NHS

Thames Valley
Strategic Clinical Network

TRANSFORMING COMMUNITY NEUROLOGY

What Commissioners Need to Know
Part B – Reference Reports

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

**Thames Valley
Strategic Clinical Network**

Document Information

Part of a 3-document set.

Document version	1.0
Release date:	20 June 2016
Enquiries	steve.williams14@nhs.net

Further copies of this report can be downloaded from: http://tinyurl.com/CNPreport

Credits

Cover designed by Freepik (www.freepik.com)

NHS

**Thames Valley
Strategic Clinical Network**

CONTENTS

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

**Thames Valley
Strategic Clinical Network**

BACKGROUND

Intended Audience

This information will be valuable for commissioners and clinicians in Clinical Commissioning Groups (CCGs). It may also be of interest to Specialised Commissioning, service providers addressing neurological needs, and people living with neurological conditions.

Aims of this Guide

From April 2016 Clinical Commissioning Groups have responsibility for commissioning all GP-initiated outpatient services, and all non-specialised services for patients with neurological conditions (Specialised Commissioning will be responsible for inpatient care within neurosciences centres, consultant-to-consultant referrals and specialised drugs and devices).

The **Five Year Forward View**[a], published by NHS England in 2014, set out a future vision for the NHS based around new models of care. The vision calls for a radical re-think on traditional ways of providing care for neurology patients, focussing on locally-provided integrated care, organised around the patient. This is particularly relevant for people with long-term conditions, including those with neurological disorders.

This guide aims to support commissioners to develop their thinking and progress their plans to transform neurological care in line with the vision set out in the Five Year Forward View. It sets out principles to embed in local transformation programmes rather than prescriptive action lists, as every case will be different. Much of the advice is of relevance to a wider transformation agenda, beyond community neurology.

How to Use this Document

The information has been organised into three parts:

(A) The **Transformation Guide** sets out the **context and case for change** then introduces the **key features of new models of care**.

(B) This **Reference Reports** document presents the **original individual findings** written by the project's leads on the core topics, which informed the writing of the Transformation Guide.

(C) To illustrate what is already being achieved around the UK by using new models of care, a compendium of **Examples** is also provided.

---

[a] Available to download from https://www.england.nhs.uk/ourwork/futurenhs/

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

**Thames Valley
Strategic Clinical Network**

3

Report 1:

Identifying Patients' Needs and Priorities

Written by Joanne Ross, Assistant Director of Neurological Services, Sue Ryder

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

**Thames Valley
Strategic Clinical Network**

INTRODUCTION

It seems obvious that people living with long term conditions, and their unpaid carers, should be involved in the design, development, implementation and evaluation of the services that are intended to support them (LTCAS and Better Together, 2010:3). If services are to be person-centred and driven it is critical to obtain patient and carer views about their needs and priorities, including the types of care they regard as important and how they wish to manage their condition.

A plethora of guidance exists detailing what and how services for people with long term neurological conditions should be provided and recognises the importance of service user involvement in both the design and day to day delivery. Some of the literature and research available also effectively records the needs, priorities and experiences of people living with a neurological diagnosis in the community.

One of the most notable is the **National Service Framework for Long-term Conditions**. The Framework was developed through consultation with service providers, people with long-term neurological conditions and their carers, and revealed examples of high quality services but also great variation in levels of provision across the country.

In developing a person centred and coordinated model of care for people with a neurological diagnosis living in the community NHS England are seeking to address these variations in service provision and develop a credible model of community based delivery. In so doing it is critical to consider:

1. the needs and priorities of people, and their carers, living in the community with a neurological condition;
2. the outcomes that are meaningful to them;
3. mechanisms that may need to be implemented to ensure ongoing feedback on the effectiveness of services in meeting these needs.

NEEDS AND PRIORITIES

The National Service Framework for Long Term Conditions recognises that 'for many people living with conditions such as multiple sclerosis or Parkinson's disease the main issue, until science can find a cure, is improving the quality of their lives, supporting them to manage their symptoms and live as independently as possible' (Department of Health, 2005: 5). It is recommended that the 11 quality requirement headings contained within it form the basis of a structure to describe the needs and priorities of people living with a neurological diagnosis in the community:

A Person-centred Service

There is growing evidence that approaches to person-centred care such as shared decision making and self-management support can improve a range of factors including patient experience, care quality and health outcomes (The Health Foundation, 2014:11). Research has demonstrated that when people play a more collaborative role in managing their health and care they are less likely to use emergency hospital services (De Silva, 2011), are more likely to stick to their treatment plans (De Silva, 2012) and take their medicine correctly (National Institute of Health and Care Excellence, 2009).

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

Thames Valley
Strategic Clinical Network

It is now widely recognised that effective care planning and coordination is an essential aspect of care for people living with a long term health condition. The National Service Framework for Long-Term Conditions recommended that 'people with long-term neurological conditions are offered integrated assessment and planning of their health and social care needs' (Department of Health, 2005:4), however despite this Neurological Alliance survey data suggests that fewer than 30% of people living with a neurological condition have been offered any form of care plan to help manage their condition (Neurological Alliance, 2015:5).

The literature suggests that people want to be involved in the planning of their care and have choice and control about how they live and die with their condition. Interviews undertaken with people with a neurological diagnosis by the University of York 'illuminated the importance participants ascribed to being involved in and making decisions about different aspects of their lives' (Aspinal et al, 2014:68).

As identified in the National Service Framework (Department of Health, 2005:4) people with long term neurological conditions stipulated that in order to make decisions about their care and support they need to have the right information available. This is substantiated in the research undertaken by Aspinal et al (2014:69), where participants suggested that having the right information available whether it be about their condition, local services or support groups was critical if they were to be effectively involved in the planning of their health and social care needs.

The literature identifies access to information as a key failing in current service provision and therefore something that people with a neurological diagnosis living in the community and their carers highlighted as a key need/priority. For example, consultation undertaken by NHS West Hampshire Clinical Commissioning Group (2013:7) found that 78% of respondents were concerned about the lack of information available on their condition, its management and awareness of services available. A survey on behalf of the Motor Neurone Disease Association also identified the provision of more information as a key area of focus for improvement (Attwood and Hopwood, 2013:5).

Community Rehabilitation and Support

The National Service Framework recommends that people with long term neurological conditions living at home, defined as the place where the individual chooses to live which may be their own accommodation or may be a residential or care home, should have 'ongoing access to a comprehensive range of rehabilitation, advice and support to meet their continuing and changing needs, increase their independence and autonomy and help them to live as they wish' (Department of Health, 2005:4).

From the literature it is possible to deduce two key areas of need and priority from a service user and care perspective: access to community neurological rehabilitation services and support and the importance of a coordinated, multi-disciplinary approach to care and support that includes a single point of contact to ensure that people are able to easily navigate and access the services they need.

Access to high quality community rehabilitation and support services

Short and long term neuro-rehabilitation services and support in the community are cited time and time again in the literature as an area that people living in the community

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

Thames Valley
Strategic Clinical Network

with a neurological diagnosis and their carers consider to be insufficient and a key area of need.

A research study by Gladman et al (2007:5-6) gathered the views of more than 200 service users, medical staff and commissioners of services. This study found that service users felt longer term care was 'severely lacking' and that services which address longer term needs, including issues around mental well-being and community reintegration are limited.

The study identified that people wanted 'easier access to services'. It was reported that 'access to services varies considerably depending on a person's condition, where they live and what stage of care they are at'. Access was also considered 'too inflexible' and an example was given of a woman with multiple sclerosis who needed adaptive rehabilitation and was refused therapy because the service criteria required her to be able to get better.

An engagement exercise in West Hampshire to understand experiences of current services from the perspective of service users, carers and health professionals identified insufficient short and long term neuro-rehabilitation services and support in the community as a key theme. Service users highlighted the importance of neurological specific teams with the right expertise and knowledge of neurological conditions and commented that intervention from generic rehabilitation teams had been unhelpful. Others emphasised the long term nature of neurological rehabilitation and explained that they had been offered a short term block of rehab following diagnosis and that this had been difficult to re-access when their condition deteriorated (NHS West Hampshire Clinical Commissioning Group, 2013:25-27).

Rapid access or re-entry to services is commonly cited by service users in the literature as a priority area given that the needs of someone with a long term neurological condition can deteriorate or progress rapidly. The National Service Framework for Long Term Conditions references the importance of community rehabilitation services offering a 'rapid and co-ordinated service to provide care and support, including specialist emotional support for the person and their family, as their needs and circumstances change' (Department of Health, 2005:37). Service users and health professionals in West Hampshire also said that one of the key priorities should be to enable rapid access or self-referral to specialist advice (for patients and professionals) when the person's condition exacerbated to avoid inappropriate emergency hospital admission (NHS West Hampshire Clinical Commissioning Group, 2013:16). NHS East Midlands Strategic Clinical Network recommends this approach in their commissioning guidance for a community based rehabilitation service for people with long term neurological conditions. They suggest that people with a long term neurological condition should be 'permanently kept on the books...' and '...able to refer themselves directly back into the service as their needs change' (NHS East Midlands Strategic Clinical Network, 2015:21).

Integrated coordinated community care

The literature commonly references the need for coordinated or integrated services for individuals with a long term neurological condition within the community. The importance of integrated care is included within the National Service Framework for Long Term Conditions, which recognises that good community rehabilitation is most effective when 'health and social care bodies work collaboratively with each other'.

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

Thames Valley
Strategic Clinical Network

(Department of Health, 2005:36). A report by Sue Ryder emphasises the complex care require requirements of those with a neurological condition and highlights the need for a 'truly integrated approach to care provision' that will 'utilise services from health, social care, housing, transport and welfare' (Sue Ryder, 2012:4).

Service users often cite frustration with the lack of joined up working and poor communication between health professionals and services. For example, service users in Dudley, expressed the importance of all professionals knowing what is available and described current services as 'very bitty' (NHS Dudley Primary Care Trust and Dudley Metropolitan Borough Council, 2009:13). This lack of coordination manifests in people feeling that there is no continuity of care when services are needed from a range of providers (Gladman et al, 2007:5).

Various sources recommend a multi-disciplinary approach to community based neuro-rehabilitation services. For example, a panel of expert service users participating in a review of service use in people with a rare long term neurological condition reached a consensus that a 'multidisciplinary approach to rehabilitation was essential' (Hoppitt et al, 2011:60). These views are supported in studies that have shown that multidisciplinary clinics are better than standard neurological care for length of survival and for quality of life (Traynor et al, 2003). Further studies have shown that service users and carers value multidisciplinary teams and case coordinators (Soltysiak, 2008).

Other sources highlight the benefits of a multi-disciplinary approach. NHS East Midlands Strategic Clinical Network suggest that a 'coordinated community-based neurological rehabilitation service would improve quality of outcomes and at the same time reduces costs' (NHS East Midlands Strategic Clinical Network, 2015:4). The Oxfordshire Neurological Alliance (2014:28) also discusses the efficiencies that would be created from this approach and state that 'individual practitioners may be offering appropriate interventions in isolation but by bringing multi-disciplinary and multi-agency expertise together in the form of teams, this will add value to individual contributions and promote communication and efficiencies of service'. The Royal College of Physicians, National Council for Palliative Care and British Society of Rehabilitation Medicine (2008:3) write that 'there is strong evidence that multidisciplinary rehabilitation can improve the experience of people living with a long-term neurological condition, both at the level of functional activity and societal participation'.

Care coordination and a single point of contact within a community neurology service was also muted by service users and carers as a key priority that would facilitate a more coordinated approach to care and considerably improve their experience and continuity of care (Oxfordshire Neurological Alliance, 2014:28).

Aspinal et al (2014:36) found 'effective co-ordination of services and joined-up working within the team was often seen [by service users] as key to finding solutions to problems which could be multifaceted'. Service users and carers in Dudley advocated for the GP to have more input into the coordination of care (NHS Dudley Primary Care Trust and Dudley Metropolitan Borough Council, 2009:13), whereas NICE Guidelines for Parkinson's Disease recommend that 'people with Parkinson's Disease should be offered an accessible point of contact with specialist services. This could be provided by a Parkinson's disease nurse specialist' (National Institute for Health and Care

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

**Thames Valley
Strategic Clinical Network**

Excellence, 2006:9). The Royal College of Physicians, National Council for Palliative Care and British Society of Rehabilitation Medicine (2008:9) also provide guidelines that specifically recommend 'general service coordination'. This recommendation states that 'Neuro rehab and palliative care services should develop closely coordinated working links to support people with long term neurological conditions from diagnosis to death, including proper flow of communication and information for patients and their families, a designated point of contact for each stage in the pathway and a needs assessment identifying the patient's individual problems'.

Vocational Rehabilitation

The National Service Framework for Long Term Conditions calls for people with long-term neurological conditions to have 'access to appropriate vocational assessment, rehabilitation and ongoing support, to enable them to find, regain or remain in work and access other occupational and educational opportunities' (Department of Health, 2005:4). Research undertaken in this field suggests that during the ten years after diagnosis 50-80% of people with MS will be out of work (Sweetland, 2010:30).

The literature reviewed supported vocational rehabilitation being an area of need as expressed by those with a neurological condition, however largely in the context of maintaining emotional/mental health and well being. For example, Aspinal et al (2014:64-65) found that 'only a minority of interviewees were in paid employment' and 'even where there was an aspiration to enter employment, their condition meant it may not be fulfilled…whether in work or not, participants talked about the role work played in their lives…paid work not only gave a sense of purpose but contributed to self-esteem and feeling valued'. Interestingly this study also found that the majority of people interviewed did not view access to training and further/higher education as important or relevant to them, although for some access to such activities were seen as a 'source of personal fulfilment, keeping motivated after stopping work or as a way of 'just keeping the cogs going'.

Providing Equipment and Accommodation

The National Service Framework for Long-term Conditions (Department of Health, 2005:4) advocated that people with long –term neurological conditions would receive 'timely, appropriate assistive technology/equipment and adaptations to accommodation to support them to live independently, help them with their care, maintain their health and improve their quality of life'. Unfortunately, a National Audit Office report on End of Life found that because of the progressive nature of neurological disease, delays in diagnosis, lack of coordination and difficulties identifying a single point of contact mean the equipment and support needed to help patients and their carers live independent lives as long as possible can be delivered too late and be of limited use, if not redundant, when they arrive' (National Audit Office, 2008:52).

Hoppitt et al (2011:141) interviewed people with a range of 'rare' neurological conditions to identify the proportion of people receiving specific adaptations, aids and assistive technology. Their findings showed that 71% of respondents had some form of home adaptation, whilst over three-quarters had received assistive aids. The proportion who received assistive technology appeared low. The findings also identified that over half of patients who received home adaptations and assistive aids

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

**Thames Valley
Strategic Clinical Network**

contributed financially. This is corroborated by a survey of people with Motor Neurone Disease, which found that when home adaptations are required the majority of respondents self-fund either in whole or part (Attwood and Hopwood, 2013:32).

The Parkinson's Disease Society Survey (2008:26) found that at least one in five of respondents had purchased aids and equipment on their own initiative rather than seeking professional advice. When people were asked about the local authority services they had received over the last two years, nearly one in ten of them said that they had not received, but needed professional help and advice about housing adaptations.

Aspinal et al (2014:53-69) also found that a key need expressed by people with a long-term neurological condition was obtaining timely access to equipment and adaptations. This manifested in a number of different ways including adaptions that would facilitate personal hygiene, such as having a shower stool; home adaptations such as the installation of grab rails or care alarms that would facilitate both independence in getting around the house and personal safety. Equipment and adaptations themselves were important, but for many people it was also important that they were able to exert choice in this significant area of personal decision-making. For some participants, this was about the type of equipment or adaptations that they felt they needed or that were acceptable, for example a lighter wheelchair or type of bathroom fittings. For others, choosing and self-funding equipment and adaptations were related to avoiding long waiting times for statutory provision and having control over the timings. The importance of coordination across health and social care teams in both assessing the need for equipment and adaptations and obtaining them was also noted.

Providing Personal Care and Support

The provision of personal care and support is an area of key need expressed by those living in the community with a neurological diagnosis and their carer and appears to be received by a number of different means including health and/or social care, privately funded care and support or voluntary sector provided care and support. Regardless of the source of care provision it is undoubtedly an area that is key to ensuring that people with a long term neurological condition and their family/carer are able to maintain a sense of dignity and independence.

The National Service Framework for Long Term Conditions (Department of Health, 2005:47) highlights the importance of the individual being able to exercise choice and control about where and how they live. Being informed and able to arrange care simply and that enables an individual to live life as they choose is also one of four key outcomes identified by the Neurological Alliance in their forthcoming ambitions strategy and is informed by a service user survey conducted in 2015. Access to a person-centred care plan, co-produced with the individual and their family/carer as required is key to achieving this outcome and the Ambitions Strategy calls for patients to have the opportunity to actively participate in the development of their care plan, supported by a named health and social care professional, to enable them to choose the support they receive and ensure they are able to live life as they choose. Care planning is also covered in some detail in section 2.1.

Aspinal et al (2014:53) identify 'personal comfort' outcomes as one of four domains that participants of the study highlighted as being important to them. The personal

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

Thames Valley
Strategic Clinical Network

comfort domain includes a range of areas relating to functional capabilities and physical and emotional health: personal hygiene, safety/security, desired level of cleanliness of home, emotional well being and physical health.

In this study well-being was often implicated in the importance that participants ascribed to personal hygiene. For example, some of those who were independent, or described being mostly independent in their care routines, talked about how being able to be independent in personal hygiene meant 'maintaining control' and avoiding a sense of 'degradement' (Aspinal et al, 2014:53).

