



Thames Valley
Strategic Clinical Network

TRANSFORMING COMMUNITY NEUROLOGY

What Commissioners Need to Know
Part A – Transformation Guide

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Credits

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Dedication

This work is dedicated to the memory of Mark Stone, an expert patient advisor who provided the editorial team with valuable insights into health care from a patient's perspective. Diagnosed with motor-neurone disease in 2012, Mark continued to work hard to improve patient experiences, as a project manager, an NHS Patient Partner and as a trustee of the MND Association amongst many other roles. Mark sadly passed away in February 2016.

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Disclaimer:

The views expressed in this article are those of the authors and not necessarily those of the organisations listed above.

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A list of interests declared by the authors is held by the project manager.

Foreword

By David Bateman, National Clinical Director for Neurology (2014-2016)

Long-term neurological conditions are very common and a typical Clinical Commissioning Group may be responsible for commissioning services for 59,000 patients, at a possible cost of £15 million. Personal Independence Payments for neurological conditions are currently the third highest group after mental health and musculo-skeletal conditions, so neurological conditions may have the highest rate of disability given the smaller numbers. Despite this, integrated care and care planning for these patients remains the exception rather than the rule. Neurology services for those with long-term conditions have traditionally been organised around secondary and tertiary sectors, to the detriment of care. Patients tend to be reviewed in consultant-led clinics, more often with a specialist nurse available now but this is not always the rule. Other members of the multidisciplinary team required to provide care are rarely available at the same time, making separate referral to therapists necessary if required. Often too, the therapists themselves are not part of a team to provide holistic care. Care services organized this way results in delayed access to expert advice, particularly at times of crisis, and a lack of integrated care. At least a fifth of neurology patients feel that they do not get enough support. £120 million is spent in England on emergency admissions for existing neurological conditions which might be considerably reduced by effective integrated community care, with appropriate care pathways to prevent crises from occurring.

Current care is therefore unsatisfactory from all perspectives: patients, carers and commissioners. Following a neurological diagnosis of a long-term condition there is no reason why patients should be seen regularly in secondary care, which tends to be organised around acute care, investigations and consultant care, rather than multidisciplinary integrated care. Patients with Parkinson's disease or multiple sclerosis, for example, require access to multidisciplinary teams with relevant expertise rather than just consultant care. One of my patients with multiple system atrophy understandably complained that she was seeing ten different specialists at different times in secondary care. How much easier would it have been for her to attend a multispecialty provider in community care?

The Five Year Forward View offers an opportunity and a requirement to reform and considerably improve community care of long-term neurological conditions. CCGs understandably have had a large number of other competing demands for their time, with little support and advice previously from neurology. This initiative was therefore set up by NHS England and a group of the clinical networks to develop commissioning models, guidance and support for CCGs for neurological conditions. The guidance set out in this document is clear, accurate and well researched to allow successful commissioning of these services. Much evidence shows that planned, organised and integrated care is cheaper with better outcomes.

I hope that you will find it helpful and it will encourage you to develop much needed improvements in services for neurology patients, so often overlooked and forgotten. Hopefully, we can stop admitting patients with motor-neurone disease in respiratory failure at the end of their life without previous discussion of end-of-life care, or management of respiratory failure, or patients with Parkinson's disease whose condition deteriorates without early access to support leading to falls with a fractured neck of femur resulting in admission to hospital for three months.

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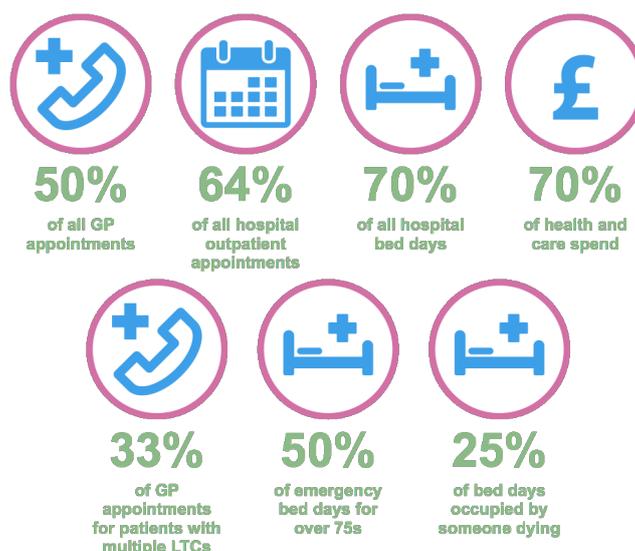
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EXECUTIVE SUMMARY

Over a year ago, the **NHS Five Year Forward View (5YFV)** outlined the transformation needed in our health and care system in order to meet the changing needs of our population, including the increasing millions of people living with multiple long-term conditions. It called for the development of more integrated and proactive approaches to care delivery, to improve the quality and efficiency of services as well as patients' outcomes, moving care closer to people's homes, from acute hospitals to community services. This is particularly relevant for people with long-term conditions, including those with neurological disorders, as they account for:



The Public Accounts Committee progress review on neurological services, published in early 2016, found that there is still wide variation across the country in access, outcomes and patient experience, and that diagnosing neurological conditions takes too long, services are too variable and local health and social care services are often poorly coordinated.

This Transformation Guide has been produced to help those with key local responsibilities for the future of the health service to meet that expectation and encourage the adoption of community-based care models that will seek to improve the quality of life for people who have long-term neurological conditions.

What are neurological conditions?

These are conditions which result from damage to the brain, spinal column or nerves, caused either by illness or through injury. There is a wide variety of conditions including multiple sclerosis (which is the biggest cause of disability of young adults), epilepsy, migraine, dementia, Parkinson's disease, neuromuscular conditions like motor neuron disease, cerebral palsy, meningitis, stroke and acquired brain injury.

Neurological conditions can impact individuals in widely varying ways. People living with neurological conditions have the highest levels of pain, anxiety and depression.

The socio-economic burden of long-term neurological conditions

Long-term neurological conditions carry a significant burden to the individual, their families and carers, the NHS and to society as a whole. It is estimated that people living with long-term neurological conditions consult their doctor up to five times more frequently than others, and will often see their GP five or more times before they are referred to a neurology specialist.

Key facts:

- £3.3 billion spent in 2012-13 on neurological services (3.5% NHS spend);
- 14% of the social care budget is spent on people who are living with neurological conditions;
- There are estimated to be 12.5 million cases in England, equivalent to an average CCG having 59,000 patients with a neurological condition;
- Patients with a neurological condition have the lowest health-related quality of life (EQ5D) of any long-term condition;
- £750 million spent on urgent and emergency care including admission to hospital with 3.6% growth in emergency admissions year on year;
- Around 9% of the NHS budget is spent on community services (£9.7bn in 2012/13), though spending varies considerably at the local level: while the average spend per commissioner per 100,000 population was £15.7m in 2012/13, it was as little as £7m in some parts of the country and as high as £31m in others;
- The shift in services from the acute to the community and primary sectors is expected to be a key enabler in delivering around £4.3bn of a total £22bn efficiency savings by 2020.

What needs to change?

