Scoping the Strategic Analytical Requirements for Clinical Neurosciences in England

Report for Professor Adrian Williams
Chair of the Neuroscience Clinical Reference Group (CRG)
& National Neurosciences Advisory Group (NNAG)

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Introduction

This report identifies six analytical priorities for clinical neurosciences in England. We hope the report contributes to the development of a national strategy for clinical neurosciences and will provide a clear steer for those delivering analytical services in this area.

The report was developed at the request of and with the involvement of Professor Adrian Williams, Chair of the Neuroscience Clinical Reference Group (CRG) and the National Neurosciences Advisory Group (NNAG).

The report was produced in five stages;

1. An initial discussion with Professor Williams to identify the greatest challenges and opportunities to delivering a high quality clinical neuroscience service over the next 10 years.
2. Structure these initial discussions into a small number of priorities, confirming the questions that need to be addressed and the objective of any analysis.
3. Conduct a rapid literature review to identify and describe previous and current work on these priorities.
4. Set out an initial specification of analytical work for each of the priorities.
5. Review the priorities, estimating the likely resource implications, and with consideration of any other work underway

Between stages 3 and 4, wider engagement was sought from national agencies involved in clinical neurosciences to confirm broad alignment the proposed priorities and identify pertinent literature or projects not previously noted.

This scoping project is a pilot for a way of working with national clinical leads to identify and structure analytical requirements. We will work with NHS England to describe the 5-stage process, to assess with Professor Williams' help, its efficacy, and to consider options for making it available to other national clinical leads who so desire.

For each of the six analytical priorities, the following information is supplied;

- An overview of the requirement
- The questions that need to be addressed
- The purpose of the analysis
- The summary of the relevant literature
- A recommendation and outline specification for the analytical project

In the final section of the report, the budget and elapsed time to undertake the work is estimated.

Analytical Priority A: Understanding the Present State of Neurosciences

Neurosciences encompasses a large number of services and interventions, delivered to individuals with a wide range of conditions by numerous providers in many settings. Describing the full range of patients, interventions and services will provide those who work in and support NHS commissioned neurosciences with the context required to holistically assess, plan and improve these services.

The Question(s)

What is the nature and level of neuroscience service utilisation commissioned by the NHS in England; who receives and delivers these services? What are the trends, patterns and variation in this activity and how does it compare with available benchmarks?

The Purpose

To ensure all involved in developing neuroscience strategies have a shared understanding of the current state of service provision. This description of the current state will prompt questions that will warrant further investigation and may lead to new service improvement ideas. The description can be used as a baseline against which changes can be modelled and improvements can be measured

Review of Literature

Several documents and tools have been published which aim to provide an overview of NHS funded activity for neurological conditions. The Neurological Alliance publication, Neuro in Numbers provides a high level summary of neurological condition prevalence and associated NHS spending.[1] In 2014, the Health and Social Care Information Centre published a Compendium of Neurology Data which contained summary statistics from other HSCIC reports on acute hospital utilisation rates, waiting times and a limited set of information on workforce and prescribing.[2] The Commissioning for Value Neurological Focus packs allow CCGs to benchmark a wide range of acute hospital utilisation and prescribing rates with other similar organisations.[3] The Public Health England Fingertips Tool contains a similar set of information and functionality.[4]

[1] http://www.neural.org.uk/store/assets/files/381/original/Final_-_Neuro_Numbers_30_April_2014_.pdf
[2] http://content.digital.nhs.uk/catalogue/PUB13776/comp-of-neur-data-report-1213.pdf
[3] http://ccgtools.england.nhs.uk/cfv2016/neurological/atlas.html
[4] http://fingertips.phe.org.uk/profile-group/mental-health/profile/neurology

In conclusion, existing reports and tools provide some data on NHS neuroscience activity, but these appear somewhat uncoordinated and overlapping and focus on the delivery of data rather than on drawing conclusions from it.