With regards safety and security participants talked about adapted routines or developed strategies to counteract potential risks to personal safety and house adaptations and use of equipment as a means of facilitating personal safety. The majority of participants indicated that independence was more important than personal safety and gave accounts of risk-taking, with people willing to take risks in order to maintain independence and control in their lives (Aspinal et al, 2014:53).

Emotional well being and mental health is cited frequently as a key need and priority for those with a long term neurological condition and is also described as a key need and priority for carers, which is covered in more detail in section 2.7.

A panel of expert service users identified that mental health difficulties, such as depression and low self-esteem, as well as feeling isolated were common amongst those with a neurological condition and are related to changes in lifestyle or disability.

The panel further identified that the need for support to reduce the risk of isolation, loneliness and promote mental health and well being was high and should include counselling or some kind of psychological support following diagnosis (Hoppitt et al, 2011:58-60). These findings are substantiated in the study undertaken by Aspinal et al (2014:54) where those interviewed talked 'less about emotional difficulties and more about their personal resilience. Some also recounted experiences of longer-term mental health issues'.

The literature would suggest that many of the support services provided to help people self-care and promote emotional/mental health and well being are provided by the voluntary sector and are considered to be a key priority for people living in the community with a neurological condition and their carers. Bernard et al (2010:14) obtained the views and experiences of staff and people with long term neurological conditions in six case study sites and identified that day services offering peer support, social and leisure opportunities, as well as access to meaningful activity and/or learning and employment opportunities were highly valued and contributed to the experience of continuity of care.

The Oxfordshire Neurological Alliance patient survey (2014:22) found that the charity/voluntary sector was the second most common source of contact accessed after the GP to help people manage their condition. Bernard et al (2010:15 and 137) also concluded that 'voluntary sector organisations, particularly those with a focus on specific neurological conditions, were central to the delivery of continuity of care in integrated neurological care delivery', although highlighted that reliance on funding 'can become problematic' and therefore jeopardise sustainability of services.

In summary, the provision of personal care and support covers a multitude of care and support service options, but is both valued and considered an important aspect of

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

Thames Valley
Strategic Clinical Network

provision by people with a long term neurological condition. The importance therefore of people with a long term neurological condition being enabled and supported to choose their own care and support options is evident from the literature and reiterates the significance of them co-producing their care plan and being involved in key decision making about their care and support.

Palliative Care

The National Service Framework recommended that 'people in the later stages of long-term neurological conditions are to receive a comprehensive range of palliative care services when they need them to control symptoms, offer pain relief, and meet their needs for personal, social, psychological and spiritual support' Department of Health, 2005:5).   Unfortunately, the literature suggests that proper palliative care is not currently being provided for people with a long term neurological condition despite this being one of the key recommendations of the National Service Framework for Long-term conditions (Hoppitt et al, 2011:13).

The GP Patient Survey (GP Patient Survey Online, 2015) is a rich source of information and demonstrates the lack of palliative care as recommended by the National Service Framework. For example: 33% of people with a long-term neurological condition report the highest levels of pain and discomfort (either extreme or severe) amongst those with a long-term medical condition.

The National End of Life Care Intelligence Network (2010:11) found that the place in which a person dies varies largely on the type of neurological condition he or she has:

- About half of people with a neurological condition die in hospital. This compares with a national average of 58%;
- 3% die in a hospice. This compares with a national average of 5%;
- 25% of Motor Neurone Disease/Multiple Sclerosis deaths occurred at home, compared with 9% of people with Parkinson's disease who die at home;
- One third of Parkinson's disease/Huntington's disease deaths occur in a nursing home.

A survey of healthcare staff providing palliative care to people with long term neurological conditions would seem to support the notion that people with a long term neurological condition don't always die in the place of their choice. Staff interviewed perceived that 'identifying the dying phase was a particular challenge, sometimes resulting in patients being admitted to hospital at the end of life in contravention of their expressed advance wishes for place of death' (Wilson et al, 2011).

The Neurological Alliance patient survey (Neurological Alliance, 2015:47) revealed that only 1.2% of those surveyed had regular contact with a palliative care team to help manage their condition. A lack of palliative care provision and support is substantiated in a number of other surveys including the MND Association's patient survey (Attwood and Hopwood, 2013:10), which found that a third of respondents were not given information about the choices and options available at the end of life and stated they would have like this opportunity and a third of respondents had discussed end of life issues with a care professional. Hospice or palliative care team members were overwhelmingly the most popular choice for most respondents to discuss end of life issues with, followed by a member of hospital staff and GPs.

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

**Thames Valley
Strategic Clinical Network**

The above evidence not only suggests a lack of provision and understanding of the importance of palliative care for people with a long term neurological condition, but a lack of advance care planning.   Advance care planning is widely recognised as the 'key means of improving care for people nearing the end of life and of enabling better planning and provision of care' (The Gold Standards Framework Online, 2016), yet worryingly, the National Council for Palliative Care (2009:1) found that 63% of people with a neurological condition when surveyed 'were not asked whether they had an advance care plan or advance decision to refuse treatment during their stay in hospital'.

A recommendation that it is important for community-based service providers to recognise that people affected by progressive LTNCs can benefit from a palliative care approach is given and that careful planning, in which judicious referral to specialists in palliative care may be required, can pay dividends in terms of quality of life, service coordination and effective use of resources as the end-of-life approaches (Hoppitt et al, 2011:63).   In summary it would appear that incorporating advance care planning and palliative services within a community neurological service is needed to ensure that people are able to express their wishes as to how they choose to die to support them to live a quality life until that time and experience a good death.

Supporting Family and Carers

Many people living with a long-term neurological condition depend on support from partners, family and friends to manage their condition. In 2003 the Neurological Alliance estimated that approximately 850,000 people in the UK care for someone with a neurological condition (Neurological Alliance, 2003:7).

The experiences and therefore needs of people caring for someone with a neurological condition are not widely documented, however the MND Association and Parkinson's Disease Society have undertaken carers surveys that demonstrate that the caring role has a significant impact on the lives and health of carers.

The carers survey undertaken by the MND Association (Fitzgerald, 2015:4 and 16) found that:

- 56% of carers spend more than 100 hours per week caring;
- 19% are not in work because of their caring role;
- 64% receive no state benefit or carers allowance.

The Parkinson's Disease Society carers survey (2008:30 and 32) established that:

- 75% of carers responding said they had been caring for 3 years or more;
- Just over half of carers felt that their own physical or mental health had deteriorated since living with or caring for someone with Parkinson's. Of those, nearly nine out of ten reported stress or fatigue.

Carers of people with a neurological condition carry out an enormous variety of roles, from physical tasks, including personal care and lifting and hoisting, to emotional support, to help with practical/everyday jobs (Fitzgerald, 2015:10). A research study conducted by Aspinal et al (2014:159) found that 'carers were providing high levels of personal care, assisting with washing, dressing, and toileting' as well as emotional support and adopting an advocacy role. Carers reported that the role of carer of somebody with a neurological condition had a significant impact on all aspects of their

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

**Thames Valley
Strategic Clinical Network**

life including their relationships within and outside the family, physical and emotional well-being, employment and financial situation.

The National Service Framework for Long-term Conditions (Department of Health: 2005:5) recommends that carers of people with long-term neurological conditions are to have access to appropriate support and services that recognise their needs both in their role as carer and in their own right. Although the literature is fairly limited in this area it is possible to identify 3 key areas for improvement: recognition of the role of carer, single point of contact and carer support services.

Recognition of the role of carer

A patient experience survey undertaken by Oxfordshire Neurological Alliance found that carers were the third most regular contact for people with a neurological condition. The report of the findings recommended that carers should be recognised as 'equal partners in care and enabled to carry out their vital role'. It also stated that the patient and carer experience would be enhanced if carers were fully engaged in the planning and development of their own support and of the services for the people they care for (Oxfordshire Neurological Alliance, 2014:24).

A carer of somebody who is disabled, ill or elderly is entitled to an assessment of their needs under the Care Act 2014. It is unknown how many people caring for someone with a long term neurological condition have, or have been offered, a Carers Assessment, however the Motor Neurone Disease Association and Parkinson's Disease Society Carers Surveys found that 33% and 29% respectively were unaware of their rights to a Carer Assessment (Fitzgerald, 2015:14 and Parkinson's Disease Society, 2008:32).

NHS West Hampshire Clinical Commissioning Group (2013:32), when surveying local GPs, identified that 'some practices don't even register carers, have no records of who do the caring and no lead practitioner who is responsible for the combined well-being of carer and cared for'.

Single point of contact

A number of reports accessed suggested that people with a neurological diagnosis living in the community and their carer deemed access to a named health professional or single point of contact who can help coordinate the services and support they need as a key priority. These findings are substantiated by Neurological Alliance survey data (2015:45), which found that only 44.5% of people were very satisfied or satisfied with the information given about their care and treatment options and 47.4% very satisfied or satisfied about the information given about the contact details for a named healthcare professional in charge of their care.

The Oxfordshire Neurological Alliance survey (2014:4) also recommended a single point of contact to support those with neurological conditions (their family and carers) to navigate through the journey of health and social care and (where possible) to reintegrate within the community.

Carer support services

Carer support services are commonly cited in the literature as vital if carers are to continue supporting their cared for and subsequently saving the statutory sector

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

Thames Valley
Strategic Clinical Network

considerable amounts of money and resources that would otherwise need to be put to this task (Oxfordshire Neurological Alliance, 2014:16). Many examples of such services are in existence and are largely provided by the voluntary sector. A nationwide survey on neurological care in Ireland found that 81% view voluntary organisations as essential or very important in providing services and support (Neurological Alliance of Ireland, 2011:1). Unfortunately, many of these services rely on fundraised monies to survive, which fails to guarantee security and sustainability.

In the literature carers identify the following types of service as valuable or priority:

Respite:

Respite is commonly cited in the literature as something that carers need access to. Aspinal et al (2014:161) found that some carers acknowledged the cumulative impact of caring as time went by, and that they would welcome practical assistance, opportunities for a break, or to work part-time.

Jackson et al (2011:73-74) have undertaken a comprehensive study on the provision of replacement care, interviewing some 140 carers of people with a neurological condition. This study identified that the main reasons for use and potential benefits for carers included, 45% accessing respite services so they could work and 84% said they would use day or home-based services so that they could take time off for rest/relaxation or leisure.

Key findings include that only 50% of the carers interviewed had used respite/replacement care services, either because they did not know about them or because the adult they cared for was not happy about the idea.

This study identified a number of barriers to using respite care including the perception that 'young people would be placed in elderly care settings with a lack of stimulating age appropriate activities and companionship' and 'bureaucratic delays, with others being deterred by the complexity of paperwork and processes' Jackson et al (2011:82). A substantial level of unmet need for respite/replacement care was therefore identified and a hypothesis reached that if the barriers cited could be surmounted the proportion of carers who would want to use services would rise from 51% to 91% Jackson et al (2011:xiii).

Jackson et al (2011:xiv) make many excellent recommendations in respect of respite care for those with neurological conditions. Of relevance to a community model of care the report recommends ensuring that information about respite care is made available to all carers at the time of their Carer's Assessment and health, social services and the voluntary sector should work collaboratively to develop appropriate day-care services across a geographic area which can accommodate the range of needs of adults with LTNCs and cater for people across a range of ages.

Practical and emotional support:

88% of carers reported that getting expert practical advice or health and social care services as 'very' or 'fairly' important (Parkinson's Disease Society, 2008:30). The MND Association (Fitzgerald, 2015:13) found that only 37% of carers felt they received the help and information they need.

The period after diagnosis is identified in a number of documents as being an area of priority as expressed by those with a neurological condition, including their carers.

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

Thames Valley
Strategic Clinical Network

Hoppitt et al conducted research in 2011 via an expert panel of service-users recruited through disease charities and found consensus that 'information, advice, and follow-up appointments after diagnosis were seen as important in informing patients and carers about the types of services that are available, and when they might need them' (Hoppitt et al, 2011:60).

The social isolation of caring for someone with a neurological condition was also evident and for some led to frustration, increased stress and depression (Aspinal et al, 2014:161). Services aimed at promoting mental health, wellbeing and resilience, such as peer support and counselling were therefore identified as a key need.

In summary it is crucial that carers needs are considered in the development of a community neurology service to ensure that the cared for can continue to remain in the community for as long as possible. In order for this to happen, carers need to be supported to manage their caring responsibilities with confidence and in good health. This can be achieved through the provision of a range of carer support services, specifically to support the complexities associated with looking after somebody with a neurological condition.   Information, support and tangible practical services are required to be provided by organisations that have the specialist knowledge to do so (Oxfordshire Neurological Alliance, 2014:28).

MEANINGFUL OUTCOME MEASURES

A multitude of tools exist to measure clinical and functional outcomes and are commonly used across services providing neurological care. These include the Goal Attainment Scale, FIM and FAM, Northwick Park Dependency Score, etc. A range of service standards also exist such as the British Society of Rehabilitation Medicine Standards for Rehabilitation Services (2009), however this literature review is focussed on user centred or personal outcomes, i.e. the things that people with a neurological condition living in the community, their carer, family member or other associated stakeholders have described as being meaningful to them.

The term 'outcome' is now in common usage in health and social care, reflecting a commitment to ensure systems support people using services and unpaid carers in ways that are person centred and effective. Despite the prevalence of the term, confusion exists about what is meant by an outcome and in particular by 'user-centred' or 'personal outcomes' (Cook and Miller, 2012:7).

There is a dearth of literature on user centred or personal outcomes for neurological services. The National Audit Office (2015:26) noted that 'there is limited specific coverage of neurological conditions in the NHS outcomes framework…. People with neurological conditions are represented within a number of broader indicators in the NHS outcomes framework, but their outcomes are not monitored separately.

Research funded by the National Institute for Health Research aimed to understand what outcomes people with long-term neurological conditions (LTNCs) want to achieve and how a list of these outcomes could be used by health and social care staff working together. This research categorises outcomes into three key areas: personal comfort outcomes; economic and social participation outcomes and autonomy outcomes.   Interestingly this research not only determines the outcomes that are important to those with a long term neurological condition, but also details what carers stipulate as being important to them. The research concludes that 'outcomes that go

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

Thames Valley
Strategic Clinical Network

beyond the clinical and functioning aspects of health are likely to be equally, or more, important to people with LTNCs…The outcomes service users wanted to achieve ranged from those focusing on health benefits and improvements to wider social outcomes concerned with more everyday aspects of life. Importantly, outcomes could be framed in the context of a deteriorating or fluctuating condition, such that they might be about maintaining a level trajectory rather than requiring specific improvements' (Aspinal et al, 2014: 51).

Other tools to measure non Neurological personal or user-centred outcomes have been developed and are in widespread use across a range of services and conditions. One such example is the Joint Improvement Team (JIT) in Scotland who have developed 'Talking Points', a personal outcomes approach that focuses on the identification of outcomes desired by users themselves. These are defined and measured according to three categories:

- Maintenance or quality of life outcomes – includes being as well as you can;
- Change outcomes - focus on short term removal of barriers to quality of life or improving wellbeing;
- Process outcomes – focus on how services are delivered, or how people feel they have been treated.

The Joint Improvement Team define personal outcomes as being 'about the impact or end result of services, support or activity on a person's life'. Most importantly they recognise that in order to focus on outcomes the person needs to be involved in 'identifying what is important to them…This means that the conversation is important, to work out what matters to the person and what needs to change' (Cook and Miller, 2012:7).

The Neurological Alliance (2012) has undertaken some excellent work in this area and has worked with its stakeholders to understand the outcomes that really matter for people with neurological conditions. They have developed a set of 'intelligent outcomes' linked to the NHS Outcomes Framework (Department of Health, 2014) that could be used to monitor 'the step-change in the quality of neurological services that is needed' and recommend three different forms of outcome measures:

- Overarching measures – these cross-cutting measures cover the outcomes that are expected for all NHS patients, regardless of their condition or specific health needs (eg waiting time measures);
- Overarching measures, disaggregated for neurological conditions – these measures, which are also cross-cutting, can relate to specific aspects of care, such as the provision of personal care plans, but require specific measurement for different cohorts of patients (e.g. people with neurological conditions);
- Neurology-specific measures – these measures relate to the outcomes that are required specifically for people with neurological conditions (e.g. time taken to reach a stable neurological diagnosis).

Bernard et al (2010:28) pertinently conclude that 'outcomes that might have real meaning to service users were largely notable by their absence'. Despite this it is possible to recommend that the effectiveness of a community based model of neurological care must be measured according to the outcomes service users want to achieve from both a clinical and personal aspect and address the needs and priorities

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

Thames Valley
Strategic Clinical Network

identified in this report. It is suggested that a good starting point would be to develop a set of outcome measures in consultation with service users, once the model of care has been agreed, using the Talking Points approach as a framework.

OBTAINING PATIENT FEEDBACK

Developing effective mechanisms to obtain patient feedback will be critical in both informing the development of models of community neurological care, but also their ongoing improvement to ensure they meet the needs and priorities of those who use them.   It is however undeniable that establishing meaningful patient and carer involvement and obtaining feedback may be challenging due to the need to cater for the varying limitations associated with long term neurological conditions. For this reason, it is probably unsurprising that the literature in this area is fairly limited.

This section of the report therefore seeks to share a number of best practice examples both specific and non-specific to neurological conditions that may inform the development of an effective mechanism to capture the views of those accessing a community based model of neurological care.

Patient Experience Surveys

Surveys are perhaps one of the most common ways of obtaining patient feedback and experiences and are extensively used across healthcare. They are the 'best method of gathering feedback when you want to know the views of a large number of people' and will provide quantitative data, which will allow the study of patterns and trends, as well as qualitative data should the design allow for it (Picker Institute, 2009:2).

