Document History

<table>
<thead>
<tr>
<th>Revision date</th>
<th>Author</th>
<th>Version</th>
<th>Summary of Changes</th>
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<tr>
<td>14 August 2014</td>
<td>Kerri Byrne</td>
<td>0.1</td>
<td>Document created</td>
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<tr>
<td>18 September 2014</td>
<td>Kerri Byrne</td>
<td>0.1 – 0.6</td>
<td>Amendments to draft</td>
</tr>
<tr>
<td>27 October 2014</td>
<td>Heidi Francis</td>
<td>0.7</td>
<td>Amendments to draft</td>
</tr>
<tr>
<td>12 January 2015</td>
<td>Aasha Greensmith</td>
<td>0.8 – 0.9</td>
<td>Amendments to draft</td>
</tr>
<tr>
<td>11 February 2015</td>
<td>Aasha Greensmith</td>
<td>0.10</td>
<td>Amendments to draft following internal consultation</td>
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<tr>
<td>13 February 2015</td>
<td>Aasha Greensmith</td>
<td>0.11</td>
<td>Amendments to draft</td>
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<tr>
<td>10 March 2015</td>
<td>Aasha Greensmith</td>
<td>0.12</td>
<td>Amendments to draft following external consultation</td>
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<tr>
<td>13 April 2015</td>
<td>Aasha Greensmith</td>
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<tr>
<td>29 April 2015</td>
<td>Aasha Greensmith</td>
<td>0.14</td>
<td>Amendments to draft following Governing Body review</td>
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<tr>
<td>16 June 2015</td>
<td>Aasha Greensmith</td>
<td>0.15</td>
<td>Amendments to draft following CCC and first Neurology Strategy Steering Group meeting</td>
</tr>
<tr>
<td>06 July 2015</td>
<td>Aasha Greensmith</td>
<td>0.16</td>
<td>Further amendments to draft (minor)</td>
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Approved By

V0.14 approved at Long Term Conditions Programme Board following internal and external consultation including CCG Governing Body comments. V0.14 was then reviewed at CCG Commissioning Committee in May 2015 where a number of suggested changes were made. Current V0.16 incorporates those changes alongside feedback from the Neurology Strategy Steering Group.

V0.15 and future versions to be approved and monitored by LTCPB alongside an associated work plan. Work plan updates will also be shared with Council of Practices for each CCG going forwards.

The LTCPB is accountable to the four individual CCG governing bodies for the implementation of this strategy.
EXECUTIVE SUMMARY

Neurological conditions can affect patients from all backgrounds, regardless of gender, age, ethnicity or socio-economic background. There is a wide variation of access to specialist services for patients with neurological conditions and there is national recognition that neurology is not always recognised as an issue, with the extent of problems underestimated. This strategy presents an opportunity to meet the needs of patients more effectively than at present, whilst achieving better value for money.

Our vision is that patients with neurological conditions will benefit from a transformed integrated neurology service spanning primary, secondary, tertiary and social care. Multi-disciplinary working will ensure patients are able to step up and step down through the system when needed. Patients will feel empowered, with increased knowledge about their conditions and signposting to resources, understanding how to navigate the system. Patients will feel less isolated and will be able to manage their condition better in the community.

This strategy has been created through engaging with multidisciplinary stakeholders, talking to patients and the public and utilising the available literature and data. The strategy aligns to several other strategies; including the Berkshire West 5 year strategy and NHS England 5 year forward view.

Over the next year there is a lot of change that we need to harness and we hope this strategy will serve as a mechanism to set up a strong programme of work to facilitate this and support future commissioning decisions. Changes include the implementation of the Care Act 2014 and imminent changes to specialised commissioning.

This strategy gives an overview of the current services available in the Berkshire West area before outlining how we plan to meet our strategic objectives. There are a lot of great services in the area providing services to patients with neurological conditions; we just must ensure the services are talking to each other and patients or health care professionals alike do not get lost in the complicated system.

Through working with stakeholders including patients, carers, care providers and social services we aim to implement this strategy over the course of 3-5 years. This strategy forms a working document from which we can start implementing change. This strategy focuses on adult services and the transition from child services into adult health and social care.
<table>
<thead>
<tr>
<th>Work Streams</th>
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<tr>
<td>1. Identify, Define and Improve Pathways</td>
<td>2. Navigate the pathway</td>
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<tr>
<td>3. Enabling Diagnosis in Primary Care</td>
<td>4. Patient facing resources for self-care and prevention</td>
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**Initial Priority Pathways**

- Headache
- Epilepsy
- Chronic Neurological Conditions – Integrated Pathway
- Functional Disorders

**Strategic Over-arching Objectives**

- Triage & Diagnose
- Patient Empowerment
- Integrated Care
- High Quality Care
- Better understanding of the data
1. INTRODUCTION

Neurological conditions arise when a patient has damage to the brain, spine or nerves. Neurological conditions can affect patients from all backgrounds, regardless of gender, age, ethnicity or socio-economic background. The onset of symptoms may be slow or fast, depending on the individual and the neurological condition they have.

Some neurological conditions will be temporary; many will be life-long requiring permanent lifestyle changes. Intermittent conditions are the most prevalent, accounting for almost 60% of all neurological cases (Neurological Alliance, 2014). Long term neurological conditions can cause a range of problems, including physical/motor, sensory, cognitive, behavioural, communication and emotional problems (National Service Framework for Long Term Conditions, 2005). Many of the causes are still however unknown.

