakness, irritable bowel syndrome (IBS), Spina bifida, osteoporosis, chronic hayfever/ allergies, hypothyroidism, hyperthyroidism, sleep behaviour disorder, testosterone deficiency, depression, diverticular disease, high cholesterol, postural orthostatic tachycardia syndrome (POTS), low mobility, overactive bladder, implanted defibrillator after sudden cardiac arrest.

The extent to which respondents felt their neurological condition(s) affected their overall health and well-being was indicated as severely (32%), somewhat (46%), once in a while (20%), not at all (2%) and other (10%)(n=41). Other includes respondents mentioning that their neurological condition(s) affected their health and well-being 'severely and on a daily basis', other respondents mentioned they 'lacked strength and energy', and 'were constantly anxious and frustrated particularly concerning employment difficulties'. Furthermore the same respondents expressed the extent to which their current health affected daily life (e.g. housework, taking care of yourself, going to work, or pursuing a hobby, getting around) which varied from severely (29%), somewhat (46%), once in a while (12%), not at all (2%) and other (10%). Other included respondents mentioned they were 'physically fatigued', suffered 'mobility problems', 'lack of social interaction with friends due to being on so much medication and being in and out of hospital', 'confinement to a wheelchair'.

The type of community services being received included, physiotherapist (4.48%), General practitioner (46%), occupational therapist (3%), Counselling (1%), day care (1%), rehabilitation services (4%), mental health services (1%), cleaning (3%), gardening (4%), social worker (3%) and other (27%). Other includes carer (care from friends, parents and or spouse), neurology

Survey Response

consultant, support from charity (e.g. Myaware), dietician, consultant for POTS, pain clinics (Lincoln county), acupuncture (Gainsborough), orthotics 'out of county' (Scunthorpe), employ personal assistant using direct payments and personal health budget. Interestingly some respondents expressed that they visited 'out of county' services including botox clinics (Nottingham), Neurology (Walton Centre, Liverpool), and general surgery (Diana Princess of Wales). Some respondents were using more than one community service.

Experiences of service use

Respondents living with neurological conditions in Lincolnshire painted a mixed picture of their experiences in service use. In relation to GPs, some respondents indicated that their experience was good, and that their GP was very understanding, helpful, polite and supportive. The majority of respondents however indicated that their experiences were poor and that their GP had little or no understanding of their neurological condition and/or different GPs seemed to have different views on the best approach, where those with personal experience 'seemed more interested'. Participants illustrated their experiences with quotes such as 'I don't think my condition was taken seriously enough', while another respondent expressed that 'my previous doctor did not believe I had a problem and I was just offered pain killers'.

The majority of respondents indicated that they had never used community services because they were either not aware of them, were not offered services or services were only available outside of the county. Some respondents indicated that they did not qualify for specific services with some not willing to disclose their experiences altogether. Where services were available and used, they were generally reported to be poor, with appointments not followed up and waiting times for some services being considerably long. The services provided by Headway Lincolnshire and the rehabilitation clinics were however highlighted as helpful. Due to lack of understanding or availability of services some respondents indicated that they have resorted to paying privately using direct payments and personal health budgets.

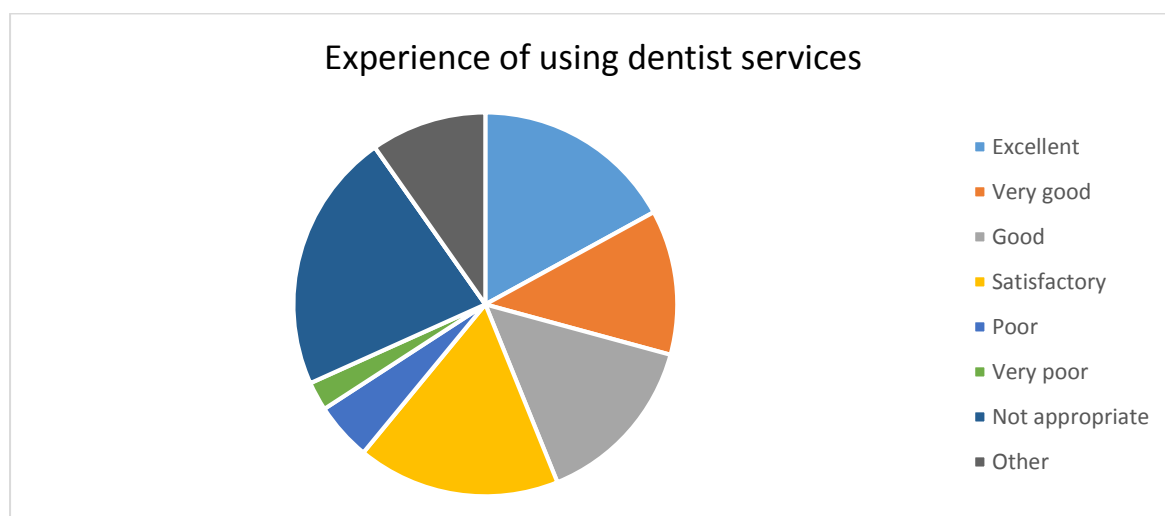


Figure 15: Experience of using dentist services for people living with neurological conditions.

Forty one respondents shared their experiences of using dentist services indicating they were either excellent (17%), very good (12%), good (15%), satisfactory (17%), poor (5%), very poor (2%) or not appropriate (22%). They felt that their neurological condition(s) affected their overall health and well-being severely (32%), somewhat (46%), once in a while (20%), not at all (2%) and other (10%). Other includes respondents changing from NHS dentist to a private dentist to receive the appropriate care citing the ‘NHS dentist did not want to help me because of my medical conditions’ while another respondent cited they would be in financial difficulties if they were not ‘supported by their husband’ while being on Denplan.

In relation to the use of hospital services (e.g. consultant, outpatient appointment), the majority of respondents expressed that their experiences were ‘good’ or ‘reasonable’, however some consultants had limited knowledge of their condition. One participant stated ‘my neurologist didn’t know anything about my condition, they googled it!’. Most respondents indicated that they had to travel ‘out of county’ to receive some form of care as there were ‘no services available in Lincolnshire’ (e.g. Nottingham Queen Medical Centre, Sheffield, Stoke on Trent, Liverpool) with long durations between appointments from consultants.

The picture in relation to urgent care was less positive. Some of the respondents indicated that they had not used urgent care services for their neurological conditions, however those who did stated that their care was ‘average’, ‘useless’, ‘or that they had received an appalling lack of care’, for example, ‘8 hours wait on a surgical emergency assessment ward’. Some respondents indicated that they had resorted to self-management through ‘buying painkillers and treating their condition at home’.

Survey Response

The majority of respondents indicated that that mental health services were not needed or required. However some respondents indicated that 'access to services were not sufficient', 'with poor information provided' and or a 'long wait to get to services to then be refused support because of eligibility criteria'. Others expressed that therapy and treatments did not continue past the first appointment and or local mental health services were only assessment services and not provider services leading to respondents having to travel 'out of county'.

Thirty seven participants responded to the question about the accessibility to lifestyle services which take into account the implications of their neurological condition(s) (e.g. dietary, smoking cessation, weight loss/ gain). 3% reported access was very easy, easy (16%), somewhat difficult (24%), very difficult (11%), not appropriate (11%), prefer not to say (3%) and other (30%). Other includes that they had not sought advice, services have not been used or services have never been offered. Others expressed that they were too unwell to access services or the waiting list for services was considerably long. For some respondents 'self research' and advice from private professionals had been key to losing weight and improving lifestyle.

When asked to identify the things the health services do well for people living with neurological conditions, the responses were mixed. The majority of respondents indicated that that health services were either 'not good' or were 'inconsistent' particularly for surgery and aftercare. Furthermore lack of availability of services in Lincolnshire resulted in respondents having to travel 'out of county' for treatments (e.g. The Walton Centre, Liverpool). Other respondents cited GPs and consultants lack of knowledge or understanding of their condition. Despite this some respondents mentioned that health services ensured they were on the 'correct medication', 'cured their condition', referrals and diagnosis from GPs and consultants were good and rehabilitation services were excellent including regular consultant appointments.

35% of respondents indicated that they had not accessed services outside of Lincolnshire for their neurological condition(s). However 65% indicated that they had accessed services outside of Lincolnshire. This included services in the East Midlands including neurology departments and clinics (botox, gluten ataxia treatment, postural orthotics tachycardia syndrome treatment) at Nottingham QMC and Sheffield Royal Hallamshire. Meanwhile some respondents indicated that they were travelling further afield, for example, to Moorfields in London for eye treatments, deep brain stimulation (DBS) surgery in London, a neurologist in Stoke on Trent, neurology and nerve block injections at The Walton Centre Liverpool and respiratory treatment at St. Thomas Hospital. Twenty seven expressed their reasons; personal choice (7%),

Survey Response

better services available (7%), or because they were not available in the county (48%). Meanwhile other respondents (37%) expressed other reasons for accessing services 'out of county' including being referred by the GP or leading specialists/ consultants in their neurological conditions available and utilising better hospitals or centres of excellence.

Participants reported a range of problems and challenges associated with living with neurological condition(s) in Lincolnshire. Some expressed difficulties in getting their GP to understand their specific needs sometimes through communication difficulties associated with their neurological condition(s) therefore leading to 'not being taken seriously' or 'being believed at all'. Some respondents indicated overall that professionals 'lacked knowledge and understanding' of neurological condition(s) and some individuals had to attend several GP appointments before being referred onto neurologists/ consultants leading to further delays and having to wait for appropriate treatment. Other respondents expressed a lack of specialist services and poor spread of services available across Lincolnshire and the 'stigma attached to living with neurological condition(s)'. One respondent expressed 'difficulties in navigating the benefit and support system to help with living with neurological condition(s)'.

When asked what type of services were not currently available participants identified a number of things that mainly related to support for living with neurological conditions such as;

- General advice, assessment and support.
- Support groups for other neurological conditions (e.g. Myasthenia, migraines, seizures, pain management and psychological support groups).
- Specialist peer support, mental health support, preventative support and emotional support.
- Clinic to help with computer forms and form filling.
- Community hubs for people living with neurological conditions (.e.g multi-disciplinary therapists, classes, massage therapists, neuro cafes or TEDS (Talk, Eat and Drink), pharmacy, benefits help, dietitians, specialist neurology nurses, etc.

Only a few of the suggestions made related to health care provision, including;

- Neurology consultants with knowledge and experience in rare neurological conditions (e.g. post-polio syndrome, POTS, ME).
- Lack of knowledge amongst Medical/ healthcare professionals concerning neurological conditions.
- Automatic referrals to counselling and other departments (Speech and Language therapists, physiotherapists).