Long-term neurological conditions have a significant burden on the community and have substantial associated costs. There is wide variation in spend, access, outcome and patient 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 for community services 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.

What are the benefits?

Transforming systems and shifting when and where care takes place, involving the patient in their care and support planning, making better efforts to coordinate care services and addressing mental health needs alongside physical health services has many benefits:

Transforming care will reduce:



visits to GPs



delays in the
patient
pathway



avoidable A&E
attendances



emergency
admissions



welfare
payments

Transforming care will help prevent:



multiple visits
to hospital



rising cost of
avoidable
admissions



poor quality of
life for people



duplication
and waste in
the system



unemployment
due to ill
health

The role for commissioners

CCGs play a key role in supporting the implementation of new models of care in community neurology. As part of their transformation programmes, they might:

- **consider how they commission appropriate community based services** that promote and embed person-centred care for people with long-term neurological conditions. This includes developing innovative payment and contracting methods which promote partnership and collaboration in local health populations;
- **consider which patients would benefit most from person-centred care** using risk stratification tools or identifying people with lower levels of health literacy or confidence;
- **commission a range of support for self-management services** to supplement traditional services and to ensure a “more than medicine” approach e.g. structured education programmes, peer support networks, health coaching, community assets;
- **promote the development of the workforce** to have the skills and competencies to work in this way, ensuring space for ongoing training, development and reflection, both for commissioners and providers;
- **ensure a robust local measurement system is in place** to inform and support continual improvement.

Delivering new models of care

This document may be of help to commissioners who wish to transform their current services to people with long-term neurological conditions. It describes the key features of new models of community-based neurological care, together with a framework to be considered when planning, implementing and reviewing their transformation programmes, to help ensure they meet the needs of patients in their communities.

Review Current Service Provision

Before undertaking service change it is important to understand, and measure, the current level of service provision. This can be used as a baseline against which improvements can be compared. Sources of data, including NHS RightCare’s commissioning for value data packs, can help CCGs identify where to look and what to change. Linking of discrete data sets can provide CCGs with insight into population-level demand and activity in their localities.

Plan

When planning new models of care, CCGs should commission services which are **person-centred, community-based**, and which **meet both the physical and the psychological needs and priorities of patients** living with long-term neurological conditions. Working with multiple agencies, services should be **integrated** so as to appear seamless to the patient, no matter which sector or organisation is involved. A multi-agency approach will require good **coordination**, based around a person-centred care and support plan that the patient was involved in writing. Commissioners should embrace opportunities afforded by new technology to support the delivery of new models of care.

Implement

The needs and priorities of patients and their carers is at the heart of the new model of care. A community neurology service needs to offer a wide range of services at varying levels of intensity, that patients access according to their needs. These may range from self care through interventions with specialist input on to complex and rapid-access emergency care. There must be **excellent communication between agencies** in order that service provision appears seamless to the patient, no matter which sector or service provider they are engaging with. **Care and support plans**, created and maintained and delivered in partnership with the patient and carer, are an essential prerequisite. A **core team** of professionals, and a **care coordinator**, will help patients and their carers to access services which meet their specific needs, which may improve patient experiences as well as helping to reduce costs to the NHS.

Review

Outcome measures form the basis for person-centred care and are key elements of a payment mechanism, helping to drive service improvement. Outcome measures which go beyond clinical and functional aspect of health are likely to be very important to patients with long-term neurological conditions. “I statements”, described by the Neurological Alliance in a forthcoming paper, such as “*I feel informed about my treatment and care which is simple to arrange and enables me to live life as I choose*”, are particularly relevant. **Feedback** should also be obtained, continually, in order to gauge whether commissioned services are meeting the needs of patients and their carers, and to inform the commissioning cycle.

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 (5YFV)**^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, focusing 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)** This **Transformation Guide**, which you are reading, sets out the **context and case for change** then introduces the **key features of new models of care**.
- (B)** The **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/>

The Community Neurology Project

Set up in 2015 by NHS England, the project's objective is to stimulate the delivery of person-centred coordinated care and to encourage the adoption of community-based care models in order to improve the quality of life for people who have long-term neurological conditions.

It's aims are:

- To build capacity and capability within primary care to support care planning, self-management and independence for people with long-term neurological conditions, especially those with complex care needs;
- To demonstrate different ways of organising and delivering care, to support new care models, by harnessing new opportunities offered by technology for example;
- To exemplify how investment in well-coordinated community services can reduce pressures on the acute healthcare system by admission avoidance and through reduced lengths-of-stay, to deliver better outcomes for patients and value for money for the NHS.

Further information on the project can be found at the Neurological Alliance's website^b.

Methodology

This Transformation Guide is the output of the project's work during the 2015/16 financial year. It was commissioned by NHS England's Long Term Conditions Unit and produced by Thames Valley SCN in collaboration with the Neurological Alliance, Sue Ryder, Southampton University Hospital, Royal Holloway London University, Windsor Ascot & Maidenhead CCG and Neural Pathways (UK) Ltd.

A number of key themes were identified for research, namely: person-centred care, integration, mental well-being, technology, benchmarking, and health economics. Leads were appointed for each one of these themes and they were asked to conduct literature reviews then summarise their findings in a report. The collection of reports (presented as Part B in this document set) was used as the basis for the Transformation Guide, along with best practice identified from local schemes we were made aware of through a survey.

This project found that much has been written on what constitutes a good model of community care but, in contrast, there is a paucity of data on costings and outcomes which would be of use in a commissioning context. The objective for the next phase of this project, therefore, is to establish further evidence and data on the subject to compliment, and enhance, the guidelines on best practice.

^b <http://www.neural.org.uk/nhs-england-community-project-for-neurology>

Living with a Neurological Condition

Neurological conditions can impact individuals in widely varying ways:

- Episodic and recurrent problems;
- Progressive, incurable conditions;
- Stable conditions that may be associated with disability;
- Isolated neurological incidents that may severely affect a person's life.

The nature of these conditions means that health professionals with appropriate specialist expertise and training are needed to help diagnose and manage them and care pathways are unusually complex, requiring coordination across primary, secondary, tertiary and social care domains.

One in three people live with a long-term condition and they account for **50% of GP appointments, 65% of outpatient appointments** and **70% of inpatient bed days**². The NHS spent **£3.3 billion** on neurological services in 2012-13³. There are **12.5 million neurology cases** in England and the Neurological Alliance estimate a **CCG will have 59,000 patients** with a long-term neurological condition⁴. Almost all of them will require long-term support.

The Case for Change

Long-term neurological conditions can have a significant burden on the community and have substantial associated costs. There is wide variation in spend, access, outcome and patient 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.

The responsibility for commissioning all neurology outpatient and community services lies with CCGs, who therefore hold the key to transforming community neurological care.

NHS RightCare^d data has identified that in over half of all CCGs neurology has the highest spend and poorest outcomes of any long-term condition, suggesting neurology should be treated as a local priority.