Recommendation & Outline Specification

A decennial 'State of Neuroscience Services' report should be produced providing a detailed description of NHS commissioned neuroscience activity in England.

The report should describe;

- Neuroscience patients – the numbers of patients, their socio-demographic characteristics, their diagnosis or symptoms and comorbidities and their geographic distribution.
- Neuroscience interventions – the type and number of diagnostic, therapeutic and surgical interventions that patients receive, the bed day use and costs, and the geographic distribution of this activity.
- Neuroscience services – the services, sites and staff that deliver neuroscience activity, the characteristics and geographic distribution of these services.

This analysis should be;

- Set in an appropriate historical and international context
- Link information about patients, interventions and services
- Draw conclusions about trends, variation and opportunities for service improvement.

The report should be inclusive in terms of scope, incorporating any activity that might be regarded as within the remit of neurosciences.

The report should draw from available primary sources (e.g. Hospital Episode Statistics, Neurosurgical National Audit) and existing summaries of neuroscience activity.

Analytical Priority B: Improving Coordination between Specialist & District General Hospitals

In some health economies, almost all neurology and neurosurgical services are delivered in specialist neuroscience centres whilst in other areas a substantial proportion of activity is retained by district general hospitals. In many cases the distribution of activity is a product of history rather than design.

Difficulties transferring patients in and out of specialist centres often results in treatment delays and inefficient use of high cost specialist centres resources.

The optimal distribution of activity between specialist neuroscience centres and district general hospitals is not fixed and the balance must be adjusted as new interventions are introduced and mature, and the incidence and prevalence of neurological conditions changes. Getting this distribution right may also present an opportunity to undertake more activities locally thereby offering both greater patient convenience and a contribution to the clinical and economic viability of more localised hospital provision.

The Question(s)

What is the range and frequency of service delivery patterns across England in terms of the distribution of activity between specialist centres and district general hospitals. From a clinical and operational perspective, what is the optimal distribution of this activity, taking account of workforce constraints and described in terms of diagnoses and interventions? How would current activity patterns change if work were divided in line with this optimal distribution? How might this change the level of bed-day use and what would be the implications for CCG and NHSE specialised commissioning budgets?

The Purpose

To build a consensus, and thereby inform guidelines and standards, on the most clinically appropriate and efficient division(s) of labour between specialist centres and district general hospitals. To assess the potential benefits, costs and scale of the opportunity in moving to this division of labour.

Review of Literature

Several papers address the different roles of specialist neuroscience centres and district general hospitals. The Royal College of Physicians in a *Local adult neurology services for the next decade* (2011) addresses the role of neurology in DGHs and the relationship with specialist neuroscience

centres, recommending an expansion of the neurology workforce in DGHs with a shift of emphasis towards unscheduled care.[5]

The Association of British Neurologists (ABN) in the *Acute neurology survey 2017*, identifies the differential access to neurological expertise and imaging between DGH's and neuroscience centres, with specific reference to neurology involvement in acute assessment and management of stroke.[6]

The ABN's *Standards for unscheduled care* specify the provision needed in DGHs and the required access to neurological expertise.[7]

Thames Valley Strategic Clinical Network (SCN) in *Transforming community neurology* (3 reports) 2016, and *Service Mapping Overview*, describe different levels of service however the emphasis in the latter paper is on effective case management and interventions to reduce avoidable hospital admissions.[8,9]

The London SCN in *Hyper acute neurology services 2016*, considers the DGH and specialist centre model for hyper acute neurology citing the benefits of moving away from the current system where emergency admissions with a primary neurological diagnosis are not admitted to the neurology service.[10] In *London Acute Neurology services: A case for change* (January 2015), the SCN advocates piloting and evaluating the impact of Hyper Acute Neurology Units.[11] This paper cites models of 'attending' and 'liaison' services in Plymouth and Leeds.