Survey Response

When asked what they would change about the current provision in Lincolnshire, participant responses fell into four clear categories. These were

- Increased service provision (neuro specialist health care professionals, allied health professionals and community based services)
- Increased and speedier referrals (to emotional and psychological support and specialist services)
- Better delivery of care (making sure services are in the right place at the right time; smoother transitions between services; increased monitoring of conditions and neuro specialists in primary and urgent care)
- Better access to services (via transport availability) and provision of information about support services early in the process.

At the end of the questionnaire respondents were given the opportunity to add any final comments about living with neurological conditions in Lincolnshire. Whilst some of the responses repeated calls for increase service provision, other useful information highlighted perceived inequalities in service provision depending on type of neurological condition. Those with rarer conditions felt that their needs are less well met by current services than those who suffer from more common conditions such as stroke. Participants also indicated that improvements to the provision of information at diagnosis and support in navigating the complex care systems would make life with neurological conditions easier. Poor knowledge by health care professionals of conditions and services was again highlighted along with poor communication between services which cause delays.

6.2.2 CARERS FOR PEOPLE LIVING WITH NEUROLOGICAL CONDITIONS

Nineteen responses were received from carers of people living with neurological conditions in Lincolnshire, however not all answered the questions fully. Respondents age ranged from 47 years old to 80 years old. Of the 19 responses received, 40% were male and 60% were female. Additionally 87% were married, the remainder were either divorced or separated. The majority (87%) lived in owner occupied housing with their partner or spouse.

Seventeen individuals responded to the question about employment status, 41% were retired, meanwhile 35% were carers (full or part time), 18% worked part time (8 to 34 hours a week) and 6% were voluntary (unpaid).

Many of the carers (60%) lived with their own existing health conditions, including angina, glaucoma, arthritis, high blood pressure (hypertension), prostate cancer, hiatus hernia, aspergers syndrome, depression, osteoarthritis, epilepsy, heart condition, brain damage, polio, post-polio syndrome, type 2 diabetes. Some 33.33% reported this had a significant impact on their ability to be a carer while others said it had no effect. Only nine people answered this question.

The majority of respondents (64%, n=17) were caring for a partner or spouse, 18% a parent, 18% a child or young adult. The length of time the individual had been acting as a carer varied and was difficult to establish as there was no free text response box to state this. Of the 14 people who completed the fixed choice response, 93% had been a carer for more than two years, the remainder for less than 12 months.

All 17 respondents highlighted the type of care they provide to the individual who lives with a neurological condition. This included help with personal care (e.g. washing, dressing, eating and drinking) (23%), help with health care (e.g. medication, catheter care, dressing) (21%), practical tasks (e.g. getting out and about, paying bills) (23%) and other (9%), including psychological help in the form of support but mainly keeping positive/ emotional and practical support, doing daily exercises, plan daily events, cover when regular carers are ill or on annual leave, on call for emergencies and motivating them to do things. The average time spent caring each week varied from 10 hours to 24 hours a day, seven days a week.

Of the 15 people who responded to the question, 80% expressed that did not have any kind of support in their role as a carer. Of those who did receive support, this included gardening, housework/ domestic help, laundry services, employment of full time carers on a rota system, weekly/ fortnightly visits from a youth support worker and employment of personal assistants through personal health budgets.

Survey Response

In relation to using community health services as carers for people living with neurological conditions, 58% (n=12) told us their experience was poor. Only 8% said their experience was excellent. Sporadic appointments, incorrect information sent out in letters and notes not being looked at properly were reported frustrations.

Outpatients services were similarly criticised, with 58% reporting a poor experience. Respondents indicated that gaps between consultant appointments were getting longer and that there were difficulties accessing services frequently enough during a crisis. A further 60% reported their experiences of inpatient services as poor. Of the remaining 40%, some had never used inpatient services and others appeared to have been cared for in regional specialist centres outside of the county. In relation to mental health services, 20% were satisfied or better with their experience, 50% felt that services were poor. The remaining 30% had either not used or were not eligible for mental health services.

Respondents were asked to rate their experiences of accessing well-being services (e.g. smoking cessation, weight management, counselling) as carers for people living with neurological conditions. Of the nine respondents 11% expressed that their experiences were satisfactory, while 33% expressed their experiences were poor and 56% expressed that they had never needed to use such services; limited or no services were available; the services available were too expensive, and/or the GP dealt with these issues.

When asked how their needs as carers for patients with neurological conditions were recognised responses were mixed. Of the 13 respondents, 8% expressed that recognition was very good, meanwhile 15% expressed recognition was satisfactory, 46% expressed recognition was poor and 31% selected other. Other included little or no recognition as a carer, with some respondents citing 'the carer is often forgotten' and 'nobody carers' even though the role as a carer is 'very demanding and draining'. Others cited they 'don't get help or support but try and help other carers at times to solve their problems e.g. filling in forms etc'. There is evidence here of informal support networks amongst those caring for individuals with neurological conditions.

Respondents (n=13) were asked to rate their experiences of receiving support as a carer. Of the responses 8% expressed the support they received as a carer was very good, meanwhile 8% expressed it was satisfactory, 62% expressed their support was poor and 23% expressed support was other. Other included no/ non existent support.

Respondents were asked how well they felt health services recognise the needs of people living with neurological conditions and make necessary amendments to the services they offer. The responses

Survey Response

were not positive. Most felt that needs were not recognised due to either a lack of appropriately qualified professionals or health care professionals lacking knowledge about neurological conditions. This perceived lack of understanding echoes what service users themselves told us.

Carers were then asked to identify the challenges that patients living with neurological conditions in Lincolnshire faced, and many issues were highlighted across all aspects of and stages in the patient journey. Getting a diagnosis; referral; access to appointments, treatment, check-ups, community and rehabilitation services were all listed. In addition, limited knowledge by health care professionals about conditions, the effects of living with a neurological condition and getting initial and ongoing support and advice were again highlighted as challenging.

Services that were perceived to be missing or not available were wide ranging. Certain specialist services (specialist nurses, disability services, therapist and psychological support were specifically highlighted). Carers also indicated that services within the county were not well integrated, inflexible to urgent need, intermittent or dependent on where you live. It was clear that the responses to this question were influenced by the condition the individual they were caring for was affected by and their geographical location. There are large perceived inequalities in provision.

When asked what they would change about current health provision for people living with neurological conditions in Lincolnshire the list covered the following;

- Improved provision
- Better integrated care
- Better access for disabled individuals
- Assessment by specialists
- Somewhere to go for help, support and advice

In relation to their own needs as carers, respondents felt that better support for carers would include;

- Easy access to support, information and advice
- Not having to continuously repeat things and give the same information to health care people
- Secured funding
- Respite care and time to recover from their own health problems
- Simpler paperwork and procedures

In the free text comments at the end of the survey it was clear that despite requests from carers for additional support and improved services within the county felt they were not being listened to. Carers

Survey Response

are frustrated that the services many of their loved ones needs are insufficient and/or unavailable and they do not seem to understand why this is the case. Greater levels of communication between service commissioners, providers, users and carers would benefit all concerned.

6.2.3 VOLUNTARY SECTOR ORGANISATIONS

Eleven responses were provided by voluntary sector organisations supporting people living with neurological conditions in Lincolnshire. They included Lincolnshire Neurological Alliance, Headway Lincolnshire, Lincolnshire MS Society, Post Polio Association, Healthwatch Lincolnshire, Myaware Lincolnshire, Narcolepsy UK, Huntingdon's Association Lincolnshire and Ataxia East Lincolnshire. All stated that they covered all seven Lincolnshire districts (North Kesteven, South Kesteven, East Lindsey, West Lindsey, South Holland, Lincoln and Boston).

The roles of those who responded on behalf of the organisations included ambassador, trustee, regional external relations office for East Midlands, specialist care advisor, chief executive officer, operations manager, county organiser, information and support worker, specialist Huntingdon's disease advisor, chairperson, representation role, campaigning and research. Of the 11 responses, 9% were full time managers, 27% full time employees in non managerial roles, 36% part time employees and 27% volunteers. Those who volunteered indicated they did so from several hours a day to three to four days a week. They had been working for their respective organisations in Lincolnshire between 18 years and 35 plus years.

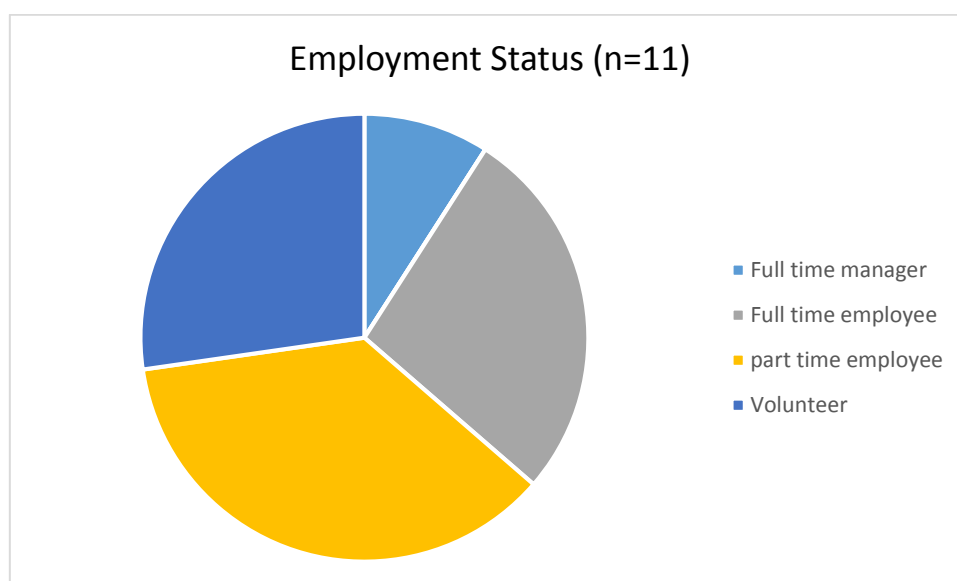


Figure 16: Employment status of Voluntary Sector Organisations supporting people living with neurological conditions

Survey Response

Together, the organisations who responded provided support for a range of neurological conditions which included;

- Multiple sclerosis (MS)
- Progressive supranuclear palsy (PSP)/ corticobasal degeneration (CBD)
- Myasthenia gravis (MG), ocular myasthenia gravis (OMG), Lambert eaton myasthenia syndrome (LEMS) and congenial myasthenic syndromes (CMS)
- Narcolepsy and cataplexy
- Acquired brain injury (ABI)
- Huntingdon's disease – occasionally rare similar conditions with no association
- Ataxia

Additionally, they provided a range of services including advice and information (14%), drop in/ support services (9%), care at home (0%), voluntary visiting/ befriending (5%), legal advice (2%), therapeutic services (e./g. alternative/ complementary therapies) (2%), social activities (8%), campaigning (12%), advocacy (8%), fundraising (11%), charitable grants (6%), equipment loans (0%), carers support services (9%), counselling (6%), crisis services (2%), respite (2%), holidays (2%) and other (5%). Other services included benefits and welfare advice, signposting, and support and advice for anyone affected in anyway by Huntingdon's disease. Several of these groups provided more than one of these services.