^d <https://www.england.nhs.uk/resources/resources-for-ccgs/comm-for-value/>

Problems Identified in the Current System of Care

Failing to Meet Patients' Needs

Services tend to be process-driven, with every patient following the same “one size fits all” pathway rather than one built around individual needs. This is compounded, by the **lack of patient involvement** in the design and delivery of their care. Only 12% of patients reported having a written care plan and few had an active hand in formulating it. Patients spend **just a few hours each year** in contact with health care services and are self-managing their conditions 99% of the time⁵. People who recognise that they have an important role in self-managing their condition experience better health outcomes⁶.

Limited Access to Care

Healthcare services are typically organised around the physical assets of the health system (such as hospital buildings and clinics) and may be provided at locations far from a patient's home, yet travel can be difficult or impossible for some patients by virtue of their condition. Failing to provide access to appropriate and timely care may lead to **poorer outcomes** for people affected by neurological conditions and can put **pressure** on other parts of the health and social care system (in terms of both demand and cost).

The NHS spends **£750 million a year** on emergency admissions to hospital for patients with a neurological diagnosis and **many of these cases might have been avoided** through more appropriate, or more timely interventions⁷. **The rate of emergency admissions to hospital has increased significantly** (there has been 3.6% growth in neurological inpatient admissions between 2010-11 and 2013-14) with wide variation in emergency admission rates between Clinical Commissioning Groups.

Poor Coordination

According to a 2012 review by the Public Accounts Committee⁸ “*health services are failing to provide an integrated range of services for people with neurological conditions*”. The National Audit Office (2011⁹, 2015¹⁰) found care to be **fragmented** and poorly coordinated with a lack of information provision. According to a 2015 GP Patient Survey¹¹, one in five patients with a neurological problem said they did not think they had enough support. A new model of care, featuring a collaborative of multi-disciplinary agencies working around a coordinated care and support plan for each patient, is widely recognised to lead to better outcomes and improved patient experience, This topic is explored further on in this document, on page 15.

Ignoring Mental Health

Patients with long-term neurological problems report some of the **highest levels of anxiety and depression**¹¹. People with mental ill health use more emergency care than people without mental ill health. In 2013/14, they had 3.2 times more A&E attendances and 4.9 times more emergency inpatient admissions¹². Patients with stroke are more likely to be readmitted and to die if they also have mental health conditions¹³. The Government has pledged to achieve **parity of esteem** for mental and physical health by 2020¹⁴.

Health Inequalities

In a recent patient satisfaction survey¹⁵ 74% thought their local NHS was providing them with a good service but when asked about services for patients with long-term conditions **only 57% felt their local NHS looked after patients with a long-term condition well or quite well**. For patients with a mental health condition the comparable figure was even lower: 31%.

Variation in Service

There is significant difference in service provision, spend and quality between areas. For example: nearly a quarter of CCGs (45) offer no local consultant neurology services whatsoever⁴. There's also up to a 30% variation between CCGs in the health-related quality of life for people with more than one long term condition¹⁶.

Limited Experience Within Primary Care

Some neurological conditions are rare, particularly in areas of low population density, so GPs may not have encountered them in their practice before. Because of limited or non-existent direct **experience**, they may lack the **confidence** to treat the patient's condition within the primary care setting. Instead, there may be more of an inclination to refer patients with neurological conditions to secondary care than for other conditions, a phenomenon which has been labelled "*neurophobia*"¹⁷. This might be addressed through improved education and information for primary care health workers. New technology could play an important role here, for example through improvements in disease management applications. In a forthcoming report from the Neurological Alliance⁴, a survey of 1,001 GPs taken in November 2015 found that 85% feel that they could benefit from further training on identifying and managing people presenting with neurological conditions.

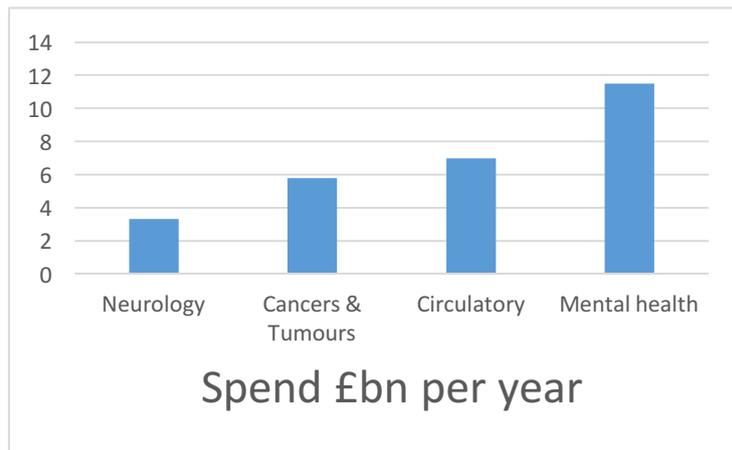
Funding Flows

Current payment models do not optimise value. Over 90% of community care funding is allocated using block contracts, with little or no relation to the number of patients who utilise the service. The Public Accounts Committee heard evidence that there is wide variation in prices paid for neurological services, with some CCGs paying much more than others for the same service⁷. According to Monitor, fewer than 1% of CCGs used outcomes-based measures¹⁸. Such contracts create little incentive for providers to understand individual service costs; Failing to link outcomes to provider reimbursement constrains the ability of commissioners to improve care. The Five Year Forward View recommends that performance data should be used to inform payment mechanisms and commissioning decisions¹⁶. New payment mechanisms are discussed further on in this report on page 28.

Competing Demands from Higher Profile Diseases

Neurology does not have a high profile compared with some other disease groups, yet patients with neurological conditions report **some of the worst states of pain**¹¹. Furthermore, 17% of all GP appointments are for patients living with neurological conditions¹⁹ and so too are 1 in 10 visits to Accident & Emergency departments. NHS England spends about 3.5% of its budget³ on neurological services, significantly less than for other diseases¹⁹, as shown in Figure 2.

Figure 2: NHS Programme Budget



“The burden of disease has shifted away from life-threatening conditions to long-term conditions. Morbidity and disability caused by long-term conditions have increased, as have the numbers of older people with dementia. The needs of people with multi-morbidity present major challenges for the future.” – The Kings Fund²⁰

The Benefits of Community Models of Care

Transforming 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. The Community Neurology Project discovered many examples where community-based person-centred care has improved outcomes and patient experiences and some of these are mentioned in the Examples section (Part C).

Shifting when and where care takes place, involving the patient in their care and support planning, making better efforts to coordinate care services and addressing mental health needs alongside physical health services can:

- reduce health system costs and pressures on the acute sector;
- improve access to health services;
- reduce variation and health inequalities;
- improve patient experiences and health outcomes;
- make better, more efficient use of the limited resources of the NHS;
- reduce costs to the NHS through inappropriate or delayed care;
- reduce the burden of disability and social care costs.

For example, The Kings Fund found²⁰ that patients who are fully informed about the risks and benefits of treatment options, choose different – and fewer – treatments.