In conclusion, there are a considerable number of papers on the models of DGH and specialist neuroscience centre working although there is a focus on the south east of England which has a relatively large number of neuroscience centres. Very little has been published which explicitly addresses the issue of facilitating hospital transfers and in particular the impact of the delays incurred at regional neurological centres when discharging patients to services close to a patient's usual place of residence.

[5] https://www.mstrust.org.uk/sites/default/files/files/Local%20adult%20neurology%20services%20for%20the%20next%20decade.pdf
[6] http://www.theabn.org/media/docs/ABN%20publications/ABN%20acute%20neurology%20survey%20final%2013%20March%202017.pdf
[7] http://www.theabn.org/media/docs/ABN%20publications/Quality%20Standards%20for%20Unscheduled%20care%20and%20for%20non%20urgent%20neurological%20conditions%20i.pdf
[8] http://www.neural.org.uk/store/assets/files/586/original/Transforming_Community_Neurology_-_Part_A_-_Transformation_Guide_-_version_1.pdf ,
http://www.neural.org.uk/store/assets/files/583/original/Transforming_Community_Neurology_-_Part_B_-_Reference_Reports_-_version_1.pdf
http://www.neural.org.uk/store/assets/files/584/original/Transforming_Community_Neurology_-_Part_C_-_Examples_-_version_1.pdf
[9] http://tvscn.nhs.uk/wp-content/uploads/2014/08/Thames-Valley-NCS-Report-Final-September-1014.pdf
[10] http://www.londonscn.nhs.uk/wp-content/uploads/2016/12/neuro-acute-hans-122016.pdf
[11] http://www.londonscn.nhs.uk/wp-content/uploads/2015/01/neuro-case-chg-052016.pdf

Recommendation & Outline Specification

The current distribution of NHS commissioned neuroscience activity between specialist centres and district general hospitals should be fully described and compared to one or a small number of agreed optimal distributions.

Phase 1 – Develop or adopt an existing approach to assigning neuroscience activity into a manageable set of activity categories. This taxonomy of activity types will draw on patient diagnoses and procedures codes and will reflect the episodic, time-limited and on-going nature of the care patients receive.

Phase 2 - Describe the current patterns of service delivery within each neurosciences network. How are these activity types shared between specialist centres and district general hospitals? Assess each network's position on a spectrum and identify the contextual characteristics of the networks that tends towards highly centralised and highly distributed systems. Identify and quantify the instances where patient care is delayed or resource is not used optimally as a result of a delay in the handover of cases between specialist centres and district general hospitals.

Phase 3 – Using the taxonomy of neuroscience activity, support a clinical reference group to define one or more optimal models of distributing activity between specialist centres and district general hospitals. The models should describe the activity types that should be managed entirely within specialist centres, those that should be managed entirely within district general hospitals and those that require some input in both settings. Where shared-care arrangements are optimal, the clinical reference group should set out the handover points and arrangements between the two settings. NORSe (Neurosurgical On-call Referral System) at University of Birmingham Hospitals NHS Foundation Trust may provide useful benchmarks.

Phase 4 - Assess the changes in activity that would result if services moved to the optimal distribution of activity. Apply the optimal clinical model(s) to distribute current activity to specialist centres and district general hospitals in each network. Estimate the change in activity and resource use at these two settings, the impact on CCG and NHS England Specialised Commissioning budgets and the net reduction in acute bed day use that could be achieved.

Analytical Priority C: Modelling the Consequences of Increased Access to Thrombectomy

Interventional neuro-radiology (INR) procedures are a small but growing feature of acute hospital activity in response to hyper acute stroke and sub-arachnoid haemorrhage, and demand is expected to grow further as innovations in clinical practice extend the scope for thrombectomies and other IR interventions. Given Interventional Radiologists capacity and the infrastructure required to support IR, there would be value in medium term modelling to determine the most efficient way to organise and configure Interventional radiology (IR) services and the services that will increasingly depend on IR interventions.

This will require consideration of the wider scope of IR across all service areas (e.g. cardiology, vascular surgery, oncology) and the clinical inter-dependencies and nature and materiality of supply constraints in neurosciences, IR and other interdependent services.