According to respondents the number of people living with neurological conditions in Lincolnshire who are members of their organisations varied from 23 to over 800, depending on the size of the organisation. The number of people living with neurological conditions who were actively involved in, or regularly using the organisations services ranged from 20+ to 3400 people, and the number of carers ranged from 20+ to 2150 people.

Respondents (n=11) were asked to rate their experiences of recognition of their needs as carers for people living with neurological conditions. 18% felt this was satisfactory and 82% poor. Comments included no specialist communitih health services for brain injuries, 'lack of services', and 'beyond GP or consultant diagnosis most patients are left to fend for themselves'. Other feedback from respondents included 'difficulty finding clinicians and services that understand the nature of MS which can result in delay in treatment of symptoms and/ or direction to specialist services which can result in worsening symptoms and reliance on crisis management and unnecessary admission to hospital. Services often feel disjointed/ uncoordinated

Survey Response

People with MS in Lincolnshire often are referred outside the county for specialist MS treatment due to the lack of neuro services in Lincolnshire which means difficult travel for people experiencing perceived symptoms such as fatigue, having a negative impact on their disease progression. There is also a problem with communication and co-ordination with external neuro services (e.g. Leicester and Nottingham) and community services in Lincolnshire making it very difficult for people with MS to manage their condition effectively’.

Respondents (n=11) were asked to rate their experiences of access to hospital outpatient services for people living with neurological conditions. 9% rated their experiences as satisfactory and 91% as poor. Comments included ‘limited access to rehabilitation medicine services’, limited services, other expressed having to travel ‘out of county’ as far as Sheffield. Another respondent expressed that ‘members report outpatient appointments being available to those already in the system and eligible for disease modifying treatments which require monitoring by specialist services. However, those people no longer eligible due to the progressive nature of their condition, report having little or no access to these services despite NICE Quality Standards for MS stating that all people with MS should receive an annual review by a clinician with a specialism in MS at least once a year. Those attending outpatient departments report short appointments leaving little time for thorough examination or discussion regarding management of their condition. One participant reported, “sadly we hear clients taken by ambulance to hospital for what is a standard cataplexy attack from which they will recover provided they have not injured themselves”. This person also asked East Midlands Ambulance Service if they knew about Narcolepsy and Cataplexy other than having heard the terminology, they did not know the illness. Most access to services seems to occur through A&E with follow up outpatient appointments arranged out of county, and physiotherapy appointments often arranged privately’.

Respondents (n=9) were asked to rate the experiences of access to hospital inpatient services for people living with neurological conditions. 11% rated the experiences as satisfactory while 89% rated the experiences as poor. Comments fell into the following themes;

- Lack of knowledge of neurological conditions, the consequences of which are not understood or catered for
- Long waiting times
- Lack of rehabilitation capacity
- Special needs are not catered for.

Survey Response

In relation to access to mental health services for people living with neurological conditions, 14% perceived the experience as satisfactory while 86% perceived the experience to be poor (n=7). The comments were quite wide ranging and highlighted different issues depending on condition. For some conditions (i.e. MS and narcolepsy) where mental health services were seen to be of benefit to patients, it was reported that access was difficult, and a greater awareness of the need for mental health support was needed. In contrast, for neurological conditions such as brain injury, mental health services were not always seen as necessary and appropriate use of mental health services was seen as the bigger issue. It is clear that need for mental health support needs to be addressed on an individual basis and may vary by neurological condition. It is important that we ensure that those who need support are able to access it.

Respondents (n=5) were asked to rate the experiences of access to well-being services (e.g. smoking cessation, weight management, counselling) for people living with neurological conditions. All respondents rated the experiences as poor, but some seemed to be disagreeing with the provision of such services rather than assessing levels of access to them. There seemed to be a general lack of knowledge in this area.

When we asked voluntary sector organisations how well, in their experience, the needs of carers for people with neurological conditions are recognised, twenty percent felt that carers needs were recognised to a satisfactory level, and 80% felt that their needs were poorly recognised (n = 10). The need for better recognition for carers, and the difficult and demanding role that they perform was the dominant position, however, one participant voiced to us that they felt the situation was improving;

'Since the Care Act 2014 and the renewal of a Commissioned Contract to Carers First in the county, Lincolnshire's support services to carers has improved considerably. This includes the rights to a Carers Assessment and a Carers Emergency Response Service in addition Respite breaks for someone looking after a Person with neurological conditions. In the Voluntary Sector, there are additional services to ease the stress for carers so that a person living with a long term condition could be referred to, for example, Adults Supporting Adults shared lives schemes'.

In response to a further question about how well they perceived carers in Lincolnshire to be supported, eight respondents told us that they felt support was good (13%), poor (87). There was a sense from the respondents that support for carers was currently limited by lack of knowledge and understanding by professionals of neurological conditions. There were also

Survey Response

several mentions of support groups and services within the county. Individual condition support groups were seen as a good source of support for carers and families. Local generic carers services (Carers First) were perceived as good, but the lack of neurology specific provision was seen as a limitation. Personal care budgets, or direct payments that are allocated to persons living with neurological conditions following assessment by Adult Social Services Social Care Team were viewed as an indirect mechanism of support for carers as they could be used to provide additional day care or respite residential services. These services were not mentioned by either people living with neurological conditions or their carers which raises questions about how widespread understanding and access to them is.

When asked whether they felt that health services in the county recognise the needs of people living with neurological conditions and make necessary adjustment, those representing voluntary and statutory sector organisations were overwhelmingly negative. All but one respondent felt that the recognition of need was very poor. There was a strong sense that despite the fact that need in the county has been highlighted and recognised, nothing had changed, and this was seemingly the result of lack of money. This very much echoed what carers of those with neurological conditions had also told us. On a more positive note, one respondent felt that there was some willingness to listen to people with MS and adjust services accordingly (i.e. with the recent introduction of a neuro outreach service providing physiotherapy across the county). This is a really positive development, but another indication that experiences are strongly related to the type of neurological condition an individual has been diagnosed with.

We asked the respondents to identify the challenges or problems that they felt people living with neurological conditions in Lincolnshire face in meeting their health needs. Again, the responses depended on the type of neurological condition and the provision, or lack of, in the county. The need to travel out of the county to access specialist services was seen as a significant barrier in terms of timely diagnosis, and access to specialist clinics and treatment. The challenge of living in a rural county and having to make frequent long, expensive journeys further complicates this. The lack of capacity in terms of neurologist care in Lincolnshire and the fact that there is no provision for neurosurgery were also highlighted. Whilst respondents indicated that those who were having surgery outside of the county received good care in specialist centres, it was highlighted that returning home caused a number of problems in terms of lack of co-ordination between services, no care plans and a lack of inpatient rehabilitation. It was reported that on returning to the county, neurology patients could be admitted to any ward and cared for by staff who do not necessarily have knowledge of their conditions. This can lead to deterioration in a patients' health. Community based rehabilitation was

Survey Response

also seen as a challenge, again in relation to a lack of specialist knowledge amongst Allied Health Professionals.

In response to the question about changing one thing about current health provision in Lincolnshire for people living with neurological conditions, the voluntary and statutory sector organisation members provided us with a list of considered proposal which are summarised below;

- Fewer assessments and more hands on therapies to support those who are recovering or experiencing a deterioration
- Bringing services together in one place to ensure better care co-ordination and case management to reduce the risk of crisis
- Follow NHS England's advice to make rehabilitation everyone business.
- More specialist neurologists and clinical nurse specialists (particularly to deal with admission to and discharge from hospital).
- Education and awareness training for all health care staff
- Improvements to inpatient and community rehabilitation services, and increased capacity

Finally, we gave respondents the chance to add anything else that they wanted to tell us and felt was important to this report. There were repeated calls here for Neurology to be included as a topic in the Joint Strategic Needs Assessment (JSNA), and a clear concern that unless this happens there will be little chance of CCG's commissioning neurology services in the county. Others highlighted specific conditions (Narcolepsy, Ataxia and Head injury) where they felt attention was needed, and the need for enhanced training of medical and health care professionals was again expressed.

6.2.4 MEDICAL/ ALLIED HEALTH PROFESSIONALS

Thirteen responses were provided by medical/ allied health professionals supporting people living with neurological conditions in Lincolnshire. They worked for Lincolnshire Community Health Services (LCHS), United Lincolnshire Hospitals NHS Trust (ULHT), Lincolnshire Partnership NHS Foundation Trust (LPFT), and Unity Physiotherapy and Wellbeing Clinic. Their roles in these organisations included Consultant Clinical Neuropsychologist, Matron for Palliative and End of Life Care, Children's Physiotherapist (also worked as a rotational physiotherapist in the adult community team), Children's Occupational Therapists, Clinical Lead for Therapists and Rehabilitation Medicine, Advanced Occupational Therapists and Team Lead, Specialist Speech and Language Therapist, Specialist Physiotherapist – Assisted Discharge Stroke Service (ADSS), Physical Health Nurse for people living with learning disabilities, Clinical Psychologist and Neurological and Pain Specialist Physiotherapist;

Survey Response

covering all seven Lincolnshire districts (North Kesteven, South Kesteven, East Lindsey, West Lindsey, South Holland, Lincoln and Boston). Interestingly, no medical doctors responded to the survey.

Of the thirteen respondents 54% worked full time as a medical/ allied health professional, with the remaining 46% working part time with hours ranging from 10 to 34.5 hours per week. The practitioners were working with individuals with a wide range of neurological conditions, including;

- Traumatic brain injuries (TBI)
- Acquired brain injuries (ABI)
- Long term neurological conditions (predominantly multiple sclerosis, occasionally others including epilepsy, Parkinson's disease and Huntington's disease).
- Cognitive problems where the cause is currently unknown, or multiple contributing factors are present.
- Cerebral palsy, Charcot-Marie Tooth syndrome, spina bifida, stroke
- Learning disabilities, developmental and motor coordination
- Progressive neurological conditions
- Spinal cord conditions
- Peripheral nervous system conditions
- Multiple trauma
- All paediatric (0-19 years) neurological conditions (predominantly cerebral palsy).