Neurological conditions can be largely classified into five groups:

<table>
<thead>
<tr>
<th>Classification</th>
<th>Examples</th>
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<tbody>
<tr>
<td>Sudden Onset</td>
<td>Stroke, Brain Injury</td>
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<tr>
<td>Stable with changing needs</td>
<td>Cerebral Palsy</td>
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<tr>
<td>Intermittent</td>
<td>Epilepsy, Migraine</td>
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<tr>
<td>Progressive</td>
<td>Dementia, Motor Neurone Disease, Multiple Sclerosis, Parkinson’s</td>
</tr>
<tr>
<td>Functional</td>
<td>Chronic Pain, Involuntary Movements, Speech Problems, Non-Epileptic Seizures</td>
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Neurological conditions account for over 4% of total NHS spend, 1.3m admissions and 700,000 emergency admissions per year (Neurological Alliance, 2014). In Primary care, they account for 1 in 10 GP consultations, with 1 in 6 people having a neurological condition (Thames Valley Strategic Clinical Network, 2014). Neurological disorders also account for up to 20% of acute medical conditions including stroke, epilepsy, and meningoencephalitis. Guillain Barre syndrome, Multiple Sclerosis, Subarachnoid haemorrhage and myasthenia gravis are a few of the conditions which may lead to an emergency hospital admission (Association of British Neurologists, 2014).

This strategy has been built on a Berkshire West PCT Joint Strategic Needs Assessment and Service Mapping Overview by the Thames Valley Strategic Clinical Networks. The strategy is also informed by a number of other reports which are referred to at the end of this document. This strategy aims to build on the progress made in these existing reports and work undertaken by the Long Term Conditions Programme Board (LTCPB). This strategy focuses on adult services and the transition from child services into adult health and social care.

Through working with stakeholders including patients, carers, care providers and social services we aim to implement this strategy over the course of 3-5 years. This strategy forms a working document from which we can start implementing change. This strategy should be reviewed in conjunction with the Berkshire West Strategic Plan 2014-2019, and consequently reviewed in the same time period to ensure continued alignment.

The strategy has been developed through engagement with key stakeholders on emerging proposals, following a review of national and local reports alongside available activity data. The development of this strategy was supported by all four CCGS who had each identified a GP neurology lead, providing an opportunity to demonstrate the power of clinically-led commissioning in driving transformational change.

The timing of this strategy is opportune. The Thames Valley Strategic Clinical Network is currently driving wider-scale neurological change, which brings about associated leadership and support. This strategy presents an opportunity to meet the needs of patients more effectively than at present, whilst achieving better value for money. An ambitious vision for the future is set out; this must be closely balanced with what is realistic to achieve.
2. VISION

Our vision is that patients with neurological conditions will benefit from a transformed integrated neurology service spanning primary, secondary, tertiary and social care. Multi-disciplinary working will ensure patients are able to step up and step down through the system when needed. Patients will feel empowered, with increased knowledge about their conditions and signposting to resources. Patients will feel less isolated and will be able to manage their condition better in the community.

This vision will be supported by the following strategic objectives:

- There is effective triage and diagnosis for patients with new or changing neurological symptoms
- Increasing patient empowerment so patients feel more knowledgeable and confident in managing their conditions, are able to access care when needed and experience reduced feelings of isolation through the voluntary sector
- Patients benefit from seamless integrated care with the ability for patients to step up and step down reducing the need for emergency admissions and enabling better care in the community
- Whether patients are at home, being treated in the community or admitted as an inpatient, they continue to receive high quality care with appropriate access to the right healthcare professionals
- We have a better understanding of the data to better inform service delivery in line with the needs of the local population

This strategy aligns with the NHS Berkshire West Federation Strategic Plan and the NHS England 5 Year Forward View.

3. NATIONAL CONTEXT

There are a variety of national documents available published from a range of sources including NICE Clinical Guidelines, Voluntary Sector organisations, the Association of British Neurologists and Strategic Clinical Networks. National guidance and documents such as the above should be used to help inform our responses locally, shaped accordingly to the needs of our local population. Some of the national documents which have been drawn upon throughout this strategy are referenced at the end of this document.

In 2005 the National Service Framework for Long Term Conditions clearly set out the national perspective on quality standards for neurological services and although the commissioning landscape has since changed, the substance of the report remains materially relevant. A recent Neurology Manifesto (The Neurological Alliance, 2014) prioritises the improvement of data, access to specialist care, and research funding.

Another recent report (Association of British Neurologists, 2014) highlights that there is a wide variation of access of specialist services for patients with neurological conditions. The report goes on to emphasise “as liaison neurology services change the diagnosis and management in a high proportion of patients, improve outcomes and reduce length of stay there is an opportunity to improve patient care and cost effectiveness”.

It has also been highlighted that patients are waiting a long time to be referred to a neurological specialist and little work has been done nationally to “promote integration across primary, secondary, tertiary and social care” (Neurological Alliance, 2015). The report also confirms there is national recognition that neurology is not always recognised as an issue and the extent of problems are underestimated.
4. LOCAL CONTEXT

A. Acute Services

Most patients requiring non-specialised neurological services and/or non-complex trauma neurological services commissioned by Berkshire West CCGs will attend the Royal Berkshire Hospital (RBH) in Reading, part of the Royal Berkshire Foundation Trust (RBFT). Some residents will attend our neighbouring Trusts including Hampshire Hospitals Foundation Trust (Basingstoke), Frimley Health Foundation Trust (Frimley) or Great Western Hospitals NHS Trust (Swindon). RBFT are currently reviewing some of the protocols and policies for patients with neurological conditions which include an epilepsy pathway and how to appropriately manage relapses for MS patients.

