Neurology Recall

Cohort 2 Activity and Outcomes Report

April 2021

Health and Social Care

Contents

Introduction

This report summarises the outpatient, clinical investigation and clinical psychology activity associated with the review of people who had been discharged from the care of an individual consultant neurologist (Dr A), who worked in the Belfast Health and Social Care Trust (BHSCT), the Ulster Independent Clinic (UIC) and Hillsborough Private Clinic (HPC), and who was restricted from clinical practice in July 2017. This group of people is referred to as Cohort 2. It comprises two sub-groups (Cohorts 2a and 2b) described below. Cohort 2 comprised a group of people based on the learning from the review of people in Cohort 1.

A review of people who were identified as being under the active care of the consultant neurologist began on 1 May 2018. This group is referred to as Cohort 1. A report describing the activity and outcomes associated with the recall and review of this group has been published separately.

Cohort 2a consists of people who were discharged by the consultant back to the care of their GPs and who were subsequently re-referred into the neurology service in the BHSCT from primary care. It is limited to those people who were waiting for an appointment on 1 May 2018 and those re-referred into the neurology service from 1 May until 2 October 2018. People re-referred were identified and assessed between those dates.

Cohort 2b consists of people who were identified from HSC information systems as having been under the care of the consultant neurologist between 1 April 2012 and 30 June 2017 who had been discharged back to the care of their GPs (and who had not subsequently been seen by another consultant neurologist), but who were recently prescribed medicines often used for neurological conditions. The first people in Cohort 2b were seen on 2 November 2018 and activity is reported up to 13 October 2019. This period of time will be referred to throughout this report as the 'review period'.

The purpose of the review was to ensure individuals who had been re-referred into the neurology service and those who were identified as still taking specific medicines had a secure diagnosis, or diagnoses (as some people had more than one neurological diagnosis); that a proper management plan is in place and that prescribing is appropriate. Each individual was informed, by the clinician who saw them, about changes to their diagnoses, management plan or treatment during their clinical review process. It was not designed as an assessment or audit of the consultant's practice.

This report was produced by the Regional Neurology Coordination Group at the request of, and in collaboration with, the Permanent Secretary Neurology Regional Assurance Group. The data were provided by BHSCT, UIC and HPC, who are responsible for the quality of the data submitted. The report summarises those data. It does not make any judgement about the care people received; nor does it provide an assessment of any harm caused to individuals.

Part 1. Cohort 2a (re-referred patients)

Description of Cohort 2a

During the review period, 424 people who had been previously discharged by Dr A had been re-referred to the BHSCT by their general practitioners. Most of these individuals were previously under the care of the consultant in the BHSCT, but a minority were previously seen in the independent sector.

The mean age of the 424 individuals was 53.5 years (standard deviation 16.2 years) (Figure 1).

There were 268 females (63 %) and 156 males (37 %). The largest percentage of people was from the Belfast Local Commissioning Group (LCG) Area (Table 1).