Services being provided to individual living with neurological conditions in Lincolnshire included;

- Neuropsychology, including neuropsychological assessments, recommendations and review.
- Specialist inpatient hospice, hospice in the hospital, day therapy, hospice at home, care homes
- Outpatient clinics, home visits and school visits, hospital inpatient visits, university visits, nurse visits (for children living with neurological conditions)
- Inpatients, outpatients, community outreach team - seeing patients at home, in community settings, in care homes
- Home based therapy
- Community stroke rehabilitation
- Physical health assessments
- Liaison services
- Private physiotherapy and physiotherapist led classes

Survey Response

The number of people with neurological conditions seen by medical/ allied health professionals on a weekly basis range from four to over 20 individuals per week. Some patients were referred to services by other health care professionals, some on transfer between inpatient and community care, and in some cases patients were able to self-refer. The average waiting time varied considerably dependent on patient need and the type of service in question. For example, patients discharged from hospital were seen within 24-48 hours by community teams, but for non-urgent services waiting times could reportedly exceed the 18 week target.

Respondents were asked to rate, from their experience, access to community health services for people living with neurological conditions. Of the 13 people who responded, 8% felt that access to services was excellent, 8% felt that access was good, 15% felt access was good and 23% felt that access was satisfactory and 38% felt that it was poor. Health care professionals agreed with patients and carers that services were 'patchy' and very much dependent on condition. Problems with a lack of care co-ordination, long waiting lists, lack of capacity and limited follow up appointments for long term neurological conditions were all highlighted. A lack of resources to facilitate ongoing community rehabilitation was again mentioned, along with a lack of clinical specialist knowledge, particularly for Physiotherapy and Occupational Therapy. For the first time we saw mention of children's services which were regarded as 'good' in relation to adult services. Although children with neurological conditions have not been included in this report, this is interesting from a perspective of older children transitioning into adult services and suggests that their needs may be less well met once that transition has been made. To finish on a positive note, the brilliant work of some very dedicated clinicians in the county was recognised despite the resource constraints they face, and there was hope that the newly established Neighbourhood Teams would lead to more effective service provision in the community. Interestingly, one participant told us that "the issue of neurology being seen as a specialism, requiring specific knowledge and expertise to be able to appropriately manage a defined condition is ongoing". Given the fact that patients with neurological conditions come into contact with many different health care professionals in emergency, inpatient and community settings the perception of neurology as a specialism may be contributing to the perceived lack of knowledge and understanding of their conditions by patients and carers. This warrants further investigation, particularly into the education and training of health care professionals in relation to neurological conditions.

Health care professionals were then asked to rate access to hospital outpatient services for people living with neurological conditions, and all 13 respondents felt that these were satisfactory or better (8% excellent, 23% very good, 31% good). The additional comments did however paint and

Survey Response

slightly different picture. Lack of capacity (for Consultant Neurologists, Consultants in Rehabilitation Medicine and specialist AHP's) and long waiting lists were highlighted as problems, and again, access to outpatient services was seen to be vary by condition.

For inpatient services, 23% of respondents felt that access for those with neurological conditions was very good. A further 15% felt that access was good, 15% satisfactory, and 47% felt access was poor. The rehabilitation ward at Lincoln County Hospital was praised for providing great care for patients, but despite a recent increase in capacity (an additional six beds) there was still not sufficient beds to meet demand. This results in long waiting lists and contributed to negative ratings of access. The fact that no other specialist inpatient units, other than stroke rehabilitation, was also highlighted.

Access to mental health services was was rated as poor by 77% of respondents (n=13) with the remainder rating access as satisfactory. Mental health services were seen as not available, not appropriate or not accessible for patients with neurological conditions. The lack of specialist psychological therapy services was identified as a problem. Patients can be seen by general psychology services, but these often fail to meet their needs due to the fact that therapists are not trained how to make adaptations to account for cognitive impairments. Some patients have not been accepted because of this and others find it hard to engage due to communication and cognitive issues. They therefore have to be referred to neuropsychology, for which there is a very long waiting list.

The picture was slightly more positive in relation to access to well-being services (e.g. smoking cessation, weight management, counselling), with 23% of respondents rating access as good, 31% rating services as satisfactory and 46% rating services as poor. In terms of NHS services, the smoking cessation provision was seen as good, but there is no weight management programme and counselling is mainly accessed via the IAPT or Steps to change programme which is subject to the difficulties outlined in the section above. The role of voluntary and statutory sector organisations was highlighted here with support groups playing an important role in self-care and wellbeing, alongside private providers

Mixed responses were received in relation to access to specialist services for people living with neurological conditions. Of the 13 respondents, 23% felt access to specialist services was good, 31% satisfactory and 46% poor. The lack of specialist psychologists, long waiting times, complex referral processes and the fact that many patients have to travel out of the county to receive specialist services were all highlighted as problems. Lack of provision in terms of pain management was specifically highlighted, along with reports of poor feedback about the Lincoln pain clinic from patients with neurological conditions due to its largely biomedical focus.

Survey Response

We asked the health care professionals, how often in their experience, people with neurological conditions were being referred out of the county for specific services. Almost half (46%) of the 13 respondents said that this was happening regularly, 38% sometimes and 16% hardly at all. The reason for these referrals was because of lack of services within the county (40% of the time) or because the current service could not meet demand. The lack of neurology services in the county means that there is a need for regular out of county referrals. One participant told us that this had increased recently due to 'hospital special measures' with advice to GP's to use out of county providers rather than referring patients to the county hospital. Again this would seem to be condition specific and dependent on what the patients needs were. The types of service that people living with neurological conditions were referred out of county for included;

- Neurorehabilitation and specialist neuro-behavioural rehabilitation,
- Neuropsychology,
- Neurology services,
- Deaf school, OT-sensory integration,
- Specialist orthotic services,
- Orthopaedic services,
- Urology,
- Spinal,
- Low awareness/ persistent disorders of consciousness,
- Neurosurgery and follow up,
- Neuromuscular (dystrophy etc) services,
- Functional Electrical Stimulation assessment and provision,
- Specialists in pain, headache, sleep and burns,
- Post stroke epilepsy management.

In response to the question about how well recognised the needs of carers for people living with neurological conditions are, 15% felt that recognition was very good, 31% felt it as good, 31% satisfactory and 23% poor. In addition, 8% felt that support for carers was very good, 15% good, 46% satisfactory and 31% poor. The respondents felt that although needs were assessed and recognised, the support that they needed was not always available. was little support for carers. This again seemed to be influenced by type of condition, location within the county and ability to access services. The excellent support provided by voluntary and statutory sector organisations was recognised, but it was stated that this was still not sufficient to meet demands.

Survey Response

When we asked health care professionals what they felt were the particular challenges or problems people living with neurological conditions in Lincolnshire face in meeting their health needs, the geography of the county came out as top of the list. The large area that the county covers means that services are often not located near to patients, this can mean travelling long distances both within, and outside of the county. Poor access to services (particularly neuropsychology and rehabilitation) alongside long waiting lists were both identified as problems, alongside the challenge of managing and co-ordinating care, which often falls under multiple teams that do not link well together.

Some of the challenges faced by people living with neurological conditions were also encountered by health care professionals in trying to meet demand. Geography, for example, was still seen as an issue. Setting up accessible services in a large, rural county is a challenge as there will always be a need for some patients to travel. In addition to this, large distances between community based patients limits the number of visits that can be carried out in a day and this can add to waiting lists. Workloads and staffing levels were also highlighted as a challenge. There are well publicised difficulties in recruiting and retaining specialist workers to Lincolnshire, this contributes to lack of service provision, high case loads for existing staff and long waiting lists. Health care professionals are having to meet increasing demand (from often ageing and increasingly complex patients) with shrinking resources. Health care professionals also talked about the challenges created by poor communication between services and the difficulties they face in ensuring that referrals are followed through and co-ordinated. The transition of care from children's to adults services was seen as problematic, particularly when those concerned do not come under the care of the learning disabilities team.

Despite the challenges they face, health care professionals were able to identify a number of areas of good practice for neurological care in the county. There was a really strong sense of people from the health and voluntary sectors working to the best of their ability with the resources that they have. This is illustrated by some of the points below;

- Some really passionate, highly skilled clinicians doing what they can with the resources they have.
- A willingness for frontline staff to innovate and collaborate to deliver person centred care
- Well organised Third Sector Support Services (although they do not directly provide care).
- Evidence based rehabilitation practices in the Stroke unit
- Outreach team have a good MDT although struggle with caseload

When we asked health care professionals whether there were health, care or support services missing for people living with neurological conditions in Lincolnshire, they were able to identify three key gaps

Survey Response

which were neuropsychology, rehabilitation and therapist services, and nurse specialists for different neurological conditions. The need for neurology and neurological conditions to be included in the Joint Strategic Needs Assessment as a topic area was again raised. We then asked them if they could change one thing, to identify what it would be. This yielded a range of responses, but still maintained a focus on the need for neuropsychology services. Other ideas are listed below;

- Improved access to specialist psychology/neuropsychology services
- Greater local provision of services to reduce travelling for patients and keep long term support closer to home
- introduce MDT meetings 3-4 times a year including orthopaedics and orthotists improved community rehabilitation for adults
- An improvement in the data and evidence collection for Neurological Conditions in Lincolnshire.
- Easier transition from Paediatric to Adult services
- More specialist community therapists
- Better communication across all NHS services and to the private sector.

Finally, we have health care professionals the opportunity to tell us anything else that they felt was important to the work that we are doing. No new information emerged here, but challenges associated with ongoing rehabilitation and the transition to adult services were reiterated.

6.3 SUMMARY

Eighty four people responded to the survey on experiences of living with or supporting someone with a neurological condition. Key findings from each of the four groups are summarised here, they are brought together with findings from the other chapters of this report in the synthesis chapter.

People living with neurological conditions

Forty one responses were provided by people living with neurological conditions in Lincolnshire. They indicated mixed experiences of service use and provision in relation to their condition, but lack of knowledge and understanding of health care professionals, long waiting lists, poor access to services, the organisation of care and having to travel out of the county were all frequently cited.

- The majority of respondents indicated that their experiences of GP care were poor, as GPs had little knowledge or understanding of their condition and did not seem to take it seriously. This resulted in delays to referral and diagnosis
- The majority of respondents had never used community services, because they were not available or not offered, but those who had reported the appointments were not followed up and waiting times were long.
- Despite the fact that they often had to travel out of county and there were long waits for appointments, the majority of respondents felt that their experience of outpatient appointments was good or reasonable
- The picture in relation to urgent care was less positive with care described as 'average' and 'useless'
- The majority of participants indicated that mental health services were not needed or required, but those who did use them felt they were insufficient, with poor information provided. Some had experienced a long wait to be seen only to be refused support.
- Lifestyle services were seen as difficult to access or not accessed because patients were too unwell and waiting lists were long.

Participants were able to identify key challenges associated with living with neurological conditions which related to difficulties in getting GPs and other health care professionals to understand their condition, a lack of specialist services in the county and poor spread of services in the county making access for some even more challenging.