Outpatients
The neurology department review referrals received in the department by fax or letter daily to ensure patients are seen urgently when required; Choose and Book\(^1\) referrals generate appointments and are not routinely reviewed unless the advice and guidance function is utilised. Common problems are headache, transient loss of consciousness, sensory symptoms, tremor and gait problems. Common final diagnoses are migraine and other primary headache syndromes, carpal tunnel syndrome, idiopathic axonal peripheral neuropathy, essential tremor and 'no neurological disease'; some people will be diagnosed with a chronic neurological disease more likely to require some ongoing specialist care: epilepsy, Parkinson’s, MS or one of a host of rarer conditions (including Motor Neurone Disease, Myasthenia Gravis, Huntington’s Disease).

Functional neurological disorder is another important final diagnosis. There is a Medically Unexplained Symptoms clinic which is ran at the Royal Berkshire Bracknell clinic. This is a local innovation providing a very important resource for patients with functional neurological symptoms.

The neurology and stroke department also runs a daily TIA Clinic providing rapid assessment for suspected TIA/minor stroke patients, aiming to see all patients within 48 hours (working days) and carry out imaging in the same visit where required. Referrals can be made by health care professionals including paramedics and GPs. The aim is these patients can be appropriately managed before going onto having a major stroke if they are at risk.

Inpatients
Patients admitted with an acute neurological problem will generally be admitted under an acute, general or elderly care physician. Clinicians within RBFT are encouraged to ask the neurology team for advice via phone or in person with the patient. The neurology team aim to do this on the same day; sometimes giving one off advice and sometimes continuing to visit the patient regularly during their inpatient stay in close collaboration with those who are directly looking after them. Patients may also be admitted with a secondary neurological condition and staff are again encouraged to engage with the neurology team.

Acute Stroke Unit (ASU)
The ASU at Royal Berkshire Hospital is a 28 bed unit, caring for patients with both complex professional health and social care needs. The ward cares for patients with a range of different acute and rehabilitation needs.

Neurological rehabilitation
RBFT also offers a neurological rehabilitation service on Caversham Ward. Typically, the ward treats and rehabilitates patients with stroke, traumatic brain injury, spinal injury and disease, MS and other complex neurological conditions and has beds for 12 adult patients.

\(^1\) In June 2015 the new NHS E-Referral system will be implemented and replace Choose and Book
Consultants in Neurology

There are currently nine Consultants across neurology, elderly care (with a neurological special interest) and neuro-rehabilitation. All 7 neurology and elderly care consultants above do the TIA clinic referred to above. The Consultants are based at the Royal Berkshire Hospital and their specialist areas are outlined below:

<table>
<thead>
<tr>
<th>Specialist Area</th>
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<tbody>
<tr>
<td>Neurologist – Thrombolysis Lead</td>
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<tr>
<td>Neurologist – Parkinson’s and Movement Disorders</td>
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<tr>
<td>Neurologist – MS</td>
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<tr>
<td>Neurologist – Epilepsy &amp; Migraine</td>
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<tr>
<td>Elderly Care – Stroke Lead</td>
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<tr>
<td>Elderly Care – Stroke</td>
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<tr>
<td>Elderly Care – Stroke &amp; Medicine</td>
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<tr>
<td>Neuro Rehabilitation</td>
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Associate Specialists
RBFT also has two associate specialists; one in neurology and one in neuro rehabilitation.

B. Community Services

Berkshire Healthcare Foundation Trust (BHFT) provides community services within the Berkshire West area (based within three localities of Reading, Wokingham and West Berkshire). BHFT operate from a number of sites including community hospitals as well as providing health care to patients in their own homes.

Community Neuro Rehabilitation Team (CBNRT)
CBNRT are an interdisciplinary team of Occupational Therapists, Physiotherapists, Psychologists, Speech and Language Therapists, Therapy Assistants and Specialist Stroke Rehabilitation Nurses. The team help patients achieve realistic goals which improve or maintain their ability to perform daily activities. The team cover areas including mobility, anxiety and swallowing difficulties, aiming to help patients return to work, improve their confidence and dignity; and are able to enjoy leisure pursuits. The team treat all neurological conditions and patients can be referred by their Consultants and other healthcare professionals where they have a neurological condition and identified rehabilitation goals that can be achieved in a limited time period. Patients can also self-refer to the service once they are known to the CBNRT.

Early Supported Discharge (ESD)
The ESD Team is provided by CBNRT and the purpose is to facilitate early discharge and to continue to support intensive rehabilitation of stroke patients at home. The team work closely with RBFT and following a referral, an assessment will determine whether the service is appropriate for a patient. This service is aimed at patients who have suffered a stroke, are medically stable and have neurological deficits that can be managed at home. The patients must be registered with a Berkshire West GP and have sufficient mobility to manage within the home environment (either independently if living at home or with minimal support from a carer). Three nurses are employed within the ESD team in the Berkshire West area; they attend the Acute Stroke Unit MDT twice a week to discuss potential and imminent referrals.

Six Month Community Stroke Reviews
The National Stroke Strategy (RCP 2007) identified the need for stroke reviews. The three nurses employed within the ESD team in the Berkshire West area carry out six month reviews for patients who have been discharged from RBFT.
Community Inpatient Neurological Rehabilitation Unit

This is a small five-bedded unit based on Donnington Ward at West Berkshire Community Hospital. The criteria for the ward are adults (over 18) patients with rehabilitation potential or patients requiring reassessment if presenting with complex neurological conditions. Therefore, this unit can be referred into from the community or also act as a step-down ward between the Acute setting and returning home. Patients continue to be overseen by a Consultant at RBFT. The ward enables patients to maximise independence, quality of life, and achievement of goals.