The Question(s)

What is the current level of IR activity in total and the subset that is carried out in response to a neurological condition? How does this differ to the numbers of people who might benefit from these procedures and what are the constraining factors? How might need for IR services change over the next 15 years with population size, age profile and disease incidence? What workforce would be required to meet this demand and how might this alter the balance between IR for neurological conditions and other forms of IR.? Does this alter perspectives about the best way to organise IR services?

The Purpose

To anticipate the interaction between IR, neurosciences and other disciplines as the supply of thrombectomies increases. To assess the impact of these changes on workforce plans and capacity requirements and to inform national and STP strategies relating to the configuration of stroke services and IR services.

Review of Literature

There are several papers assessing the need for IR across a range of specialties/services and conditions and identifying the current shortfall in workforce. The Royal College of Radiologists (RCR) addresses the standards to be achieved in providing 24 /7 IR, but with only brief reference to

INR and thrombectomy.[12] RCR assess the current IR workforce and the investment needed in the workforce including all the services requiring support and safe rotas, however this is not specific to INR.[13 14]

There are several publications specifying the service requirements and standards to be achieved in the provision of thrombectomy, including models of provision.[15 16]

In conclusion, very little is published which explicitly addresses the relationship between the provision of IR for thrombectomy and hyper acute stroke services; the co dependencies, including workforce issues, between INR and IR; and the co-dependencies between IR and other specialties.

Recommendation & Outline Specification

Quantify recent and anticipated increases in the delivery of thrombectomies and other IR procedures and consider the impact of these changes on the optimal configuration of IR and specialist neurosciences centres. Although the results of this exercise will be of interest nationally, for practical purposes, we suggest that the later modelling phases are based on a single English region.

Phase 1 - Through discussions with clinicians and clinical coders, examine Hospital Episode Statistics and create a list of procedures (using OPCS4.7 codes) that are routinely carried out by interventional radiologists, commonly carried out in catheterisation labs and IR procedures carried out by non-IR consultants in other settings.

Phase 2 - Using Hospital Episode Statistics produce a detailed descriptive analysis of NHS commissioned interventional radiology activity in England including the volume of procedures by type and specialty; the socio-demographic and clinical characteristics of patients undergoing IR procedures; the mode of service delivery (emergency admission, day case, etc); the geographic distribution of patients and service locations; the trends in procedure volumes by type.

Phase 3 - Using national reference resources (e.g. HSCIC Organisational Data Service's list of current hospital consultants) and through discussions with hospital trusts, estimate the number of interventional radiologists and neurosurgeons employed by the NHS in England, the number of vacancies and the number of catheterisation labs.

[12] https://www.rcr.ac.uk/system/files/publication/field_publication_files/bfcr171_24hr_ir.pdf
[13] https://www.rcr.ac.uk/system/files/publication/field_publication_files/bfcr166_cr_census.pdf
[14] https://www.rcr.ac.uk/publication/investing-interventional-radiology-workforce-quality-and-efficiency-case
[15] http://basp.ac.uk/wp-content/uploads/2016/12/Final_ThrombectomyStandardsSeptember-2015-2-1-1.pdf
[16] https://www.sitsinternational.org/media/1320/sits-report-2016_5_low_res.pdf

Phase 4 – Conduct semi-structured interviews with the relevant clinicians and operational managers at a sample of hospital trusts to explore issues about the organisation of interventional radiology services such as; resource planning for catheterisation labs, the role and use of interventional radiologists in other specialties, joint working / rotas with adjacent trusts / sites, potential productivity opportunities, the implications of recent or imminent service reconfigurations. Summarise the content of these interviews.

Phase 5 - Estimating growth in demand for interventional radiology procedures over the next 5 and 10 years taking account of anticipated changes in population size and age profile; changes in age specific morbidity; wider diffusion of recently developed procedures (e.g. thrombectomy); and the emergence of new IR procedures. Summarise the results showing the baseline activity levels, future estimated activity levels, the contribution of the change factors above to any growth and differential growth rates for activity subgroups (e.g. by procedure, modality). This demand growth model will consider a time horizon of 5 and 10 years and will where possible be set alongside international benchmarks.

