NEUROLOGY REVIEW – INTERIM REPORT

October 2019

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FOREWORD

The Regional Review of Neurology Services has been tasked with identifying the optimal service configuration for neurology services through to 2035.

The need for change, as explored in this report, is clear. The service currently falls short in meeting demand, in workforce and in meeting the needs and expectations of people with neurological conditions and their carers. There is significant work to do in respect of each.

The scale of the challenge should not be underestimated. I am confident, however, that the Review Team, as it moves into the next stage of its workplan, has put in place the necessary foundations to identify the changes required to improve and modernise our neurology service to better meet the needs of people in Northern Ireland.

Dr John Craig

Chair of Neurology Review Team

INTRODUCTION

Neurological conditions such as epilepsy, multiple sclerosis, Parkinson's disease and motor neurone disease result from damage to the brain, spinal cord or peripheral nervous system. Some neurological conditions are life threatening, with many severely affecting an individual's quality of life.

There are hundreds of neurological conditions, which are broadly categorised into:

- Sudden onset conditions (e.g. stroke, acquired brain injury or spinal cord injury)
- Intermittent and unpredictable conditions (e.g. epilepsy, certain types of headache, or the early stages of multiple sclerosis)
- Progressive conditions (e.g. motor neurone disease, Parkinson's disease, or later stages of multiple sclerosis)
- Stable neurological conditions (e.g. post-polio syndrome, or cerebral palsy in adults)[1]

Long term neurological conditions are common. For example, in NI, there are approximately 15,000 people diagnosed with epilepsy, 4,600 with multiple sclerosis, 3,700 with Parkinson's Disease, 910 adults with inherited or acquired neuromuscular disease and 140 people with Motor Neurone Disease.

Current Neurology Services

Neurology services are provided across each Trust area in NI. There is one Regional Neurosciences Centre based at the Royal Victoria Hospital in the Belfast Trust. In addition to providing local neurology services to the greater Belfast population, the Centre also provides most sub-specialist services including specialist inpatient care to the wider NI population.

While the current neurology service model in NI has largely focused on outpatient delivery, there is considerable demand for neurology support within unscheduled care with neurological disorders (including stroke) accounting for about 15% of

[1] NHS England

emergency department attendances and about 10% of emergency medical admissions (excluding stroke).

Neurology services rely heavily on the skills of associated specialities including neuroradiology, neurophysiology and neurosurgery as well as other healthcare professionals including specialist neurology nurses, psychologists and allied health professionals.

For those with neurological conditions and those caring for them, care and support is provided by a range of primary and community-based services from across the statutory and community sectors.

ABOUT THE REVIEW

On 31 July 2018, in the context of the commitment in Health and Wellbeing 2026: Delivering Together to undertake a programme of service configuration reviews, the Department announced a comprehensive regional review of neurology services covering all neurology specialties.

The Review is tasked with identifying an optimal service configuration of neurology services through to 2035. In identifying this configuration, the review will work closely with patients and carers to consider:

- Future demand taking into account demographics and interlinking specialties;
- The role of technology in improving neurology services;
- New models of care which are more effectively integrated across primary, community, secondary and tertiary care;
- The workforce and training required to deliver the optimum configuration; and
- Actions required to ensure services are underpinned by effective governance and quality assurance mechanisms.

Terms of Reference for the Review are outlined at Appendix One.

ABOUT THIS REPORT

The Review is being taken forward in two phases. This interim report reflects the work taken forward in this initial stage of the review and provides a summary of the priority areas identified for exploration in the second phase of the Review.

A final report, with an implementation and investment plan, will be published in March 2020.

CASE FOR CHANGE

Pressures on the service

As part of this first phase of work, a population health needs assessment for the neurology service was undertaken. A number of the key findings from the assessment which reflect the pressure on current neurology services are outlined below:

Outpatients

- First or new referrals to neurology outpatients for face to face assessment or for 'virtual' clinic advice were relatively stable between 2015/16 and 2018/19 averaging just under 18,500 per year;

- However, the capacity of the system to see these patients is much lower than the referral numbers at just under 12,000 per year. This has resulted in a rise in patients waiting for a first appointment from 9,123 in March 2015 to 19,376 in March 2019;

- At 31 March 2019, 11,249 patients had been waiting more than one year to be seen; 5,816 of those patients had been waiting more than two years;

Review appointments

- There are on average 22,500 neurology review attendances every year;

- There is a considerable backlog of patients needing an appointment. In January 2019, 5,240 patients had been waiting more than 3 months past the date which their clinician had proposed for review. Of these 1,167 had been waiting more than 2 years past that date;

Workforce

Northern Ireland currently has 21 Consultant Neurologists, 3 of whom work on a part-time basis. In addition to the core neurology service, Consultant Neurologists also assist in aspects of stroke and dementia care. In addition, there are 37 Nurse Specialist posts within the Neurology service.