Other Community Services

There are a number of other services on offer which may be appropriate for patients with neurological conditions. This includes speech and language, community physiotherapy and continence services.

C. Specialist Nursing Services

The role of Clinical Nurse Specialists is to engage with patients and their carers helping to avoid unnecessary admissions to hospital and reducing length of stay. They work closely with the Consultants and the GP’s and improve access to services. They all have expertise in particular areas and provide cross-cover for one another. The Parkinson’s specialist nurses work very closely with each other across both Royal Berkshire Foundation Trust and Berkshire Healthcare Foundation Trust to ensure continuity for patients. The specialist nurses can free up GP and Consultant time when access is available.

The role varies slightly between specialties but generally the Clinical Nurse Specialists will do clinics and home visits, see patients on wards as appropriate and as requested, carry out joint visits with multi-disciplinary teams (including mental health, physiotherapy, speech & language therapy, community matrons) to promote integrated health and working together. They can also support patients via email and the telephone.

The Lead Clinical Nurse Specialist Neurological Long Term Conditions has recently reviewed patient satisfaction surveys. Some of the positives in relation to specialist nursing include having good support, understanding the options available to them and simply having someone to talk to. The most recent data indicates that the rare neurological conditions nurses caseload for 2014 primarily consisted of patients diagnosed with Motor Neurone disease and Huntington’s disease alongside rarer conditions such as post-polio.

<table>
<thead>
<tr>
<th>Specialist Area</th>
<th>WTE</th>
<th>Trust / Funding</th>
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<tr>
<td>Lead Clinical Nurse Specialist and Parkinson’s</td>
<td>1.0 WTE</td>
<td>RBFT</td>
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<tr>
<td>Multiple Sclerosis</td>
<td>1.0 WTE</td>
<td>RBFT</td>
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<tr>
<td>Epilepsy</td>
<td>1.0 WTE</td>
<td>Hosted by RBFT</td>
</tr>
<tr>
<td>Parkinson’s X 2</td>
<td>1 x 0.4 WTE &amp; 1 X 6.0 WTE</td>
<td>BHFT</td>
</tr>
<tr>
<td>Parkinson’s</td>
<td>0.4 WTE</td>
<td>Pump primed by Parkinson’s UK</td>
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<tr>
<td>Rarer neurological conditions</td>
<td>1.0 WTE</td>
<td>RBFT</td>
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In 2002 the Multiple Sclerosis Risk-Sharing Scheme (RSS) was set up and Royal Berkshire FT is one of 72 centres across the UK participating. This is a drug access scheme covering both the legal framework for routine NHS prescribing and collection of data to assess cost efficacy over a 10 year period with routine clinical usage (Multiple Sclerosis Trust, 2014). Part of this funding has included two MS nurse posts who are employed by Quintiles but have honorary contracts with Royal Berkshire FT. Combined they are currently 1.2 WTE.
D. Commissioning of Specialist Neurology Services

CCGs commission neurology inpatient and outpatient services provided at local hospitals but not specialist services provided at Adult Neurosciences or Neurology Centres such as neurosurgery or specialist diagnostics. (NHS England, 2014a). These services are currently commissioned by NHS England as the number of individuals requiring the service is small and the cost of treating patients can be high (NHS England, 2014b).

Some specialist services are provided at the John Radcliffe hospital in Oxford, the local Centre of Excellence for this area. Patients may be referred here for reasons including electroencephalogram (a test used for managing epilepsy) currently not offered locally. While RBFT offers most nerve conduction studies (used to manage neuropathy), complex patients may go to Oxford.

Ministers have recently agreed that the following services should no longer be commissioned by NHS England and should be reflected in CCGs contracts from April 2015: specialised wheelchair services, outpatient neurology referrals made by GPs to adult neurology centres or neurosciences centres (NHS England, 2014b). At the time of writing, an imminent publication around neuro-pathology service specifications is also expected.

E. Primary Care

Berkshire West CCGs have designated GP Neurology Leads who are a point of contact for any issues arising relating to neurological conditions. If a CCG does not have a neurology lead in place, feedback and information will go through Council of Practices to ensure two way clinical engagement across the four CCGs continues. Issues can be escalated to LTCPB as necessary.

F. South Central Ambulance Service

The Berkshire West area is serviced by South Central Ambulance Service (SCAS) who cover Buckinghamshire, Hampshire and Oxfordshire as well as Berkshire. SCAS provide accident and emergency service support responding to 999 calls, patient transport services and they are also the provider for 111 services in the area.

SCAS have pathways in place to ensure patients are taken to the appropriate place of care (or remain at home where appropriate) dependent on their symptoms. The best known example is the stroke pathway, where patients who have suffered an onset of symptoms within 4 hours should be transported to a Hyper Acute Stroke Unit (South Central Ambulance Service, 2014). As outlined above, SCAS are able to make referrals into the TIA clinics at RBFT.

G. Symptom Management and other Services

Patients with neurological conditions may need to manage a variety of symptoms including respiratory (e.g. for Motor Neurone Disease), pain management (e.g. for Fibromyalgia) or fatigue (e.g. for M.E). These symptoms can vary in severity both between patients but also at different points in time for individual patients. Management of these symptoms can help patients to have improved quality of life so it is important they are diagnosed and can be treated.
Patients with long term neurological conditions may also need to access other services such as: Continence, Tissue Viability, Environmental Controls, Intermediate care & Reablement, Berkshire Equipment, Wheelchair and Orthotics.

H. Social Care Services

Social Care Services will carry out a health and social care assessment to determine what help and support patients require. Patients with neurological conditions are likely to need some form of social care assistance and this may range from disability equipment and home adaptations to assistance with cleaning and shopping.

