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Dear *Colm,*

Regional Review of Neurology Services and Neurology Recall

Introduction

1. This paper provides an update in respect of the Regional Review of Neurology Services and the Neurology Recall.

Part One: Regional Review

Background

2. In the context of a significant shortfall in outpatient clinic capacity, challenges in terms of waiting list size, length of wait and the vulnerabilities in neurology services highlighted by the recall of patients in the Belfast Trust, the Department agreed the need for a regional review of neurology services on 25 July 2018.
3. In line with 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 commenced on 05 December with the establishment of the Neurology Review Team, chaired by Dr John Craig.
4. The Review is tasked with identifying the optimum configuration of neurology services for the next 10-15 years. This will include:

- Identifying future demand for adult neurology services taking into account future demographic changes and the range of interlinking specialties/specialists;
 - Reviewing the existing policy framework and developments across the UK;
 - Taking into account service user and carer views, considering how the future configuration of neurology services will adopt advancements in technology, new models for both scheduled and unscheduled care and integrated care pathways;
 - Identifying the training needs of future service models;
 - Considering the potential for joint initiatives nationally and internationally, including on a cross border basis;
 - Identifying actions required to ensure services are underpinned by effective governance and quality assurance mechanisms, taking into account the findings of the RQIA Review;
 - Producing a strategic framework with accompanying implementation and investment plan setting out a resilient platform for neurological services for the future.
5. The Review Team includes representation from the Consultant, Nursing and AHP workforce, Primary care, Public Health Medicine, Commissioning and the third sector through the NI Neurological Charities Alliance (niNCA).

Interim Report

6. An interim report was published in October 2019. This report set out the case for change, with data from a population health needs assessment to illustrate the pressure on neurology services and an ongoing gap between outpatient referrals and capacity. The report summarised pressures on the current workforce and patient and carer views on areas for improvement.
7. The Interim Report highlighted the identification 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 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.
8. 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.

9. The Association of British Neurologists has published standards for both scheduled and unscheduled care. 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.
10. 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.
11. The Interim report also outlined priority areas for exploration in phase two of the Review. Specific workstreams have been established to progress work in the following priority areas:
- **First presenters** - This workstream is building on the experience of the Southern Trust's Virtual Clinic and e-triage. This workstream is considering the optimum approach to provide support to primary care and the processing of referrals.
 - **Unscheduled care** - This workstream is considering the extent of change required to provide a service in line with the Association of British Neurologists standards.
 - **Long term care** - This workstream is focusing on the multi-disciplinary management and care of those with long term neurological conditions. It is utilising the NHS RightCare Framework and Association of British Neurologists Quality Standards and will build on work including published NICE guidelines for Multiple Sclerosis, Parkinson's Disease and Epilepsy.
 - **Workforce** - This workstream is focusing 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** - The Department and niNCA are working closely to identify tools and methodologies to enable engagement with neurology patients and carers.
 - **Coordination** - This workstream will consider how best to support patients and carers to navigate the system and streamline access to the right support.
12. At the time of publication, it was intended that a final report with an implementation and investment plan would be published in March 2020. While it was subsequently estimated that a final report would be complete by May 2020, work on the Review was paused in March 2020 in the context of the need to prioritise the response to COVID-19 pressures.

Restarting the Review

13. The Neurology Review Team reconvened for the first time since March 2020 on 15 June 2021 and agreed an outline work plan. This will see a scoping phase to determine how services have changed over the past 18 months and the impact those changes have on the workstreams followed by the identification of longer term reforms to form the basis of a final report.
14. Initial meetings considered the status of the Review when it was paused in March 2020 and changes in service provision in response to the COVID-19 pandemic. At its most recent meeting on 12 October 2021, the Review Team discussed forward work programmes for the workstreams.
15. Review Team members have noted ongoing pressure on their capacity and an exercise is currently underway to identify the extent of this with a view to implementing mitigations to address this, as far as possible. Given these ongoing constraints, it is likely that a final report will not be completed until Spring 2022 at the earliest.

Coproduction

16. The Department has worked with niNCA to identify opportunities to engage with service users, their carers and other stakeholders. The Chair of niNCA, David Galloway is a member of the Review Team to directly represent the view of Charities and service users.
17. Working with niNCA, the Department and HSCB hosted a workshop with service users and carers on 2nd July 2019. The workshop focused on establishing priorities from the perspective of service users and carers both for the Review as a whole and the work of the care coordination workstream.
18. Subsequent to this, planning was advanced on an online survey on the work of each workstream. Following a final review of the draft survey prior to going live it was agreed that, given the complexity of some of the issues, it would be better instead to focus on workshops on specific workstreams rather than this general approach.
19. Officials had subsequently planned two workshops to be held on 2nd and 3rd April 2020 in relation to obtaining service user and carer input in the development of care pathways for the long-term conditions workstream. However these events were postponed in the context of restrictions introduced in response to the Covid-19 pandemic.
20. Following the restart of the Review, the Department and niNCA met with the Patient Client Council (PCC) to discuss the engagement of service users and carers during this latest phase. These discussions led to an agreement from the Review Team to focus on the PCC's Neurology Engagement Platform as the primary means of engagement going forward.
21. It is intended that that the Platform will provide support to both the Neurology Review and the Neurology Recall. In this way service users impacted by the Neurology Recall will have a say in the future neurology service. In terms of the Review, it is intended that the Platform will identify tools and methodologies to enable engagement and will work with workstream leads to identify key points in respective work plans and opportunities for engagement. It is anticipated that an initial meeting of the Neurology Engagement Platform will be held in early December 2021.