A number of national NHS patient surveys are in existence, are mandated across the country and take place on a regular basis. These are particularly valuable as they help to not only enable changes over time to be monitored but performance to be compared across a number of provider organisations and geographies.   These tailored surveys enable specific areas of care to be examined including different care settings, such as inpatient or emergency care or can be condition specific, such as the National Cancer Survey. These surveys can be particularly influential in terms of leading to service improvement as they are commonly used by commissioners and regulators as an indicator of performance.

Clinical audit tools and disease registries, although not a patient experience survey, are perhaps worthy of comment here too.   The Neurological Alliance (2013:8) have suggested that 'it is possible to draw on best practice from other condition areas such as cancer and cardiovascular disease in order to establish a mechanism to inform service improvement and deliver better outcomes for patients. Tools such as patient experience surveys, disease registries and clinical audit tools have all been tried and tested and have helped to drive progress for a number of different patient groups'. The Sentinel Stroke National Audit Programme (SSNAP) is a good example of this.

Unfortunately, there is not currently a national NHS patient experience survey, clinical audit tool or disease registry specific to neurological services – the closest we have is perhaps the UK Rehabilitation Outcomes Collaborative, although the NHS England GP Patient Survey (2015) does allow for identification of individuals with neurological conditions, meaning that they can be compared against people with other conditions

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

**Thames Valley
Strategic Clinical Network**

to see how outcomes vary. An online analysis tool is also a good example of how the data can easily be analysed and compared.

A number of patient organisations also undertake regular national surveys, which are particularly helpful in identifying the needs and priorities of people with neurological conditions, how services have progressed over time and where service improvement effort needs to be focussed. Although these tend to be condition specific they still provide useful context and help to build a picture of the experiences of those with neurological conditions. Examples include the Motor Neurone Disease Association Care Survey, 'Improving MND Care', which is undertaken bi-annually and was last published in 2013 (Attwood and Hopwood, 2013). Parkinson's UK undertake the 'UK Parkinson's Audit' (Parkinson's UK Online, 2015), which helps healthcare professionals measure their services for people with Parkinson's against national guidelines. The Neurological Alliance also published the results of their patient experience survey and commissioning audit, 'The Invisible Patients: Revealing the state of neurology services' in 2015, which is perhaps the first and most comprehensive survey across neurological service users, their carers and patient organisations in England.

Given the communication, cognitive and functional impairments that result from neurological conditions and the need to support family and unpaid carers (as identified in section 2) it will also be important to capture the experience of families and carers. The Motor Neurone Disease Association undertook a Carer's Survey in 2015 (Fitzgerald, 2015) and other patient organisations have captured carer statistics such as the Parkinson's UK survey in 2008.

Generic, national carer surveys are also undertaken. For example, Carers UK undertake an annual survey of carers to collect evidence on a whole range of issues affecting carer's lives (Carers UK, 2015). Edge Hill University (2014) have also developed the Carers Alert Thermometer. The thermometer is an alert to identify and support the needs of unpaid carers providing end of life care at home. The alert consists of 10 questions, suggestions of the next steps to be taken for any alerts identified and space to write an action plan. Although it is not neurological specific it may be a useful tool to explore when thinking about how best to capture the experiences, needs and priorities of those caring for someone with a neurological condition in the community.

A number of organisations and health care services have been using patient experience trackers for a number of years, which provides an electronic tool to survey patients and obtain real time feedback as well as enabling quick analysis and reporting. Sue Ryder is currently trialling such a tool with its neurological service users. Survey questions are loaded into a tablet device and service users are encouraged to complete the survey with the support of a volunteer or relative/friend.

Although the system is not due to be evaluated for some months, early signs are that it is proving more beneficial than the traditional annual survey. An initial pilot showed that services users, families and the recruited volunteers found the devices easy to use with the majority of responses completed with the help of volunteers. The ability to respond to concerns or feedback in real time is perhaps the greatest benefit. During the pilot one resident recorded that "the night staff were noisy at times …", which

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

**Thames Valley
Strategic Clinical Network**

enabled the service manager to discuss this with the service user and staff to make an immediate improvement; the free text boxes allowed such detailed feedback.

The value of a patient experience survey to record and monitor the views of people using a community neurology service is indisputable, however the design, content and delivery, i.e. whether paper based, online, by telephone, using a hand held electronic device, etc. would need careful planning and research with the involvement of service users, their carers and relatives and staff to ensure people are able to respond in a way that best suits their needs.   This is substantiated by a study to assess the feasibility of surveying people with long-term neurological conditions prepared for the Healthcare Commission in 2007, which stated that although 'self completion questions were generally well received, particularly if respondents are provided with the option of completing an emailed or web survey instead…..it will be important to allow flexibility in terms of the mode of the survey, and in how involved carers can be to ensure that the survey does not exclude people who have communication or other cognitive difficulties that make it difficult for them to take part in a survey' (National Centre for Social Research, 2007:14).

Patient Groups and Forums

Patient participation groups, service user forums or focus groups are an excellent way to ensure ongoing engagement. The Picker Institute (2009:4) suggest that 'recruiting a panel of people from the local community provides a sounding board for new ideas and an opportunity to debate and test opinion on an ongoing basis'.

This approach may be adopted to both inform and test the design of a community based model of neurological care and once implemented provide ongoing feedback and recommendations for service improvement. Examples of such groups already exist across the country and tend to be local or regional groups:

Neurological Alliance Regional Groups:

Regional groups linked to the Neurological Alliance provide a united voice and authoritative single point of contact for health and local authority commissioners. They also provide support and information for patients and their carers. They all work in partnership with commissioning bodies to ensure the service user voice is heard in the design, delivery and monitoring of local services. Regional groups aim to raise the profile and understanding of neurological conditions and work together to improve the quality of local services.

These regional groups operate in different ways, although most are operating various mechanisms to obtain feedback including plans for a neurological forum based on 'Question Time' in the Black Country and a comprehensive 'Your Voice' programme hosting blogs, stories and user polls on the Northern Neurological Alliance website. Tees Valley, Durham and North Yorkshire Neurological Alliance also facilitates multi-neuro and pain management reference groups of service users and caregivers involved in a 360° cycle of communication - from responding to strategic initiatives to distributing information within their networks.

Charity and patient organisation user groups:

- Parkinsons UK runs a number of regional working groups and also themed working groups focussed on education, evidence-based practice, research

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

**Thames Valley
Strategic Clinical Network**

development, service development, underserved groups and service user involvement.

- Sue Ryder operates a national service user group 'Acorns'. This group is active in supporting the recruitment of executive and senior health leaders within the organisation. It is also active in shaping the Quality Account, which identifies areas for improvement across all service areas. Attendance at Acorns includes members of the Executive Leadership Team and Trustees, ensuring that feedback is acted upon.

Permanent Feedback Channels

A number of permanent patient feedback channels also exist online such as NHS Choices and Patient Opinion, where patients may record their feedback or rate a service. The bulk of the information collected via these mechanisms is qualitative and is passed onto the relevant service providers to enable them to take action or respond as appropriate, but does not provide data that can be easily compiled and analysed.

Although a community based neurology service would be included on such online channels it might be worth considering social media or other online options. The Care Quality Commission for example are currently running their 'Invisible Conditions' campaign which asks people living with a long term condition to tell them about their experiences of care by joining the conversation on Twitter or providing feedback via their website (Care Quality Commission, 2015).

Online discussion forums are another option that might encourage people to talk about their experiences of services and what was lacking. A number of charities/patient organisations such as the Brain and Spine Foundation and Multiple Sclerosis Society have established online discussion forums via their own website. Ataxia UK are currently trialling a forum hosted by HealthUnlocked, which provides a platform through which people can provide peer support. These forums largely encourage peer support and some provide clinical advice or signposting, however a similar mechanism designed for a community neurology service could provide useful intelligence if set up and managed effectively.

Interviews

One-to-one interviews are an effective method of undertaking 'in-depth investigation of attitudes and beliefs' and can 'provide you with additional information to explore the issues raised by surveys in greater depth…' (Picker Institute, 2009: 2-3).

The National Centre for Social Research (2007:22) found that 'face-to-face interviews, where the questionnaire is administered by an interviewer, was the favoured method for collecting information from people with long-term neurological conditions amongst service users, carers and experts'. It would 'extract richer information from those with cognitive difficulties and may be the only option for those who are unable to complete a paper survey'. It was recognised that face to face interviews would be 'beneficial when compared with telephone surveys, as interviewers are able to recognise if a respondent is becoming tired and would like to take a break'. It was however also noted that 'using face-to-face interviews will have cost implications and will be difficult to manage if the sample is not concentrated in a small number of geographical areas'.

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

Thames Valley
Strategic Clinical Network

In summary there are a variety of feedback mechanisms and good practice examples already in existence that may be adopted for the use of a Community Neurology service. Given the range and number of neurological conditions that will most likely result in a cognitive or functional impairment it is clear that a traditional or one size fits all approach to obtaining patient feedback will not be suitable. Instead it is suggested that a holistic and inclusive approach, combining patient experience and outcome measures, will need to be adopted in order to adequately obtain the views of those using a community based model of neurological care. A number of different methods should therefore be used to obtain feedback to ensure that patients, carers and staff can provide feedback.

Research undertaken by the National Centre for Social Research (2007) on the feasibility of surveying people with long-term neurological conditions and also more generic research undertaken by the Kings Fund on behalf of the Department of Health and NHS Institute for Innovation & Improvement (Robert et al, 2011) will be useful resources in developing a holistic and inclusive feedback mechanism for the Community Neurology service that enables measures of experience and outcome to be combined in order to obtain a rounded view of the quality of care.

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

Thames Valley
Strategic Clinical Network

REFERENCES FOR REPORT 1

Aspinal, F., Bernard, S., Spiers, G. and Parker G. (2014), 'Outcomes assessment for people with long-term neurological conditions: a qualitative approach to developing and testing a checklist in integrated care', Health Services and Delivery Research, 2 (9).

Attwood, A. and Hopwood, B. (2013), 'Improving MND Care. Motor Neurone Disease (MND) Association's Tracking Survey: The experiences and views of people living with MND', Picker Institute, MND Association [online], http://www.mndassociation.org/wp-content/uploads/2015/02/improving-mnd-care-report.pdf?c8bf39

Bernard, S., Aspinal, F., Gridley, K. and Parker, G. (2010), 'Integrated Services for People with Long-term Neurological Conditions: Evaluation of the Impact of the National Service Framework', Social Policy Research Unit, University of York [online], http://www.york.ac.uk/inst/spru/research/pdf/LTNC.pdf

British Society of Rehabilitation Medicine (2009), 'BSRM Standards for Rehabilitation Services, Mapped on to the National Service Framework for Long-Term Conditions', BSRM [online], http://www.bsrm.org.uk/downloads/standardsmapping-final.pdf

Carers UK (2015), 'State of Caring 2015', Carers UK [online], https://www.carersuk.org/for-professionals/policy/policy-library/state-of-caring-2015

Cook, A. and Miller, E. (2012), 'Talking Points Personal Outcomes Approach: Practical Guide', Joint Improvement Team [online], http://www.jitscotland.org.uk/wp-content/uploads/2014/01/Talking-Points-Practical-Guide-21-June-2012.pdf

Care Quality Commission (2015), 'Invisible Conditions', Care Quality Commission [online], http://www.cqc.org.uk/content/invisible-conditions

Department of Health (2014), 'The NHS Outcomes Framework 2015/16', Department of Health: London.

Department of Health (2005), 'The National Service Framework for Long-term Conditions', Department of Health: London.

De Silva, D. (2011), 'Helping people help themselves: A review of the evidence considering whether it is worthwhile to support self-management', Health Foundation [online], http://www.health.org.uk/sites/default/files/HelpingPeopleHelpThemselves.pdf

De Silva, D. (2012), 'Helping people share decision making: A review of evidence considering whether shared decision making is worthwhile', Health Foundation [online], http://www.health.org.uk/publication/helping-people-share-decision-making

Edge Hill University (2014), 'Carers' Alert Thermometer', Edge Hill University [online], https://www.edgehill.ac.uk/carers/2014/09/10/carers-alert-thermometer/

Fitzgerald, S. (2015), 'Experiences and views of carers of people living with MND: Findings of the MND Association Carers Survey 2015', Motor Neurone Disease Association [online], http://www.mndassociation.org/wp-content/uploads/MND-Association-Carers-Survey-2015-findings-report.pdf?5c9559

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

**Thames Valley
Strategic Clinical Network**

Gladman, J., Radford, K.A., Edmans, J.A., Sach, T., Parry, R., Walker, M.F., Lincoln, N., Sackley, C.M., Drummond, A., Standen, P. Dewey, M., and Pinnington, L. (2007), 'Specialist rehabilitation for neurological conditions: literature review and mapping study: Report for the National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDO)', National Institute for Health Research [online], http://www.netscc.ac.uk/hsdr/files/project/SDO_FR_08-1604-132_V01.pdf

Gold Standards Framework (2016), 'Advance care planning', Gold Standards Framework [online], http://www.goldstandardsframework.org.uk/advance-care-planning

GP Patient Survey (2015), 'GP Patient Survey Analysis Tool', GP Patient Survey [online], http://results.gp-patient.co.uk/report/explanation.aspx

The Health Foundation (2014), 'Person-centred care made simple: What everyone should know about person-centred care', The Health Foundation [online], http://personcentredcare.health.org.uk/sites/default/files/resources/person-centred_care_made_simple_1.pdf

Hoppitt, T., Calvert, M., Pall, H., Gill, P., Yao, L., Freemantle, N. and Sackley, C. (2011), 'Review of Epidemiology and Service Use in Rare Long-Term Neurological Conditions', Research Initiative for Long Term Neurological Conditions [online], http://www.ltnc.org.uk/download_files/final%20reports/April%2012/2012/2012/RESULT%20study%20Final%20Report.pdf

Jackson, D., Williams, D., Turner-Stokes, L., Saleem, T., Higginson, I., Harris, J. and McCrone, P. (2011), 'How do carers of people with long term neurological conditions experience the provision of replacement care?', Research Initiative for Long Term Neurological Conditions [online], http://www.ltnc.org.uk/download_files/final%20reports/Oct_11/Final_Report_Replacement_Care.pdf

Long Term Conditions Alliance Scotland and Better Together (2010), 'Self Management Fund - Special Report: Valuing People's Experiences', Health and Social Care Alliance Scotland [online], http://www.alliance-scotland.org.uk/what-we-do/self-management/self-management-fund/

National Audit Office (2011), 'Services for people with neurological conditions', National Audit Office: London

National Audit Office (2015), 'Services for people with neurological conditions: progress review', National Audit Office: London

National Audit Office (2008), 'End of Life Care', National Audit Office: London

National Centre for Social Research (2007), 'Long-term Neurological Conditions Feasibility Study: Consultation Report, NHS Surveys [online], http://www.nhssurveys.org/Filestore//documents/LTC_neurological_consultation_rpt.pdf

National Council for Palliative Care (2009), 'Improving the Experience of Hospital Admission for People with Neurological Conditions: Summary of Survey Results and Recommendations', National Council for Palliative Care [online], http://www.ncpc.org.uk/sites/default/files/HospitalAdmissionsSurveyDocument.pdf

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

**Thames Valley
Strategic Clinical Network**

National End of Life Care Intelligence Network (2010), 'Deaths from Neurodegenerative Diseases in England, 2002 to 2008', National End of Life Care Intelligence Network [online], http://www.endoflifecare-intelligence.org.uk/resources/publications/deaths_from_neurodegenerative_diseases

National Institute for Health and Care Excellence (2006), 'Parkinson's disease in over 20s: diagnosis and management', National Institute for Health and Care Excellence [online], https://www.nice.org.uk/guidance/cg35

National Institute for Health and Care Excellence (2009), 'Medicines adherence: Involving patients in decisions about prescribed medicines and supporting adherence, National Institute for Health and Care Excellence [online], http://www.nice.org.uk/guidance/cg76

Neurological Alliance (2012), 'Intelligent Outcomes: Applying the health and social care reforms to improve outcomes for people with neurological conditions', Neurological Alliance [online], http://www.neural.org.uk/store/assets/files/275/original/Intelligent-Outcomes-Neurological-Alliance-MHP-Health-Mandate-report.pdf

Neurological Alliance (2013), 'Navigating neurology services: helping strategic clincial networks to be a success story', Neurological Alliance [online], http://www.neural.org.uk/store/assets/files/355/original/Neurological_Alliance_navigating_neurology_services_September_2013.pdf

Neurological Alliance (2015), 'The Invisible Patients: Revealing the state of neurology services', Neurological Alliance [online], http://www.neural.org.uk/store/assets/files/495/original/Invisible_patients_-_revealing_the_state_of_neurology_services_final_14_January_2015_.pdf

Neurological Alliance (2016), Ambitions Strategy: report unpublished at time of writing (05/2016)

Neurological Alliance of Ireland (2011), 'Experiences of Neurological Care in Ireland', Irish Heart Foundation [online], http://www.stroke.ie/media/pub/advocacy/NAI%20Survey%202011%20-%20Experiences%20of%20Neurological%20Care.pdf

NHS Dudley Primary Care Trust and Dudley Metropolitan Borough Council (2009), 'Dudley Joint Commissioning Strategy for Long Term Neurological Conditions 2009-2014', The Dudley Group NHS Foundation Trust [online], http://dudleygroup.nhs.uk/wp-content/uploads/2014/02/neurological-conditions-strategy-summary.pdf

NHS East Midlands Strategic Clinical Network (2015), 'Community-based rehabilitation of people with long-term neurological conditions: Commissioning guidance and sample service specification', East Midlands Clinical Senate [online], http://www.emsenatescn.nhs.uk/media/1886/commissioning-guidance-final.pdf

NHS West Hampshire Clinical Commissioning Group (2013), 'Patient, Carer and Staff Engagement Report: Neuro Action', NHS West Hampshire Clinical Commissioning Group

Oxfordshire Neurological Alliance (2014), 'The Neurological Alliance Patient Experience Survey Engagement Project', Health Watch Oxfordshire [online],

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

**Thames Valley
Strategic Clinical Network**

http://www.healthwatchoxfordshire.co.uk/sites/default/files/oxna_survey_report_final_.pdf

Parkinson's Disease Society Survey (2008), 'Life with Parkinson's today – room for improvement: Results of the UK's largest ever survey of people with Parkinson's and carers', Parkinson's UK [online]
http://www.parkinsons.org.uk/sites/default/files/publications/download/english/memberssurvey_fullreport.pdf

Parkinson's UK (2015), '2015 UK Parkinson's Audit', Parkinson's UK [online], http://www.parkinsons.org.uk/professionals/uk-parkinsons-audit/upcoming-audit

Picker Institute (2009), 'Using patient feedback', NHS Surveys [online], http://www.nhssurveys.org/Filestore/documents/QIFull.pdf

Robert, G., Cornwell, J., Brearley, S., Foot, C., Goodrich, J., Joule, N., Levenson, R., Maben, J., Murrells, T., Tsianakas, V. and Waite, R. (2011), 'What matters to patients'? Developing the evidence base for measuring and improving patient experience', NHS Institute for Innovation and Improvement [online], http://www.institute.nhs.uk/images/Patient_Experience/Final%20Project%20Report%20pdf%20doc%20january%202012.pdf

Royal College of Physicians, National Council for Palliative Care and British Society of Rehabilitation Medicine (2008), Long-term neurological conditions: management at the interface between neurology, rehabilitation and palliative care, Concise Guidance to Good Practice series, No. 10, London.