We know that there are staff shortages across the neurology workforce. For example, there are insufficient consultant neurologists to deliver a 24/7 on call rota on any site other than the Royal Victoria Hospital (RVH). Consultant neurologists based in other hospitals offer a ward consult service to selected inpatients, but there is insufficient capacity to ensure that all patients admitted with a neurological emergency can be provided with advice within 24 hours as advised by the Association of British Neurologists (ABN).

Compounding these shortages, there are also significant challenges in developing expertise in neurology among trainees. For example, of 138 core training places, a maximum of 2 will be attached to neurology. This current restriction presents a clear limitation on the potential to address workforce shortages.

Staff shortages also extend to nursing staff with NI having significantly fewer Epilepsy, Multiple Sclerosis and Parkinson's Disease specialist nurses than is recommended by the National Institute for Health and Care Excellence for our population. This also extends to AHP, psychology and neuro-psychiatry.

Patient and Carer Views

Engagement with patients and carers prior to the commencement of the Review have identified a number of key areas where the experience of neurology services could be significantly improved. These included timely access to treatment, improved information and better communication particularly around symptom management and medication advice, increased support for self-management, the need for a connector/coordinator to help people navigate the system, increased public awareness of the impact of neurological conditions and an increase in Nurse Specialists and improved access to exercise classes.

The issues outlined above represent a clear need to improve, strengthen and modernise neurology services. While there are some issues which can be in part addressed in the shorter term (these are explored in the next section of this report) others will require a fundamental change in approach which can only be considered through a strategic review.

DEVELOPMENTS ALREADY TAKING PLACE

While there is a clear need to undertake a strategic review of neurology to establish the long term direction for services, we are not losing sight of the need for improvements which can be made in the shorter term.

To that end, the HSC Board has been taking forward a Neurology modernisation programme. The programme has identified three short-term top priorities for action:

1. To secure and fund additional training places in Neurology to give some junior doctors more experience of the specialty;
2. Support the development of new ways of responding to patients suffering from some of the more common conditions such as headache;
3. Increase opportunities for different healthcare professionals to work more closely together for neurology patients.

An update of actions both already taken and planned is outlined below:

On **training**, discussions between the HSC Board, Public Health Agency and NIMDTA have highlighted the need for a long term increase in training places. While this will be taken forward within the context of this Review, progress has been made to improve support in 2020/21. This includes maintaining the existing number of specialist registrar places for training, funding an additional one year placement to promote the specialty and supporting additional doctors wanting to improve their skills and knowledge in the specialty.

On **headache pathways**, the Southern Trust, on behalf of the region, is piloting a new way to meet demand from primary care. Through quicker access to advice from a consultant neurologist, and additional education in common neurological issues, GPs will be better equipped to manage more neurology patients in the community without the need for a referral to hospital. Particularly for patients with recurring headaches, early experience suggests that up to 70% of cases can be appropriately managed in primary care. Those who cannot be managed this way are referred to specialist headache clinics. The Review will capture learning from this development to inform the requirement for NI-wide cover.

There have also been a number of developments on **multi-disciplinary working.** For Multiple Sclerosis (MS), a new Clinical Fellow post (someone who combines specialty training with academic work) has been appointed to Belfast Trust. This has increased the capacity of the service for MS patients. The waiting time for new referrals to the MS Clinic has dramatically reduced from over 6 months, to effectively being eliminated for urgent referrals. The post is also helping to see new patients referred from all Trust areas and seeing patients who have been waiting the longest for their review appointment.

MS clinics, supported by more Nurse Specialists, are now taking place across Northern Ireland instead of just Belfast, improving accessibility.