Transforming care will reduce:

visits to GPs delays in the patient pathway avoidable A&E attendances emergency admissions welfare payments

Transforming care will help prevent:

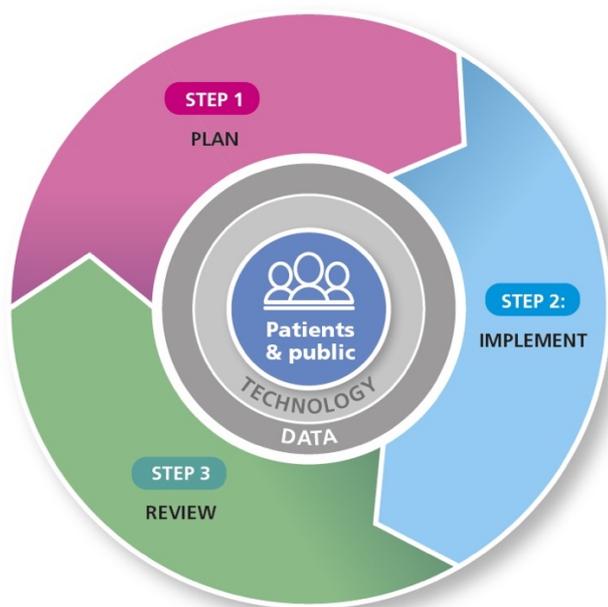
multiple visits to hospital rising cost of avoidable admissions poor quality of life for people duplication and waste in the system unemployment due to ill health

Supporting Transformation

During 2016/17 NHS England is asking every health and care system to come together to create their own local blueprint – a **Sustainability and Transformation Plan (STP)** – based not on individual institutions but on local populations. This place-based planning involves bringing local leaders together as a team, developing a shared vision with the local community, agreeing a set of activities to make it happen, and carrying out the plan. The STPs will provide the roadmap for local areas over the next five years in spreading new care models. From 2017/18, transformational funding will be available for areas with the most compelling STPs, and access to further **funds will depend on progress** in implementing them.

This document may be of help to **commissioners** who wish to **assess** and **transform** their current service provisions for people with long-term neurological conditions. It describes the **key features** of new models of community-based neurological care, together with a framework to be considered when **planning, implementing** and **reviewing** their transformation programmes, to help ensure they meet the needs of patients in their communities. Technology and data can support the transformation, as illustrated in Figure 3.

Figure 3: Patients, Technology and Data at the Heart of Transformation

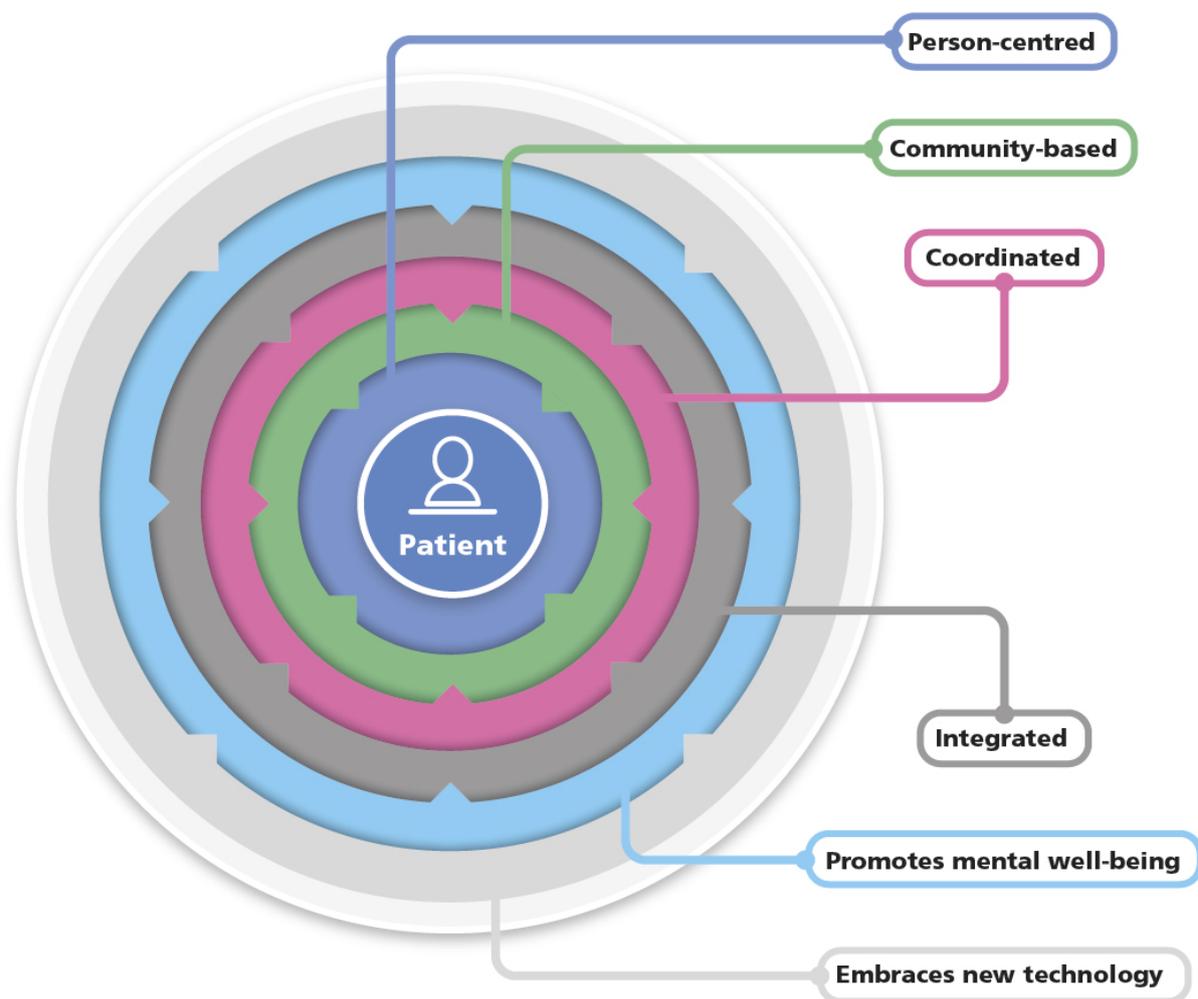


STEP 1: PLANNING

Features of New Care Models

Much guidance exists detailing what and how services for people with long-term neurological conditions should be provided. Although there are many neurological conditions, several principles of good care are common to all, and these are illustrated in Figure 4 and discussed below.

Figure 4: Features of New Models of Care



Person-centred

There is mounting evidence that when an individual's needs are considered the health improvement process is accelerated²¹. If services are to be person-centred it is critical to understand the needs and priorities of individuals, their unpaid carers, and their families. This includes the type of care they regard as important to them and how they wish to manage their condition.

A credible model of community-based care for patients with long-term neurological conditions must consider:

- The needs and priorities of patients, and their carers;
- Outcomes that are meaningful to them;
- Mechanisms for obtaining ongoing feedback on how effective services are in meeting these needs.

This topic is explored in more detail in the Reference Reports document (Report 1: Identifying Patients' Needs and Priorities).

Community-based

Wherever possible, care should be delivered near to the patient, in the community or at home, rather than in a hospital. Benefits include improved health and better experience for the patient, with more effective and efficient use of costly, scarce, healthcare resources.