Soltysiak, B., Gardiner P. and Skirton, H. (2008), 'Exploring supportive care for individuals affected by Huntington disease and their family caregivers in a community setting', Journal of Nursing and Healthcare of Chronic Illness, 17 (7b), 226-234.

Sue Ryder (2012), 'The forgotten millions. Social care for people living with neurological conditions: A blueprint for reform', Sue Ryder [online], https://www.sueryder.org/~/media/files/about-us/the%20forgotten%20millions%20-%20nov%202012.ashx

Sweetland, J., Riazi, A., Canon, S.J. and Playford, E.D. (2010), 'Vocational rehabilitation services for people with multiple sclerosis: what patients want from clinicians and employers', Multiple Sclerosis, 13 (9), 1183-9.

Traynor, B.J., Alexander, M., Corr, B., Frost, E. and Hardiman, O. (2003), 'Effect of a multidisciplinary amyotrophic lateral sclerosis ALS clinic on ALS survival: a population based study, 1996-2000', Journal of Neurological and Neuroscience Psychiatry, 74, 1258-61.

Wilson, E., Seymour, J. and Aubeeluck, A. (2011), 'Perspectives of staff providing care at the end of life for people with progressive long-term neurological conditions', Palliative Supportive Care, 9(4), 377-85.

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

Thames Valley
Strategic Clinical Network

26

Report 2:

Integrating Care Pathways

Written by Jill Kings, Clinical Director, Neural Pathways (UK) Ltd

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

**Thames Valley
Strategic Clinical Network**

INTRODUCTION

The purpose of this report is to identify the key elements of an integrated and coordinated neurological care system and provide case studies of how and where that element has been successfully met. This can be used by commissioners and providers of care to benchmark their existing service and see where the opportunities are for improvement.

In addition to researching and writing about the key topic of integrating care pathways, Jill Kings reviewed each of the survey responses, creating a thematic analysis and mapping them onto the three-tier model mentioned in Part A (the **Transformation Guide**). The exercise resulted in a valuable reference source which informed the writing of Part A. The collection of **Case Studies** has been provided as a separate document, namely Part C of this set.

Scene setting

In 2012, the Public Accounts Committee (PAC), reviewing progress on the implementation of recommendations from the national service framework reported "individual care is often poorly coordinated and the quality of services received depends on where you live. Some areas simply don't have enough expertise, both in hospitals and the community…health and social services are failing to provide an integrated range of services for people with neurological conditions".

More recently the Five Year Forward View set out proposals for new models of care which are being taken forward by vanguard sites across the country. Integration is a key feature in the models: multispecialty community providers (MCP), primary and acute care systems (PACS), urgent and emergency care services, and specialised care - networks of services over a geography, integrating different organisations and services around patients.

However, the current reality is that neurological services are a challenge for commissioners with competing demands from higher profile disease groups. There are few national levers to focus neurological improvement and there are still significant variations in services and patient outcomes for neurology.

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

**Thames Valley
Strategic Clinical Network**

Definition of integration.

For health, care and support to be 'integrated', it must be person-centred, coordinated, and tailored to the needs and preferences of the individual, their carer and family. It means moving away from episodic care to a more holistic approach to health, care and support needs, that puts the needs and experience of people at the centre of how services are organised and delivered, as **Figure 5** illustrates.

**<u>Figure 5: Integrated Multi-Agency Care</u>**

Risks

The impact of not having an integrated service has the potential to lead to:

- Failure to take steps to prevent or delay onset of needs through prevention or early intervention;
- Multiple and uncoordinated assessments from health and social care, leading to delay of provision;
- Packages of health and social care provision that do not fit in with the person's lifestyle or are not age-appropriate;
- Multiple, uncoordinated visits from health and social care professionals;
- Multiple trips to hospitals for tests, diagnostics and treatment;
- Unsafe transfers from hospital to residential care;
- Unreliable transitions through care pathways, including from childhood to adult care;
- Emergency admission to hospital, e.g. after avoidable worsening condition or avoidable fall Emergency readmission following unsafe discharge from hospital or lack of information for people managing their conditions;
- Failure to meet a person's wish to die at home or receive end of life care in their own home.

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

**Thames Valley
Strategic Clinical Network**

CARE CLOSER TO HOME

Merging the Interfaces of Primary and Secondary Care

Traditional secondary outpatient / medically led functions undertaken in different ways:
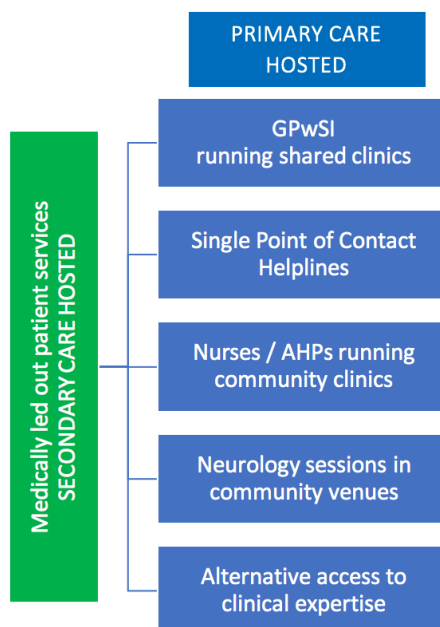
Why the System Needs to Change

Bottle neck re: neurologist that are at critical levels in parts of the country.

Solution - role substitution or role replacement with other skilled team members.

E.g. increase use of GPwSI, increase use of non-medical clinical decision makers e.g. ANP, CNS, AHPs.

Overstretched system with demand exceeding capacity year on year

Solutions - need to differentiate functions between new (diagnostic) and follow-up sessions.

E.g. enable FU patients to self-manage, seek advice using groups, non-face-to-face interventions.

Process driven and not client-centred

Patients say they want access to experts, closer to home.

e.g. services don't need to be a doctors or need to be face-to-face.

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

**Thames Valley
Strategic Clinical Network**

Report 3:

Optimising Mental Well Being

Written by Dawn Langdon, Professor of Neuropsychology and Director of Health and Medicine,

Royal Holloway, University of London

MENTAL HEALTH AND WELL-BEING IN COMMUNITY NEUROLOGY SERVICES

Neurological conditions are often accompanied by raised prevalence of mental health conditions (for example, depression and anxiety) and cognitive difficulties (for example memory problems). These affect patients' quality of life in many ways, including employment, safety, family life and disease management (Ettinger et al., 2014). It is crucial that both health professionals and patients are aware that many mental health issues and cognitive difficulties in the context of neurological disorders can be successfully managed and quality of life improved. All health workers supporting people with neurological conditions need basic mental health training and skills. For patients to access appropriate services, those experiencing mental health and cognitive difficulties need to be identified by frontline staff and appropriate referral and care pathways need to be in place.

Qualitative work suggests that living well with a long-term condition requires social connectedness, changed identities, acceptance and self-care (Stenberg and Furness, 2016). Support, training and coaching can help achieve these outcomes. An important contribution to managing psychological aspects of neurological conditions is to build/facilitate resilience in those who are coping well (Jeste et al., 2015). Resilience is the result of active adaptation mechanisms and a positive coping style should be encouraged and supported (Shamaskin-Garroway et al., 2016). Resilience is linked to better quality of life, less depression and less anxiety, but not disease severity (Robottom et al., 2012). Mindfulness may enhance psychological resilience and wellbeing (Burschka et al., 2014). Brain health is another important concept that involves patients making life style choices that protect their daily function and preserve physical and cognitive competence, thus achieving optimum outcomes for patients with financial benefit to providers (Giovannoni et al., 2015). Resilience and brain health can help to maintain a better quality of life, reduce morbidity and consequently service use.

There is evidence that early intervention and prevention can deliver measurable improvement in quality of life and service costs. The Sandwell primary care approach has save £800,000 in prevention costs and by arranging for 3,000 people to attend talking therapies, a further £600,000 has been saved (NHS Confederation). Crucially the commissioners for the Sandwell services allocated considerable time and resources to listen to the needs of their communities, mapped best practice evidence and explored options for working in partnership.

Investment in specialist services can also be cost-effective. The cost of a clinical neuropsychologist to support a multidisciplinary team for stroke was nearly NHS cost-neutral and saved £39,000 in two years in social care costs (NHS Improvement, 2011). Southend and South Essex Trust found that a saving of nearly £300,000 was achieved in six months, after appointing a whole time neuropsychologist and a 0.5 psychology assistant (BPS, 2015).

A care manager responsible for co-ordination of different components of care is a key element of the collaborative care model (NICE, 2009). Key workers make an essential contribution to initiating and maintaining good quality care for patients with neurological conditions. They may be specialist nurses (Hussain et al., 2013) or

neuropsychologists, where there is a high complexity of related and emotional and cognitive difficulties (Failla et al., 2016). People with neurological conditions can experience a range of psychosocial impacts, including difficulties with cognition, pain, community participation, emotions, sleep, working, relationships and carrying out their daily routine (Coenen et al., 2015). The key worker is able to take a comprehensive view of the individual patient's needs and service provision for the patient. This holistic and expert review and monitoring often makes the health care package more efficient and targeted to the patients' specific needs, throughout their disease journey.

Commissioners need to consider how the emotional, behavioural and mental health impacts of neurological conditions can be addressed routinely within care pathways. Expert neuropsychological and other mental health advice will be required to develop new integrated solutions. Services should be commissioned with the express goal of enhancing interaction among primary care, mental health professionals and social care workers engaged in supporting people with neurological conditions (Naylor et al., 2012). Although integrating physical and mental health services has been rightly identified as "a new frontier", services to support well-being, mental health and cognition for people with neurological conditions has been given less explicit consideration (Naylor et al., 2016). It is time that this neglected area of need and unnecessary morbidity is appropriately accommodated in service provision.

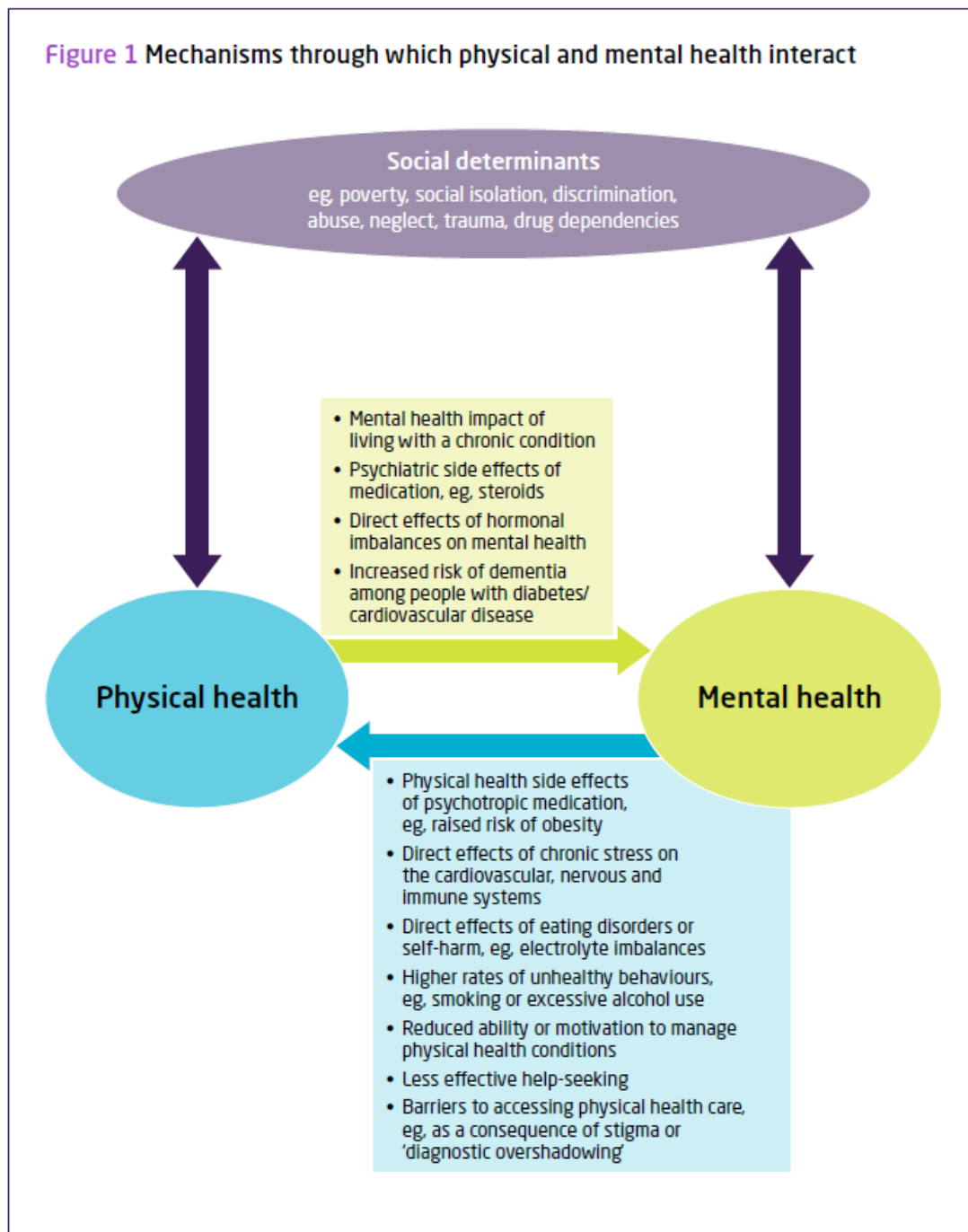TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

**Thames Valley
Strategic Clinical Network**

Figure 1 Mechanisms through which physical and mental health interact

Figure after Naylor et al., 2016

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS
Thames Valley
Strategic Clinical Network

MANAGING EMOTIONAL DISTRESS IN COMMUNITY NEUROLOGY

People living with long term conditions have an increased prevalence of psychiatric morbidity. For example, up to 50% of people with Parkinson's Disease (PD) will experience depression, 28% will have formal anxiety disorder and 40% will have anxiety symptoms. Depression, anxiety, fatigue and apathy are experienced by over 30% of people after a stroke and less commonly, emotional lability, personality changes, psychosis and mania may also occur (Hackett et al., 2014). In MS, the probability of a comorbid depression is 50%. Depression is linked to disability in MS, with over 70% with high disability reporting at least mild depression (Jones et al., 2014).

Psychiatric co-morbidity has a significant negative impact. In PD, depression and anxiety are linked to faster disease progression, unemployment, increased dependency, increased care-giver burden and reduced quality of life (Fernie et al., 2015). All psychiatric conditions reduce QoL in PD (Alvarado-Bolaños et al., 2015). Functional disability and physical illness are linked to suicidal behaviour (Fassberg et al., 2016). Physical disease without mental illness is a common reason for suicide (Fegg et al., 2016). However, depression is also linked to suicide (Dickstein et al., 2015). Emotional distress in neurological conditions can often be managed. Health professionals and patients should not expect depression and other mental health conditions to be an inevitable accompaniment to neurological disease. Patients who are under functioning, in terms of social activity or disease management, should be assessed for depression (see pathway).

Although the evidence base for psychotropic medication in neurological conditions is incomplete, many patients can be helped by standard prescribing (Calleo et al., 2015). However, for many patients with neurological conditions, additional or alternative treatment options are required. Non-pharmacological interventions can reduce agitation in dementia and have a positive monetary net benefit in mild to moderate dementia (Livingston et al., 2014). Cognitive Behavioural Therapy has promise for treatment in depression in neurological conditions (Fernie et al., 2015) and for some conditions the evidence is robust (Feinstein et al., 2014). However, generic CBT protocols require amendment for neurological conditions. IAPT is moving towards treating patients with long term conditions, but as yet has not precisely targeted neurological populations. Significant development will need to occur in staff skills, referral pathways and availability of expert supervision by neuropsychologists, before IAPT can offer a fully appropriate response to people with long term neurological conditions (Naylor et al., 2012). Patients should be offered their treatment of choice. A full consideration of these issues is available (NICE 2009).