There are three local authorities in the Berkshire West Area providing social care services; these are West Berkshire, Reading and Wokingham.

The implementation of the Care Act 2014 removed the current eligibility framework, replacing it with a single set of criteria outlining the minimum thresholds for eligibility alongside a set of criteria for carers. Therefore all three local authorities will need to provide social care services at a ‘Substantial’ Level.

During the development of this strategy, the existing framework was made up of four banding levels which are determined locally (Critical, Substantial, Moderate and Low (Social Care Institute for Excellence, 2013). Reading Council operated at Substantial level whilst West Berkshire and Wokingham operated at Critical level.

I. Continuing Health Care

NHS continuing healthcare is the name given to a package of care that is arranged and funded solely by the NHS for individuals who are not in hospital and have been assessed as having a “primary health need” (NHS Choices, 2013). This will apply to some patients with long term neurological conditions and will need to be considered.

J. Voluntary Sector

The voluntary sector in Berkshire West is very active in offering a wide range of support services for patients with neurological conditions including general support, exercise facilities and patient campaigns. There is an increasing role of the Voluntary Sector in supporting people funded by statutory services. We expect the Voluntary Sector to continue expanding and will continue to work closely with them. The Berkshire West 5 year strategy highlights the need to take a more strategic approach to commissioning services from the voluntary and third sector, capitalising upon the specific expertise and influence that these organisations may have to offer. The Berkshire West CCGs recognise the invaluable contribution of the voluntary sector towards the care, support and advice given to those with long term neurological conditions.

West Berkshire Neurological Alliance (WBNA) represent a large number of charities who are involved in campaigning, research and fund raising on behalf of those who are affected by neurology conditions (both common and rarer conditions).

Family and Support Services are provided by the Stroke Association (Reading and Wokingham) alongside Stroke Care (West Berkshire). These services work with patients in a variety of settings including inpatient settings.
other community settings (such as gyms and places of work) as well as in their own homes. They provide workshops and support groups.

Berkshire West CCGs have commissioned services from Headway, an independent charity which promotes a wider understanding of all aspects of brain injury, providing information, support and services to people with brain injury, their families and carers (Headway, 2015). They work in collaboration with the CBNRT through Living with Brain Injury groups to empower patients and enable patients to manage their condition.

There are also a number of local support groups and associations available to assist patients with rarer neurological conditions such as Fibromyalgia and Myasthenia Gravis.

K. Strategic Clinical Network (SCN)

Neurology is now on the agenda for the Strategic Clinical Networks and it sits within the network of Mental Health, Dementia and Neurological Conditions (MHDN). The overall aim of the SCN is to facilitate improved patient outcomes through evidence based, transformational change and to influence commissioning priorities (Thames Valley Strategic Clinical Network, 2013). The current priorities for neurology include integrated neurology services. Recently the National Mental Health, Dementia and Neurology Intelligence Network (NMHDNIN) was set up and the purpose is to “analyse information and data turning it into timely meaningful health intelligence for commissioners, policy makers, clinicians and health professionals to improve services, outcomes and reduce the negative impact of mental health, dementia and neurology problems”. (Public Health England, 2014).

L. Mental Health, Dementia and Neurological Conditions Intelligence Network (MHDNIN) Data

Recent data published by the MHDNIN (Public Health, 2014) highlights that Berkshire West CCGs are largely in line with the national averages for admissions for a range of neurological conditions including headache, migraine, MND, Parkinson’s and Huntington’s Disease. The data did however highlight that there are discrepancies between CCGs. Therefore this strategy needs to be mindful that the broad strategic objectives may need to be localised where necessary.

Although this same dataset indicated our cost of epilepsy medicines was much higher than the national average, recent HES data (January 2015) has indicated we are now in line with the national average. This has been confirmed by the medications optimisation team.

It should also be noted that local data was not always available for rarer neurological conditions which can make it difficult to make meaningful comparisons.
**5. LOCAL DATA**

An analysis of SUS data has recently been undertaken for the period April 2011 – January 2015 to assist with setting priorities and a work plan for the strategy.

During this time period there were 30763 total outpatient appointments for the Berkshire West CCGs recorded under the neurology specialty. The average number of appointments per month has risen from 629 in 2011/12 to 712 in 2014/15 (up to month 10). Each of the four CCGs has seen a similar increase. The majority of outpatient referrals have been from GPs (46.1%, n=14183) and non A&E Consultants (23.3%, n=7172).

An analysis of inpatient data was completed based on categorisations developed by the Neurology Intelligence Network to define adult neurological conditions (Public Health England, 2015). We chose to use these categorisations to enable comparisons to other CCG areas and to avoid duplication of work by creating a new categorisation. The biggest proportion of activity (23.3%) related to spondylotic myelopathy and radioculopathy but it is likely this will include patients from other specialties so further work will be undertaken based on individual diagnosis codes. Other categories which had high activity included tumours of the nervous system (16.6%), headache and migraine (11.7%), epilepsy (8.9%) and MS (6.9%).

It is important to also analyse secondary diagnosis data, as many patients with a neurological condition will be admitted for another primary reason (for example respiratory problems). This is highlighted using the Parkinsonism and other extra pyramidal disorders/tic disorders category which only makes up 1.8% of activity for primary diagnosis, but rises to 14.0% when looking at second, third, fourth or fifth diagnosis.

This data will be interrogated in more detail as further work is undertaken, for example to set baseline data and measure improvements for specific initiatives. Berkshire West CCGs are currently working toward developing a clear picture of the extent to which issues are affecting patients with neurological conditions locally. Implementation of the strategy will help us to achieve our strategic objectives and strong progress is being made to give us a strong foundation going forwards.