Phase 6 - Model potential configurations of interventional radiology in a single region of England. Using a clinical reference group, define a small number of potential future configurations of interventional radiology services. These might include for example;

a) A highly centralised model where all IR procedures are carried out only at specialist centres

b) A hub and spoke model with complex and out-of-hours interventions taking place at tertiary centres and other procedures at district general hospitals

c) A fully devolved model where all procedures are carried out at the most local hospital

d) A service / specialty based configuration where IR relevant services / specialties are commissioned from a varying subset of hospitals.

For each potential configuration, estimate in 5 and 10 years' time the flows of activity to each trust and site; the level of resource (IR consultants and catheterisation labs.) required at each site; the average and upper decile ambulance journey times for patients requiring emergency IR interventions; the utilisation rates (productivity estimates) of the catheterisation labs.

Analytical Priority D: Defining Quality & Outcomes Measures for Neurology Services

In contrast to many other clinical services and specialties, there is no nationally recognised set of quality and outcome measures for neurology services. As a result, variation in the quality of the service is poorly understood. The development of such a set of measures would assist services to track progress, identify areas for development and draw comparisons between services and consultant teams. Where appropriate, the set might include clinical and patient reported outcomes, processes measures, prescribing practices, intermediate outcomes and measures of patient experience. The definition of measures may be seen as a precursor to the development of a neurology audit programme. The work should learn from the development of other similar national programmes such as SSNAP (Stroke Sentinel National Audit Programme) and NNAP (Neurosurgical National Audit Programme) and draw on existing resources such as Right Care, GIRFT, Neurology Information Network and NICE quality standards.

Some neurological conditions are rare and in the absence of large clinical trials, routinely collected quality and outcome measures could provide useful early intelligence about the efficacy of new treatments and new ways of organising care.

The Question(s)

What are the most important outcomes and markers of service quality from a clinical and service user perspective? This assessment should incorporate clinician and service user opinion, an international review of evidence and practice, an assessment of the data that is currently available, a technical assessment of measurement tools and the suitability of potential metrics.

The Purpose

To establish a clinically and patient-endorsed set of quality and outcome measures for neurology services in England which would underpin any future national clinical audit and support systematic assessments of variations in neurology services and opportunities for service improvement.

Review of Literature

The Royal College of Physicians (RCP)and Multiple Sclerosis Trust have audited services for people with MS (2008 and 2011) revealing significant gaps in provision compared to the NICE clinical

guideline Management of multiple sclerosis in primary and secondary care (NICE CG8) and the National Service Framework for Long-term Conditions (NSF-LTC).[17] [18] [19]

The Neurology Alliance has undertaken several studies and surveys of patients, commissioners and providers with the aim of using the results to improve provision and producing five key tests to measure how the prioritisation of the improvement in neurology provision is progressing.[20] [21] The Neurology Alliance has recommended that there is national support to develop neurological outcome measures using their standards as a starting point and mapping outcome measures to the NHS quality improvement system and NHS Outcomes Framework Domains..[22]

The Association of British Neurologists (ABN) has determined 13 standards for unscheduled care for 'acute' neurology focusing on patients admitted through acute medical services (including for example, standards for accessing neurological expertise and lumbar puncture) and 12 standards for non-urgent neurological conditions (including, for example, referral to treatment times and access to rehabilitation).[23] The ABN acute neurology survey identified a significant variation of provision of service across the UK: for example, 20% of acute hospitals have access to a neurologist on 3 days or fewer per week and 72% of district general hospitals do not have 24/7 access to MRI.

In 2013, the West Midlands Quality Review Service published a pathway report on the care of people with chronic neurological conditions as a supplementary report to the '*Care of Adults with Long-Term Conditions: West Midlands Overview Report*'.[24] Across providers and commissioners in the West Midlands, the review showed the level of compliance against a wide range of standards agreed by stakeholders.