Figure 1. Histogram of age distribution for people in Cohort 2a

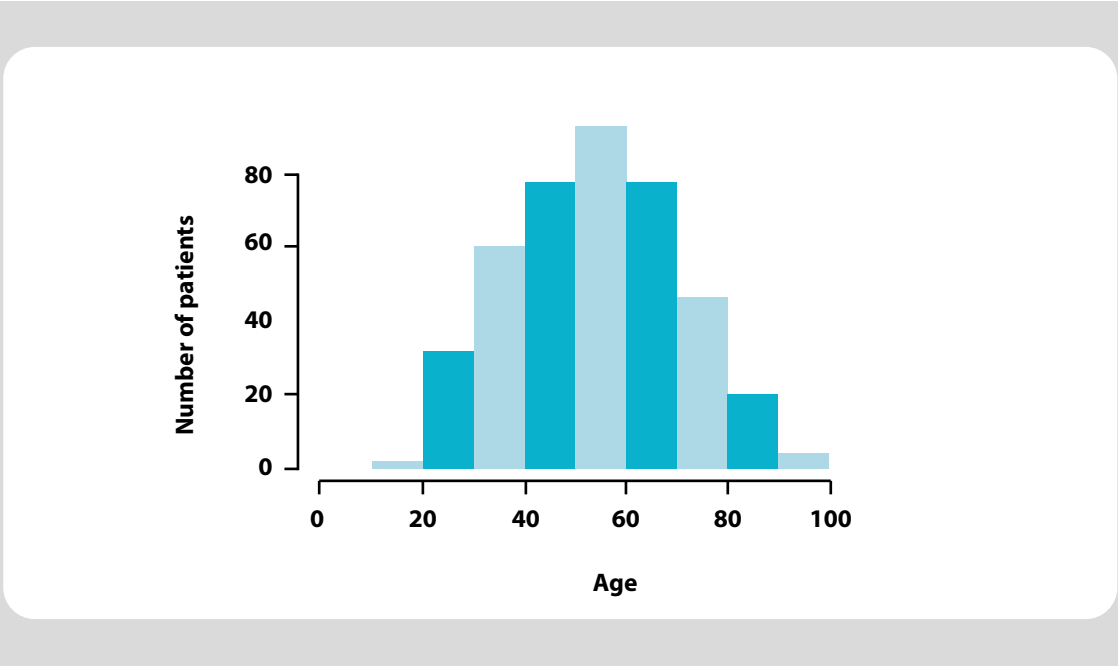

Table 1. Cohort 2a by Local Commissioning Group area of residence

LCG	Percent %
Belfast	55
Northern	23
South Eastern	17
Southern	5
Western	1

Cohort 2a activity

Of the 424 people who were re-referred, 344 were reviewed during the review period.

There was a variety of reasons why 80 people had not been reviewed by this date. Some people (22) did not attend on two occasions and were discharged. 43 had alternative arrangements made for review, such as review in their local Trust (if it was not BHSCT) or in the independent sector. The remaining 15 people declined an appointment or died before they could attend an appointment. The number of people who died (≤5) or declined is combined here to avoid disclosing small numbers that could reveal information about individual patients.

Of the 344 individuals who were reviewed, 250 (73%) were discharged and 94 (27%) were continuing to receive care. A small number of people (≤5) were known to have died following their review appointment (counted among the discharged group).

The 344 people had attended 537 appointments during the review period.

There were 225 investigations requested on 156 people. The number of investigations not completed because patients declined or did not attend was 21. Of the remaining 204 investigations requested, 203 were completed (Table 2) during the review period.

Table 2. Investigations requested and completed on people in Cohort 2a

Test type	Requested (excluding declined or DNA)	Completed number	Completed %
Neurological	192	191	99
Cardiac, Vascular and Other investigations	12	12	100
Total	**204**	**203**	**100**

The most commonly conducted test was magnetic resonance imaging (MRI) (107), followed by electroencephalogram (EEG) (35), nerve conduction studies (NCS) (34) and computerised tomography (CT) (10). A small number of other investigations were undertaken (17).

To avoid putting extra demand on core clinical investigation services, the majority of tests were conducted in the independent sector. Some specialist tests were conducted by the HSC as they were not available in the independent sector.

Outcomes for Cohort 2a

This section provides an analysis of the outcomes for people in Cohort 2a. The purpose of the recall was to see and assess individuals to ensure they were receiving the care and treatment they required. The recall was not designed or intended to be an audit of Dr A's practice.

During or after review clinic appointments, a paper form **(Appendix 1)** was completed by a consultant neurologist answering questions about each person's care, and these data were added to a database. The form completed by the consultant neurologist asked the following questions:

1. Having reviewed this patient do you consider their existing working diagnosis to be secure?
2. Has the patient had an appropriate plan in place for their neurological condition?
3. After reviewing the patient and the management plan, has the prescribing of all medications been appropriate for their neurological condition?

The possible responses were "Yes", "No" or "Uncertain".

The questions were based on the recommendations of a report by the Royal College of Physicians.