**6. ACHIEVEMENTS SO FAR**

Achievements so far includes:

- Identification of GP neurological leads within Berkshire West CCGs
- Ongoing work of the Long Term Conditions Programme Board including headache pathway review working group and headache pathway review
- Alignment to Berkshire West CCGs five year strategic plan
- Patient representation at neurology working groups and LTCPB
- Investments toward reablement and admission avoidance services
- Joint appointment of epilepsy nurses across both BFHT and RBFT
- Investment towards continence services
- Support to community services to maintain admission avoidance and timely discharge weekend cover for neurological nurses (£57k Call to Action funding for 2014/15)
- Engagement with the Thames Valley Strategic Clinical network to ensure coordinated working
- First neurology steering group well attended with good multidisciplinary engagement
- PDF grants for the MS Centre and West Berkshire Therapy Centre
- Pilot of an integrated and local Chronic Fatigue/Myalgic Encephalomyelitis service
- Review of access to OT services across Berkshire West and sharing of good care examples and models
- Local recognition of the work around neurological conditions from WBNA
7. NEUROLOGY STRATEGY STEERING GROUP

The Neurology Strategy Steering Group has been set up to finalise and implement with Berkshire West Neurology Strategy. They are accountable to the Long Term Conditions Programme Board in ensuring objectives are met and project benefits delivered. This is a multidisciplinary group comprising of colleagues from primary care, commissioning, providers, community pharmacy, the local authority, public health, the ambulance service and the Strategic Clinical Network. Importantly the group also includes the voluntary sector and patient representatives. Some of the healthcare professionals involved in the group includes GPs, Consultant Neurologists, Nurse Specialists and Occupational Therapists.

The responsibilities of the group will include:

- Coordinating and driving change
- Reducing duplication
- Developing engagement across organisations
- Agreeing objectives and approach for the programme
- Setting our priorities of the programme and developing individual work plans
- Ensuring each work stream is aligned to deliverables and milestones set out in each work plan
- Monthly monitoring of deliverables against project plan
- Production of a monthly highlight report
- Developing a framework which can facilitate good practice for other long term conditions
- Reviewing business cases and service specifications relevant to neurology as necessary, to ensure they align with the strategy and are escalated appropriately

Following the first Neurology Strategy Steering group meeting and a group discussion around priorities, proposed work streams have been documented below. This work plan aims to identify a number of issues presented both locally and nationally, enabling implementation of the strategic objectives.

8. STRATEGIC OBJECTIVES

Whilst recognising the wide range of services available to patients with neurological conditions, there is room for improvement. Although we are largely in line compared to our national counterparts, we should not be complacent. The strategic objectives have been identified through both stakeholder engagement and referenced papers.

Our strategic objectives will enable us to improve patient experience by utilising a multi-agency approach. We emphasise the need to focus on the following overarching objectives:

- There is effective triage and diagnosis for patients with new or changing neurological symptoms
- Increasing patient empowerment so patients feel more knowledgeable and confident in managing their conditions, are able to access care when needed and reducing feelings of isolation
- Ensuring patients benefit from seamless integrated care. focusing on the ability for patients to step up and step down reducing the need for emergency admissions and enabling better care in the community
- Whether patients are at home, being treated in the community or admitted as an inpatient, they continue to receive high quality care with appropriate access to appropriate healthcare professionals
- We have a better understanding of the data to better inform service delivery in line with the needs of the local population.
## 9. PROPOSED WORK STREAMS

### Work stream 1: Identify, Define and Improve Pathways

The Neurology Steering Group has firstly identified condition specific pathways for headache and epilepsy; two intermittent neurological conditions. This is due to activity data and the range of initiatives available for these patients.

A third pathway for review will be chronic long term conditions as a whole. Many patients with a variety of conditions will need access to similar services; and indeed the needs of two patients with the same condition may be very different depending on the progression of the disease. One size does not fit all. At the moment we will also map traumatic neurological injuries within this wider pathway as these patients too will need to access many of the same services; albeit sometimes for a shorter period of time. Once the pathway becomes clearer it may be logical to separate some conditions away from another again, but this must be in a way that enables the different services patients with neurological conditions use integrated.

A final pathway for consideration as an initial priority is that for functional neurological conditions. Functional diagnosis is important because patients may feel anxious they are being diagnosed simply because it was impossible to confirm an alternative diagnosis.

**Things to consider**

- Mapping of current pathways taking into account all services a patient may require access to across health and social care
  - Include mental health and psychological
  - Identify all access points to pathway, both elective and emergency
  - Consider out of area patients
  - Consider how young people transition into an adult pathway
  - Consider how the pathway is kept open for patients who may suffer relapses so it
  - Consider where services are available
  - Consider the impact any changes to specialised commissioning will have
  - Incorporate new and existing pathways for example NICE (various conditions), Strategic Clinical Network (Parkinson’s), Royal Berkshire FT (Epilepsy, MS relapse)
- Incorporate local voluntary sector and support groups into pathway
- Ensure deterioration and end of life are included in the pathways
- Review pathways to understand if adequate for patient needs and identify any gaps

### Work stream 2: Navigate the pathway

Whilst there are a good range of services available to patients with neurological conditions, we recognised it is not always easy to navigate the pathway and provide coordinated care for our patients and this is the next step. We need to ensure our patients have equal access to the pathway and do not get lost in between services. We cannot expect our patients to navigate the complex system themselves and need to be able to assist them.