In relation to unmet needs, people living with neurological conditions in Lincolnshire want to see improved knowledge of neurological conditions among all health care professionals and neurology

Survey Response

consultants with knowledge and experience of rare conditions. They also perceived a lack of support and identified gaps in relation to support groups for certain conditions; mental health and emotional support, and practical support. They called for community hubs where people living with neurological conditions could access a range of support and services in one place.

Clear inequalities in service provision were perceived depending on the type of condition individuals were diagnosed with. Those with rarer neurological conditions felt that their needs were being less well met than those with more commonly occurring neurological conditions.

Carers for people living with neurological conditions

Nineteen people who were caring for individuals with neurological conditions in Lincolnshire responded to the survey. Their experiences seemed to be largely negative. There was a strong sense of frustration that the services their loved ones needed were insufficient or unavailable in the county and that despite repeated requests for additional support and improvements to be made they felt they were being ignored.

- The majority of carers told us that their experiences of using community health services, inpatient services, outpatient services, mental health and community services as carers for people living with a neurological condition was poor. Sporadic appointments and difficult accessing services when they were really needed were highlighted issues.
- Those who responded felt that their needs as carers were not recognised, and they were not getting the support that they needed.
- Carers also felt that the needs of those they were caring for were not being recognised by health services, this was mainly attributed to a lack of appropriately qualified health care professionals, or health care professionals lacking knowledge about neurological conditions.
- A number of challenges faced by people living with neurological conditions were identified by the carers at different stages in the patient journey. Getting a diagnosis; referral; access to appointments and treatment; check-ups; community and rehabilitation services were all highlighted.
- Services identified as missing or not available were wide ranging, with specialist services (nursing, disability, therapy and psychological support) top of the list. Concerns were also raised about poor integration between services.

Survey Response

- Carers would like to see improved provision, better integrated care, better access for disabled individuals, assessment by specialists and somewhere to go for advice help and support for those living with neurological conditions in Lincolnshire.
- For their own role as carers, they would like to see easier access to support, information and advice; better joined up care and communication; proper funding; respite care and simpler paperwork and procedures.

Voluntary Sector Organisations

Eleven responses were received from voluntary sector organisations that provide support for people living with a wide range of neurological conditions in Lincolnshire. They highlighted a number of issues with a lack of service provision, lack of knowledge by health care professionals and difficulties created by out of county care again being prominent.

- Voluntary sector respondents rated community services for people living with neurological conditions as poor. They highlighted a lack of service provision; lack of knowledge and understanding among clinicians and disjointed and un-coordinated services
- Hospital outpatients services were also seen as poor, with limited access to rehabilitation and patients having to travel out of the county. Access to outpatient appointments seems to be particularly difficult for those in more advanced stages of disease.
- Inpatient services were similarly seen as poor due to long waiting times, lack of rehabilitation capacity and the specific needs of patients with neurological conditions not been catered for. This, once again, seemed to be attributed to a lack of knowledge and understanding by clinicians.
- Mental health services were perceived to be poor, but the wider ranging comments highlighted different issues for people with different conditions. Where mental health services were needed, access was often reported to be difficult, but for other conditions there were concerns about appropriate use of mental health services. Questions were also raised about the appropriateness of wellbeing services for individuals with neurological conditions.
- 80% of those who responded felt that carers needs were poorly recognised, and in addition support from health care professionals was limited. Individual condition support groups were seen as fulfilling a vital gap here. Local carers services, whilst available, had a lack of knowledge about the specific needs of caring for people with neurological conditions.

Survey Response

- The perceived challenges faced by those living with neurological conditions were dependent on the type of neurological condition and service provision, or lack of it, within the county. The need to travel out of county has been seen as a challenge in terms of timely diagnosis and access to treatment. Repatriation into the county after treatment in specialist centres was also an area of concern due to lack of co-ordination between services.
- Voluntary sector organisations called for better co-ordination of services, more focus on rehabilitation, more specialist neurologists and clinical nurse specialists and increased awareness and education for all health care staff.

Medical/Allied Health Professionals

Thirteen responses were provided by medical/allied health professionals supporting people living with neurological conditions in Lincolnshire. Whilst this added a new perspective and new understanding, it also corroborated a lot of what had been said by the other groups.

- Medical/allied health professionals agreed with service users and carers that community health services were patchy and very much dependent on condition. Lack of care co-ordination, long waiting lists and limited follow up appointments were all highlighted. Lack of capacity within community rehabilitation teams was also discussed.
- Although outpatients services were rated quite positively, the comments again suggested lack of capacity in certain areas (neurology, rehabilitation and specialist AHPs) and long waiting lists were problems and that these varied by condition.
- Just over half of the respondents felt that inpatient services were satisfactory or better, but despite recent increases in capacity, demand still outstrips supply. This results in long waiting lists, and specialist inpatient units only exist for stroke patients
- Mental health provision was rated as poor by the majority of respondents. The lack of specialist psychological therapy services was seen as a particular problem
- The smoking cessation service was seen as good, but other wellbeing services were seen to be lacking or inappropriate. The role of voluntary sector organisations in promoting self-care was highlighted here.
- Medical/allied health professionals felt that the needs of carers for people living with neurological conditions were being assessed and recognised, but the support they needed was not always available and often provided by voluntary sector organisations, although this could be condition dependent.
- The geography of the county was seen as a challenge to people living with neurological conditions in Lincolnshire as it can mean travelling long distances for appointments and

Survey Response

- treatments. The lack of certain services in the county (particularly neuropsychology and rehabilitation) along with long waiting lists and difficulties in care co-ordination were all mentioned.
- Geography was also a challenge in terms of service provision.
- The medical/allied health professionals who responded to this survey identified three key gaps in provision, these were neuropsychology, rehabilitation and therapist services and the need for nurse specialists



Chapter 7.0

Synthesis and

Recommendations

7.0 SYNTHESIS AND RECOMMENDATIONS

7.1 SYNTHESIS

There is currently a lack of robust data on which a comprehensive health needs assessment for people living with neurological conditions can be based. This report has drawn together information from the published literature; epidemiological data on two of the most prevalent neurological conditions; service activity data and the views and experiences of those living with and caring for individuals with neurological conditions to present as accurate a picture as possible.

As the incidence and prevalence of most neurological conditions has had to be estimated from national rates, it is not possible to compare the local and national picture apart from in the case of stroke and epilepsy. Within Lincolnshire, multiple sclerosis, Parkinson's disease, cerebral palsy and traumatic brain and spinal injury appear to have relatively higher incidence and prevalence rates than other neurological conditions.

The data for both stroke and epilepsy indicate that rates of disease are higher in Lincolnshire than for England as a whole, and highest in NHS Lincolnshire East CCG. The prevalence of stroke in Lincolnshire has risen by 17.83% between 2005/06 and 2016/17. This may reflect the fact that the proportion of the population aged over 65 has increased during the same period (Public Health England, 2018). As the population aged over 65 and life expectancy are predicted to continue to increase it is possible that we will continue to see a rise in stroke prevalence. Taking action to tackle key risk factors (i.e. poor diet, physical activity, smoking and hypertension), all of which are shown to have higher prevalence in Lincolnshire when compared with the England average may help to slow this trend. High levels of obesity are a particular concern. Both stroke and epilepsy are patterned by deprivation, with higher rates of disease occurring in the most deprived areas. This is consistent with existing published literature (Cox et al, 2006; Chen et al, 2014; Steer et al, 2014; Pickrell et al, 2015) and brings with it all of the challenges of tackling the social determinants of health in a rural county.

The patterns of data on service activity are unsurprisingly similar to the patterns of disease across the county. Highest rates of service use in relation to inpatient admissions, day case admissions, emergency admissions and outpatients appointments are all highest in NHS Lincolnshire East CCG. Together these data suggest that the greatest burden of disease caused by stroke occurs in the east of the county. Higher levels of service use may also indicate that other neurological conditions are more prevalent in this area but it is not possible to confirm this with the current data

Synthesis and Recommendations

set. A more extensive data collection exercise would need to be undertaken in order to accurately estimate the prevalence of other neurological conditions and to examine patterns within the county. It would be interesting to know whether other neurological conditions are also patterned by deprivation in the county as this appears to be a gap in the current literature.

The results of the surveys undertaken help to explain some of the patterns seen with the service activity data. They must however be interpreted with caution. The small sample size means that the experiences presented in this report are unlikely to be representative of service users, carers, voluntary sector organisations and medical/allied health professionals across the county. Further work needs to be undertaken to triangulate the data, but that should not detract from the perspectives provided by those who chose to participate in this study.

The number of inpatient admissions with a mention of a neurological condition in Lincolnshire has fluctuated in recent years, but overall inpatient admissions have fallen slightly. This is a reveal of the trend in England, although admissions nationally are also in decline. It is difficult to pinpoint the exact cause of this trend, but it is likely to be the result of a combination of reduced capacity, admissions not recording a neurological condition and patients being treated outside of the county. It seems unlikely that the reduction in inpatient admissions is a result of reduced prevalence of neurological conditions given the data on stroke. The survey results would seem to support this. Lack of capacity within the service, particularly in relation to rehabilitation, resulting in long waiting lists was highlighted as a problem. It is clear that demand for inpatient care currently outstrips supply and it is therefore not possible to meet the needs of all neurology patients. Provision by inpatient services seems to cater best for those with a diagnosis of Stroke.

In a reversal of the pattern for inpatient admissions, the number of day case admissions has risen steadily since 2012/13. This may indicate a different pattern of service delivery being adopted with a greater number of patients receiving planned treatment as day case patients. Clinicians working within the service, and/or patients may be able to corroborate this suggestion if interviewed.

Emergency admissions with a mention of a neurological condition have again been relatively stable since 2012/13. A significant proportion of emergency admissions have a primary diagnosis other than a neurological condition on admission, this suggests one or a combination of the following;

- Neurological conditions are difficult to diagnose based on symptom presentation, and/or are being misdiagnosed by urgent care practitioner

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Synthesis and Recommendations

- Patients with neurological conditions have co-existing health problems which result in symptoms that are more prominent on admission.

There is some support for both of these explanations within the survey findings and the existing literature. Service users, carers and individuals involved with voluntary sector organisations reported that patients with neurological conditions faced frequent challenges created by a lack of knowledge and understanding of neurological conditions by health care professionals. Those working in primary and urgent care are not neurology specialists and it therefore possible that some experience difficulty in recognising neurological symptoms, particularly for less prevalent conditions. Several stories of doctors and consultants being unfamiliar with a patient's condition were shared and this has led to significant delays in diagnosis.