In conclusion, there has been considerable work undertaken in recent years to establish for specific acute and long-term neurological conditions and for the specialty of neurology, measures of outcomes, standards of care and patient and carer experience. There is not, however a single, nationally recognised set of quality and outcome measures for neurology services.

Recommendation & Outline Specification

[17] https://www.rcplondon.ac.uk/projects/national-audit-services-people-multiple-sclerosis
[18] https://www.nice.org.uk/guidance/cg8
[19] https://www.networks.nhs.uk/nhs-networks/vocational-rehabilitation/documents/DoH-NationalServiceFramework.pdf
[20] http://www.neural.org.uk/updates/245-invisible%20patients%20variations%20report
[21] http://www.wbna.org.uk/documents/Goingthedistance-nationalcallstoaction-March2014.pdf
[22] http://www.neural.org.uk/store/assets/files/275/original/Intelligent-Outcomes-Neurological-Alliance-MHP-Health-Mandate-report.pdf
[23] http://www.theabn.org/media/docs/ABN%20publications/ABN%20acute%20neurology%20survey%20final%2013%20March%202017.pdf
[24] http://www.wmqrs.nhs.uk/download/417/WMQRS-CNC-pathway-report-V1-20131007_1381312550.pdf

Build on previous work to establish a set of quality and outcome measures for neurology services that has the support of clinicians and patient groups.

Phase 1: Establish a reference group that will be used to consider potential metrics. The reference group should include neurologists, other relevant health professions, representatives of patients and their carers and information specialists.

Phase 2: Confirm the approach that will be used to assess potential metrics. This framework may include assessments of relevance and materiality, clinician and patient acceptability, technical assessments of the metrics suitability (e.g. responsiveness, the presence of perverse incentives, cost of collections etc) and assessments of coverage to expose gaps by condition or against a specific quality dimensions.

Phase 3: Review literature to identify existing metrics, nationally and internationally. Document and assess these against the framework. Where gaps exist, propose additional metrics and assess these against the same criteria.

Phase 4: Facilitate a meeting of the reference group to review this long list of potential metrics and select a final set.

Phase 5: Produce a document that itemises the metrics, providing detailed technical information about sources and definitions, along with information about the rationale for the metric and issues that services might consider to bring about improvement.

Analytical Priority E: Reducing the Variation in Neurology Referrals and Diagnostic Tests

The number of referrals from primary care to neurology and the type and volume of tests ordered in response to new referrals are likely to exhibit variation. This variation will be driven in part by chance and differences in casemix, but also by the experience and confidence of the practitioner, the support services that are available and the variation in explicit eligibility criteria.

A hypothesis generation and testing exercise guided by an expert reference group may provide insight into the quantity of referrals and tests that might be avoided and the mechanisms that might lead to reduced demand (e.g. the use of 'advice and guidance'). The management of patients with 'medically unexplained symptoms' is particularly relevant here and should be addressed explicitly to ensure that patients are not exposed to unnecessary tests and receive clear advice and prompt support for allied services where appropriate.

The Question(s)

What is the current variation in referral patterns, tests ordered and the outcomes of these events? How much of that variation reflects differences in population need and how would this alter if an agreed set of assumptions about demand and the impact of standardised pathways were applied?

The Purpose

To identify potential opportunities to improve patient experience, clinical effectiveness and system efficiency in relation to neurological referral activity and testing, and to quantify that for national and local planning.

Review of Literature

There are many documented pathways for neurology services and numerous sources of information on rates of referral and diagnostic imaging for neurology.[25] [26] [27] [28] But these rarely seek to explore or explain the variation in rates between practices.