Over the past 12 months in the Belfast Trust a couple of new multidisciplinary meetings have been established. These meetings provide protected time for different healthcare professionals to meet and agree the best way to treat patients with complex needs or for example, how to address service issues.

For example, a Neuroinflammatory Imaging Meeting brings together Neurologists, the MS Clinical Fellow and Neuroradiologists to discuss challenging cases. Another group meets to discuss the approval of high cost drugs and involves Neurologists, Neuroradiologists, the MS Clinical Fellow, Pharmacy, and MS Nurses.

Proposals are being considered for a multi-disciplinary team to support the Neurology Hub at South Eastern Trust. The aim is to ensure patients receive the treatment and care they require at all stages of their condition, have access to information about their diagnosis and are supported in all aspects of their care and treatment.

Clinical Neuropsychology, located within the Royal Victoria Hospital, is an important aspect of regional neurological care. For many years the service was provided by one Consultant Clinical Psychologist. Four new posts have been funded to help the consultant and offer patients the support they need.

These measures alone will not address the challenges within the neurology service, but they will go some way to strengthening and improving existing services while the longer term objectives of this review are implemented.

DESIGNING FUTURE NEUROLOGY SERVICES

Principles

The Review Team identified the establishment of principles and standards as a key first step in developing a future framework for neurology services.

Following a review of learning from engagement with stakeholders including patients, carers, staff and the voluntary sector, the Review Team has agreed the following principles as a basis for the development of future neurology services:

- Person-centred with involvement from patients, clinicians, AHPs, nursing and other stakeholders;
- Safe and effective;
- Comprehensive provision across primary, secondary and community settings;
- Available on an equitable basis;
- Designed to develop multidisciplinary team working;
- Evidence-based and benchmarked against best practice and NICE guidance;
- Appropriately resourced.

These principles provide a robust test for the development of future services.

Standards

While the principles provide a firm basis on which to develop future neurology services, the Review Team agreed that the adoption of Standards of performance would strengthen the principles by establishing desired performance levels for neurology services. Reflecting the demands on different parts of the neurology pathway, the Review Team agreed that separate standards should be adopted for unscheduled care, scheduled care and long term conditions.

The Association of British Neurologists has published standards for both scheduled and unscheduled care. Each consists of 10 statements of performance which the Review Team has agreed should be adopted in NI. These are outlined at Appendix One.

It is recognised, however, that achievement of some aspects of the standards, including that adults admitted as a neurological emergency should see a neurology specialist within 24 hours of admission, is not currently possible and will be contingent on the successful implementation of the recommendations arising from this Review.

In addition, the Review Team is in the process of identifying standards for Long Term Neurological Conditions. These will be developed in the next phase of the Review Team's work and will build on the framework developed by NHS RightCare which focuses on driving improvement in the areas of referral and diagnosis, symptom management, use of multidisciplinary teams, care coordination and mental health support. These will be tailored for NI's integrated health and social care system.

WORKSTREAMS

In identifying priority workstreams, the Review Team has reflected on the principles and standards outlined in the previous section of this report.

In addition, the Team has considered developments in neurology services across the UK as well as guidance from the Association of British Neurologists and the Royal College of Physicians.

Taking this, and the Review's Terms of Reference into account, the Review Team has agreed the following priority areas for exploration in phase two of the Review.

First presenters

- This workstream builds on the experience of the Southern Trust's Virtual Clinic and e-triage. This workstream will consider the optimum approach to provide support to primary care and the processing of referrals.

Unscheduled care

- This workstream will consider the extent of change required to provide a service in line with the Association of British Neurologists standards. This will include potential relocation of services, taking into account learning from the introduction of a Hyperacute Neurology model in London.

Long term care

- This workstream focuses on the multi-disciplinary management and care of those with long term neurological conditions. It is utilising the NHS RightCare Framework and ABN Quality Standards and will build on work including published NICE guidelines for Multiple Sclerosis, Parkinson's Disease and Epilepsy.

Workforce

- This workstream will focus on roles, skill mix, career progression and the training of the neurological nursing workforce. This is in the context of recognised significant shortages in the nursing workforce and particular challenges within the neurology field. It is recognised that other workforce pressures exist such as AHP and psychology services and whilst there is no dedicated workstream for these groups, it is anticipated that the outputs of other workstreams will capture the workforce requirements for these groups to enable improved multidisciplinary working.

