

Neurology Recall

Activity and Interim Outcomes Report for the Active Caseload (Cohort 1)

19 December 2019

Contents

| | |
|--|----|
| Introduction | 3 |
| Section 1. Activity | 5 |
| Numbers of people recalled by each organisation | 5 |
| Belfast Health and Social Care Trust | 5 |
| Other Health and Social Care Trusts | 6 |
| Ulster Independent Clinic | 6 |
| Hillsborough Private Clinic | 6 |
| Cohort 1 description | 7 |
| Belfast Health and Social Care Trust | 7 |
| Ulster Independent Clinic | 8 |
| Recall activity | 9 |
| Belfast Health and Social Care Trust | 9 |
| Ulster Independent Clinic | 12 |
| Core neurology activity in BHSCT | 14 |
| Section 2. Outcomes | 15 |
| Method for data collection and validation | 15 |
| Belfast Health and Social Care Trust | 15 |
| Ulster Independent Clinic | 15 |
| Hillsborough Private Clinic | 16 |
| Limitations of the analysis and results | 17 |
| Analysis of outcomes | 18 |
| Introduction | 18 |
| Completeness | 19 |
| Questionnaire responses | 19 |
| Change in diagnosis | 21 |
| Next steps | 22 |
| Appendix 1. Summary of BHSCT Cohort 1 activity | 23 |
| Appendix 2. Investigations BHSCT | 24 |
| Appendix 3. Data Collection Form | 25 |
| Appendix 4. Outcomes for BHSCT and UIC separately | 26 |

Introduction

This report summarises information about the recall of people who were identified as being under the active care of an individual consultant neurologist working in the Belfast Health and Social Care Trust (BHSCT), who was restricted from clinical practice in July 2017. In this report the consultant is referred to as Dr A.

The purpose of the recall was to assess people to ensure they were receiving the care and treatment they required. It was not an assessment or audit of the consultant's practice.

The recall included people who were attending Health and Social Care (HSC) outpatient clinics and people who were attending clinics in the independent sector; at the Ulster Independent Clinic (UIC) and Hillsborough Private Clinic (HPC)¹. This group is referred to as Cohort 1.

Cohort 1 comprises two groups of people – the first was a group of people who were invited to be reviewed by another consultant neurologist (ie were recalled) and the second was a group of people that had already been seen by another neurologist before the recall began (ie were already reviewed).

This report is split into two main sections. The first section details the outpatient attendance, clinical investigation and clinical psychology activity associated with individuals in Cohort 1 who were recalled. It does not detail the activity for the group who were already reviewed before the recall commenced.

The second section summarises the outcomes for people in Cohort 1 (for both the recalled and already reviewed groups of people). It provides a summary of the assessments of the care received by individuals in Cohort 1 made by the reviewing consultant neurologists. Specifically it provides information on their answers to the following three questions:

1. Having reviewed this patient do you consider their diagnosis to be secure?
2. Do you think that the proper management plan is in place?
3. Do you think that prescribing is appropriate?

The above questions were based on the recommendation of a report by the Royal College of Physicians, which stated:

¹ For people attending HSC clinics, those who were still on the active outpatient list going back to 8 April 2010 were included. For people attending independent sector clinics, those who were identified as still under review going back to 1 June 2016 were included.

The Trust should risk stratify the remainder of Dr A's outpatients and systematically ensure their review. The review should consider whether the diagnosis is secure; that a proper management plan is in place; and that prescribing is appropriate.

The focus of the review was to ensure individuals 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.

The recall of individuals in Cohort 1 began on 1 May 2018 and people in the recall group were invited for review within 12 weeks of that date.

This report was produced by the Regional Neurology Coordination Group at the request of, and in collaboration with, the Department of Health's 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.

A further group of people was recalled at a later date (referred to as Cohort 2). Information about people in Cohort 2 is not included in this report. Cohort 2 includes people who were discharged by Dr A back to the care of their GPs and who were still being treated with specific medicines often used for neurology conditions. In addition, a number of people previously discharged by the consultant, and who were re-referred into the neurology service by their GP, are also included in Cohort 2. An activity report relating to Cohort 2 will be published at a later date.