There are a number of limitations in the analysis and caution should be exercised when drawing any conclusions. These data limitations were set out in the Cohort 1 report published in December 2019. These are reproduced in **Appendix 2.**

Individuals who were re-referred to the BHSCT neurology service, having been previously under the care of Dr A, were identified from waiting lists at the time the recall began and others were referred by their GPs during the recall period. In both cases, a number of people were found never to have seen Dr A but had been nominally under the care of Dr A at a Transient Ischaemic Attack clinic. These people had actually received their care from other consultants.

For those who had been under the care of Dr A, some were re-referred to the service for an issue related to their previous care, but for others, re-referral was for a new issue. For a small number of people, it was unclear or unknown whether the re-referral related to the original condition (Table 3).

Table 3. People in Cohort 2a referred for the same condition

Re-referred for the same condition	Number
Yes	250
Never saw Dr A	78
No	11
Unknown	5
Total	**344**

For those who were referred for the same reason, the results of the questionnaires completed by reviewing consultants are shown in Tables 4-7.

All questions were answered for all 250 people who had been previously seen by Dr A and who were reviewed by a consultant neurologist as part of the recall. In response to question one, 191 (76.4%) people were considered by the reviewing neurologist to have a secure diagnosis. In 18 (7.2%) people the reviewing neurologist was uncertain if the diagnosis was secure and in 41 (16.4%) people the diagnosis was considered not to be secure (Table 4).

Table 4. Cohort 2a. Q1. Having reviewed this patient do you consider their existing working diagnosis to be secure?

Response	Number	Percent %
Yes	191	76.4
Uncertain	18	7.2
No	41	16.4
Total	**250**	**100**

In response to question two, 190 (76.0%) of the 250 people were considered by the reviewing neurologist to have a proper management plan in place. In 18 (7.2%) people the reviewing neurologist was uncertain that a proper management plan was in place and in 42 (16.8%) people a proper management plan was not considered to be in place (Table 5).

Table 5. Cohort 2a. Q2. Had the patient has an appropriate plan in place for their neurological condition?

Response	Number	Percent %
Yes	190	76.0
Uncertain	18	7.2
No	42	16.8
Total	**250**	**100**

In response to question three, 190 (76.0%) of 250 people were considered by the reviewing neurologist to have appropriate prescribing. In 18 (7.2%) people, the reviewing neurologist was uncertain that prescribing was appropriate and in 42 (16.8%) people the reviewing neurologist considered that prescribing was not appropriate (Table 6).

Table 6. Cohort 2a. Q3. After reviewing the patient and the management plan, has the prescribing of all medications been appropriate for their neurological condition?

Response	Number	Percent %
Yes	190	76.0
Uncertain	18	7.2
No	42	16.8
Total	**250**	**100**

Change in diagnosis

The reviewing neurologists recorded, for each person, if any neurological diagnosis had changed following the review appointment or subsequent diagnostic tests. The responses to any change in diagnosis were recorded as: change in diagnosis; uncertain if change in diagnosis and no change in diagnosis (table 7).

Of the 191 people whose diagnosis was considered secure, none had a change in diagnosis.

Of the 41 people whose diagnosis was considered not secure, all had a change in diagnosis.

Of the 18 people for whom the security of diagnosis was considered to be uncertain at the time of their review (recall) appointment, the diagnosis after the review remained uncertain. These individuals continued to have uncertainty regarding the security of their diagnosis and many were still receiving investigations or care.

Table 7. Cohort 2a. Was there a change in diagnosis?

Response	Number	Percent %
Yes	41	16
Uncertain	18	7
No	191	76
Total	**250**	**100**

Part 2 Cohort 2b (Recalled Patients)

Description of Cohort 2b

Cohort 2b consists of people who:

- attended an outpatient clinic with Dr A, between 1 April 2012 and 30 June 2017, and were discharged back to the care of their GPs;
- had not subsequently been seen by another consultant neurological; and
- were prescribed specific medicines often used for neurological conditions between 1 January 2018 and 30 June 2018.