**Things to consider**

- Sharing pathways with the relevant health care professionals including clear information about how patients can be referred into and across different services
  - Patients with the same neurological condition may require very different services and one size does not fit all. We need a ‘pick and mix’ approach
  - There is a clear information and a defined escalation route for seeking advice from specialist staff
• Development of a Directory of Services for health and social care staff to consolidate all information as necessary. Cornwall and Isles of Scilly Alliance of Neural-Domain Organisation (CAN-DO) have provided a good example of what this may include for neurology.
  o There has been some work in the local authorities around creating a directory of services locally. Through engagement with our social service members we will ensure work is again not duplicated.
• Use of care plans in neurology to stop patients needing to repeat themselves and ensure their wishes are adhered to as they deteriorate or begin palliative treatment. Patients with neurological conditions may find it harder to communicate or remember things. The steering group should learn from the respiratory care plans.
• Establishing who the single point of access for the patient can be
  o We need help identifying which parts of the pathway are relevant to each patient and help them to access it. The Clinical Nurse Specialists have provided this service to their patients. We need to consider who can provide this for other conditions such as neuro navigators or care coordinators
  o Establish how the voluntary sector can help patients to navigate the pathway
• Ensure all inpatients with a secondary neurological conditions also can benefit from the pathway and services available
• Consider any potential impact to waiting times for patients
• Ensure carers are included, regardless of whether they provide full or part time care for the patient

Work stream 3: Enabling Diagnosis in Primary Care

One of the key issues identified in creating this strategy and particularly from the patient feedback is getting a diagnosis. Any initiatives around diagnosis should be piloted carefully to understand patient outcomes and impacts on the system. There is also a need to make it clear to patients why they may not be referred to a specialist immediately, and explaining what they should be looking out for during a ‘watchful wait’ period.

We therefore need to do more to alleviate anxiety, reassure, understand any social impacts and increase patient engagement during this period. Problems with diagnosing patients will be more complex for some conditions. There are a number of factors to consider here and it is important we do not destabilise the healthcare system with an influx of referrals for example.

Things to consider
• Patient and clinician facing tools to assist diagnosis
  o Tools that will help identify patterns and keep patients engaged/reassured
  o This may include Headmat (currently being trialled in Wessex, clinician facing) or True Colours (currently being trialled in Oxford, patient facing)
  o This can include simple paper based tools such as diaries to monitor symptoms
• Joint referral reviews to identify areas of difficulty and increased shared learning
• Neurology “champions”, CCG leads and GPs with a special interest in Neurology (GPWSI)
• Some of the work in this stream may be applicable to the ambulance service, dentist, opticians and other professionals.
• Use of data to help target initiatives
• Ensuring patients have adequate social and psychological support during a period of unknown – what this support is must be considered carefully as it may be inappropriate to refer them to voluntary sector organisations or support groups before a diagnosis is confirmed.
• Ensure opportunities to learn from specialists are utilised for example the epilepsy specialist nurse will run educational sessions at practices.
  o We must take into consideration current pressures on GPs mean they cannot physically take up all opportunities available. However the evidence does indicate there is a greater need to improve training around neurological conditions.
Work stream 4: Patient facing resources for self-care and prevention

Although this is an equally important work stream, it is important to consider this area once sufficient work has been done on the three proceeding work streams. This ensures resources developed for patients are in line with what the healthcare system provides and we do not cause confusion to our patients by disseminating lots of changing information. We must be mindful of balancing what patients need to know now and what we can promote and assist with once the foundations are laid.

Things to consider

- Empowering patients to recognise when their physical or mental symptoms are bad and they require attention from health or social care professionals (i.e. they may need to come back into the pathway, be it temporarily or as part of longer term deterioration or end of life care)
  - It is therefore important the piece in work stream is complete around ensuring patients have a main point of contact they can go to
  - This must be clinically safe for patients
- Establishing a ‘patient friendly’ directory of services, potentially assisted by the voluntary sector
- Support getting patients back to work where possible
- Working with community pharmacy to help patient self-manage; this is particularly pertinent to headache
- Ensure resources for patients are not restrictive
  - Consider braille, large text and audio
  - Consider different languages to reflect our local communities
- Encourage patients to participate in exercise and leisure activities for physical and mental stimulation
- Increase awareness about psychological initiatives such as talking therapies
- Patients with neurological conditions may have trouble communicating effectively; consider the opportunities to assist patients with simple solutions like picture cards. These can also be used for patients in hospital.
- Consider multimedia packages and videos that patients can show their friends and family to help them understand what is like living with their neurological conditions
  - Consider exploring with the voluntary sector how these can be made if not available for certain conditions
- Again it is important to ensure carers are not forgotten

10. ACHIEVING THE STRATEGY: INTERDEPENDENCIES

There are a few interdependencies to consider during the implementation of this strategy. This includes:

- Implementation of the Care Act 2014
- Changes to Specialised Commissioning
- Development of integrated records including care plans
## Translating the strategy into operational plans

It is important to note that at this stage, whilst we can be clear on what we need to achieve, the how we achieve will be developed over time as part of the Neurology Strategy Steering group and there are still lots of questions to be answered. Whilst there will be some overlap between work streams, it is expected the majority of the work will need to be undertaken chronically. This is because pathways need to be defined and correct before we can effectively navigate them and offer useful meaningful advice for our patients.

The more progress we make through the work plans, the more noticeable changes will be and the more empowered our patients can become. The strategy will continue to evolve over time as engagement continues but the initial proposed work plan should build a strong foundation to start from. It is important to recognise that due to changes in best clinical best practice, technology and treatments are likely to change in this area of care, the strategy cannot be a rigid document and needs to be flexible to allow for the changing landscape.