The Regulation and Quality Improvement Authority (RQIA) will be conducting a clinical case notes review of people who attended Dr A and who have died.

Section 1. Activity

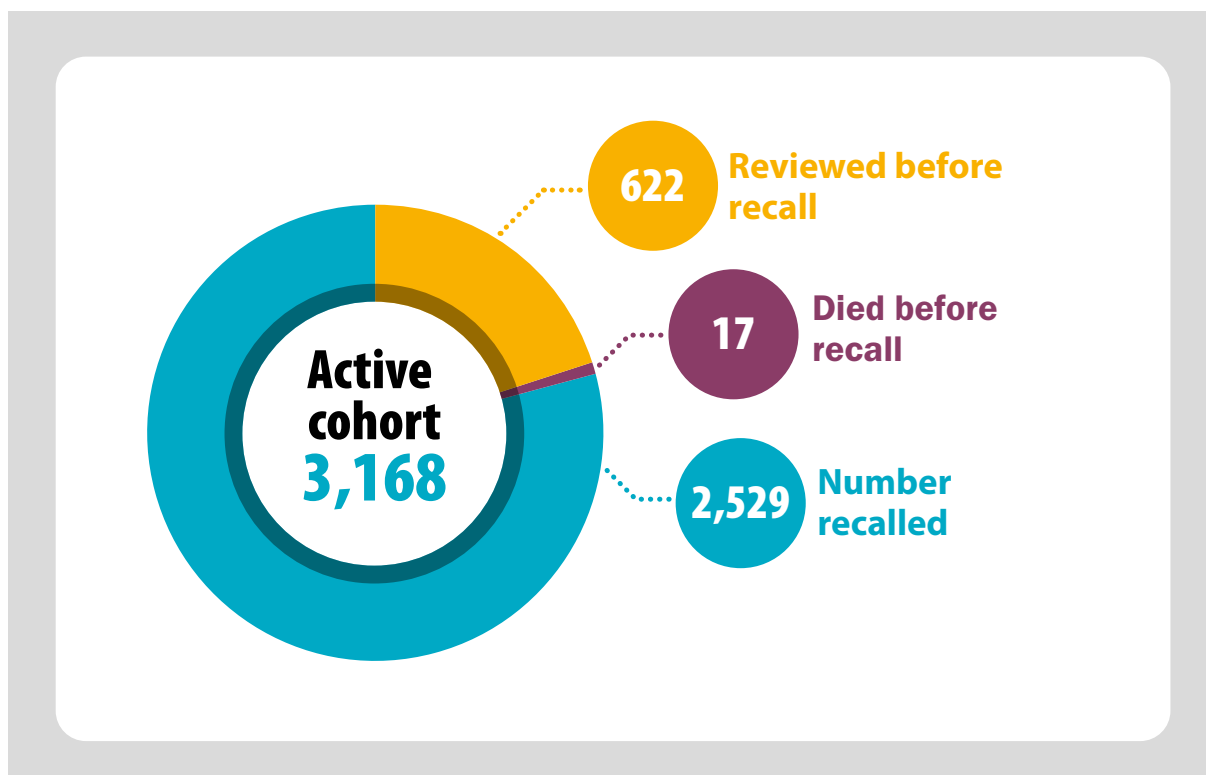
This section provides an update to the *Interim activity report for active caseload (Cohort 1)* which was published on 20 February 2019.

Numbers of patients recalled by each organisation

Belfast Health and Social Care Trust

There were 3,168 BHSCCT patients identified as being under the active care of the consultant at the time the recall commenced on 1 May 2018 (Figure 1). Of these, 622 had already been reviewed by another consultant neurologist and 17 were known to have died before the recall began. The remaining 2,529 patients were recalled (invited for review).

Figure 1. Recall status on 1 May 2018 for BHSCCT active Cohort 1



Other Health and Social Care Trusts

No individuals were identified as being under the active care of Dr A in other Health and Social Care Trusts at the time of the recall.

Ulster Independent Clinic

There were 110 people identified as being under the active care of Dr A at the UIC and all were invited for review.