Advice from the consultant neurologists involved in the review of Cohort 1 informed this approach, which was focused on prioritising people who might be at risk of harm due to the medications they were prescribed. The list of specified medicines was agreed by the neurologists in the Belfast HSC Trust. A summary of the types of medicines identified and the number of people prescribed these medicines between 1 January and 30 June 2018 is shown in table 8. This risk-based approach was supported by the Royal College of Physicians, London and the Department of Health. A break down of the outcome data by risk group category is not provided in this report due to the small numbers this produces across most of the categories which might risk disclosing information about individual people.

Table 8. Inclusion criteria for Cohort 2b

Risk Group	Description	BHSCT	UIC	HPC	Total
1	Females born on/after 1/1/63 prescribed valproate	≤5	≤5	≤5	≤5
2	Females born on/after 1/1/63 prescribed other epilepsy medicines	120	75	7	202
3	Others prescribed epilepsy medicines	498	189	29	716
4a	Antiplatelets / Anticoagulants	52	23	≤5	76
4b	Cannabinoids/Opioids	14	≤5	≤5	18
4c	Immunotherapy	11	9	≤5	25
4d	Disease Modifying Therapies	≤5	≤5	≤5	≤5
	Total	**700**	**300**	**44**	**1044**

People who met the criteria for the recall were identified using hospital administrative records linked to primary care prescribing (dispensing) records. Linkage was conducted by the Business Services Organisation data warehouse information professionals on the basis of criteria specified by the Regional Neurology Coordinating Group in collaboration with clinical neurologists involved in the recall of Cohort 1 patients. Through this process, 1,044 people were identified as eligible for review in Cohort 2b. Two thirds of the people had been under the care of BHSCT and were invited for review in BHSCT. A small number of people had originally been cared for by Dr A through Orthoderm, an independent sector provider, as part of waiting list initiative clinics conducted on behalf of Health and Social Care Trusts. These people were invited for review in BHSCT. Three hundred people who had been seen by the Dr A at the Ulster Independent Clinic were invited for review in BHSCT under a contractual arrangement between the two organisations. Hillsborough Private Clinic invited 44 patients for review. Investigations for these individuals were carried out by BHSCT.

Health and Social Care Trusts

For the purposes of analysis, the 17 people who were seen at clinics run by Orthoderm were included with the 683 people who were originally under the care of BHSCT in a single Health and Social Care Trusts (HSCTs) category of 700 people. This group had a mean age of 61 years (standard deviation 16.2 years) (Figure 2). There were 400 females (57%) and 300 males (43%). The largest percentage of people was from the Belfast Local Commissioning Group (LCG) area (Table 9).

Figure 2. Histogram of age distribution for people in HSC Cohort 2b

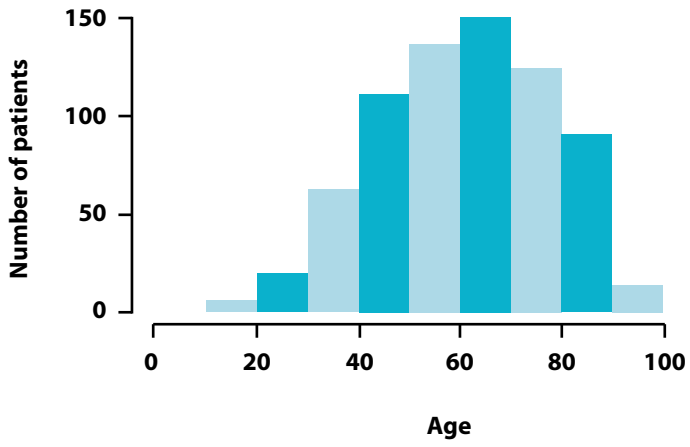

Table 9. HSC Cohort 2b by LCG area of residence

Local Commissioning Group Area	Percent (%)
Belfast	46
Northern	25
South Eastern	19
Southern	7
Western	3

Ulster Independent Clinic

The 300 people from UIC had a mean age of 58 years (standard deviation 17.4 years) (Figure 3). There were 183 females (61%) and 117 males (39%). The largest percentage of people were from the Northern and South Eastern Local Commissioning Group (LCG) areas (Table 10).