It is known that individuals with neurological conditions may be affected by other health problems. Almost all of the 41 individuals who took part in this survey reported having co-existing health problems. A study by Thomas et al (2011) suggested that service users often felt their neurological condition was ignored or overlooked when admitted to hospital which may explain the pattern above. Greater awareness of neurological conditions and neurological symptoms among health care professionals may help to reduce mis-diagnosis and missed diagnosis and enable patients to get the right support and treatment more quickly. This may also reduce length of stay in hospital and the corresponding number of bed days which is higher for emergency than elective admissions.

Over one million outpatient appointments for people living with neurological conditions were made in Lincolnshire in 2012/13. These are most commonly for pain management, and service use peaks between the ages of 40 and 49 which suggests that neurological conditions are not just affecting older adults in the county. Despite the fact that patients often have to travel outside of their CCG of residence (and sometimes out of the county) for outpatient appointments, and that waits could be long, those who responded to the survey were satisfied with their experience of care. Those caring for people or supporting people with neurological conditions did not however feel the same. They highlighted difficulties in getting appointments, long waiting lists, long gaps between appointments and gaps within certain areas of provision which exacerbated all of the above. Waiting times for outpatient care at ULHT are longer (average 7 weeks) compared with England (4.2 weeks) which reinforces the outcomes of the survey. Lack of community based provision for those living independently, particularly rehabilitation, was frequently cited. This was reported by Thomas et al (2011) and therefore does not seem to be unique to Lincolnshire.

Synthesis and Recommendations

In addition to difficulties in accessing services, patients and carers reported that co-ordination of community based care, and communication between different services could be problematic. This seems to be worse when patients return to the county after receiving specialist treatment elsewhere. This issue of poorly integrated care has been widely reported in the literature (NAO, 2011; Gallacher et al, 2013) and can lead to delays in treatment and worsening symptoms. This can have a severe, negative impact on the psychological wellbeing of individuals and their families (Rigby et al, 1999).

Together, difficulty in accessing outpatient and community based services in a timely manner or getting the support, treatment and rehabilitation needed may be contributing to the number of emergency admissions to hospital in the county. Reviewing the reasons for emergency admission to hospital where patients have a neurological condition would help to understand whether this was the case. The costs of non-elective treatment in Lincolnshire are significantly higher than the costs of elective treatment, and whilst some of this might be due to the type of neurological condition that results in emergency admission (I.e. traumatic brain and spinal injury), it may also be due to gaps in community based provision. Improving community services, and/or further promotion of self-care, may help to reduce emergency hospital admissions (and re-admissions) and therefore reduce the costs of non-elective treatment.

The literature details the emotional, physical and cognitive impact on people living with neurological conditions (e.g. McLaughlin et al, 2011; Foley et al, 2012; Draper et al, 2013 and Bergin & Mockford, 2016). This impact can result from the conditions themselves, but is often exacerbated by a perceived lack of support, advice and information, and a lack of understanding from health care professionals. Support for living with neurological conditions in Lincolnshire seems to vary by condition and is strongly influenced by the availability of condition specific support groups often run by voluntary sector organisations.

Psychological support, particularly neuropsychology, was highlighted as a gap in service provision by service users, carers and the medical/allied health professionals who responded to the survey. Although patients can access general mental health services, they do not seem to meet their needs and this is not always appropriate. Therapists are not always able to adapt interventions to meet the needs of people living with neurological conditions, especially when cognitive impairment has occurred. These patients need to be referred to specialist neuropsychology services for which waiting times can be very long. Draper et al (2013) argued that psychological support for neurological patients was of paramount importance, and the Neurological Alliance (2017) identified mental health and wellbeing for people living with long term neurological conditions as one of four key priority areas. This does not appear to be sufficiently provided for within Lincolnshire at the present time.

Caring for someone with a neurological condition can also have significant physical and psychological costs. Many feel unprepared for and unsupported in the role. A large proportion of the carers who responded to the survey expressed frustration in the lack of service provision in the county for their loved ones and the lack of recognition and support for their role as a carer. Although voluntary sector organisations play a key role here, specific support is not available for all conditions and carers felt that general carers services were ill equipped to meet the needs of those caring for people living with neurological conditions. This again often came back to a lack of knowledge and understanding about neurological conditions.

7.2 RECOMMENDATIONS

In light of the data presented in this report and the synthesis and analysis in this chapter, the report team offer the following recommendations for consideration by all key stakeholders involved in the care of people living with neurological conditions in Lincolnshire;

- A more extensive primary data collection exercise needs to be undertaken to gain an accurate picture of the incidence and prevalence of neurological conditions in Lincolnshire and to establish how the county compares with the national picture. This could be achieved by a comprehensive review of GP records across all four CCGs. Until this has taken place it is not possible to determine the prevalence of disease or need within the county.
- Any new and existing data needs to be explored to establish whether social inequalities exist for neurological conditions other than Stroke and Epilepsy. This would aid understanding of patterns of disease and service use and add to the existing body of knowledge within the field.
- A review of current training provided to all Health Care Professionals, particularly in primary and urgent care, needs to be undertaken in relation to recognising and understanding neurological conditions. Due to high levels of co-morbidity in the population of neurological patients, and the frequency of non-elective care, all primary and urgent care staff need to be able to recognise and direct patients to the most appropriate services and resources, at a very minimum. This may help to reduce delays in diagnosis and treatment particularly if it is supported by clear guidelines about the recognition and management of neurological conditions. Raising awareness of neurological conditions could be incorporated into the 'Making Every Contact Count' initiative. Neurological conditions, such as mental health and dementia should be understood by all Health and Social Care professionals.
- A review of the reasons for emergency admissions may help to identify areas for service re-organisation and the promotion of self care which could ultimately reduce non-elective admissions and the associated costs.

Synthesis and Recommendations

- Key gaps in service provision, specifically neurosurgery, rehabilitation and neuropsychology have been identified by this report. These need to be explored further by commissioning teams in relation to the need to balance local health and social care service developments with development of national centres of excellence for specific conditions, particularly given the geography of the county and the additional challenges that this brings.
- A review of communication between services and health care integration both within the county and across county borders needs to be undertaken to ensure that people living with neurological conditions receive continuous provision and are not allowed to 'fall through the gaps', particularly when they are repatriated to the county following care at specialist centres.
- To explore the feasibility of setting up a network of peer support groups to extend the work of existing voluntary organisations for people living with neurological conditions across the county. There is a need for widespread, easy to access practical advice and emotional support. 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 as appropriate.
- To review the support provided for carers of people with neurological conditions. The specific needs of carers for those with neurological conditions need to be expressed to the Lincolnshire Carers Service who would be ideally placed to incorporate this group into their existing provision.
- In light of the limited resource to address the gaps in service provision in the county, it is recommended that steps are taken to improve communication between the CCGs, voluntary sector organisations and patients and carers. Much could be achieved through open and transparent discussion about the challenges being faced, the possibilities of self-care and the opportunities presented by Neighbourhood Teams as outlined in the Lincolnshire Sustainability and Transformation Plan.



Chapter 8.0

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Chapter 9.0

Appendices

9.0 APPENDICES

APPENDIX ONE

Survey for people living with neurological conditions

04/12/2017

Qualtrics Survey Software

Default Question Block



Project title: Developing a Health Needs Assessment for People living with neurological conditions in Lincolnshire

Thank you for taking the time to read the project information sheet and for your interest in taking part in this survey. Don't forget, if you have any queries, questions or concerns about taking part, please contact: Mr Thomas George tgeorge@lincoln.ac.uk Telephone Number: 01522 837496

If you decide that you would like to complete a paper survey or you need help to complete a survey, please contact: Mr Thomas George tgeorge@lincoln.ac.uk Telephone number: 01522 837496

Below, you will find information about consenting to take part in the survey. Please read this carefully. If you have any queries or questions, do please contact us. We will be glad to help you. Otherwise, please now proceed to the on line survey.

04/12/2017

Qualtrics Survey Software

Thank you for agreeing to take part in this project as part of the development of a health needs assessment for people living with neurological conditions in Lincolnshire.

CONSENT PROCESS

BY COMPLETING AND SUBMITTING THIS SURVEY YOU HAVE CONFIRMED THAT

1. I have read and understood the project information sheet about the study (Developing a Health Needs assessment for people with neurological conditions)
2. I have had the opportunity to consider the information as well as talk to someone about it if I needed to ask more questions or get more information about the project
3. That my participation is voluntary and that I am free to withdraw up to the point of analysis (projected date end December 2017) without giving any reason, and that my data will be removed from the survey and destroyed
4. That all the information I give will be confidential and that the results from this survey will only be presented in an anonymous form
5. The finding from this survey will be included in a written report and may also be used in a subsequent presentation or published article about the project
6. Short quotations from my survey may be used in the report and subsequent presentation and article - in anonymous form
7. I agree to take part in the study

About you:

What is your date of birth? (Please write in) (DD/MM/YY)

Please select your answer to the following questions by clicking on the button next to your chosen response.

What is your gender?

- Male
- Female
- Other gender identity
- Prefer not to say

What is your relationship status?

- Single
- Married
- Widowed
- Divorced
- Separated
- Civil partnership
- Living together
- Prefer not to say

Which statement best describes your current housing?

- Housing Association
- Local Authority
- private rented
- Owner occupied
- Other (please describe)

Which type of housing best describes where you currently live?

- House
- Bungalow
- Apartment/ flat
- Extra Care Housing
- Other (please describe)

Has your home been adapted to meet your current needs?

- Yes
- No
- If yes what kind of adaptations have been made (e.g. stair lift, grab rails, ramps)

Which statement best describes your living arrangements?

- I live alone
- I live with a partner/ spouse
- I live with other family (e.g. brother/ sister)
- I live with friends
- Prefer not to say
- Other (please describe)

What is your current work situation?

- Working full time (more than 35 hours a week)
- Part time work (eight to 34 hours a week)
- Voluntary (unpaid work)
- Carer (full or part time) (e.g. children, caring for a disabled person)
- Student (full or part time)
- Temporarily unemployed (looking for work)
- Unable to work
- Retired
- Prefer not to say
- Other (please describe)

Please tell us what neurological condition(s) you have been diagnosed with? (tick all that apply)

- Motor Neurone Disease (MND)
- Amyotrophic Lateral Sclerosis (ALS)
- Multiple Sclerosis (MS)
- Epilepsy
- Stroke
- Cerebral Palsy
- Huntingdon's Disease

- Parkinson's Disease
- Other (please specify)

Please tell us how long you have been diagnosed with your neurological condition(s)?

- (Years/ Months)
- Don't know

Please tell us if you have any other long-term conditions? (please select all that apply)

- Heart disease
- Heart attack/ Angina
- Chronic Obstructive Pulmonary Disease (COPD)/ Asthma
- Bronchitis
- Asthma
- Arthritis
- Diabetes
- High blood pressure (Hypertension)
- Other (please describe)

To what extent would you say your neurological condition(s) affects your overall health and well being?