Psychiatric conditions involving significant behavioural disturbance, such as agitation in the context of dementia, challenging behaviour after head injury or socially intrusive disinhibition in MS, should be assessed promptly by a mental health specialist and this may require a neuropsychologist's or psychiatrist's opinion. Patients' or relatives' reports of emotional distress or psychiatric symptoms should be fully evaluated.

Health professional teams and pathways should be constructed to manage emotional distress promptly and effectively. Successful integration of physical and mental health

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

**Thames Valley
Strategic Clinical Network**

care requires that all physical health providers should have a board member who leads for mental health and also a liaison psychiatrist to focus on mental health (Royal College of Psychiatrists, 2013). There is evidence that if mental health professionals work more closely with primary care, quality of care improves and costs are reduced. In the USA, patients in the Intermountain mental health integration programme were 54% less likely to visit emergency departments than those in usual care and their total medical costs were reduced by 48% (Reiss-Brennan et al., 2010).

MANAGING COGNITIVE DIFFICULTIES IN COMMUNITY NEUROLOGY

Cognitive difficulties often accompany neurological conditions. For example, 56% of stroke patients have been shown to experience significant reasoning and planning difficulties ("executive dysfunction"), 33% a behaviour disorder alone (hypoactivity, disinterest) and 22% a cognitive syndrome alone (impairments in initiation, Roussel et al., 2016). Cognitive impairments negatively impact on quality of life, with the more severe impairments having the most impact (Lawson et al., 2014). They can affect employment, driving safety, risk of falls, personal and social function, independence and disease management.

Even mild cognitive impairment (MCI) results in poorer healthcare decision making (Han et al., 2015). Older adults with MCI have an increased risk of both hospitalization and 30-day readmission (Callhan et al., 2015). The cognitive status of older adults with early neurodegenerative disease predicts risk of functional disability (Lau et al., 2015). Support of those at risk can delay loss of independence. Cognitive assessment can indicate which patients will not fill their pill box correctly, and are consequently at risk of poor adherence to medication schedules (Anderson et al., 2014). There may be a role for community pharmacists (Hudani and Rojas-Fernandez, 2015). Severity of cognitive impairment in dementia predicts eating competence and particular support interventions can maintain eating independence (Edahiro et al., 2012).

Some brief cognitive assessments with good psychometric properties can be used by any qualified health professionals to identify cognitive impairment (e.g. Langdon et al., 2012). However detailed assessment of cognitive impairment requires specialist expertise, usually by a neuropsychologist. Partly this is because they often overlap with emotional and physical symptoms. Partly this is because cognitive impairment profiles are heterogeneous even within one disease group (Yarnall et al., 2014). Usually the assessment would be completed by a neuropsychologist for patients with significant cognitive concerns. Some neurological disorders have recommended schedules of assessments, for example stroke patients should be assessed for both emotional and cognitive status at 6 weeks (NSF Stroke) and people with MS should receive a cognitive assessment annually (NICE 2014).

Management of cognitive difficulties should ideally be co-ordinated by a key worker and will optimally involve both personal and social networks. Families need to be fully engaged, advised and supported for optimal care to be delivered. Caregiver burden is higher when co-morbidities increase, however dementia is the most significant (Dauphinot et al., 2016). Social support is protective of the caregiver and therefore of the person with dementia (Raggi et al., 2015). Caregivers need to be included in

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

**Thames Valley
Strategic Clinical Network**

support and monitoring. Staff training should include working effectively and expertly with caregivers.

PARITY OF ACCESS

Treating the mental health problems of those with long term conditions uses 12-18% of the long term conditions budget, amounting to at least £8 million in England every year (around £1 in every £8 spent on long term conditions in general, King's Fund 2012). Yet this considerable sum is not spent optimally, because health and social care are largely organised separately for physical and mental illness. Because of this lack of cohesion and integration, optimal efficiency and outcomes are not achieved.

It is essential that commissioners adopt a parity approach to planning, commissioning and delivery of both physical and mental health services. It has been pointed out that true parity would mean that patients in primary care with neurological conditions should have the same access to a consultant psychiatrist as they do to consultant neurologist (Academy of Medical Royal Colleges, 2009). Commissioners should ensure that assessments throughout care pathways address both physical and mental health (Royal College of Psychiatrists, 2013). Routine data collection should include the full spectrum of co-morbidities, including cognitive, emotional and behavioural impacts, so that service quality can be monitored and improved comprehensively.

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

**Thames Valley
Strategic Clinical Network**

Figure after Case Study Report on Sandwell. NHS Confederation 2012.

High volume
Minor, self-limiting and longer-term conditions
Graduate workers
Community development workers
MIND community wellbeing service
Confidence and wellbeing team
Faith networks
Schools
Community

Step 0
Local community prevention, advice, prevention
Whole population

Outreach, self-help and guided self-help
Mental wellbeing promotion
Targeted and universal lifestyle services
Employment, accommodation
Education
Self-care
Health improvement programmes
Personalisation
Pt education – co-produced programmes

Step 1
Access to talking therapies
Population: 230 per 1000

Access to talking therapies and consultation
NHS independent/voluntary sector/chaplains for wellbeing
Low-intensity service integrated counselling and therapy service

Low intensity
Mainly minor/mild (anxiety and depression)
Improving access to psychological therapies (IAPT)
Counselling services
GP leads
Psychology

Step 2
Practice-based primary care
Population: 101–105 per 1000

Primary care workforce
Community primary care services
Early detection/intervention
Access to crisis prevention services
Ongoing management of long-term conditions including physical and psychological needs
Service users and carers

Medium/high-intensity therapies
Mixed presentations (moderate/complex)
Esteem team, probation, youth offending team
Gateway workers
Community matrons
Health trainers and health visitors, maternity services
Link workers

Step 3
Collaborative/ shared care
Population: 20.8 per 1000

High-intensity service
Psychiatric liaison
Shared protocols and assessment
Integrated/shared care
Mental health, alcohol, dementia and wellbeing screening
Gateway workers
Patient register audit and management across long-term conditions
Home treatment
Effective medicines management more considered
Ambulatory pathway from A&E
Co-morbidities

Severe illness
(Urgent/Crisis)
Single point access for crisis all ages
Rapid, Assessment, Interface and Discharge (RAID)

Step 4
Hospital and community beds
Population: 3.3 per 1000

Assessment beds, respite beds, crisis beds
Hospital liaison
Consultation
Booked day case inpatient
Booked discharge
Specialised inpatient services

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

**Thames Valley
Strategic Clinical Network**

REFERENCES FOR REPORT 3

Mental Health and Well-Being in Community Neurology Services

British Psychological Society (2015) Clinical Neuropsychology Services - Delivering value for the NHS: A briefing paper for NHS commissioners and policy makers. British Psychological Society. Leicester. UK.

Burschka JM, Keune PM, Oy UH, Oschmann P, Kuhn P. Mindfulness-based interventions in multiple sclerosis: beneficial effects of Tai Chi on balance, coordination, fatigue and depression. BMC Neurol. 2014 Aug 23;14:165.

Coenen M, Cabello M, Umlauf S, Ayuso-Mateos JL, Anczewska M, Tourunen J, Leonardi M, Cieza A; PARADISE Consortium. Psychosocial difficulties from the perspective of persons with neuropsychiatric disorders. Disabil Rehabil. 2015 Aug 18:1-12. [Epub ahead of print]

Ettinger AB, Good MB, Manjunath R, Edward Faught R, Bancroft T.The relationship of depression to antiepileptic drug adherence and quality of life in epilepsy.Epilepsy Behav. 2014 Jul;36:138-43.

Failla MD, Juengst SB, Graham KM, Arenth PM, Wagner AK. Effects of Depression and Antidepressant Use on Cognitive Deficits and Functional Cognition Following Severe Traumatic Brain Injury. J Head Trauma Rehabil. 2016 Jan 29. [Epub ahead of print]

Giovannoni et al., 2015 www.msbrainhealth.org

Hussain J, Adams D, Campbell C. End-of-life care in neurodegenerative conditions: outcomes of a specialist palliative neurology service. Int J Palliat Nurs. 2013 Apr;19(4):162-9.

Jeste DV, Palmer BW, Rettew DC, Boardman S. Positive psychiatry: its time has come. J Clin Psychiatry. 2015 Jun;76(6):675-83.

NHS Confederation. Case Study Report on Sandwell. A Primary care approach to mental health and wellbeing.

NHS Improvement (2011). Psychological Care after stroke –improving stroke services for people with cognitive and mood disorders. Retrieved from http://www.nice.org.uk.

Naylor et al., Long-term conditions and mental health. The cost of co-morbidities. Kings Fund. 2012.

Naylor et al., Bringing together physical and mental health. A new frontier for integrated care. Kin's Fund. 2016.

Robottom BJ, Gruber-Baldini AL, Anderson KE, Reich SG, Fishman PS, Weiner WJ, Shulman LM. What determines resilience in patients with Parkinson's disease? Parkinsonism Relat Disord. 2012 Feb;18(2):174-7.

Shamaskin-Garroway AM, Lageman SK, Rybarczyk B. The roles of resilience and nonmotor symptoms in adjustment to Parkinson's disease. J Health Psychol. 2015 Jul 6. pii: 1359105315590268. [Epub ahead of print]

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS
Thames Valley
Strategic Clinical Network

Stenberg N, Furness PJ. Living Well With a Long-Term Condition: Service Users' Perspectives of a Self-Management Intervention. Qual Health Res. 2016 Feb 12. pii: 1049732316628834. [Epub ahead of print]

Managing Emotional Distress in Community Neurology

Alvarado-Bolaños A, Cervantes-Arriaga A, Rodríguez-Violante M, Llorens-Arenas R, Calderón-Fajardo H, Millán-Cepeda R, Leal-Ortega R, Estrada-Bellmann I, Zuñiga-Ramírez C. Impact of Neuropsychiatric Symptoms on the Quality of Life of Subjects with Parkinson's Disease.J Parkinsons Dis. 2015;5(3):541-8. doi: 10.3233/JPD-150597.

Calleo J, Amspoker AB, Marsh L, Kunik ME Mental health diagnoses and health care utilization in persons with dementia, Parkinson's disease, and stroke. J Neuropsychiatry Clin Neurosci. 2015;27(2):e117-21.

Dickstein LP, Viguera AC, Nowacki AS, Thompson NR, Griffith SD, Baldessarini RJ, Katzan IL. Thoughts of death and self-harm in patients with epilepsy or multiple sclerosis in a tertiary care center. Psychosomatics. 2015 Jan-Feb;56(1):44-51.

Fässberg MM, Cheung G, Canetto SS, Erlangsen A, Lapierre S, Lindner R, Draper B, Gallo JJ, Wong C, Wu J, Duberstein P, Wærn M. A systematic review of physical illness, functional disability, and suicidal behaviour among older adults. Aging Ment Health. 2016 Feb;20(2):166-94.

Fegg M, Kraus S, Graw M, Bausewein C. Physical compared to mental diseases as reasons for committing suicide: a retrospective study. BMC Palliat Care. 2016 Feb 9;15(1):14.

Feinstein A, Magalhaes S, Richard JF, Audet B, Moore C. The link between multiple sclerosis and depression. Nat Rev Neurol. 2014 Sep;10(9):507-17.

Fernie BA, Kollmann J, Brown RG. Cognitive behavioural interventions for depression in chronic neurological conditions: a systematic review. J Psychosom Res. 2015 May;78(5):411-9. doi: 10.1016/j.jpsychores.2015.02.012. Epub 2015 Feb 26.

Hackett ML, Köhler S, O'Brien JT, Mead GE. Neuropsychiatric outcomes of stroke. Lancet Neurol. 2014 May;13(5):525-34.

Jones KH, Jones PA, Middleton RM, Ford DV, Tuite-Dalton K, Lockhart-Jones H, Peng J, Lyons RA, John A, Noble JG. Physical disability, anxiety and depression in people with MS: an internet-based survey via the UK MS Register. PLoS One. 2014 Aug 25;9(8):e104604.

Livingston G, Kelly L, Lewis-Holmes E, Baio G, Morris S, Patel N, Omar RZ, Katona C, Cooper C. A systematic review of the clinical effectiveness and cost-effectiveness of sensory, psychological and behavioural interventions for managing agitation in older adults with dementia. Health Technol Assess. 2014 Jun;18(39):1-226, v-vi.

NICE 2009 Depression in adults with chronic physical health problem: recognition and management. Clinical Guideline 91.

Reiss-Brennan B, Briot PC, Savitz LA, Cannon W, Staheli R. Cost and quality impact of Intermountain's mental health integration program. J Healthc Manag. 2010 Mar-Apr;55(2):97-113

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

**Thames Valley
Strategic Clinical Network**

Managing Cognitive Difficulties in Community Neurology

Anderson K, Willmore C, Doran E, Oki N, Vonnahme J, Gates BJ. Cognitive and literacy screening as predictors of ability to fill a pillbox using two pillbox assessment scoring methods. Consult Pharm. 2014;29(5):304-16.

Callahan KE, Lovato JF, Miller ME, Easterling D, Snitz B, Williamson JD. Associations Between Mild Cognitive Impairment and Hospitalization and Readmission. J Am Geriatr Soc. 2015 Sep;63(9):1880-5.

Dauphinot V, Ravier A, Novais T, Delphin-Combe F, Moutet C, Xie J, Mouchoux C, Krolak-Salmon P.Relationship Between Comorbidities in Patients With Cognitive Complaint and Caregiver Burden: A Cross-Sectional Study. J Am Med Dir Assoc. 2016 Mar 1;17(3):232-7. Epub 2015 Nov 24.

Edahiro A, Hirano H, Yamada R, Chiba Y, Watanabe Y, Tonogi M, Yamane GY. Factors affecting independence in eating among elderly with Alzheimer's disease. Geriatr Gerontol Int. 2012 Jul;12(3):481-90.

Goldman JG, Weis H, Stebbins G, Bernard B, Goetz CG. Clinical differences among mild cognitive impairment subtypes in Parkinson's disease. Mov Disord. 2012 Aug;27(9):1129-36. doi: 10.1002/mds.25062. Epub 2012 Jul 6.

Han SD, Boyle PA, James BD, Yu L, Bennett DA. Mild cognitive impairment is associated with poorer decision-making in community-based older persons. J Am Geriatr Soc. 2015 Apr;63(4):676-83.

Hudani ZK, Rojas-Fernandez CH. A scoping review on medication adherence in older patients with cognitive impairment or dementia. Res Social Adm Pharm. 2015 Dec 2. . [Epub ahead of print]

Langdon DW, Amato MP, Boringa J, Brochet B, Foley F, Fredrikson S, Hämäläinen P, Hartung HP, Krupp L, Penner IK, Reder AT, Benedict RH. Recommendations for a Brief International Cognitive Assessment for Multiple Sclerosis (BICAMS). Mult Scler. 2012 Jun;18(6):891-8.

Lau KM, Parikh M, Harvey DJ, Huang CJ, Farias ST. Early Cognitively Based Functional Limitations Predict Loss of Independence in Instrumental Activities of Daily Living in Older Adults. J Int Neuropsychol Soc. 2015 Oct;21(9):688-98.

Lawson RA, Yarnall AJ, Duncan GW, Khoo TK, Breen DP, Barker RA, Collerton D, Taylor JP, Burn DJ. Severity of mild cognitive impairment in early Parkinson's disease contributes to poorer quality of life. Parkinsonism Relat Disord. 2014 Oct;20(10):1071-5.

Raggi A, Tasca D, Panerai S, Neri W, Ferri R. The burden of distress and related coping processes in family caregivers of patients with Alzheimer's disease living in the community. J Neurol Sci. 2015 Nov 15;358(1-2):77-81. Epub 2015 Aug 17.

Roussel M, Martinaud O, Hénon H, Vercelletto M, Bindschadler C, Joseph PA, Robert P, Labauge P, Godefroy O; GREFEX study group. The Behavioral and Cognitive Executive Disorders of Stroke: The GREFEX Study. PLoS One. 2016 Jan 29;11(1):e0147602

Parity of access

Academy of Medical Royal Colleges. No Health Without Mental Health: The ALERT Summary Report. Academy of Medical Royal Colleges. 2009.

Royal College ofPsychiatrists. Whole-person care: from rhetoric to reality. Achieving parity between mental and physical health. Occasional Paper OP88. 2013.

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

**Thames Valley
Strategic Clinical Network**

Report 4:
E-Health

Written by Zam Cader, Consultant Neurologist and Clinical Director, Thames Valley Strategic Clinical Network

& Dawn Langdon, Professor of Neuropsychology and Director of Health and Medicine,

Royal Holloway, University of London

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

**Thames Valley
Strategic Clinical Network**

NEW OPPORTUNITIES ENABLED BY TECHNOLOGY

This report will help commissioners and their partners to understand how technology can be used to:

- Support new models of care with patients at the centre, empowering patients to manage their own care;
- Access real-time information on a patient's health status;
- Enable specialist support to provided to neurology patients in the community when it is needed to prevent morbidity and mortality;
- Develop integration of care and delivering transformation in quality of care.

TECHNOLOGY'S ROLE IN HEALTH

Digital technology has an increasingly significant role to play in the management of neurological conditions. Providing patients with knowledge about their disease and facilitation their active involvement in disease management improves acceptance and helps with maintenance of a healthier lifestyle. This effect is augmented by e-health interventions, through websites or platforms (Allen et al., 2016). Technology can enable or improve information exchange between patients, carers and health professionals, helping people manage long-term conditions, supporting self-care and self-management across a pathway and throughout a patient journey.