Figure 3. Histogram of age distribution for people in UIC Cohort 2b

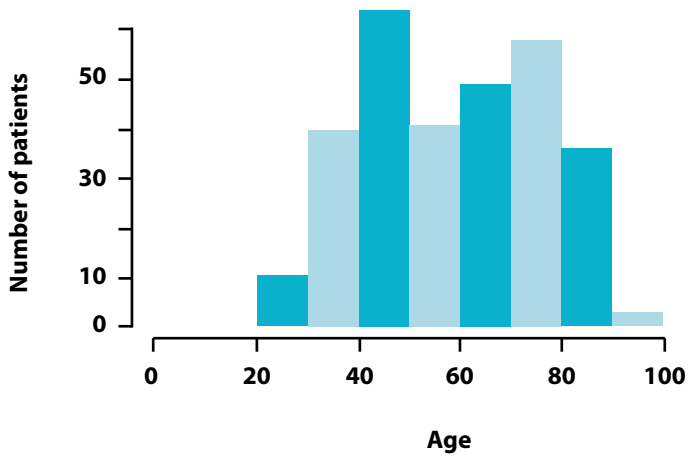

Table 10. UIC Cohort 2b by LCG area of residence

Local Commissioning Group Area	Percent (%)
Belfast	19
Northern	30
South Eastern	30
Southern	11
Western	9

Hillsborough Private Clinic

The 44 people from HPC had a mean age of 61.7 years (standard deviation 18.0 years). There were 28 females (63.6%) and 16 males (36.4%). The largest percentage of people was from the South Eastern LCG (46%), followed by the Southern LCG (41%). The percentages across the other three LCG areas were very small and are not shown.

Recall Activity

Health and Social Care Trusts

Of the 700 people eligible for review, 523 had been reviewed during the review period and 177 had not been reviewed (Table 11). Fifty-three of the 523 people reviewed were found never to have seen Dr A but had seen a different consultant at a shared Transient Ischaemic Attack clinic that was operated under an administrative code for Dr A. A small number (65) of those who did not attend a recall were also noted to have never seen Dr A.

Table 11. Attendance status for people in HSC Cohort 2b

Attendance Status	Number	Percent (%)
Attended	523	75
Declined	111	16
Did not attend, no further appointment*	43	6
Not Contactable	10	1
Died Before Review	8	1
Alternative Arrangements	5	1
Total	**700**	**100**

* Those who did not attend were offered appointments on two occasions.

Most of those who were not reviewed declined appointments, did not attend appointments or made alternative arrangements. Some people (8) died before review and 10 people were not contactable.

The 523 who were reviewed had 668 appointments during the review period.

There were 189 investigations requested for 133 individuals (Table 12). Of these, 165 were completed during the review period (87%).

Table 12. Investigations requested and completed on people in HSC Cohort 2b during the review period

TestType	Completed	Requested	Percent Complete
Neurological	151	175	86
Vascular	14	14	100
Total	**165**	**189**	**87**

Of those seen, 80% were discharged during the review period (Table 13).

Table 13. Discharge status of people in HSC Cohort 2b during the review period

Discharged	Number	Percent %
Yes	416	80
No	66	13
Not Yet Recorded	41	8
Total	**523**	**100**

Ulster Independent Clinic

Of the 300 people eligible for review, 193 had been reviewed during the review period and 107 had not been reviewed (Table 14).

Table 14. Attendance status for people in UIC Cohort 2b

Attendance Status	Number	Percent (%)
Attended	193	64
Declined	86	29
Did not attend, no further appointment	9	3
Alternative Arrangements	8	3
Died Before Review	≤5	1
Not Contactable	≤5	1
Total	**300**	**100**

Most of those who were not reviewed declined appointments, did not attend appointments or made alternative arrangements. Some people (five or fewer) died before review and five or fewer people were not contactable.

The 193 who were reviewed had 281 appointments during the review period.

There were 127 investigations requested for 79 patients (Table 15). Of these, 125 were completed during the review period (98%).