- Severely
- Somewhat
- Once in a while
- Not at all
- Comment

How would you say your current health affects your daily life (e.g. housework, taking care of yourself, going to work or pursuing a hobby, getting around)?

04/12/2017

Qualtrics Survey Software

- Severely
- Somewhat
- Once in a while
- Not at all
- Comment

What kinds of community health, social care or support services do you currently use to consult or get treatment for your neurological condition(s)? (tick all that apply)

- Community nurse
- Community physiotherapy
- GP
- Occupational Therapist
- Community dietician
- Counselling
- Home care
- Day care
- Rehabilitation services
- Psychologist
- Mental Health services
- Cleaning
- Care driving service
- Gardening
- Advocate
- Social Worker
- Neighbourhood Team
- Other (please specify)

The next set of questions asks you about your experience of using health services for your condition/s. If you do not have any experience of a particular service, please say that you don't know. If you prefer not to answer a question, please indicate that you prefer not to answer.

What is your experience of going to the GP to consult about your neurological condition(s)?

What is your experience of using community services for your neurological condition(s)?

What is your experience of getting community services (e.g. physiotherapy) for advice, assessments and treatments for your neurological condition(s)?

What is your experience of going to the dentist and, if appropriate, having your neurological condition(s) being recognised/ take account of?

- Excellent
- Very Good
- Good
- Satisfactory
- Poor
- Very poor
- Not appropriate
- Prefer not to say
- Comment

How have you experienced using hospital services for your neurological condition(s) (e.g. Consultant, outpatient appointments)?

What about emergency or urgent care, if appropriate?

And, mental health services, if appropriate?

How easy has it been for you to access life style advice which take into account of the implications of your condition(s)? (e.g. dietary, smoking cessation, weight loss/ gain)

- Very easy
- Easy
- Somewhat difficult
- Very difficult
- Not appropriate
- Prefer not to say
- Comment

What things do you think the health services for neurological conditions do well from your perspective and experience?

What, if any, services do you access outside the county of Lincolnshire?

What is the reason for you accessing services outside the county of Lincolnshire?

- Personal choice
- Better service
- Not available in the county
- Prefer not to say
- Other (please describe)

What, if any, particular problems or challenges do you think people living with neurological condition(s) face in meeting their health needs in the county?

In your experience, are there any health services, or any other types of support services currently not available for people living with neurological condition(s) in Lincolnshire?

Please tell us what you think they are:

If there was one thing that you would change about current health provision in Lincolnshire, for people with neurological conditions, what would it be?

Is there any other information about your experience of accessing services in support for your condition that you feel is important to share with us?

Thank you ever so much for taking the time to complete this interview.

Your participation is greatly appreciated. Please press the submit button below:

SUBMIT

Further resources and information:

If, as a result of completing this survey, you feel you would like to access support, help or further information, the following resources may be of help to you:

Lincolnshire Neurological Alliance

(An umbrella group for neurological conditions in Lincolnshire which is part of a national group)

<http://www.lincolnshire-neurological-alliance.org.uk/>

Lincolnshire County Council Call Centre (including making referrals for assessment, and

advice about care, housing) <https://www.lincolnshire.gov.uk/>

Age UK (advice, services and support for older people and their families)

<https://www.ageuk.org.uk/>

Citizens Advice Bureau (advice and support on a range of topics including housing, finance and legal) <https://www.citizensadvice.org.uk/>

Carers UK (advice, support and services for family carers) <http://www.carersuk.org/>

Every-one (advice, support and services for family carers) <http://www.every-one.org.uk/>

CRUSE (bereavement and loss) <https://www.cruse.org.uk/training/loss-and-bereavement-awareness>

APPENDIX TWO

Survey for carers of people living with neurological conditions

04/12/2017

Qualtrics Survey Software

Default Question Block



Project title: Developing a Health Needs Assessment for People living with neurological conditions in Lincolnshire - Carers

Thank you for taking the time to read the project information sheet and for your interest in taking part in this survey. Don't forget, if you have any queries, questions or concerns about taking part, please contact: Mr Thomas George tgeorge@lincoln.ac.uk Telephone Number: 01522 837496

If you decide that you would like to complete a paper survey, or if you need help completing a survey, please contact: Mr Thomas George tgeorge@lincoln.ac.uk Telephone number: 01522 837496

Below, you will find information about consenting to take part in the survey. Please read this carefully. If you have any queries or questions, do please contact us. We will be glad to help you. Otherwise, please now proceed to the on line survey.

Thank you for agreeing to take part in this project as part of the development of a health needs assessment for people living with neurological conditions in Lincolnshire.

CONSENT PROCESS

BY COMPLETING AND SUBMITTING THIS SURVEY YOU HAVE CONFIRMED:

- 1. I have read and understood the project information sheet about the study (Developing a Health Needs assessment for people with neurological conditions)**
- 2. I have had the opportunity to consider the information as well as talk to someone about it if I needed to ask more questions or get more information about the project**
- 3. My participation is voluntary and that I am free to withdraw up to the point of analysis (projected date end December 2017) without giving any reason, and that my data will be removed from the survey and destroyed**
- 4. That all the information I give will be confidential and that the results from this survey will only be presented in an anonymous form**
- 5. The finding from this survey will be included in a written report and may also be used in a subsequent presentation or published article about the project**
- 6. Short quotations from my survey may be used in the report and subsequent presentation and article - in anonymous form**

- 7. I agree to take part in the study**

About you and your role as a carer.

Please fill in the following responses from the questions below:

What is your date of birth? (Please write in DD/MM/YY)

What is your gender?

- Male
- Female
- Other gender identity
- Prefer not to say

What is your relationship status?

- Single
- Married
- Widowed
- Divorced
- Separated
- Civil partnership
- Living together
- Prefer not to say

Which statement best describes where you currently live?

- Housing Association
- Local Authority
- Private rented
- Owner occupied
- Other (please describe)

What type of housing best describes where you currently live?

- House
- Bungalow
- Apartment/ flat
- Extra care housing
- Other (please describe)

Which statement best describes who you live with?

- I live alone
- I live with a partner. spouse
- I live with other family (e.g. brothers/ sisters)

04/12/2017

Qualtrics Survey Software

- I live with friends
- Prefer not to say
- Other (please describe)

What is your current work situation?

- Working full time (more than 35 hours a week)
- Part time work (eight to 30 hours a week)
- Voluntary (unpaid) work
- Carer (full or part-time) (e.g. children, caring for a disabled person)
- Student (full or part time)
- Temporarily unemployed (looking for work)
- Unable to work
- Retired
- Prefer not to say
- Other (please describe)

Do you have any existing health condition(s)?

If so, can you tell us what they are?, if No, move to Q9.

- Yes
- No
- Prefer not to say
- If you have ticked 'yes', can you tell us what they are?

To what extent, if at all, do your health conditions impact on your ability to care for the person you currently support?

- A great deal
- To some extent
- To a little extent
- Not at all

Comment

Please could you tell us your relationship to the person with neurological condition(s) you currently care for?

Spouse/ partner

Brother/ sister

Parent

Child/ young adult

Friend

Neighbour

Prefer not too say

Comment

How long have you provided care for this person?

<12 months

12 - 24 months

24 - 48 months

> 48 months

Don't know

What kind of care do you give to this person? (tick all that apply)

Help with personal care (e.g. washing, dressing, eating and drinking)

Help with health care (e.g. medication, catheter care, dressing)

Practical help (e.g. getting out and about, paying bills)

Domestic help (shopping, cooking, laundry)

Other help (please specify)

On average, how much time each week would you say you spend caring for the person?

Do you currently have any other kinds of care to help you in your role as a carer?

- Yes
- No
- Prefer not to say

If you have answered yes to Q14, can you tell us what kind of care you have to help you in your role as a carer? (please tick all that apply)

- Home care
- Day care
- Lunch clubs
- Transport services
- Access to respite care
- Gardening
- Housework/ domestic help
- Night sitting services
- Laundry
- Help from other family members
- Help from friends
- Comment

Health care services in Lincolnshire

The next section asks for your views, based on your experience and perceptions, about health care for people living with in Lincolnshire. If you do not have a view or choose not to answer any questions, please leave this section blank. Please add any additional comments you might wish to make to explain or expand upon your answer in the 'comments' boxes.

How would you rate, from your experience, access to community health services for people living with neurological conditions?

04/12/2017

Qualtrics Survey Software

- Excellent
- Very good
- Good
- Satisfactory
- Poor
- Don't know
- Comment

How would you rate, from your experience, access to outpatient services for people living with neurological conditions?

- Excellent
- Very good
- Good
- Satisfactory
- Poor
- Don't know
- Comment

How would you rate, from your experience, access to inpatient services for people living with neurological conditions?

- Excellent
- Very good
- Good
- Satisfactory
- Poor
- Don't know
- Comment

How would you rate, from your experience, access to mental health services for people living with neurological conditions?

- Excellent
- Very good
- Good
- Satisfactory
- Poor
- Don't know
- Comment

How would you rate, from your experience, access to well being services (e.g. smoking cessation, weight management, counselling) for people living with neurological conditions?

- Excellent
- Very good
- Good
- Satisfactory
- Poor
- Don't know
- Comment

How would you rate, from your experience, recognition of the needs of carers for people living with neurological conditions?

- Excellent
- Very good
- Good
- Satisfactory
- Poor
- Don't know
- Comment

How would you rate, from your experience, support to carers for people living with neurological conditions?

- Excellent
- Very good
- Good
- Satisfactory
- Poor
- Don't know
- Comment

To what extent would you say that health services recognise the needs of people living with neurological conditions and make necessary adjustments to the services they offer?

What, if any, particular challenges or problems do you think people living with neurological conditions face in meeting their health needs in the county?

Are there, in your opinion, health, care or support services currently missing or not available for people living with neurological conditions in the county?

If there was one thing that you would change about current health provision in Lincolnshire for people living with neurological conditions, what would it be?

If there was one thing that you would change about support for carers of people with neurological conditions in Lincolnshire, what would it be?

Is there anything else you would like to tell us that you feel it important to our enquiry?