Coproduction

- This workstream is jointly led by the Department and the Neurological Charities Alliance. This workstream will identify tools and methodologies to enable engagement and will work closely with other workstream leads to identify key points in respective workplans and opportunities for engagement.

Coordination

- This workstream will consider how best to support patients and carers to navigate the system and streamline access to the right support.

Elective Care

- Neurology daycase has been included as one of the seven specialties included within the Daycase Elective Care project. This project will consider future demand and capacity, workforce and optimal sites for the delivery of elective care, resulting in a regional reconfiguration of services to improve the efficiency and effectiveness of elective care.

NEXT STEPS

Over the coming months, each workstream will complete its analysis and produce recommendations to deliver improvements in the neurology services.

These recommendations will be considered in the round, including investment required, and an implementation plan will be developed. These will be incorporated in a framework setting out the optimal configuration for future neurology services through to 2035.

This framework will be published in March 2020. A public consultation may be required depending on the nature of the final recommendations within the framework.

Terms of Reference

Introduction/Background

The current neurology service model in NI has largely focused on outpatient delivery. There are approximately 11,000 referrals from GPs for outpatient neurology per annum and 7,000 referrals from other consultants. Current outpatient clinic capacity is for 11,535 patients per year to be seen. There is, therefore, a significant shortfall in outpatient capacity, which is compounded when the capacity required for planned reviews is taken into account.

Neurological disorders (including stroke) also account for about 15% of emergency department attendances and about 10% of emergency medical admissions (excluding stroke). The involvement of neurologists in unscheduled care, in addition to that provided from the Regional Neurology Unit in the Belfast Trust, is an area of increasing focus.

As currently configured, neurology therefore faces significant challenges in terms of waiting list size and length of wait. There are large waiting lists for patients waiting for a first consultant-led neurology outpatient appointment. At the beginning of June 2018 there were 17,987 people on the waiting list with 15,751 waiting more than 9 weeks, 14,168 people waiting more than 18 weeks and 9,325 people waiting more than one year.

On 1 May 2018, the Belfast Trust recalled 2,529 neurology patients following an internal Trust review of one consultant's patients and an external review carried out by the Royal College of Physicians (RCP) which raised a number of concerns.

On 31 July 2018, in the context of the commitment in Health and Wellbeing 2026: Delivering Together to undertake a programme of service configuration reviews, the Department announced a comprehensive regional review of neurology services covering all neurology specialties. While the review focuses on the neurology service for adults, consideration will be given to the challenges faced in the transition from paediatric to adult neurology services.

Following a workshop with stakeholders in September to help shape the review, work commenced in December 2018 with the aim of producing an initial report by early 2019.

Objectives

- Building on existing information from an earlier Neurology Service Needs Assessment, National guidance and benchmarking against professional best practice, identify future demand for adult neurology services taking into account future demographic changes and the range of interlinking specialties/specialists;

- Review the existing policy framework and developments across the UK and, taking into account service user and carer views, consider how the future configuration of neurology services can adopt:

    - advancements in technology including the use of e-triage and virtual clinics;
    - new models for both scheduled and unscheduled care; and
    - integrated care pathways spanning primary and community, secondary and tertiary care.

- Building on the Neurological Workforce Planning report 2017-2024, which estimated consultant workforce requirements, identify the workforce and training needs of future service models having regard to:
    - extant professional, clinical and Departmental guidance;
    - new clinical roles, skill-mix, multi-disciplinary working and limits of professional competence;
    - building effective networks of care across the region;
    - ensuring region-wide service resilience with appropriate escalation arrangements.

- To consider the potential for:
    - joint initiatives nationally and internationally including on a cross-border basis; and
    - the development of research capacity including participation in clinical trials.

- Identify actions required to ensure services are underpinned by effective governance and quality assurance mechanisms, taking into account the findings of the RQIA review.

- Produce a strategic framework with accompanying implementation and investment plan setting out a resilient platform for neurological services that will:

- ensure that patients across Northern Ireland receive timely access to neurological assessment, diagnosis, treatment, condition management support, and rehabilitation; and
- enhance primary and community service provision so that unnecessary admissions, excess bed days and length of stay are reduced.

Membership

The review will be chaired by Dr John Craig, Consultant Neurologist.