Table 15. Investigations requested and completed on people in UIC Cohort 2b during the review period

TestType	Completed	Requested	Percent Complete
Neurological	118	119	99
Vascular	7	8	88
Total	**125**	**127**	**98**

Of those seen, 66% were discharged during the review period (Table 16).

Table 16. Discharge status of people in UIC Cohort 2b during the review period

Discharged	Number	Percent %
Yes	128	66
No	36	19
Not Yet Recorded	29	15
Total	**193**	**100**

Hillsborough Private Clinic

Of the 44 people eligible for review, 14 had been reviewed during the review period, 8 declined an appointment and 22 made alternative arrangements (Table 17).

Table 17. Attendance status for people in HPC Cohort 2b

Attendance Status	Number	Percent %
Attended	14	32
Declined	8	18
Alternative Arrangements	22	50
Total	**44**	**100**

A small number of people required investigations which have been completed.

Outcomes for Cohort 2b

This section provides an analysis of the outcomes for people in Cohort 2b. The purpose of the recall was to see and assess individuals to ensure they were receiving the care and treatment they required. The recall was not designed or intended to be an audit of Dr A's practice.

During or after review clinic appointments, a paper form **(Appendix 1)** was completed by a consultant neurologist answering questions about each person's care, and these data were added to a database. The form completed by the consultant neurologist asked the following questions:

1. Having reviewed this patient do you consider their existing working diagnosis to be secure?
2. Has the patient had an appropriate plan in place for their neurological condition?
3. After reviewing the patient and the management plan, has the prescribing of all medications been appropriate for their neurological condition?

The possible responses were "Yes", "No" or "Uncertain".

The questions were based on the recommendation of a report by the Royal College of Physicians.

There are a number of limitations in the analysis and caution should be exercised when drawing up any potential conclusions. These data limitations were set out in the Cohort 1 report published in December 2019. These are reproduced in **Appendix 2.**

The outcomes of the questionnaires completed for people in Cohort 2b (HSC, UIC and HPC) are shown in Tables 18-21.

Questionnaires were completed for all of 677 people who were reviewed as part of cohort 2b. Questionnaires were not completed for the 53 people who had seen another consultant other than Dr A at the Transient Ischaemic Attack clinic.

The question about appropriate prescribing was not completed for three people because the reviewing neurologist indicated that the medicines that these people were taking (and which were part of the criteria for inclusion this cohort) were not prescribed or recommended by Dr A, and the question was not relevant.

In response to question one, 511 (75.5%) were considered by the reviewing neurologist to have a secure diagnosis. In 26 (3.8%) people the reviewing neurologist was uncertain if the diagnosis was secure and in 140 (20.7%) people the diagnosis was considered not to be secure (Table 18).

Table 18. Q1. Having reviewed this patient do you consider their existing working diagnosis to be secure?

Response	Number	Percent %
Yes	511	75.5
Uncertain	26	3.8
No	140	20.7
Total	**677**	**100**

In response to question two, 529 (78.1%) of the 677 people were considered by the reviewing neurologist to have a proper management plan in place. In 13 (1.9%) people the reviewing neurologist was uncertain that a proper management plan was in place and in 135 (19.9 %) people a proper management plan was not considered to be in place (Table 19).

Table 19. Q2. Has the patient had an appropriate plan in place for the neurological condition?

Response	Number	Percent %
Yes	529	78.1
Uncertain	13	1.9
No	135	19.9
Total	**677**	**100**

In response to question three, 522 (77.1%) of 674 people who had this question answered were considered by the reviewing neurologist to have appropriate prescribing. In 21 (3.1%) people the reviewing neurologist was uncertain that prescribing was appropriate and in 131 (19.4%) people the reviewing neurologist considered that prescribing was not appropriate (Table 20).

Table 20. CQ3. After reviewing the patient and the management plan, has the prescribing of all medications been appropriate for their neurological condition?