Types of technology

There is a huge diversity of technology, with many new innovations emerging. Three major types of technology likely to have significant impact in the care of long-term neurological conditions include the following:

Telehealth

Remote monitoring of patients to obtain real-time health status and to monitor exacerbations of chronic neurological problems to allow timely intervention.

Telemedicine

Remote consultations between patients and those providing care.

Self-care apps

Applications available on computers and smart mobile devices that facilitate patient empowerment and self-management.

E-health

Patient online communities provide self-management, emotional and illness support.

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

**Thames Valley
Strategic Clinical Network**

Fig. 1. The rationale for the use of telemedicine. Telemedicine has been applied successfully in almost all aspects of neurological practice. The application of telemedicine may take the form of real-time communication (telephone, videoconference), store-and-forward technology (postal service, web-based systems), or remote monitoring (electronic devices).

Fig from Sola-Valls et al., Telemedicine for Monitoring MS Activity and Progression. Curr Treat Options Neurol. 2015 Nov;17(11):47

Effectiveness

A large randomized trial in the UK involving several hundred GP practices compared telehealth support for people with chronic conditions with treatment as usual. After a year, the telehealth group had fewer acute admissions and lower mortality (Steventon et al., 2012).

In chronic neurological conditions, remote monitoring provides a more comprehensive and 7 day assessment of the disease, than can be achieved in a rare specialist appointment or even regular community visits. This allows optimal management (Tzallos et al., 2014). Remote monitoring systems and virtual visits deliver improved care, whilst reducing health costs (Papapetropoulos et al., 2015). A number of devices have acceptable reliability, validity and sensitivity to change (Godinho et al., 2016). However, devices must accommodate a wide range of symptoms, personal preferences and comfort level with technology to be successful (Zhao et al., 2015). A smartphone app did as well as personalised gait training in Parkinson's Disease (Ginis et al., 2016).

Telemedicine can also reduce stress and hardship for patients. Half of patients needing routine follow-up clinic visits after stroke expressed an interest in telemedicine, including significant numbers who had missed medical appointments due to travel problems and experienced travel-imposed financial hardship (Bashiri et al., 2015). A recent study of "virtual house calls" saved participants on average 100 miles and three hours of travel (Dorsey et al., 2013).

Technology and mental health

Teleconferencing has been demonstrated to be a valid way of assessing cognition (Grosch et al., 2015). Telemedicine does at least as well as face-to-face care for dementia (Kim et al., 2015). A smartphone app for people with dementia serves as both a reminder to overcome forgetfulness and a log for usage and compliance, thus determining suitability for individual patients (Hartin et al., 2014).

Table 1. Advantages and limitations of telemedicine interventions

Advantages of telemedicine	Limitations of telemedicine
Accessibility to remote areas	Technical difficulties
Expansion of medical education	Disruption of traditional doctor-patient relationship
Increased efficiency of clinical consultations	Partial loss of information related to physical examination
Improved patients' HRQoL and satisfaction	Reduction of confidentiality
Collection of data for better understanding/monitoring disease course	Difficulty to transfer TM records and documentation to patients' medical records
Reduction of waiting list/medical costs	Not well-established legal issues
Development of tools to measure clinical variables in a real environment	Training on the technologies to use
Promotion of clinical research	Intense and frequent patient and clinician participation

HRQoL health-related quality of life, *TM* telemedicine

Table from Sola-Valls et al., Telemedicine for Monitoring MS Activity and Progression. Curr Treat Options Neurol. 2015 Nov;17(11):47

Stakeholders

Who are stake-holders in developing a technology enabled care model?

- Health commissioners
- Commissioning Support Unit
- Academic Health Sciences Network
- Clinical Networks
- Health care providers (GPs, community hospitals, pharmacy, hospitals)
- Voluntary care providers
- Patients and patient support groups
- Technology suppliers, innovators and software developers

Implementing technology through the commissioning cycle

Identifying care and service needs

Care and service gaps for long-term neurological conditions may vary significantly from one region to another. Defining the need and scope of service transformation is the most critical step. Ideas for transformation can arise from multiple sources including technology innovators who may identify a previously hidden unmet need.

Evaluating existing and new technologies

Once existing practice and the desired changes are mapped, the areas in which technology may be used to support a new care model can be evaluated. Many technologies are being deployed at local level, often as pilot schemes and with numerous innovations, there are likely to be significant learning opportunities. Maps of existing technology use may be available.

Identifying suitable patient groups

It is important to consider whether the patient group would be will to engage with technology, what their preferences are, and whether they perceive benefit. It may also be the case that there may be vulnerable at-risk groups that would benefit from a particular type of technology such as telehealth.

Understanding the benefits

Technology may reduce cost, improve productivity, allow safer and more effective care, enable rapid intervention, enrich clinical encounters and improve patient experience. For patients with long-term neurological conditions, specific outcomes include:

- Improved self-care with patient empowerment, patient held records;
- Early identification of disease exacerbations such as MS relapse or infective exacerbations;
- Improve communications and information exchange between multiple providers typically involved in a patient with a long term neurological condition (GPs, allied health professionals, social care, nurses, out-of-hours and emergency departments);
- Reduced out-patient attendance and avoidance of routine checks for patients with long-term neurological conditions who are stable but still feel part of their healthcare team;
- Access to specialist care in the community, where patient travel to the hospital may be difficult.

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

**Thames Valley
Strategic Clinical Network**

REFERENCES FOR REPORT 4

Allen C, Vassilev I, Kennedy A, Rogers A. Long-Term Condition Self-Management Support in Online Communities: A Meta-Synthesis of Qualitative Papers. J Med Internet Res. 2016 Mar 10;18(3):e61.

Bashiri M, Greenfield LJ Jr, Oliveto A.Telemedicine Interest for Routine Follow-Up Care Among Neurology Patients in Arkansas. Telemed J E Health. 2015 Dec 18.

Dorsey ER, Venkataraman V, Grana MJ, Bull MT, George BP, Boyd CM, Beck CA, Rajan B, Seidmann A, Biglan KM. Randomized controlled clinical trial of "virtual house calls" for Parkinson disease. JAMA Neurol. 2013 May;70(5):565-70.

Ginis P, Nieuwboer A, Dorfman M, Ferrari A, Gazit E, Canning CG, Rocchi L, Chiari L, Hausdorff JM, Mirelman A. Feasibility and effects of home-based smartphone-delivered automated feedback training for gait in people with Parkinson's disease: A pilot randomized controlled trial. Parkinsonism Relat Disord. 2015 Nov 10.

Godinho C, Domingos J, Cunha G, Santos AT, Fernandes RM, Abreu D, Gonçalves N, Matthews H, Isaacs T, Duffen J, Al-Jawad A, Larsen F, Serrano A, Weber P, Thoms A, Sollinger S, Graessner H, Maetzler W, Ferreira JJ. A systematic review of the characteristics and validity of monitoring technologies to assess Parkinson's disease. J Neuroeng Rehabil. 2016 Mar 12;13(1):24.

Hartin PJ, Nugent CD, McClean SI, Cleland I, Norton MC, Sanders C, Tschanz JT. A smartphone application to evaluate technology adoption and usage in persons with dementia. Conf Proc IEEE Eng Med Biol Soc. 2014;2014:5389-92.

Kim H, Jhoo JH, Jang JW. The effect of telemedicine on cognitive decline in patients with dementia. J Telemed Telecare. 2015 Nov 4.

Papapetropoulos S, Mitsi G, Espay AJ.Digital Health Revolution: Is it Time for Affordable Remote Monitoring for Parkinson's Disease? Front Neurol. 2015 Feb 26;6:34.

Steventon A, Bardsley M, Billings J, Dixon J, Doll H, Hirani S, Cartwright M, Rixon L, Knapp M, Henderson C, Rogers A, Fitzpatrick R, Hendy J, Newman S; Whole System Demonstrator Evaluation Team. Effect of telehealth on use of secondary care and mortality: findings from the Whole System Demonstrator cluster randomised trial. BMJ. 2012 Jun 21;344:e3874.

Sola-Valls N, Blanco Y, Sepúlveda M, Martinez-Hernandez E, Saiz A. Telemedicine for Monitoring MS Activity and Progression. Curr Treat Options Neurol. 2015 Nov;17(11):47.

Tzallas AT, Tsipouras MG, Rigas G, Tsalikakis DG, Karvounis EC, Chondrogiorgi M, Psomadellis F, Cancela J, Pastorino M, Waldmeyer MT, Konitsiotis S, Fotiadis DI.

Sensors (Basel). PERFORM: a system for monitoring, assessment and management of patients with Parkinson's disease. 2014 Nov 11;14(11):21329-57.

Zhao Y, Heida T, van Wegen EE, Bloem BR, van Wezel RJ .E-health Support in People with Parkinson's Disease with Smart Glasses: A Survey of User Requirements and Expectations in the Netherlands. J Parkinsons Dis. 2015;5(2):369-78.

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

**Thames Valley
Strategic Clinical Network**

Report 5:

Costs of Care
and Payment Mechanisms

Written by Christopher Kipps[1,2,3,4]

[1] *University of Southampton, Clinical Neurosciences;* [2] *Wessex Neurological Centre, Dept Neurology;* [3] *Wessex NIHR CLAHRC, Ageing and Dementia Theme;* [4] *Wessex Strategic Clinical Network, Mental Health, Dementia, Neurology*

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

**Thames Valley
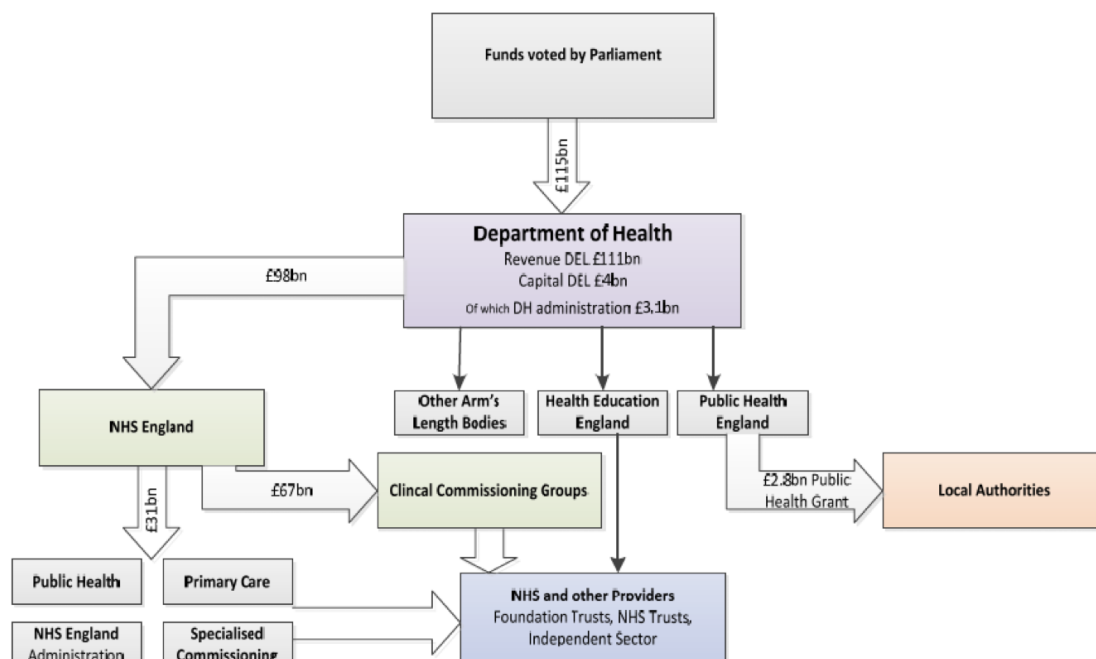Strategic Clinical Network**

INTRODUCTION

The lack of a robust financial case is often cited as a barrier to changing clinical and commissioning practice to provide person-centred care for people with long-term conditions. New models of care can only be realised through funding release from other activities within existing pathways of care. It is crucial therefore, to understand the cost implications of a community-based neurological service, and the elements that drive this. It is also imperative that a wide range of potential funding models are considered in order to identify opportunities to align the objectives of community neurological care, with the financial mechanisms to support such models.

Financial models for a neurology community service will need to encompass the elements considered crucial by patients, their carers and clinicians, namely: a person-centred service; simple and effective access to community rehabilitation and support for patients and carers; facilitation across the entire pathway from vocational re-enablement to respite and palliative care; identification and adoption of meaningful outcomes at patient and clinician level with mechanisms for feedback; development of risk stratification models to allow appropriately focussed delivery of care and funding based on need.

FUNDING

Nearly £100 billion is allocated annually to provide healthcare to people living in England. The majority of this funding (£67 billion) is provided directly to Clinical Commissioning Groups (CCG) to commission services from appropriate provider organisations[i]. The commissioning of specialised services is a prescribed direct responsibility of NHS England, and accounts for approximately 14% of the total NHS budget, circa £13.8 billion per annum.

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

**Thames Valley
Strategic Clinical Network**

Department of Health

Annual Report and Accounts 2014-15

Figure 1: Flow of funding in Health Care Sector 2014-15

This figure is based on budgeted position and is included as a representation of funding flow and may not reconcile directly with financial outturn.

Figure 1 NHS funding flows[ii]

COMMUNITY SERVICES

By one estimate, patients come into contact with community services about 100 million times per year. These services are commissioned via Clinical Commissioning Groups, and in 2012/13, the NHS spent about £9.7 billion on Community Services from a range of providers including NHS trusts which accounted for about 69% (£6.6bn) of this; 13% (£1.3bn) was run by the not-for-profit sector and 18% (£1.8bn) by the private sector.

In 2014, many commissioners extended or renewed community services contracts first put in place as part of the Transforming Community Services programme. This programme resulted in PCTs transferring provisions of community services to providers, creating a purchaser/provider split in community services to mirror that which was already in place in primary, secondary and mental healthcare. In a recent survey of CCGs, Monitor recently identified that many commissioners expect to roll over the current contracts in 2015 for at least one year. The greatest challenge identified by commissioners was a lack of robust activity, cost and quality data. This is in part due to the fact that fixed-sum payments have created little incentive for providers to understand individual service costs[iii].

NHS REIMBURSEMENT

The reimbursement system should support the overall policy objectives of the NHS. Its success relies on three elements - information, incentives and compliance[iv]. An effective reimbursement system should incentivise improvements in both the quality of patient care and the efficiency of providers (and therefore the system as a whole). It requires a rigorous and comprehensive set of information from providers about the volume of activity, the cost of service delivery, and the quality of those services. Prices, whether national or local, provide signals to providers and commissioners to inform their decision-making. Commissioners must decide what services they can afford to buy, and providers must decide what services they can sustainably provide.

NHS Payment Responsibilities

As a consequence of the Health and Social Care Act 2012, the Department of Health responsibility for Payment by Results (PbR) function has been split for determination of currencies for NHS services and determination of their associated prices, between the NHS England (previously NHS Commissioning Board). NHS England is the lead body with accountability for the definition and variation to the scope and content of services or currencies. Monitor is the lead body with accountability for the determination of prices for these currencies, development of rules and guidance and publication of the National Tariff Document. The ability to design pricing systems and set prices is intended to be a key lever available to these organisations to allow them to discharge their wider functions under the Act. To deliver these responsibilities the two organisations effectively need to work closely together.

Currencies, pricing and payment design

In a tariff-based payment system, payments are made for defined units of healthcare (such as an outpatient appointment), known as currency units[v]. The pricing framework, mandated nationally, is supplemented by local tariff negotiation (top-up) and outcome-specific incentives (CQUIN). Ideally payment approaches should comprise the following:

- a fixed core component;
- an outcomes based incentive payment;
- a component that share financial gains or losses between providers and commissioners, relative to the total.