Membership of the project team will include:

- HSC Board - Commissioning;
- HSC Board - Data
- PHA Public Health Medicine;
- HSC Neurology X 2;
- PHA Nursing/AHP;
- niNCA;
- NIMDTA;
- Royal College GPs.

Membership will be kept under review to ensure suitable representation. The work of the Project Team will also be supported by workstreams as required.

Meetings

Meetings will take place at least every four weeks, with workstreams meeting more frequently as required.

Proposed Approach

The Review Team will produce an interim report by March 2019 with a final report by Summer 2019.

Outputs

- Identification of future demand and capacity;
- Engagement strategy;
- Identification of new/revised service pathways;
- Revised governance procedures; and
- Strategic framework with investment and implementation plan underpinned by a robust business case.

Outcome

Identification of optimal service configuration of neurology services for the next 10-15 years

APPENDIX TWO

ABN Standards

Unscheduled Care

- **Statement 1 -** Adults referred to hospital as a neurological emergency should have access to care in an appropriate inpatient setting without delay (no more than 2 hours after presentation to hospital).
- **Statement 2 -** Adults admitted as a neurological emergency should be able to receive advice on their management from a neurology specialist at all times.
- **Statement 3 -** Adults admitted as a neurological emergency should see a neurology specialist within 24 hours of admission to hospital.
- **Statement 4 -** Adults referred to hospital with an acute neurological problem should have access to care in appropriate inpatient setting within 4 hours after presentation to hospital.
- **Statement 5 -** Adults admitted to Acute Medical Units with an acute neurological problem should have access to daily consultation or advice from neurology specialists, if necessary by telemedicine.
- **Statement 6 -** Adults admitted to hospital with an acute neurological problem should have access to urgent inpatient imaging (CT and MRI) where indicated.
- **Statement 7 -** Lumbar Puncture, when indicated, should be available 24/7 to all patients admitted with an acute neurological problem
- **Statement 8 -** Rapid access pathways need to be established for adults referred from Emergency Departments and Acute Medical Units to neurology outpatient services on discharge. ***(RANC clinics)***
- **Statement 9 -** No patient should be discharged from a hospital setting without documentation of the neurological examination, including fundoscopy.
- **Statement 10 -** Immediate transfer of care information should be sent electronically to a named GP for all patients, as well as printed information for the patient.

Scheduled Care

- **Statement 1** New patients referred to the general neurology service will be seen in a timely fashion: in keeping with NICE guidance where appropriate (e.g. first seizure, 2 weeks) and within NHS waiting time standards for N Ireland.
- **Statement 2** General practitioners will have access to advice from a neurologist by letter, phone or email. **(Advice and Guidance 24/7 access)**
- **Statement 3** All neurology patients should have a plan of care indicating the diagnosis, intended investigation pathway, treatment and where necessary the arrangement for follow up. **(standards for review)** In most cases, hospital policy dictates that all clinic letters are copied to the patient, which provides

the relevant information. Patients should be entitled to receive written information within 5 days following their appointment.

- **Statement 4** Patients will have appropriate access to follow up appointments with the neurology team, to discuss results or monitor progress, at the time interval stated in their care plan. Patients with long term neurological conditions will have a named point of contact for re-accessing the service, in keeping with appropriate Quality Standard/NICE guidance) (e.g. Parkinson's disease, 2 weeks)
- **Statement 5** The service will be provided by appropriately trained and revalidated neurologists and members of the neurological care team, including specialist nurses, General Practitioners with a special interest (GPSI) and junior doctors, who will be appropriately trained and work within an appropriate framework of supervision and clinical governance.
- **Statement 6** Patients accessing the neurology service will have appropriate and timely access to neuro-imaging (MRI and CT), neurophysiology, neuropsychological testing, and ancillary investigations (serology and lumbar puncture), including in-patient assessment where indicated.
- **Statement 7** The service will have appropriate access to neurological rehabilitation including physiotherapy, occupational therapy, speech and language therapy, dietetics and neuro-psychology. Any patient discharged from hospital should have an appropriate handover to a ‘named, accountable GP’.
- **Statement 8** The service will have clear referral pathways to neurosurgery and orthopaedic spinal surgery.
- **Statement 9** The service will provide, where appropriate, information facilitating access for patients to enrol in clinical trials.
- **Statement 10** The service will maintain expertise through training, audit, and continued professional development.