Response	Number	Percent %
Yes	522	77.4
Uncertain	21	3.1
No	131	19.4
Total	**674**	**100**

The reviewing neurologists recorded, for each person, if any neurological diagnosis had changed following the review appointment or subsequent diagnostic tests. The responses to any change in diagnosis was recorded as: change in diagnosis; uncertain if change in diagnosis and no change in diagnosis.

Change in diagnosis

Of the 511 people whose diagnosis was considered secure, none had a change in diagnosis.

Of the 140 people whose diagnosis was considered not secure, 130 had a change in diagnosis.

Of the 26 people for whom the security of diagnosis was considered to be uncertain at the time of their review (recall) appointment, most retained a status of 'uncertain'. These individuals continued to have uncertainty about their diagnosis and many were still undergoing investigations and receiving clinical care.

Table 21. Was there a change in diagnosis?

Response	Number	Percent %
Yes	131	19
Uncertain	28	4
No	518	77
Total	**677**	**100**

Next steps

This report provides a summary of activity and outcomes for those people previously seen by Dr A in the period April 2012 to June 2017 and subsequently discharged to the care of their GPs.

It is recognised that a further cohort of individuals (Cohort 3), comprising those people seen between June 1996 and March 2012 who were discharged to the care of their GPs and who are still receiving specific medicines will need to be further analysed and invited for review.

Appendix 1

Belfast Health and Social Care Trust

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CONSULTATION OUTCOME PROFORMA

Dear Colleague

Please complete the following proforma for each individual patient:

Patient Addressograph Label

Date: _____

Diagnosis: _____

Current medication: _____

1 Having reviewed this patient on (date _____) do you consider their existing working diagnosis to be secure?

Yes ☐ No ☐ Uncertain ☐

Comments: _____

2 Has the patient had an appropriate management plan in place for their neurological condition?

Yes ☐ No ☐ Uncertain ☐

Comments: _____

3 After reviewing the patient and their management plan, has the prescribing of all medications been appropriate for their neurological condition?

Yes ☐ No ☐ Uncertain ☐

Recommendations for further investigations to include prioritisation: _____

_____

Consultation outcome:

Current working diagnosis after consultation: _____

Discharge: Yes / No _____

Requires further investigation (include tests) : Yes / No _____

Requires review (incl suggested timeframe): Yes / No _____

Onward referral (incl. subspecialist or general clinic): _____

Signature _____ PRINT NAME: _____ Date _____

Appendix 2

Limitations of the analysis and results

There are a number of limitations in the analysis and caution should be exercised when drawing up any potential conclusions. Some limitations include:

- The Royal College of Physicians (RCP) did not propose definitions for the responses to the three questions about whether the diagnosis was secure, whether there was a proper management plan and whether prescribing was appropriate. The consultant neurologists, who carried out the review, completed the questions on the basis of their clinical judgement, and not on formally agreed definitions for what constituted a secure diagnosis, an appropriate management plan or appropriate prescribing.
- The reviewing consultant neurologists recorded their responses to the three RCP questions as they related to the clinical presentation, investigations, management plan and prescribing at the time of the recall review, not at the time that they were previously seen at a clinic by Dr A. They considered a diagnosis to be secure if, at the time of review, he or she agreed with the diagnosis applicable when the person was last seen by Dr A.
- The questions posed by the RCP were asked for each individual, not for each person's individual diagnoses, symptoms or treatments if these were multiple.
- If an individual had more than one neurological diagnosis then 'diagnosis secure' meant that all neurological diagnoses were agreed and remained unchanged.
- If an individual with more than one diagnosis was recorded as 'diagnosis not secure' or 'diagnosis security uncertain' this meant that at least one diagnosis was not secure or the security of at least one diagnosis was uncertain.
- Information about responses to the RCP questions or diagnostic change is presented only for people who attended for review. Information about people who were not reviewed (because they died, declined an appointment, did not attend or made alternative arrangements) is not included.
- BHSCT validated its own information for this report. Analysis of the HSC data was undertaken by PHA staff using an anonymised dataset.
- UIC and HPC provided summary information about the data that they held, and undertook their own validation processes.