### Technology

It is important that we align ourselves to the Berkshire West IM&T strategy as the work plans progress. This will also ensure we do not duplicate work yet be mindful about what is already ongoing including integrated electronic records and the use of DXS within primary care to promote referral methods, pathways and patient information once available. The Berkshire West Neurology Strategy should consider technology as an enabler wherever possible. A final thing to monitor in this area is the use of text message reminders for patients with neurological conditions.

### Shared Learning, Pilots and Outcomes

The steering group should continue to engage with the Strategic Clinical Networks to understand what initiatives have worked well elsewhere so we can learn from others and build on existing models. Literature reviews should also be undertaken to ensure evidence based practiced wherever possible.

To measure success, the steering group will need to agree metrics for various initiatives which should be a combination of quantitative and qualitative data including patient outcomes. It is important that pilots are undertaken to ensure the health care system is not destabilised.

### Strong Leadership in Project and Programme Management

Tight programme management is required for forward planning, vigilant monitoring of milestones, deliverables and expected benefits realisation. The Long Terms Conditions Programme Board (LTC PB) should take steps to ensure that sufficient time is taken to work through the overall programme milestones and ensure that enough resource is assigned to keep delivery of individual projects on track; this is particularly relevant for projects which require large-scale change involving multiple teams and which may present significant logistical issues. Tight project management is needed to avoid delays. Integration of services and systems is complex and difficult and requires consistent commitment, leadership and drive in order to achieve true integration.

### Finance

Any project requiring investment should be accompanied by a full business case to ensure financial calculations are robust before the project is authorised. Where the creation of a new service or other intervention is recommended, this may require up-front investment in order to mobilise the service, before funding is diverted or re-allocated to the service from other areas. This depends on the funds available from CCGs or the alternative sourcing of funds.

### Stakeholder engagement

Success in implementing pathway changes ultimately depends on the cooperation of provider and partner organisations therefore it is imperative that all stakeholders are fully engaged with any work-streams by which
they will be affected. Responsibility for implementation of projects may lie with provider organisations, depending on the type of project. We will also need to engage to promote a willingness to embrace change. Engagement should continue as part of the working group.

External Factors
It is important to changes to specialist commissioning in 2015 may alter the commissioning landscape. In addition CCG allocations or unexpected events requiring financial input may prohibit the implementation of the programme or particular projects requiring up-front or recurrent investment.

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CONTRIBUTORS TO STRATEGY

The author would like to thank the following for their contributions towards the development of this strategy:

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
<th>Organisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr Lindsey Barker</td>
<td>Clinical Director for Networked Care</td>
<td>Royal Berkshire NHS Foundation Trust</td>
</tr>
<tr>
<td>Dr Zameel Cader</td>
<td>Consultant Neurologist</td>
<td>Oxfordshire University Hospitals &amp; Chair of TV Neurological Conditions SCN</td>
</tr>
<tr>
<td>Dr Rosemary Croft</td>
<td>Lead of Mental Health</td>
<td>Berkshire West CCGs</td>
</tr>
<tr>
<td>Caroline Cross</td>
<td>Quality Lead</td>
<td>Wessex Clinical Senate and Strategic Clinical Networks</td>
</tr>
<tr>
<td>John Holt</td>
<td>Liaison Officer</td>
<td>West Berkshire Neurological Alliance</td>
</tr>
<tr>
<td>Nicola Hunt</td>
<td>GP Neurology Lead</td>
<td>North &amp; West Reading CCG</td>
</tr>
<tr>
<td>Carrie James</td>
<td>Lead Clinical Nurse Specialist Neurological Long Term Conditions</td>
<td>Royal Berkshire NHS Foundation Trust</td>
</tr>
<tr>
<td>Elizabeth Johnston</td>
<td>Former Clinical Lead of Neurological Conditions</td>
<td>Berkshire West CCGs</td>
</tr>
<tr>
<td>Eleanor Mitchell</td>
<td>Operations Director</td>
<td>South Reading CCG</td>
</tr>
<tr>
<td>Eva Morgan</td>
<td>Quality Lead</td>
<td>TV Neurological Conditions SCN</td>
</tr>
<tr>
<td>Dr Richard Perry</td>
<td>GP Neurology Lead</td>
<td>Wokingham CCG</td>
</tr>
<tr>
<td>Dr Maha Saeed</td>
<td>Locum Consultant Public Health</td>
<td>Wokingham Borough Council</td>
</tr>
<tr>
<td>Dr Anil Sagar</td>
<td>GP Neurology Lead</td>
<td>South Reading CCG</td>
</tr>
<tr>
<td>Catherine Sutherland</td>
<td>Service Manager for Neuro Rehabilitation</td>
<td>Berkshire Healthcare NHS Foundation Trust</td>
</tr>
<tr>
<td>Carol Valentine</td>
<td>Interim Locality Manager, Older Persons &amp; Disabled Adults</td>
<td>Reading Borough Council</td>
</tr>
<tr>
<td>De Heike Veldtman</td>
<td>GP Neurology Lead</td>
<td>Newbury CCG</td>
</tr>
<tr>
<td>Dr Andrew Weir</td>
<td>Consultant Neurologist</td>
<td>Royal Berkshire NHS Foundation Trust</td>
</tr>
<tr>
<td>Susan White</td>
<td>Head of Adult Services</td>
<td>Berkshire Healthcare NHS Foundation Trust</td>
</tr>
<tr>
<td>Dr Richard Wood</td>
<td>GPwSI</td>
<td>Oxford CCG</td>
</tr>
</tbody>
</table>