Payment Models

A variety of payment models are currently in use in the NHS. These range from aggregated payments (block funding), to payments which are entirely atomised (individual fee for service), see **Figure 2**. The precise model in use varies by healthcare setting and service type[vi].
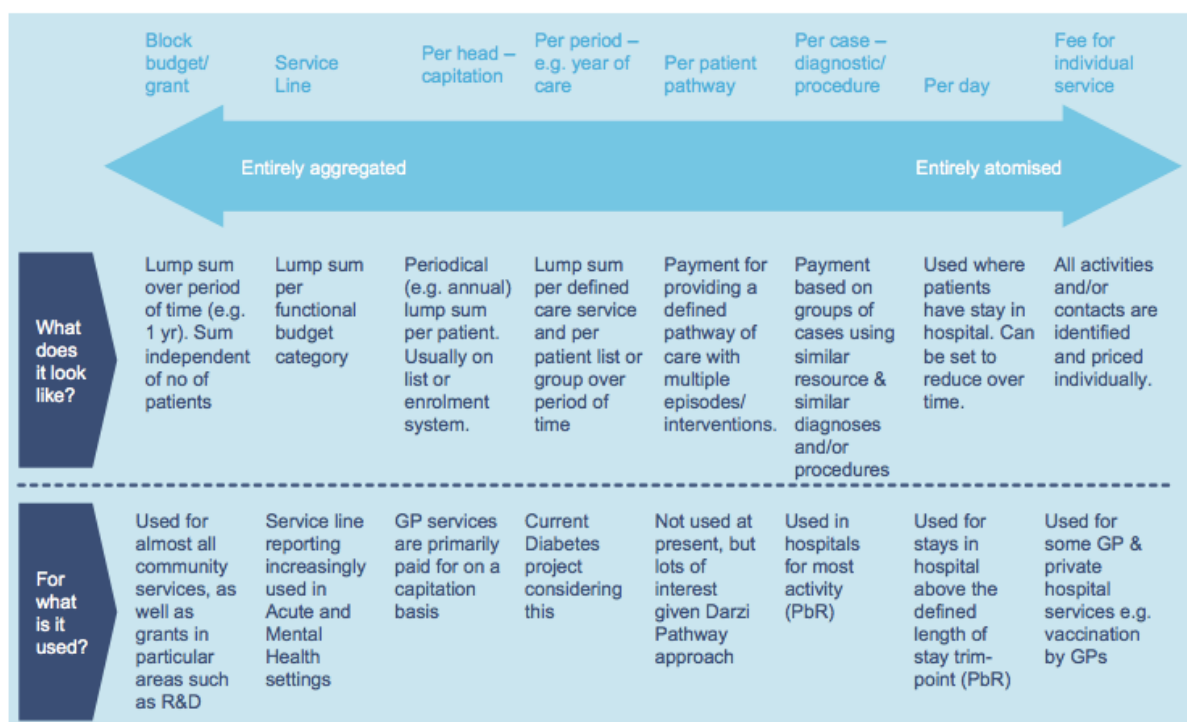
TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

**Thames Valley
Strategic Clinical Network**

	Block budget/ grant	Service Line	Per head – capitation	Per period – e.g. year of care	Per patient pathway	Per case – diagnostic/ procedure	Per day	Fee for individual service
	Entirely aggregated						Entirely atomised	
What does it look like?	Lump sum over period of time (e.g. 1 yr). Sum independent of no of patients	Lump sum per functional budget category	Periodical (e.g. annual) lump sum per patient. Usually on list or enrolment system.	Lump sum per defined care service and per patient list or group over period of time	Payment for providing a defined pathway of care with multiple episodes/ interventions.	Payment based on groups of cases using similar resource & similar diagnoses and/or procedures	Used where patients have stay in hospital. Can be set to reduce over time.	All activities and/or contacts are identified and priced individually.
For what is it used?	Used for almost all community services, as well as grants in particular areas such as R&D	Service line reporting increasingly used in Acute and Mental Health settings	GP services are primarily paid for on a capitation basis	Current Diabetes project considering this	Not used at present, but lots of interest given Darzi Pathway approach	Used in hospitals for most activity (PbR)	Used for stays in hospital above the defined length of stay trim-point (PbR)	Used for some GP & private hospital services e.g. vaccination by GPs

Figure 2 Spectrum of Currencies for Healthcare services

Block Contracts

Over 90% of community care funding is allocated via block contracts (see **Figure 3**). Such contracts are based on historic activity, and are generally independent of the number of patients who utilise the service. In a recent Monitor survey[vii], fewer than 1% of CCGs surveyed had outcomes-based measures, and most commissioners expected to roll over the current contracts in 2015 for at least another year. Fixed sum (block) contracts create little incentive for providers to understand individual service costs, but rather to manage total cost and ensure that this matches revenue. Efficiency savings are unlikely in the absence of activity and quality outcome data, and variation in service provision across providers is high.

Table 1: Current remuneration methods[20]

Description	Type of payment	%
Percentage of total annual value of contracts in our sample remunerated by:	Fixed-sum payment	93%
	Cost and volume	5%
	Activity	1%
	Outcomes-based	1%
Total		100%

Source: Monitor's analysis of questionnaire responses
Note: AQP contracts, typically remunerated on an activity basis, are not included in the analysis

Figure 3 Monitor analysis of community service funding arrangements based on CCG questionnaire (excludes Any Qualified Provider (AQP) contracts)[viii]

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

**Thames Valley
Strategic Clinical Network**

Payment by Results (PbR)

Most secondary and tertiary care acute providers are reimbursed through diagnostic and procedure coding (HRG) linked to national reference costs. There is evidence that PbR has increased efficiency in secondary care services, but efficiency improvements are blunted by inadequate tariff setting at the individual patient level. Care is coded by activity, and complexity of delivery, but there is wide variation across individual patients, and a scarcity of accurate cost information, which creates unstable revenue streams for providers. There is evidence to suggest that providers cross-subsidise non-tariff activities and revenue gaps to stabilise service mix which is unlikely to change significantly from year to year. This limits the ability of payment incentives to deliver efficiency gains at individual activity level[ix]. Cost and coding lags put PbR pricing behind clinical practice, which can stifle innovation. The focus on activity and not outcomes also creates barriers to integrated care.

Weighted bed day payment model

PbR guidance for 2013/14 introduced a multi-level weighted bed day (WBD) commissioning currency for specialist (level 1 and 2) rehabilitation services together with a set of indicative tariffs. The WBD currency supports the admission of highly complex patients by reimbursing at a higher rate - but only while they continue to have complex needs. Reduction in the level of reimbursement at lower levels of complexity discourages excessive lengths of stay and admission of non-complex patients whose needs could be met in their local services. The tariff is based on serial assessment of complexity using the Rehabilitation Complexity Scale[x], which is applied at fortnightly intervals throughout the patient's stay. The longitudinal aspect of this payment recognises the changing needs of this particular patient group over time, many of whom have long-term neurological conditions[xi].

Capitation Models

Capitation models are relevant to delivery of community care, and may facilitate the drive to improve value through linkage of activity and outcomes across the cycle of care. Capitated payments are one such payment arrangement that several local care economies are developing. Broadly speaking, capitated payment or capitation means paying a provider or group of providers to cover the majority (or all) of the care provided to a target population, such as patients with multiple long term conditions (LTCs), across different care settings. The regular payments are calculated as a lump sum per patient.

If a provider meets the specified needs of the target population for less than the capitated payment, they will generate a financial gain to the local health system. Allowing providers to share in any such gain gives them an added incentive to keep patients in their target population healthy. They are more likely to identify risks, intervene early and arrange the right treatment for patients, at the right place and the right time to aid patients' recovery, continued wellness and better management of long term conditions.

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

Thames Valley
Strategic Clinical Network

To design a capitation approach, commissioners and providers need to[xii]:

- Identify the patient cohort to be included (should benefit from coordinated care, be relatively homogenous, and large enough to mitigate risk due to random variation);
- Determine the scope of services to be included;
- Determine the unit price per person per year;
- Agree the mitigation mechanisms to ensure capitation budget holder can manage financial risk;
- Agree provider to provider payment mechanisms to be put in place to allow subcontracting of appropriate services;
- Identify performance measures (quality and patient outcomes) that could influence final payment to ensure provider focus on outcomes for the entire patient cohort.

At present several limitations to capitation models exist including existing arrangements, lack of capitation familiarity of providers and commissioners, sparse patient data linked across different care settings, and difficulty in determining average total cost per individual across the care cycle. In many systems, a risk pool is established as a percentage of the capitation payment. Money in this risk pool is withheld from the provider until the end of the fiscal year. If the plan does well financially, the money is paid to the provider; if the health plan does poorly, the money is kept to pay the deficit expenses.

Year of Care Model

Year of Care models are capitated payments designed cover the annual care related to a particular condition, such as paediatric diabetes or cystic fibrosis[xiii]. Payments are based on current spend on a defined patient cohort, with risk scores stratifying the cohort in terms of predicted care requirements. It requires an integrated needs-based assessment, with common assessment tools linked to categories and pathways of support. Implicit in this approach is robust agreement on methodologies and currencies to establish costs, and a focus on outcomes, which should be defined within contracting mechanisms, and monitored appropriately for compliance. The systems architecture to support integrated commissioning of these types of models is being actively developed, with a focus on integrated datasets, shared care plans and needs assessments, and shared costing information.

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

**Thames Valley
Strategic Clinical Network**

Capitation models (examples from other healthcare systems)[xiv] [xv]

- Alzira model (Valencia): capitated payments, single integrated provider; resulted in significant shifts from hospital to community (25% reduction);
- CREG (Lombardy): multiple providers, but common risk-adjusted pathways developed by capitated contractual model;
- Netherlands: Bundled payments, but disease-specific orientation; costs increased;
- Gesundes Kinzigtal (Germany): multiple providers and insurers with bundled capitation payments since 2007 as part of care change; reduction in morbidity and mortality, with morbidity adjusted efficiency gain (16%);
- Beacon Health (USA): used phased-in transition towards full financial risk transfer, with options for more limited risk sharing, built around a series of quality and outcome measures which impact the size of the shared savings for the capitated budget holder;
- ChemMed (USA): fill transfer of financial risk to capitated budget holder, with uptake driven by patient choice;
- CareFirst (USA): combines a one-sided gain/loss sharing arrangement (downside risk remains with the commissioner) to incentives to encourage specific elements of best practice.

Capitation Models: Risks and Benefits

Financial, operational and quality-related risks are present in all models of care. Particular risks include, providers restricting access to care, 'cherry-picking' the least complex patients, or reducing the equality of care provided. Providers may become financially unstable if the risk-sharing arrangements are prejudiced against them. Commissioners may pay twice for the same service where there are overlapping capitation payments for an individual with multiple conditions. To ensure high quality care is delivered, in addition to setting minimum quality standards, commissioners can require a proportion of the payment itself to be dependent on the provider or network of providers achieving specified quality targets and outcomes for patients in the target group. Patient choice can also be restricted if the patient is unable to choose 'out of network' care at a cost to the capitated budget holder[xvi].

The benefits include promotion of prevention activities, incentivising care taking place in the right setting, with the right person, and more effective resource use across health and social care. Capitation models also enhance predictability of provider income, making it more feasible for them to plan and implement service changes. Similarly, capitation payments create a greater requirement for coordinated care. As financial risk is transferred to providers, it aids the investment in preventative care, and care provision in the lowest cost setting.

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

Thames Valley
Strategic Clinical Network

EMERGING MODELS OF CARE

There are several initiatives underway within the UK healthcare system to implement and evaluate alternative models of care.

Vanguard Sites

The Five Year Forward View (5YFV) outlines a new care model for primary care using *multispecialty community providers* (MCP), designed to offer a wider scope of services, such as community and outpatient services, and enable new ways of delivering care through extending group practices to form federations, networks or single organisations. Vertically integrated *primary and acute care systems* (PACS) permit single organisations to provide NHS list-based GP and hospital services, together with mental health and community services[xvii].

Personal Health Budgets

Personal health budgets are being introduced in various NHS and social care settings to help people manage their care in a way that suits them[xviii]. Since October 2014, adults receiving NHS Continuing Healthcare have had a right to a personal health budget. This is an amount of money provided to support identified health and wellbeing needs, planned and agreed between an individual and a local NHS team to give people with long-term conditions and disabilities greater choice and control over the healthcare and support they receive. This may supplement personal budgets offered by social services.

COSTS OF NEUROLOGICAL CARE

The 2011 National Audit Office report on services for people with neurological conditions[xix] reported that between 2004 and 2010 there was more than a 30% increase in neurological inpatient admissions (compared with 20% for the NHS as a whole), and emergency admissions also rose by 30% (compared with a 17% rise in the NHS as a whole). Reporting in 2015 on progress in services for people with neurological conditions since 2010[xx], the NAO highlighted an estimated overall spend of £3.3bn on neurological services in 2012-13, a figure which accounts for 3.5% of total NHS spending. Over £8.3bn was spent by social care services on people with disabilities, of which, one quarter are estimated to have a neurological condition. Admissions of neurological conditions increased by 3.6% between 2010-11 and 2013-14.

At a local level, in a population of 2.8 million people, analysis of Wessex Hospital Episode Statistics (HES) data for 10 major neurological conditions (5 years to 2013/14) identified annual spending rising from £51M, to £83M in 2013/14 during this period, at an average cost of £1,537 per admission[xxi].

Neurological Conditions

Across the NHS, non-elective admissions for people with multiple sclerosis in England cost £43M, with an average LOS of 7.7 days[xxii]. Considerable variability exists in Payment by Results (PbR) costs for the same condition: in MS, the mean cost of a non-elective admission for a person with MS in 2013/14 was £1,820, but this ranges from £1,042 to £2,861 between CCGs across the country. Simple MS relapse

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

**Thames Valley
Strategic Clinical Network**

management across one NHS trust achieved £66,000 saving in avoided admissions over a one year period.

Individuals and their Carers

People with LTNCs typically present with physical and/or cognitive, behavioural, emotional disabilities and have diverse health and social care needs that vary over time. Annual informal care costs have been estimated at a mean of £82,620, almost 4 times higher than formal care costs (£18,117) with huge inter-individual variation[xxiii]. Recently published data on the costs of services for a sample of 152 people with LTNCs discharged from neurological rehabilitation units in London found the mean cost of medical and therapy services relevant to rehabilitation (both outpatient and home-based) was £2,516 in the first six months following hospital discharge, largely distributed across nursing and therapy services. During the following 6 months the average cost of these rehabilitation-related services fell to £1,983[xxiv]. These costs take no account of social care contributions. During this one-year period, informal care costs rose from £14,615 to £15,468, requiring an average of 8.8 hours per day to perform.

There are no figures available for social care costs in long-term neurological conditions. In a postal survey of 282 individuals with long-term neurological conditions, marked variability was present, with average costs identified at £8,496 per annum (with a range from £0 to £180,333)[xxv]. The mean expenditure (per individual) was £1203 for outpatient and £739 for home-based services. Costs were highest for progressive conditions. It is likely that people with neurological conditions are over-represented amongst those requiring Continuing Healthcare support.

Several other factors such as individual productivity loss, reduced carer productivity, tax revenue loss and cost of benefits provision are likely to have an effect on the overall economic impact of long-term neurological conditions. At present, these remain unquantified.

Factors Affecting Costs of Neurological Care

A range of factors will influence the local costs of neurological care. Neurological conditions can be static (e.g. stroke), relapsing (e.g. epilepsy, multiple sclerosis), progressive (e.g. Parkinson's disease, Huntington's disease), and care requirements vary as a function of the aetiology. In an individual, the presentation may vary considerably, with extent of disability, age and co-morbidities playing key roles.

Some conditions are costly to the community by virtue of high prevalence, but may have little direct impact on requirements for community support. For example, migraine is estimated to affect 14.7% of Europeans, and costs the European Community over €27M annually, with average UK 3-month costs of €929 for chronic migraine through hospitalisations, healthcare provider visits, procedures and medications[xxvi]. The impact on work absenteeism is even higher, estimated at £2.25bn per year. Most people with migraine self-manage their condition, and a significant proportion of the true cost of migraine is hidden.

The nature and extent of disability plays a crucial role, and may range from mild disability through immobility to complete dependence. This impacts on carer burden, requirement for neurological workforce, and equipment maintaining individuals at

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

**Thames Valley
Strategic Clinical Network**

home. An ageing population, with associated co-morbidity, will impact on community care resource allocation.

While some neurological conditions have impact through their relatively high prevalence, other conditions such as motor-neuron disease and Huntington's disease have high complexity, major dependency and require co-ordination across multiple services (both health and social care). Fragmented care, and poor co-ordination has a direct effect on the cost of such care.

COST RELEASE IN NEUROLOGICAL CARE

The economic incentives of health and social care systems overlap with the needs of service users. A community neurology service should optimise healthcare costs by expediting hospital discharges, reducing rates of readmission through preventative approaches, and relieving pressure on emergency and out-of-hours services. In addition, it should utilise informal family and community resources, tailor the size of care packages to individual need, reduce premature or unnecessary admission to institutional care, and maximise the ability of individuals to fulfil societal roles. From a commissioning point of view, it is highly desirable for services to be delivered by connected agencies, integrating aspects of care to minimise duplication and inefficiency.

Care Coordination

In Cambridge a care coordinator post for MND saved 771 bed days over a three-year period with financial savings equivalent to £33,000 per annum achieved over and above the cost of the co-ordinator[xxvii]. Evaluation of a specialist physiotherapist post, created to offer patients with MND and their families a co-ordinated approach to complex care needs, avoid unnecessary admissions, interventions and outpatient referral, found £81,944 in net costs saved over a one-year period. Patient feedback was overwhelmingly positive, and the post allowed 9 out of 10 patients to die at home rather than in hospital[xxviii]. A 2009 case study showed that costs of £16,500 per month required to maintain a patient with MND in the community, had the potential to rise to over £30,000 per month when care was not co-ordinated, and a crisis management only approach adopted. In the 'My Needs Now' project, a care co-ordinator caring for people with rare and rapidly progressive neurological conditions, could demonstrate a 98% reduction in the likelihood of a hospital admission[xxix]. In West Berkshire, average length of stay decreased by 37% following the appointment of a clinical nurse specialist for rare neurological conditions[xxx]. Cost reduction estimates are impressive, however, the lack of data on costs managed elsewhere as a result of avoided admissions, or decreased LOS, makes it difficult to identify the true levels of cost benefit.

Improved Community Comorbidity Management

Review of non-elective admissions in three major conditions (Parkinson's disease, multiple sclerosis and epilepsy) showed significant potential for cost release from improved treatment of co-morbidities such as urinary tract and respiratory infections, and injuries related to falls. In Parkinson's disease, admissions due to urinary tract infections in the Wessex region cost £2.4M over 4 years, and injuries due to falls over £4.0M[xxxi]. While not all admissions due to co-morbidities are preventable, evidence from a rapid treatment protocol for urinary tract infection in multiple sclerosis, shows

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

**Thames Valley
Strategic Clinical Network**

considerable cost savings in prompt identification and treatment of UTI in the community.

Improved Community Support

The use of the RENEW exercise course in people with MS and Parkinson's disease estimated a 20% reduction in hospital admissions, a reduction of one visit by a specialist nurse in 50%, and improvement in core stability preventing falls and a Falls Team referral in 30%[xxxii]. Applying the relevant cost savings across a typical CCG population (250,000) and assuming approximately 483 people with Parkinson's disease and 403 people with MS, a net benefit of £260,366 could potentially be realised after taking into account the cost of the course[xxxiii].