Coordinated

Lack of coordination may contribute towards delays and dissatisfaction in provision of care as well as increased morbidity and mortality. Good coordination improves movement through care pathways by reducing duplication, avoiding unreliable transitions through elements of the pathway, and minimising risks such as unsafe transfers between hospital and residential care. It enhances prevention activity and rehabilitation, while reducing emergency admission to hospital or unsafe discharge, and improves information provided to people to self-manage their condition.

Integrated

Patients' needs are met by a variety of agencies from community, primary and secondary care and the voluntary sector so it is crucial that these operate as a unified, integrated system rather than discrete, detached "islands of care". Integrated care reflects an ambition to improve patient experience and achieve greater efficiency and value from health delivery systems. The aim is to address fragmentation in patient services, and enable better coordinated and more continuous care, frequently for a population which has an increasing incidence of chronic disease.

Achieving this kind of approach in England requires action and alignment across a number of different levels, from central government and national bodies to local communities and individuals. With the emphasis on new care models described in the Five Year Forward View, there are already a number of best practice examples within the Vanguard programmes, redesigning within wider population footprints to support an integrated approach across primary, community and secondary care.

Multi-agency services which are integrated are, by necessity, also coordinated. These themes are discussed in more detail later on in this report on page 24.

Promotes Mental Well-being

Neurological conditions are often accompanied by a higher prevalence of mental health conditions (such as depression and anxiety) and cognitive difficulties (for example, memory problems). These affect a person's quality of life in many ways, including their employment, personal safety, family life and disease management²². It is crucial that both health professionals and patients, and their unpaid carers, are made aware that many mental health issues and cognitive difficulties (in the context of neurological disorders) can be successfully managed and their quality of life can be improved. The NHS has established a Parity of Esteem Programme^e, which requires mental health to be valued equally with physical health, and the association between physical and mental health to be comprehensively addressed by commissioners. Commissioners need to consider how the emotional, behavioural and mental health impacts of neurological conditions can be addressed routinely within care pathways. There is evidence that early intervention and prevention can deliver measurable improvement in quality of life as well as service costs. Some brief assessments can be used by any qualified health professional to identify cognitive impairment²³.

The Sandwell primary care approach²⁴ saved £800,000 in prevention costs. By arranging for 3,000 people to attend talking therapies, a further £600,000 was saved. 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.

The role of addressing mental health in community-based neurological care is discussed in greater detail in the **Reference Reports** document (Report 3: Optimising Mental Well-being).

Embraces New Technology

Rapid advances in technology, especially a wide adoption of smart hand-held devices such as smartphones and tablets, afford a rich set of opportunities for supporting new models of care. This may include enabling the patient to drive care according to their needs; delivering specialist advice in a timely manner in the community and supporting coordination among partners involved in care.

Further information can be found in the **Reference Reports** document (Report 4: E-Health).

Scope and Scale of Change

It may be reasonable, when considering implementing a new model of care, to initially focus on a specific disorder group, such as multiple sclerosis, rather than planning to change all of community neurology services at the same time, whilst still using the same core principles described above.

^e <https://www.england.nhs.uk/mentalhealth/parity/>

Reviewing Current Service Provision

Before undertaking service change it is important to understand, and measure, the current level of service provision. This can be used as a **baseline** against which improvements can be compared.

Both the Department of Health and NHS England agree that data is vital to improving the quality of services⁷. The collection of **data** to describe demand, activity and cost is essential to understanding local health care requirements and for better business planning. It is recommended that CCGs have access to key data sources to help to identify (if not already known) **where to look** and **what to change** before embarking on a transformation programme.

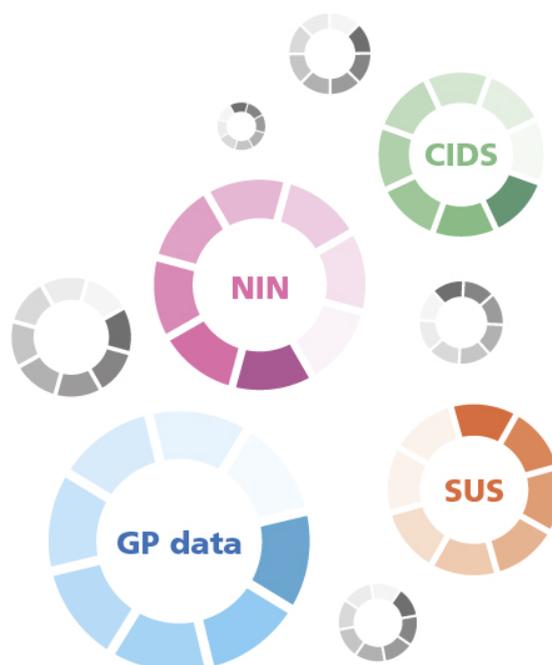
Sources of Data

Public Health England's Neurology Intelligence Network has released "Fingertips" neurology profiles^f and launched a data catalogue for neurology^g. Recently released RightCare commissioning for value data packs also provide data and information on neurology that will be useful to CCGs. These are described further on page 21.

Data Sets

A number of data resources exist, at a national or local level, or are being developed, including GP clinical systems, Secondary Uses Service (SUS) data, Neurology Intelligence Network (NIN) data and the Community Information Data Set (CIDS).

Figure 5: Discrete Data Sources



^f <http://fingertips.phe.org.uk/search/neurology>

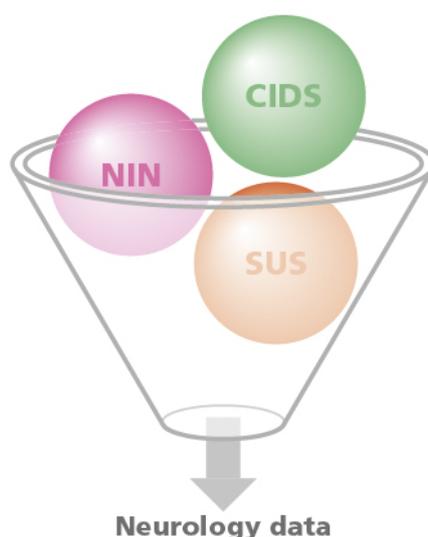
^g <http://www.yhpho.org.uk/resource/view.aspx?RID=226279>

Data Linking

NHS “*care.data*” is currently under development but one immediate solution might be to link discrete data sets, which would normally sit in their disconnected silos, using NHS numbers as common keys.

Aggregating of data in an accredited safe-haven, automatically (i.e. without human intervention) allows mapping of patient flows at a *population* level, reducing privacy and information governance concerns.

Figure 6: Data Linked by NHS Number



Using aggregated, anonymised data, CCGs can match capacity, demand and cost when reviewing a commissioned service, ensuring any commissioned service meets the needs of their local population.

This practice has already been implemented successfully by a group of CCGs in Southern England, using software developed by their local Commissioning Support Unit. Here they describe the process they underwent to discover what to change and how they went about it:

Case Study:

A local stakeholder workshop was held to help identify commissioning objectives and opportunities to improve patient care. Parkinson's disease was highlighted as a local priority and the CCG took the decision to begin the development of a new service for patients with Parkinson's disease, to be commissioned in 2016/17 financial year.