[25] https://pathways.nice.org.uk/pathways/neurological-conditions
[26] http://www.ekhuft.nhs.uk/EasySiteWeb/GatewayLink.aspx?alId=416826
[27] https://fingertips.phe.org.uk/profile-group/mental-health/profile/neurology
[28] https://ukgtn.nhs.uk/fileadmin/uploads/ukgtn/Documents/Resources/Library/Reports_Guidelines/Right_Care_Diagnostics_Atlas_2013.pdf

Many studies have sought to test the effectiveness of referral management interventions in other specialities and a systematic review on this subject was published in 2014.[29] The study classified interventions to 4 types; GP education, process change, system change and patient focused interventions. Only 1 of the studies considered in this review assessed referrals to neurology services.[30]

A report by the Neurological Alliance in 2016, *Improving the transition from primary care for people with neurological conditions*, found that many GPs were not confident making an initial assessment and referral for people presenting with neurological conditions.[31]

In conclusion, whilst there are a number of contextual documents and data sources, there is little published on the factors that underpin variation in referral and diagnostic imaging rates, or on the effectiveness of interventions to reduce this variation for neurology services.

Recommendation & Outline Specification

Measure prima-facie variation in the rates of primary care referrals to neurology and of diagnostics tests ordered in responses to referrals; explore and assess explanations for this variation; and assess the opportunity to reduce referrals and tests by standardising pathways and services.

Phase 1: Use existing data sources to assess variation in the rates of primary care referrals to neurology and of diagnostic tests ordered in response to referrals. Present this information so that the role of chance in explaining this variation can be readily understood.

Phase 2: Establish a reference group, with representatives from primary and secondary care, to review this information and propose potential explanations for this variation. The group should be guided to consider explanations relating to differences in data capture and coding, casemix, structure of healthcare services, referral and eligibility criteria and clinician behaviour. These hypotheses should be documented and if the list of hypotheses is long, then the group should be asked to order the list in terms of plausibility.

Phase 3: Assess the credibility of these hypotheses. Additional informational and bespoke analysis should be carried out and information that might support or counter the hypotheses should be documented. The results of this exercise should be shared with the reference group with a recommendation to accept or reject each of the hypotheses using a 'balance of probabilities'

[29] http://bjgp.org/content/bjgp/64/629/e765.full.pdf
[30] http://jnnp.bmj.com/content/75/4/617.info
[31] http://www.neural.org.uk/store/assets/files/597/original/Neurology_and_primary_care_report_Final_version_-_August_2016_.pdf

threshold. Further analysis should be conducted or presented until the reference group reach a consensus on all hypotheses or until no additional information can be supplied.

Phase 4: Elicit expert opinion from the reference group about the extent to which the factors that explain variation in referral rates and tests might be controlled through specific interventions. Use this expert opinion to assess the feasible opportunity to reduce variation in referrals and test rates.

Analytical Priority F: Assessing the Total Service Use of People with Neurological Conditions

Specialist neurology services typically represent a small but high cost part of the total health and social care usage of patients with long-term neurological conditions. Because the overall resource utilisation patterns at a patient level aren't well understood, opportunities to improve patient care, service continuity, outcomes and system efficiency through greater integration may be being missed (e.g. unnecessary or prolonged UTI admissions for patients with MS or Parkinson's disease due to lack of community resource such as specialist nurses).

Analysis of linked health and social care datasets (specialised, acute AE/IP/OP, mental health, CHC, community healthcare, social care and primary care) would provide insight into the patterns of health and social care utilisation for patients with neurological conditions as a whole and for specific patient subgroups and highlight opportunities for greater service integration.

The Question(s)

What are the current patterns of health and social care utilisation for patients with long-term neurological condition? How does this vary in patient subgroups defined diagnostically, demographically and geographically? What opportunities for improvement might be achieved through greater service integration?

The Purpose

To support the development of specific quantified recommendations that can support local business case development and implementation of integrated services to maximise benefits for people with long-term neurological conditions.