Part Two: Neurology Recall

Background

22. Since May 2018, in response to the concerns regarding the treatment and care provided by the consultant neurologist, Dr Michael Watt, at the Belfast Health & Social Care Trust (BHSCT), a number of different work streams have been initiated by the Department, including the neurology patient recalls.

Neurology Patient Recall - Cohort 1

23. In response to the emerging concerns at the standard of treatment being provided by the consultant neurologist, a recall of the consultant's current patients was initiated in May 2018 (Phase 1 of recall). A report on the outcomes "Cohort 1 Outcomes Report" was published in December 2019. (Previously shared with the Committee).

Neurology Patient Recall - Cohort 2

24. In October 2018, the previous patients of the consultant neurologist in high risk groups, seen by Dr Watt between 2012 and 2017, but discharged back to the care of their GP, were invited for a further recall (Cohort 2b). Cohort 2b was focused on patients who had been prescribed anti-epileptic drugs, immunosuppressants and disease modifying therapies used to treat epilepsy and MS. In addition, Cohort 2 (a) included a number of other previous patients of Dr Watt, who were discharged from Dr Watt's care and identified as being on a waiting list within the Belfast Trust for a further appointment with a consultant neurologist. The Belfast Trust did not write out to Cohort 2a patients and invite them to attend an appointment to attend the recall and their appointments on the waiting list were expedited.
25. A report on the outcomes "Neurology Recall: Cohort 2 Activity and Outcomes" was published on Tuesday 20th April 2021. A copy of the report can be found at <https://www.health-ni.gov.uk/publications/neurology-recall-activity-and-outcomes-report-active-caseload-cohort-2>

Neurology Patient Recall - Cohort 3

26. The Cohort 3 Recall was announced by Oral Assembly Statement on 20th April 2021. In the context that a significant proportion of the Cohort 2 patients did have an insecure diagnosis, the advice from the reviewing consultants was that it would be appropriate to also review an additional cohort of the consultant neurologist's patients, Cohort 3.
27. Cohort 3 includes; 277 patients who were discharged between 1996 –2012 and met certain criteria, alongside a number of patients that had not been reviewed as a 'young stroke' patient in the previous recall cohort, due to the a change to the agreed criteria around age (Category 1). All of the 277 patients identified as being part of category 1 of cohort 3 were invited to attend recall appointments by their respective healthcare provider (209 with Belfast Trust, 59 with Ulster Independent Clinic and 9 with Hillsborough Private Clinic). A further group of 495 patients (Category 4) was also identified by the Trust and Independent Sector Providers (436 with Belfast Trust, 51 with Ulster Independent Clinic and 8 with Hillsborough Private Clinic).this group of patients are currently being prescribed 'low risk' anti-platelet medication, for which the Trust and Independent Sector providers required additional information from their GP to establish whether a further consultation is needed.

28. The Belfast Trust has advised that the Cohort 3 patient recall process has now completed and the information relating to the validated reviews was passed to Health and Social Care Board (HSCB) and Public Health Agency (PHA) at the end of August, for compilation into an Outcomes Report.
29. The Cohort 3 Outcomes Report is currently in development and is expected to be completed in the coming weeks. The appropriate communication and stakeholder engagement, through the Patient Client Council (PCC), will be arranged to support the publication of the Cohort 3 Outcomes Report. The Assembly, Health Committee and neurology stakeholders will be updated on relevant neurology recall work streams in a suitable and timely fashion.
30. The Belfast Trust has confirmed that all patients who were invited in the neurology recall have now had an appointment with the appropriate consultant. The service arranged expedited pathways for patients who required any investigations or additional appointments. This was to ensure that all patients could be provided with the necessary reassurance regarding their condition and treatment. The Trust has advised that whilst most patients have been discharged from the Trust there are some patients who continue to attend the neurology service. These patients continue to avail of expedited pathways for treatment if this is clinically indicated.
31. The Department has been assured that expedited pathways were arranged for all patient cohorts including fast-track to psychological services at the Trust. The Belfast Trust continues to support those patients affected through the Neurology Advice Helpline (0800 980 1100), which remains available from 9am to 5pm from Monday to Friday each week for anyone who has concerns or has been affected by the neurology recall.

Epidural Blood Patch Review

32. The Belfast Trust had asked the Royal College of Physicians (RCP) to validate a random selection of a third of the 66 patients whose case notes had been reviewed as they had undergone a blood patch procedure under the care of Dr Watt.
33. The 66 patients' were not part of Cohorts 1 or 2 because they had since been reviewed by a different consultant neurologist. Initial findings from the Trust indicated that 46 out of 66 patients had care that was unsatisfactory and fell below the standard expected. Additionally, the review established that, for 45 patients there is no clinical evidence to support that a blood patch procedure was required.
34. The RCP convened a panel of specialist clinical reviewers to provide independent opinion regarding the quality assurance of the Trust Review, looking at a third of these 66 cases. A final copy of the Quality Assurance Report and Clinical Record Review has been shared with the Department. The report indicates there was a high level of concordance between the judgements reached by the RCP Review Team on the 22 cases and the judgements reached by the Trust.
35. The overriding conclusion from the review is that the desktop review of cases undertaken within the Trust was robust and effective. The report makes 12 recommendations to the Trust. The Trust has confirmed acceptance of all 12 recommendations and will take all steps to implement them in the timescales set.

36. The Trust has previously written to the patients, whose case was randomly selected as part of the review by the RCP and is currently in the process of writing to these patients, to provide them with the review outcome, specific to their own individual case. The Trust continues to support those patients affected, like all patients impacted by any aspect of the Recall, they have access to fast-tracked psychological support through the Neurology Advice Line.

Yours sincerely

A handwritten signature in blue ink, appearing to read 'Robin Swann', is positioned above the printed name.

Robin Swann MLA
Minister of Health