A working group, representing patients, providers, the voluntary sector and commissioners, was created to develop the project brief. First of all, the group mapped out current pathways of care. It became apparent that services had developed organically, over many years, and as a consequence there were wide variations in service provision around the region.

The group then mapped current services which were following best practices, using guidelines and examples of good practice found nationally. This resulted in the creation of a comprehensive end-to-end pathway, from diagnosis to end-of-life.

A lack of population-level data was identified as a significant barrier to creating a full business case to justify the proposed changes. Although patient flows had been mapped, the available data services did not allow for this to be accurately populated. The commissioners had two options: to use a best-guess method of taking national prevalence data and extrapolating it locally, or to find an alternative solution to utilise local data more efficiently such that commissioned services would accurately match the needs of the local population.

The technology group within the CCGs were asked to explore how data could be used better. It became clear that our accredited safe-haven had access to all appropriate data sets (pseudonymised), but used them in isolation. The group researched international literature and found examples of data science in action (for example, in Western Australia and in South Wales).

We hypothetically explored how we could use primary care data to identify patients within the region with Parkinson's disease and then link this with other data sets, providing a dashboard for patient flows and economic impacts in the health economy. By using a software product developed by the CSU, data is automatically pseudonymised and linked without human interaction, resulting in collated population-level data for commissioners. As the data is managed in an accredited safe-haven this ensures stringent governance and data security. CCGs do not hold the key to re-identify individuals from the data and therefore cannot therefore identify any patient. Dashboards have been created using dummy data and have shown this method to be highly efficient and cost effective.

We reviewed how other regions link data and found that where this occurred, to varying degrees, in England, primary care data is often excluded. A key reason for this has been concerns about information governance. We have created (with our CSU) a new data sharing agreement for local secondary uses, and obtained multidisciplinary feedback from a regional Information Governance Steering Group, (which has representation from members of the public and all providers, commissioners, voluntary sector partners and Local Medical Committees).

These new information sharing agreements are currently being signed off by data providers and the CCG's plan to use this method of data linkage to develop knowledge of current activity, costs and outcomes for those with Parkinson's Disease, then use this to ensure that the new commissioned services meets the needs of the local population.

RightCare Commissioning for Value packs

NHS RightCare has recently produced a set of Commissioning for Value (CFV) focus packs on neurology, to help CCGs identify the best opportunities for improving value for their populations. The focus packs are personalised for each CCG and provide detailed information, including a wide range of outcome measures and information on the most common procedures and diagnoses.

The information contained in each pack is designed to support local discussions and inform a more in-depth analysis around common conditions and pathways. It should be used alongside other local intelligence and reports to ensure local health economy planning focuses on those opportunities which have the potential to provide the biggest improvements in health outcomes, resource allocation and reducing inequalities.

All the new packs, together with all the previous Commissioning for Value resources and tools, can be found at the Commissioning for Value section on the NHS England website^h.

Software

Commissioners can also utilise data analysis software to capture activity of commissioned services. For example, in East Berkshire, the Windsor, Ascot & Maidenhead CCG use a program called Intelligence Point, an analytic product developed by their local Commissioning Support Unit (South, Central & West CSU). CSUs in other areas have their own products (RADIR and WHYSE to name a few) which could develop similar functionality.

Future Developments

- Public Health England has created a central catalogue of neurology data sets, which will, in time, be enhanced with further sets;
- NHS RightCare will develop a digital dashboard for neurology care;
- SNOMED-CT (a semantic terminology) is becoming the preferred UK terminology and this may improve accuracy and detail in coding;
- NHS England has started developing a community data set.
- NHS England's Care.Data programme, being developed by HSCIC

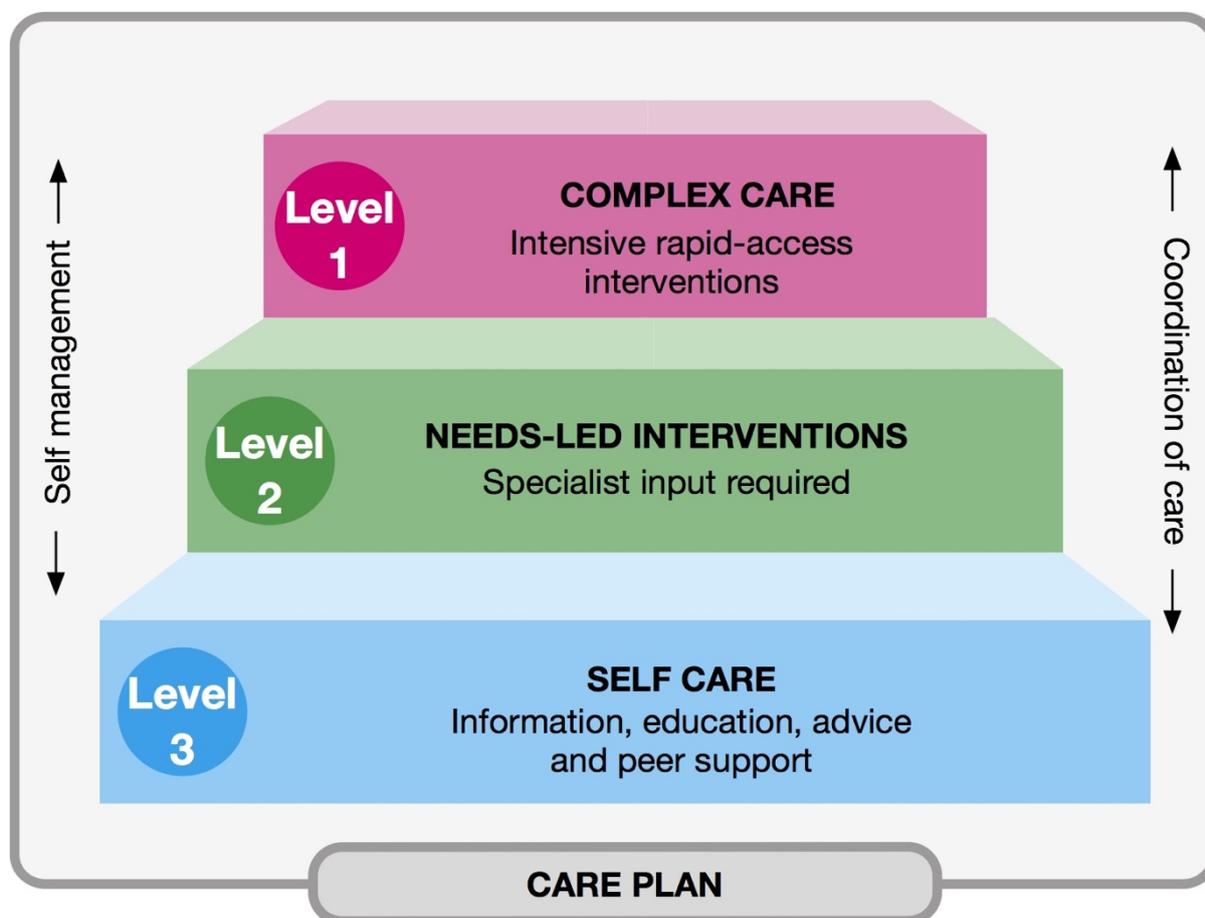
^h <https://www.england.nhs.uk/resources/resources-for-ccgs/comm-for-value/>

STEP 2: IMPLEMENTING

Needs-based Services

The needs and priorities of patients and their unpaid carers is at the heart of the new model of care. Requirements vary between individuals, and over time, and they need access to a wide range of services at varying levels of intensity. These might be represented as a number of levels, as illustrated in Figure 7, with patients moving up or down through levels, accessing services according to clinical need.