Review of Literature

The literature points to a wide spectrum of health and social care needs of patients with neurological conditions.[32,33] These needs arise from the neurological condition directly and from the high level of comorbid conditions experienced by this group. Some of these reports include high level estimates of the costs of meeting the needs of neurological patients, but there is a lack of studies which describe the patterns of health and social care service usage of this patient cohort in detail.

[32] https://www.publications.parliament.uk/pa/cm201012/cmselect/cmpubacc/1759/1759.pdf
[33] http://www.bsrm.org.uk/downloads/long-term-neurological-conditions-concise.pdf

Recommendation & Outline Specification

Phase 1: Identify a small number (two to five) of CCGs that would be interested in participating in a programme to link a range of health and social care datasets to explore the patterns of service utilisation for patients with long-term neurological conditions. Interested CCGs should be asked to confirm their willingness to put appropriate data-sharing arrangements in place and allow the results of the analysis to be shared.

Phase 2: Secure pseudonymised datasets from acute trusts, mental health trusts, community trusts (if applicable), continuing healthcare services, social care services and primary care services from each of the participating CCGs. Link the data and create a master patient index of all individuals with long-term neurological conditions.

Phase 3: Describe, visualise and summarise data on the healthcare utilisation and costs across these service sectors. Analysis should consider variation by demographic and diagnostic sub-groups, classify patients by service usage patterns and identify activity that might be avoided

Phase 4: Present the result to the CCGs and participating stakeholders and facilitate discussions on the opportunities that this data suggests to improve health service provision.

Phase 5: Model the impact of these opportunities, informed by stakeholder's expert opinion, and produce a report for national dissemination describing methods and findings and setting out how other areas might take advantage of or replicate the work locally?

Potential Cross-Cutting Themes

In addition to the topics described above, the following issues emerged from the discussions that informed the development of this report and should be considered as potential cross-cutting themes in the undertaking of the analytical projects and in the development of the neurosciences strategy:

1 The adequacy and consistency of clinical coding in neurology services. Identifying and minimising differences in coding practice is essential to ensure high quality modelling of potential service improvements and fair comparisons between services.

2 High quality neurology services rely on the ability to refer to and work closely with neuropsychiatry services. However, the availability and delivery arrangements for neuropsychiatry are thought to be highly variable.

3 Neuro-rehabilitation services and facilities are poorly developed in many parts of the country and are often the limiting factor in treatment pathways.

4 Patient information and use of newer technologies using disease specific apps for example is an expanding and exciting area for self-management that should be encouraged.

Estimated Resource Requirements to Undertake the Work

The Strategy Unit has significant experience in undertaking complex, wide-ranging analytical projects with the necessary methodological robustness to support national roll-out of findings (e.g. STP level presentation of results). To facilitate budgeting and prioritisation, The Strategy Unit has estimated the likely cost and elapsed time required to undertake the analytical projects described in the report, based on its working practices and day rates. This is summarised below:

Analytical Priority	**Cost estimate**[34]	**Elapsed time estimate**
A: Understanding the Present State of Neurosciences	£50-75k	4 months
B: Improving Coordination between Specialist & District General Hospitals	£75-100k	8 months
C: Modelling the Consequences of Increased Access to Thrombectomy	£100-125k	9 months
D: Defining Quality & Outcomes Measures for Neurology Services	£25-50k[35]	3 months
E: Reducing the Variation in Neurology Referrals and Diagnostic Tests	£50-75k	6 months
F: Assessing the Total Service Use of People with Neurological Conditions	£50-75k	6 months
TOTAL	**£350-500k**	

The Strategy Unit has also assessed the technical requirements for each project and is of the opinion that there are no critical dependencies between the projects.

Professor Williams has led further discussions with interested parties following production of the stage 4 version of this report. This has identified that there is detailed work underway nationally in NHSE relating to the roll-out of thrombectomy. As a result, there is a need to understand in detail what elements of the specification set out in this report for project C are already in train. This may reduce the budget envelope required for that project

[34] All estimates assume the required data is availability in a suitably structured environment without additional cost.
[35] This excludes the time and costs of extensive consultation.

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