**Thank you ever so much for taking the time to complete this interview.
Your participation is greatly appreciated. Please press the submit button below:**

SUBMIT

Further resources and information:

If, as a result of completing this survey, you feel you would like to access support, help or further information, the following resources may be of help to you:

Lincolnshire Neurological Alliance

(An umbrella group for neurological conditions in Lincolnshire which is part of a national group)
<http://www.lincolnshire-neurological-alliance.org.uk/>

Lincolnshire County Council Call Centre (including making referrals for assessment, and advice about care, housing) <https://www.lincolnshire.gov.uk/>

Age UK (advice, services and support for older people and their families)
<https://www.ageuk.org.uk/>

Citizens Advice Bureau (advice and support on a range of topics including housing, finance and legal) <https://www.citizensadvice.org.uk/>

Carers UK (advice, support and services for family carers) <http://www.carersuk.org/>

Every-one (advice, support and services for family carers) <http://www.every-one.org.uk/>

CRUSE (bereavement and loss) <https://www.cruse.org.uk/training/loss-and-bereavement-awareness>

APPENDIX THREE

Survey for Voluntary Sector Organisations

04/12/2017

Qualtrics Survey Software

Default Question Block



Project title: Developing a Health Needs Assessment for People living with neurological conditions in Lincolnshire - Voluntary Sector

Thank you for taking the time to read the project information sheet and for your interest in taking part in this survey. Don't forget, if you have any queries, questions or concerns about taking part, please contact: Mr Thomas George tgeorge@lincoln.ac.uk Telephone Number: 01522 837496

If you decide that you would like to complete a paper survey, please contact: Mr Thomas George tgeorge@lincoln.ac.uk Telephone number: 01522 837496

Below, you will find information about consenting to take part in the survey. Please read this carefully. If you have any queries or questions, do please contact us. We will be glad to help you. Otherwise, please now proceed to the on line survey.

Thank you for agreeing to take part in this project as part of the development of a health needs assessment for people living with neurological conditions in Lincolnshire.

CONSENT PROCESS

BY COMPLETING AND SUBMITTING THIS SURVEY YOU HAVE CONFIRMED:

1. I have read and understood the project information sheet about the study (Developing a Health Needs assessment for people with neurological conditions)
2. I have had the opportunity to consider the information as well as talk to someone about it if I needed to ask more questions or get more information about the project
3. My participation is voluntary and that I am free to withdraw up to the point of analysis (projected date end December 2017) without giving any reason, and that my data will be removed from the survey and destroyed
4. That all the information I give will be confidential and that the results from this survey will only be presented in an anonymous form
5. The finding from this survey will be included in a written report and may also be used in a subsequent presentation or published article about the project
6. Short quotations from my survey may be used in the report and subsequent presentation and article - in anonymous form
7. I agree to take part in the study

What is the name of the agency you work for?

What is your role/ job title?

What is your employment situation?

- Full time Manager
- Part time Manager
- Full time employee
- Part time employee (how many hours per week?)

- Volunteer (how many hours per week?)
- Other (please specify)

Please tell us which location your service is currently based in Lincolnshire? (tick all that apply)

- North Kesteven
- South Kesteven
- East Lindsey
- West Lindsey
- South Holland
- Lincoln
- Boston

How many years has your organisation operated in Lincolnshire?

How many people currently work in your organisation - or in your branch organisation?

How many people currently volunteer in your organisation - or in your branch organisation?

What kind(s) of neurological condition(s) do you provide services for at your organisation?

Please tell us what kind(s) of services you provide in your organisation? (tick all that apply)

- Advice and information
- Drop in / support services
- Care at home
- Voluntary visiting/ befriending
- Legal advice
- Therapeutic services (e.g. alternative/ complementary therapies)
- Social activities
- Campaigning
- Advocacy
- Fund raising
- Charitable grants
- Equipment loans
- Carers support services
- Counselling
- Crisis services
- Respite
- Holidays
- Other (please specify)

Are your services funded or commissioned by Lincolnshire County Council/ CCGs/ other health commissioning?

- Yes
- No
- Don't know
- If yes, can you say what services are currently commissioned?

How many people with neurological condition(s) are members of your organisation?

How many people with neurological condition(s) are actively involved in or regularly use your services?

And carers?

Health care services in Lincolnshire

The next section for your views, based upon your experience and perceptions, about health care for people with neurological conditions in Lincolnshire. If you do not have a view or choose not to answer any questions, please leave the section blank. Please add any additional comments you might wish to make and explain upon your answer.

How would you rate, from your experience, access to community health services for people living with neurological conditions?

- Excellent
- Very good
- Good
- Satisfactory
- Poor
- Don't know
- Comment

How would you rate, from your experience, access to hospital outpatient services for people living with neurological conditions?

- Excellent
- Very good
- Good
- Satisfactory
- Poor
- Don't know
- Comment

How would you rate, from your experience, access to hospital inpatient services for people living with neurological conditions?

- Excellent
- Very good
- Good
- Satisfactory
- Poor
- Don't know
- Comment

How would you rate, from your experience, access to mental health services for people living with neurological conditions?

- Excellent
- Very good
- Good
- Satisfactory
- Poor
- Don't know
- Comment

How would you rate, from your experience, access to well-services (e.g. smoking cessation, weight management, counselling) for people living with neurological conditions?

- Excellent
- Very good
- Good
- Satisfactory
- Poor
- Don't know
- Comment

How would you rate, from your experience, recognition of the needs of carers for people living with neurological conditions?

- Excellent
- Very good
- Good
- Satisfactory
- Poor
- Don't know
- Comment

How would you rate, from your experience, support for carers of people living with neurological conditions?

- Excellent
- Very good
- Good
- Satisfactory
- Poor
- Don't know
- Comment

Based on your knowledge of services for people living with neurological condition(s) in the county, to what extent would you say that health services recognise the needs of people living with neurological condition(s) and make necessary adjustments in the services they offer?

What, if any, particular challenges or problems do you think people living with neurological condition(s) face in meeting their health needs in the county?

And there, in your opinion, health, care or support services currently missing or not available for people living with neurological conditions in the county?

If there was one thing that you would change about the current health provision in Lincolnshire for people with neurological condition(s), what would it be?

Is there any else you would like to tell us that you feel is important to our enquiry?

Thank you for taking the time to complete this interview. Your participation is greatly appreciated. Please press the submit button below:

APPENDIX FOUR

Survey for Medical/ Allied Health Professionals

04/12/2017

Qualtrics Survey Software

Default Question Block



Project title: Developing a Health Needs Assessment for People living with neurological conditions in Lincolnshire - Medical/ Allied Health Professionals

Thank you for taking the time to read the project information sheet and for your interest in taking part in this survey. Don't forget, if you have any queries, questions or concerns about taking part, please contact: Mr Thomas George tgeorge@lincoln.ac.uk Telephone Number: 01522 837496

If you decide that you would like to complete a paper survey, please contact: Mr Thomas George tgeorge@lincoln.ac.uk Telephone number: 01522 837496

Below, you will find information about consenting to take part in the survey. Please read this carefully. If you have any queries or questions, do please contact us. We will be glad to help you. Otherwise, please now proceed to the on line survey.

Thank you for agreeing to take part in this project as part of the development of a health needs assessment for people living with neurological conditions in Lincolnshire.

CONSENT PROCESS

BY COMPLETING AND SUBMITTING THIS SURVEY YOU HAVE CONFIRMED:

1. I have read and understood the project information sheet about the study (Developing a Health Needs assessment for people with neurological conditions)
2. I have had the opportunity to consider the information as well as talk to someone about it if I needed to ask more questions or get more information about the project
3. My participation is voluntary and that I am free to withdraw up to the point of analysis (projected date end December 2017) without giving any reason, and that my data will be removed from the survey and destroyed
4. That all the information I give will be confidential and that the results from this survey will only be presented in an anonymous form
5. The finding from this survey will be included in a written report and may also be used in a subsequent presentation or published article about the project
6. Short quotations from my survey may be used in the report and subsequent presentation and article - in anonymous form
7. I agree to take part in the study

What is the name of the agency you work for?

What is your role/ job title?

Are you?

- Full time
- Part time (how many hours per week?)
- Other (please specify)

Please tell us which location your service is currently based in Lincolnshire? (tick all that apply)

- North Kesteven
- South Kesteven
- East Lindsey
- West Lindsey
- South Holland
- Lincoln
- Boston

What kind(s) of neurological condition(s) do you provide services for at your?

Please tell us what kinds of services your provide? (e.g. outpatient clinics, inpatient)

How many people with neurological conditions do you see, on average, each week?

What is the referral process?

What is the average wait timing for an appointment to your service?

Health care services in Lincolnshire

The next section for your views, based upon your experience and perceptions, about health care for people with neurological conditions in Lincolnshire. If you do not have a view or choose not to answer any questions, please leave the section blank. Please add any additional comments you might wish to make and explain upon your answer.

How would you rate, from your experience, access to community health services for people living with neurological conditions?

- Excellent
- Very good
- Good
- Satisfactory
- Poor
- Don't know
- Comment

How would you rate, from your experience, access to hospital outpatient services for people living with neurological conditions?

- Excellent
- Very good
- Good
- Satisfactory
- Poor
- Don't know
- Comment

How would you rate, from your experience, access to hospital inpatient services for people living with neurological conditions?

- Excellent
- Very good
- Good
- Satisfactory

- Poor
- Don't know
- Comment

How would you rate, from your experience, access to mental health services for people living with neurological conditions?

- Excellent
- Very good
- Good
- Satisfactory
- Poor
- Don't know
- Comment

How would you rate, from your experience, access to well-services (e.g. smoking cessation, weight management, counselling) for people living with neurological conditions?

- Excellent
- Very good
- Good
- Satisfactory
- Poor
- Don't know
- Comment

How would you rate, from your experience, access to specialist services for people living with neurological conditions? (e.g. pain clinics)

- Excellent
- Very good
- Good
- Satisfactory

04/12/2017

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- Poor
- Don't know
- Comment

To what extent, in your experience, are people with neurological conditions referred 'out of county' for specific services?

- More often than not
- Regularly
- Sometimes
- Hardly at all
- Never
- Don't know
- Comment

Based on your experience, what kinds of services are people referred out of county for? (please specify)

What is the reason for out of county referrals, in the main? (please tick all that apply)

- The service is not available in the county
- The in county service cannot currently meet demand/ need for the service
- Patient preference/ choice
- Consultant preference/ choice
- Jointly commissioned service
- Accessibility (geographical location)
- Other (please specify)

How would you rate, from your experience, recognition of the needs of carers for people living with neurological conditions?

- Excellent

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- Very good
- Good
- Satisfactory
- Poor
- Don't know
- Comment

How would you rate, from your experience, support to carers of people living with neurological conditions?

- Excellent
- Very good
- Good
- Satisfactory
- Poor
- Don't know
- Comment

What, if any, particular challenges or problems do you think people living with neurological condition(s) particularly face in meeting their health needs in the county?

What, if any, particular challenges do health care professionals face in meeting the demand for services from people with neurological conditions?

What areas of good practice in neurological care would you identify?

Are there, in your opinion, health, care or support services currently missing or not available for people living with neurological conditions in Lincolnshire?

Appendices

04/12/2017

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If there was one thing that you would change about the current health provision in Lincolnshire for people with neurological condition(s), what would it be?

Is there any else you would like to tell us that you feel is important to our enquiry?

Thank you for taking the time to complete this interview. Your participation is greatly appreciated. Please press the submit button below:

SUBMIT