Reduced Cost Variability

Quite marked variation in exists across the UK in various neurological indicators. Commissioning for value indicators identify a 4-fold variation in non-elective admissions for neurological conditions across CCGs, and significant variation in outcomes, where measured. Payment by Results (PbR) costs for the same condition: for example, in MS, the mean cost of a non-elective admission for a person with MS in 2013/14 was £1,820, but this ranges from £1,042 to £2,861 between CCGs across the country. Simple MS relapse management across one NHS trust reported a £66,000 saving in avoided admissions over a one-year period. The wider introduction of Neurology Commissioning for Value packs may help with improved identification of unwarranted variation in neurological services, and offer opportunities to reduce inefficiency via comparison with spending and outcomes in similar CCGs.

Development of RightCare casebooks to illustrate the benefits of pathway re-design have potential to apply more rigorous costing data to divergent clinical pathways in neurological disorders.

CASE FOR CHANGE

Value

Long-term neurological conditions are a significant burden in the community and have substantial associated cost. There is wide variation in spend, access, outcome and experience across the UK. These costs are poorly quantified, with resource burden falling on health and social care, as well as the individual with the condition and their carers. Improved community care for neurological conditions can improve care co-ordination for the individual across service boundaries, optimise self management, and focus specific resources on those with the greatest need. This effort is limited by poor risk stratification of individuals, and poor data on activity and outcomes. Funding is currently allocated by funding models that do not optimise value through the linkage of activity and relevant outcomes, and pricing structures have limited ability to incentivise improved community neurological care.

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

**Thames Valley
Strategic Clinical Network**

Several principles have been outlined by the NHS Confederation for the purpose of developing appropriate payment mechanisms for community services[xxxiv]:

1. **Develop a mixed and flexible system**, with different approaches applied depending on the availability and extent of evidence on costs and patient outcomes; this system will evolve over time as data and good practice evolve;
2. **Focus on outcomes and pathways**, not inputs and processes; this could facilitate integrated working and joint accountability, and should include patient-defined (and reported) outcomes;
3. The payment system should **enable (and remove barriers to) new models of care**, with greater integration, and community focus; consistency of measurement of care across the whole system is required;
4. **Stability and transparency to enable planned change** should be generated within the system to support planning and investment.

Evidence from tariff re-design elsewhere in Europe suggests a combination of the following elements is required[xxxv]:

- Capacity payments (with some activity based payment and performance monitoring);
- Block contracts and PbR/bundled pathways for different kinds of planned care;
- Year of Care, or other capitated payments, to incentivise proactive, preventative approaches.

DEVELOPMENT OF PATIENT CURRENCIES

Patient currencies offer an opportunity for improved transparency and better measurement of healthcare value. Several examples of transferrable practice exist for improving the linkage of individual patients, their needs and their outcomes, to reimbursement for providers.

Mental Health Currencies

In mental health, risk stratification model principles are increasingly linked to payment. Mental health conditions are clustered to one of 21 groupings, each incorporating a severity and needs-based measurement, and organised within one of three super classes: non-psychotic, psychotic and organic. There is an expected cost per cluster, which can be used for reimbursement, and set interval reviews allow for changes in intensity and cluster transitions over time. Implementation of this system relies on adequate common data capture with appropriate IT infrastructure, and constructive risk-sharing between providers and commissioners.

Child and Adolescent Mental Health Services Payment Project

This project is currently attempting to categorise service users in terms of their 'needs for advice or help'. Overall categories of support are defined as: getting advice, getting help; and getting more help[xxxvi]. Each grouping has a range of subgroupings (e.g. Getting Help: ADHD, Bipolar Disorder; Getting More Help: Eating Disorders, Psychosis), with an expectation of the proportion of service demand each category will fill. *Clinical meaningfulness* and the *ability to identify periods of similar resource use* are important principles guiding this effort. The project identifies outcome

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

**Thames Valley
Strategic Clinical Network**

measurement as being crucial to monitoring of progress and appropriateness of intervention.

Improving Access to Psychological Therapies (IAPT)

IAPT currency models combine outcome and process targets where half of the price paid depends on clinical outcomes, with patient satisfaction, reduction in disability and employment outcomes accounting for a further 31.25% of the price[xxxvii]. Access targets and preferential focus on individual diagnoses are also taken into account. The payment structure is modified by the Mental Health Cluster price to account for case-mix weighting.

Longitudinal Care-Cycle Evaluation (UK-ROC)

Care requirements change over time depending on the complexity and stage of a condition. New treatment options emerge, and dependency levels can fluctuate depending on community resources and carer support. The UK-ROC study has substantial data on the changing rehabilitation requirements over time for inpatients with complex rehabilitation needs[xxxviii]. Accreditation for rehabilitation centres is now dependent on mandatory collection of relevant datasets.

Risk Stratification

The principles of risk stratification in community neurological care, outlined in the section on Integrating Care support the use of an appropriate patient currency. At present, however, there is little best practice, and no standardised, data on how to allocate risk classification across major neurological conditions. This is an important area for future development.

RESOURCES

Community services already provide substantial resource to support people with neurological conditions. Indeed, it was noted in a recent report from the Neurological Alliance, that although only 11% of individuals with a long-term neurological condition had an active care plan, over 65% said they definitely, or to some extent, had enough support from local services, however one-fifth did not[xxxix]. There is wide variation in the way such support is provided (see section on Integrating Care) however, it is important to identify the key elements of such services, particularly with respect to resources.

Professional Competencies

Specialist competencies required include: the ability to diagnose and interpret neurological impairment, to link this to the individuals presenting problems, and to identify associated medical and psychiatric co-morbidity; an ability to prescribe, and where necessary, carry out appropriate interventions (drug, other medical and non-medical); ability to refer appropriately to other agencies (local or further afield) where professional competencies are insufficient to deal with the presenting problem.

A community neurological service requires input from a range of professionals[xl], but the following should be regarded as core members of the team[xli]:

- Therapists (Occupational, Speech and Language, Physiotherapy)
- Medicine (Neurology, rehabilitation or geriatrics)
- Mental Health (Neuropsychiatry, Neuropsychology, Clinical Psychology)

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

**Thames Valley
Strategic Clinical Network**

- Nursing
- Case management or social work

Service Domains

The service should also have access to a range of other qualified individuals to refer to for specific needs based on the clinical and social care problems faced by an individual with a long-term neurological condition[xlii]. This list includes: Nutrition (dietician); Fatigue; Pain; Palliative Care; Pressure area care (tissue viability service); mobility, posture and balance assessment; spasticity management; sleep; respiratory dysfunction (respiratory nurse and physician); mobility aids and driving assessment; visual disturbance (optometry, ophthalmology); cognition and memory assessment; low and higher level emotional difficulty; continence service; psychosexual counselling; support for family relationships; social participation support; vocational rehabilitation; carer needs assessment and support.

Diagnosis-specific Expertise

Although many long-term neurological problems can be managed by a team with core neurological knowledge, there are some needs that are unique to particular conditions, and require extensive experience to manage effectively. Clear indications exist for specialist nursing (or other professional) in Parkinson's disease, epilepsy, multiple sclerosis, head injury and Huntington's disease. These highly skilled individuals can play a crucial role in appropriately risk-stratifying individuals with long-term neurological conditions and linking them to appropriate services across the health and social care divide, in addition to integrating primary, secondary and community care.

Third Sector Organisations

Third sector organisations provide enormous resources to individuals with neurological conditions, particularly with respect to information provision, self-management and community support. In some diseases, funding is provided for some aspects of community care including care coordinators and advisors. They may have a key role in bridging gaps between health and social care.

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

**Thames Valley
Strategic Clinical Network**

ENABLERS FOR CHANGE

Data

The Community Information Data Set (CIDS) is a patient level, output based, secondary uses data set which will deliver robust, comprehensive, nationally consistent and comparable person-based information on patients who are in contact with Community Services[xliii]. As a secondary uses data set it intends to re-use clinical and operational data for purposes other than direct patient care. It defines the data items, definitions and associated value sets to be extracted or derived from local systems.

The CIDS collates data in the following categories:

- Patient Demographics
- Referrals
- Care Contact and Activities
- Group Sessions (that aim to improve health, reduce health risks and promote healthy behaviours)
- Social Circumstances
- Diagnoses, Tests and Observations

Ideally, a community neurology dataset should include the above, together with appropriate clinical and patient-related outcome measures to better inform service improvement and accountability in healthcare delivery.

Shadow Pricing

One mechanism to reduce reluctance to embark on wholescale payment reform in the absence of adequate information is to initiate the process with shadow outcome and pricing, facilitating direct comparison with the current system of care[xliv].

Pilot sites

A number of pilot sites could provide data to facilitate the case for change. Such efforts would need to be adequately coordinated to ensure maximum usefulness of data. Pilot sites should agree a common data collection set to allow efforts to be compared. This should include amongst other items:

- CIDS dataset
- Defined list of conditions to include:
    - Identification of competencies required to support community neurological care delivery;
    - Detailed costing of inputs across relevant settings;
    - Agreed outcome measures (clinical, patient-related).

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

**Thames Valley
Strategic Clinical Network**

REFERENCES FOR REPORT 5

[i] NHS England Our 2014-15 Annual Report. 2015.

[ii] Department of Health. Annual Report and Accounts 2014-15. 2015 Jul pp. 1–210. Report No.: 20041501 07/15.

[iii] Commissioning better community services for NHS patients. 2015 Jan. Report No.: IRG 01/15.

[iv] Price Waterhouse Cooper. An evaluation of the reimbursement system for NHS-funded care. 2012.

[v] Equity and excellence: Liberating the NHS. 2010 Jul. Report No.: P002377484 07/10.

[vi] Department of Health Payment by Results team. A simple guide to Payment by Results. 2012 Nov 15;:1–72.

[vii] Commissioning better community services for NHS patients. 2015 Jan. Report No.: IRG 01/15.

[viii] Commissioning better community services for NHS patients. 2015 Jan. Report No.: IRG 01/15.

[ix] Price Waterhouse Cooper. An evaluation of the reimbursement system for NHS-funded care. 2012.

[x] Turner-Stokes L, Disler R, Williams H. The Rehabilitation Complexity Scale: a simple, practical tool to identify "complex specialised" services in neurological rehabilitation. Clin Med. Royal College of Physicians; 2007 Dec 1;7(6):593–9.

[xi] Turner-Stokes L. Specialised Rehabilitation (Level 1 and 2a services). 2014. pp. 1–9.

[xii] Monitor. Capitation: a potential new payment model to enable integrated care [Internet]. 2014 Nov pp. 1–44. Report No.: IRCP 16/14. Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/445731/LPE_Capitation.pdf

[xiii] Devlin S. How can the NHS payment system do more for patients? [Internet]. 2013 [cited 2016 Mar 20]. pp. 1–22. Available from: https://www.england.nhs.uk/2013/06/nhs-pay-syst/

[xiv] Capitation payment - international examples [Internet]. gov.uk. [cited 2016 May 30]. Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/445741/Capitation_payment_-_international_examples.pdf

[xv] Monitor. Capitation: a potential new payment model to enable integrated care [Internet]. 2014 Nov pp. 1–44. Report No.: IRCP 16/14. Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/445731/LPE_Capitation.pdf

[xvi] Monitor. Capitation: a potential new payment model to enable integrated care

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

**Thames Valley
Strategic Clinical Network**

[Internet]. 2014 Nov pp. 1–44. Report No.: IRCP 16/14. Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/445731/LPE_Capitation.pdf

[xvii] Ham C, Murray R. Implementing the NHS five year forward view: aligning policies with the plan. 2015 Feb 10;:1–36.

[xviii] Care Pathways and Packages Project [Internet]. cppconsortium.nhs.uk. [cited 2016 Mar 20]. Available from: http://www.cppconsortium.nhs.uk/admin/files/1427122592CPPP%20The%20legacy%20-%20March%202015.pdf

[xix] National Audit Office. Services for people with neurological conditions. 2011 Nov. Report No.: HC 1586 Session 2010-2012

[xx] National Audit Office. Services for people with neurological conditions: progress review. 2015 Jul pp. 1–36. Report No.: HC 301 Session 2015-16.

[xxi] Kipps CM, Thomas S, Matthews D. Wessex Strategic Clinical Network Neurology Intelligence Report 2015 [Internet]. clahrc-wessex.nihr.ac.uk. 2016 [cited 2016 May 31]. Available from: http://www.clahrc-wessex.nihr.ac.uk/img/publications/NHiS-CE-Wessex-Report-Preview-Single-Page-V17.pdf

[xxii] Thomas S, Mynors G, Simpson S, Meade N, Bowen A. Measuring the burden of hospitalisation in multiple sclerosis: A cross-sectional analysis of the English Hospital Episode Statistics database 2009-2014 [Internet]. nhis.com. 2015 [cited 2016 May 31]. Available from: http://www.nhis.com/uploads/reports/NHiS-MS-Report-2015.pdf

[xxiii] Jackson D, McCrone P, Turner-Stokes L. Costs of caring for adults with long-term neurological conditions. 2013 Jul;45(7):653–61.

[xxiv] Jackson D, McCrone P, Mosweu I, Siegert R, Turner-Stokes L. Service use and costs for people with long-term neurological conditions in the first year following discharge from in-patient neuro-rehabilitation: a longitudinal cohort study. PLoS ONE. 2014;9(11):e113056.

[xxv] Jackson D, McCrone P, Turner-Stokes L. Costs of caring for adults with long-term neurological conditions. 2013 Jul;45(7):653–61.

[xxvi] Bloudek LM, Stokes M, Buse DC, Wilcox TK, Lipton RB, Goadsby PJ, et al. Cost of healthcare for patients with migraine in five European countries: results from the International Burden of Migraine Study (IBMS). J Headache Pain. 2012 Jul;13(5):361–78.

[xxvii] Thomas S. Cost saving Cambridge Care Co-ordinator [personal communication:email].

[xxviii] Foster J. Specialist Respiratory Physiotherapist Role Position Statement. NHS Wiltshire Clinical Commissioning Group. 2015 May pp. 1–11.

[xxix] Rare Disease UK (RDUK). Rare Disease Care Coordination: Delivering Value, Improving Services. 2013 Feb 25;:1–30.

[xxx] Quinn A. Evaluation of a New Post: The West Berkshire Nurse Specialist for Rare Neurological Conditions. 2006 pp. 1–32.

[xxxi] Kipps CM, Thomas S, Matthews D. Wessex Strategic Clinical Network Neurology Intelligence Report 2015 [Internet]. clahrc-wessex.nihr.ac.uk. 2016 [cited 2016 May 31]. Available from: http://www.clahrc-wessex.nihr.ac.uk/img/publications/NHiS-CE-Wessex-Report-Preview-Single-Page-V17.pdf

TRANSFORMING COMMUNITY NEUROLOGY
What Commissioners Need to Know
Reference Reports

NHS

**Thames Valley
Strategic Clinical Network**

xxxii Improving access to exercise for people with neurological conditions
[Internet]. 2014 [cited 2016 May 31]. pp. 1–4. Available from:
http://impact.ref.ac.uk/casestudies2/refservice.svc/GetCaseStudyPDF/17024

xxxiii NHis. Cost benefit of RENEW exercise course across typical CCG.

xxxiv NHS Confederation Community Health Services Forum. Position paper:
Reforming payment mechanisms for community services [Internet]. 2013 Nov.
Available from:
http://www.nhsconfed.org/~/media/Confederation/Files/public%20access/Reforming_
payment_mechanisms_for_community_services.pdf

xxxv NHS Confederation Community Health Services Forum. Position paper:
Reforming payment mechanisms for community services [Internet]. 2013 Nov.
Available from:
http://www.nhsconfed.org/~/media/Confederation/Files/public%20access/Reforming_
payment_mechanisms_for_community_services.pdf

xxxvi Wolpert M, Vostanis P, Young S, Clark B, Davies R, Fleming I, et al. Child and
Adolescent Mental Health Services Payment System Project. London; 2015 Jun pp.
1–11.

xxxvii The IAPT PbR Currency Model v0.22 [Internet]. 2014 [cited 2016 Mar 20]. pp.
1–5. Available from: http://www.iapt.nhs.uk/silo/files/iapt-pbr-currency-model.pdf

xxxviii Turner-Stokes L. The UK rehabilitation Outcome Collaborative (UK-ROC)
Database [Internet]. 2015 [cited 2016 Mar 20]. pp. 1–7. Available from:
http://www.kcl.ac.uk/lsm/research/divisions/cicelysaunders/research/studies/ukroc/in
dex.aspx

xxxix The Invisible Patients [Internet]. neural.org.uk. 2015 [cited 2016 May 30].
Available from:
http://www.neural.org.uk/store/assets/files/495/original/Invisible_patients_-
_revealing_the_state_of_neurology_services_final_14_January_2015_.pdf

xl Royal College of Physicians. Local adult neurology services for the next decade.
London; 2011.

xli Ward C, McCloughry H, Tomlin K. Community based rehabilitation of people with
long term neurological conditions. 2015 Nov 5;:1–76.

xlii Ward C, McCloughry H, Tomlin K. Community based rehabilitation of people with
long term neurological conditions. 2015 Nov 5;:1–76.

xliii HSCIC. Community Information Data Set (CIDS). 2015 May 20;:1–1. Available
from: www.hscic.gov.uk/comminfodataset

xliv Monitor. Capitation: a potential new payment model to enable integrated care
[Internet]. 2014 Nov pp. 1–44. Report No.: IRCP 16/14. Available from:
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/44573
1/LPE_Capitation.pdf