Figure 7: Stratification of Care



Patient Journey over time

Change over time is inevitable in long-term neurological conditions, and individuals vary in their requirements for care. When healthcare services are delivered in a community setting, nearer to where the patient lives, and the health care system is largely proactive, with an effective response to sudden deterioration, care may be provided more effectively, more efficiently and at a lower cost through reducing the frequency of emergency admissions, and shortening the length-of-stay in hospital because the community services support more rapid discharge.

Responding to changing requirements and wishes is especially relevant with end-of-life care (EoLC). Planning for EoLC can be especially challenging for patients with long-term neurological conditions (because of the long duration of the condition, a course that's hard to predict, or neuro-psychiatric problems such as behavioural or cognitive changes which may affect a person's wishes towards the end of their life). Everyone should get the palliative care and support they need, from diagnosis through to the end-of-life. Identifying when someone is approaching this phase is important, because it enables the appropriate care to be planned.

Levels of Intervention

Services might be defined, and differentiated, by grouping into three levels according to the intensity of the care intervention offered and who they are offered by, as shown in Figure 8.

Figure 8: Levels of Intervention

TIER	INTERVENTIONS	CARE GIVERS
 COMPLEX CARE	<ul style="list-style-type: none"> • Rapid access • To prevent morbidity or unnecessary hospital admission • To support individuals who experience sudden change in condition and need • Multiple daily inputs from a variety of teams 	Neurologist, specialist nurses, psychologist, occupational therapist, psychotherapist, speech and language therapists Keyworker Neuro-navigator
 NEEDS-LED INTERVENTIONS	<ul style="list-style-type: none"> • Team assembled after needs of patient assessed • Skills-level input to support functional performance • Support adjustment and change, incl. mental health • Support carers and family to look after patient • Support to find or stay in work 	GP, neurologist, specialist nurses, psychologist, occupational therapist, psychotherapist, speech and language therapists, vocational rehab team Keyworker Neuro-navigator
 SELF CARE	<ul style="list-style-type: none"> • Information, education and advice • technology and resources to support self care • Keeping well initiatives • Peer support • Advocacy • Expert patients • Self-help programmes 	GP, neurologist, specialist nurses, psychologist, occupational therapist, psychotherapist, speech and language therapists, social services, third sector, peers, social media Keyworker Neuro-navigator

The bottom level represents services accessed much more frequently (generally at low unit cost). Examples at this level might include patient information, peer support groups and self-management. In between are services of varying complexity. Patients will access services according to clinical need, moving up or down through the levels, or between services within a level (there would typically be more providers at the community care level than at the secondary care level).

Multi-agency approach

The effective provision of such a care model needs a multi-agency approach. Providers of care may be co-located, either physically or virtually, but will need to be organised to provide team working from experts who meet frequently (in person, by phone or video-conferencing, for example) to **coordinate activities** and to **review data on performance**.

Case Study:

In the north east of England, CABIS are delivering a service for patients with acquired brain injury by using a multi-agency partnership. See example 11 in the **Examples** document (Part C) for further information.

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. For such a model to work there must, clearly, be **excellent communication between providers** and with the patient and their carers, in order that service provision appears **seamless from the patient's perspective**, no matter which sector or service provider they are engaging with.

Person-centred **care and support plans**, created, maintained and delivered in partnership with the patient and carer, are an essential prerequisite, as is planning for end-of-life care.

In 2015 The Health Foundation reported²⁵ on health economies in Leeds and Somerset which were dedicated to new models of care and had found that by adopting a coordinated approach to personal care and support planning, health and healthcare for people with long-term conditions had been transformed.

Personal care and support planning is widely recognised as an essential gateway to better supporting people, and their carers. By utilising their own experience of living with long-term neurological conditions they can develop the knowledge, skills and confidence to manage their own health, care and wellbeing in a partnership of equality with health service professionals. There is evidence that this may lead to better outcomes²⁶.

The “Ambitions for palliative and end of life care: a national framework for local action 2015-2020” demonstrates how care should be provided in any setting, based on the perspective of the patient nearing the end of lifeⁱ. As new models of care emerge, approaches have to develop to enable a better system-wide response to dying people.

ⁱ www.endoflifecareambitions.org.uk

Care Co-ordination

At the centre of this approach is coordination. Having a **care coordinator** helps patients and their carers to access services which meet their specific complex care needs, whilst avoiding unnecessary hospital admissions, interventions and outpatient referrals. In this way, care coordination may improve patient experiences of the health service as well as helping to reduce costs to the health service.

Case Study:

In Cambridge a care coordinator for motor-neurone disease saved 771 bed days over a three-year period, with financial savings equivalent to £33,000 per annum (even after the cost of employing the coordinator was taken into account)²⁷.

Competencies

A community neurology service requires input from a range of professionals²⁸. Key aspects to consider when assembling a core team are shown here in Figure 9.

Figure 9: Core Team Competencies



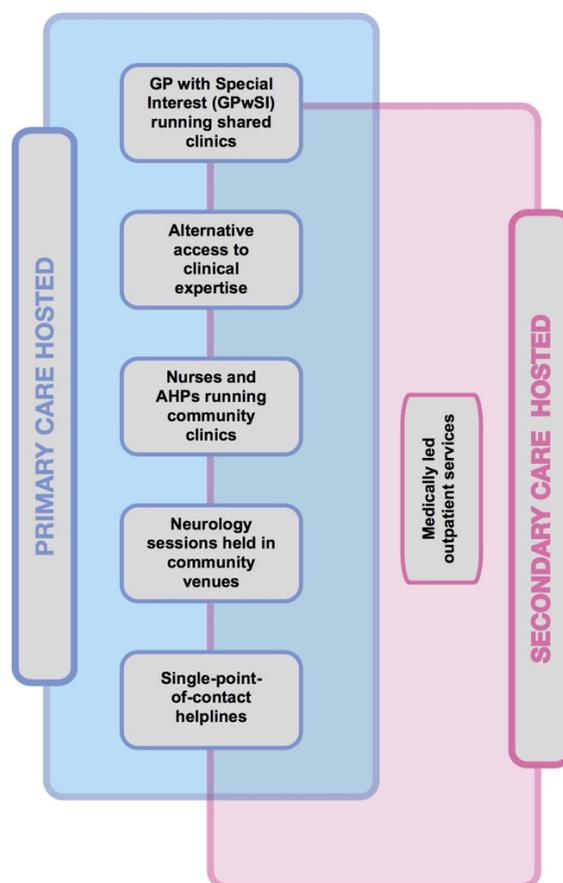
Care Closer to Home

To better meet the needs of patients with long-term neurological condition and ensure timely and appropriate access to care, the traditional secondary care outpatient and Consultant Neurologist-led functions can be undertaken in different ways, as illustrated in Figure 10.

This is important because:

- The **numbers of neurologists are at critical levels** in many parts of the country, leading to bottlenecks in the timely provision of care. Role substitution or replacement with other skilled team members, such as GP with special interest, or the increased use of other clinical decision makers (including nurse specialists and allied health professionals) can be an effective solution.
- The **system is overstretched**, with demand exceeding capacity year-on-year. Follow-up patients may be highly suited to self-manage, seek advice through peer support groups or non-face-to-face interventions. This would be a significant release on capacity.
- The traditional model is **process driven and not patient-centred**. Patients say they want access to experts closer to home.

Figure 10: Merging the Interfaces of Primary and Secondary Care



Essential Requirements for a New Model of Care

Quality Requirements

Services commissioned will be:

- Needs-led, not diagnosis-led, and be responsive to both generic LTC needs and diagnosis-specific needs;
- required to use person-centred practices promoting good health, well-being and self-management;
- required to illustrate added value and outcomes using defined Key Performance Indicators which are directly tied to patient experience;
- share skills across non-specialist and other specialist teams as per prevailing clinical need.

Process Requirements

Services commissioned will be:

- required to keep a mandatory data set;
- delivered in discrete time limited spells with clear entry and exit points;
- coordinated with defined self-referral pathways and scheduled touch-points;
- required to communicate across multiple service boundaries;
- required to provide data on the full cycle of care and outcomes over time.

Outcomes Requirements

Services will be required to identify and measure outcomes of relevance to patients, including:

1. Health Status Achieved

- Survival (e.g. Mortality rate);
- Degree of health or recovery (e.g. Seizure freedom);
- Rehabilitation outcomes regarding impairment, activities and participation;
- Rates of Goal Attainment Scaling (GAS) success.

2. Process of recovery

- Time to recovery or normal activities;
- Adverse effects of treatment or care.

3. Sustainability of health or recovery

- Maintained functional levels;
- Recurrence/ Relapse rates;
- Long-term consequences of therapy (for example: loss of mobility due to inadequate rehabilitation, avoidable secondary consequences).

Payment Mechanisms

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.

A community neurology service should minimise healthcare costs by **expediting hospital discharges, reducing rates of admission** (and readmission) through preventative approaches, and **relieving pressure on emergency services** and out-of-hours services.

It is 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.

Principles

Several principles have been outlined by the NHS Confederation²⁹ for the purpose of developing appropriate payment mechanisms for community services:

- **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;
- **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;
- 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;
- **Stability and transparency** to enable planned change should be generated within the system to support planning and investment.

Elements

Evidence from tariff re-design elsewhere in Europe²⁹ suggests a combination of the following elements is required:

- **Capacity payments** (with some activity based payment and performance monitoring);
- **Block contracts** and **Payments-by-Results (PbR)** or bundled pathways for different kinds of planned care;
- **Capitated payments** (such as Year of Care) to incentivise proactive, preventative approaches.

Future Developments

Community Patient Currencies are in development, and will help identify the service elements required to cost care appropriately, and track service provision itself for reimbursement.

Self care approaches using **Personal Health Budgets** are a means of improving self-participation and creating outcomes meaningful to patients and carers³⁰.

STEP 3: REVIEWING

To ensure value creation within community neurology pathways, providers need to develop a means to monitor outcome measures and acquire feedback from service users for the services they deliver.

Why do outcome measures matter?

- They form the basis for person-centred care;
- They are central elements of a payment mechanism;
- They are drivers for service improvement and research;
- They can provide evidence of meeting statutory obligations.

These outcome measures could also be collated at a national level and fed back into the value-based commissioning benchmarking activity (i.e. stage 1 of the commissioning cycle). This would allow the development of evidence-based outcome measures and the continual development of benchmarking for neurological (and other) conditions.

Outcome measures

There are multiple repositories of evidence-based outcome measures which could be utilised, for example:

- Epilepsy Action's Commissioning Toolkit^j
- National Institute for Health and Care Excellence (NICE)
- International Consortium for Health Outcomes Measurement (ICHOM)

In particular, ICHOM encourage the use of measurable patient-related outcome measures (PROMs). According to research by the National Institute for Health Research³¹ "*outcomes that go beyond the clinical and functioning aspects of health are likely to be equally, or more, important to people with long-term neurological conditions*". It categorised outcomes into three key areas: **personal comfort; economic and social participation; autonomy**.

The Neurological Alliance is developing an Ambitions for Neurology strategy which describes four key outcomes, written in the form of an "I statement", that were identified as priorities by people living with a neurological condition or disability:

"I received a timely and accurate diagnosis and was given the support I needed throughout the process"

"I feel informed about my treatment and care which is simple to arrange and enables me to live life as I choose"

"My treatment and care is excellent"

"I see scientific innovations benefitting me and my family"

^j <http://www.epilepsytoolkit.org.uk/>

Feedback

To ensure that new community neurology models of care are in fact meeting the needs and priorities of people living with long-term neurological conditions, it is essential to obtain feedback. Suggested best practice mechanisms to achieve this include those include surveys and forums, as shown in Figure 11.

Figure 11: Feedback Mechanisms



Feedback mechanisms are discussed in more detail in Report 1 (Identifying Patients' Needs and Priorities) in the **Reference Reports** document.

CONCLUSION

The NHS Five Year Forward View outlined the transformation needed in our health and care system in order to meet the changing needs of our population, including increasing millions of people living with multiple long-term conditions. It called for the development of more integrated and proactive approaches to care delivery in order to improve the quality and efficiency of services and to improve patient outcomes, moving from reactive care to proactive care.

Long-term neurological conditions are very common, associated with significant disability and considerable demands on health providers. Because of their complexity perhaps they do not receive the attention they deserve, especially when compared with other major disease categories.

There is growing evidence that patient experiences and outcomes for those living with long-term neurological conditions can be greatly improved, and the health care system can become more efficient and cost effective at delivering services to them, when a different model of care is adopted. This project believes that optimal care models are those which place a high value on the needs and priorities of the patient. That care should be delivered close to home using a multi-agency multi-disciplinary team that transcends traditional health and social care provider boundaries.

Commissioners are key to initiating a transformation of care from the process-driven asset-based system to a needs-led community-based coordinated service because they hold the statutory responsibility for commissioning care services for people with long-term neurological conditions.

There is currently little incentive for providers to change the services they offer so attention needs to focus on encouraging them to adopt new models of care by establishing new contract and payment mechanisms that match reimbursement to outcomes. In order for such an arrangement to work data collection and analysis must be enhanced to measure outcomes and patient experiences, to ensure they meet the needs of patients.

This Transformation Guide set out the case for change, described what a good model of care looks like and seeks to encourage commissioners to examine their current service provision then consider how this compares with the new model of patient-centred community-based coordinated care. Commissioners should be equipped to develop a strategy for the delivery of high quality care as part of a system transformation that includes long-term neurology patients.

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