Hillsborough Private Clinic

There were a very small number of people (≤ 5) identified as being under the active care of Dr A at the HPC at the time of the recall and they were invited for review. They are not included in any of the activity figures in this section; nor are they included in the outcome figures in section 2 of this report. This is due to the risk of disclosure of personal information about them.

Cohort 1 Description

Belfast Health and Social Care Trust

The mean age of the 3,168 people in the active cohort was 52.9 years (standard deviation 15.9 years; Figure 2). There were 2,006 females (63%) and 1,162 males (37%). The largest percentage of people was from the Belfast Local Commissioning Group (LCG) Area (Table 1).

Figure 2. Histogram of age distribution for BHSCT Cohort 1

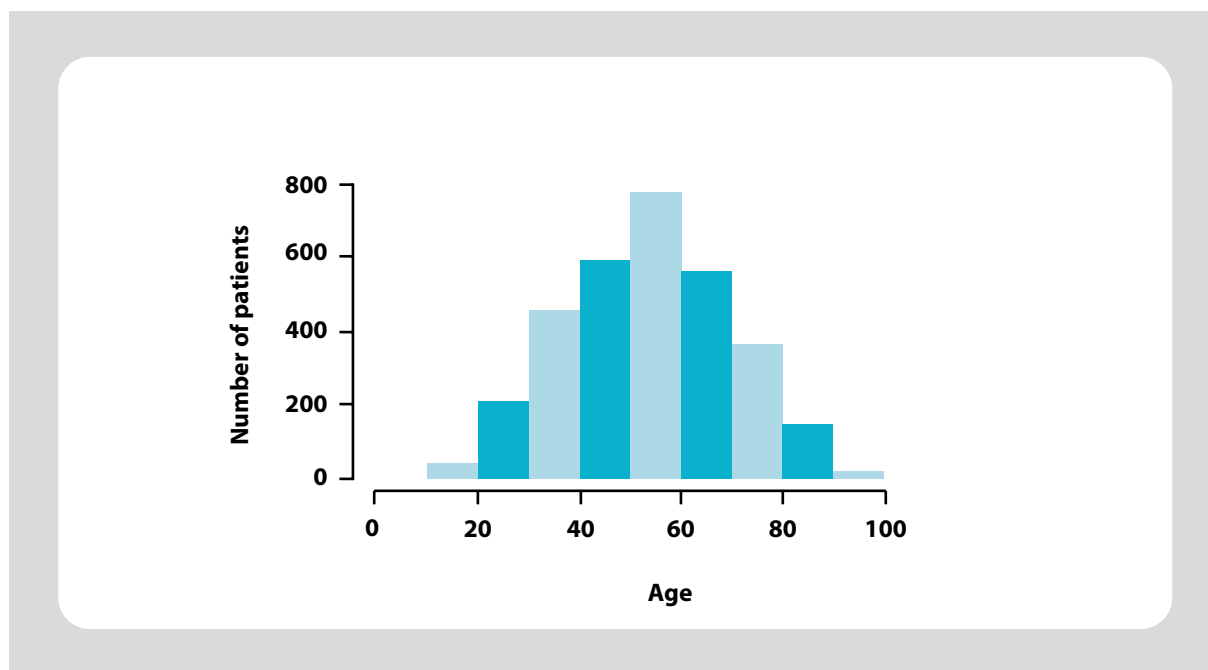


Table 1. BHSCT Cohort 1 by LCG area of residence

| Local Commissioning Group Area | Percent (%) |
|--------------------------------|-------------|
| Belfast | 36 |
| Northern | 26 |
| South Eastern | 23 |
| Southern | 9 |
| Western | 5 |
| Outside Northern Ireland | <1 |

Ulster Independent Clinic

There were 110 people identified as being under the active care of Dr A at the UIC at the time of the recall. The age distribution of patients at UIC was older than the BHSCT patients (Figure 3). There were 65 females (59%) and 45 males (41%). UIC patients were more commonly from the South Eastern area, with a smaller proportion from the Belfast area, compared to the BHSCT cohort (Table 2).

Figure 3. Histogram of age distribution for UIC Cohort 1

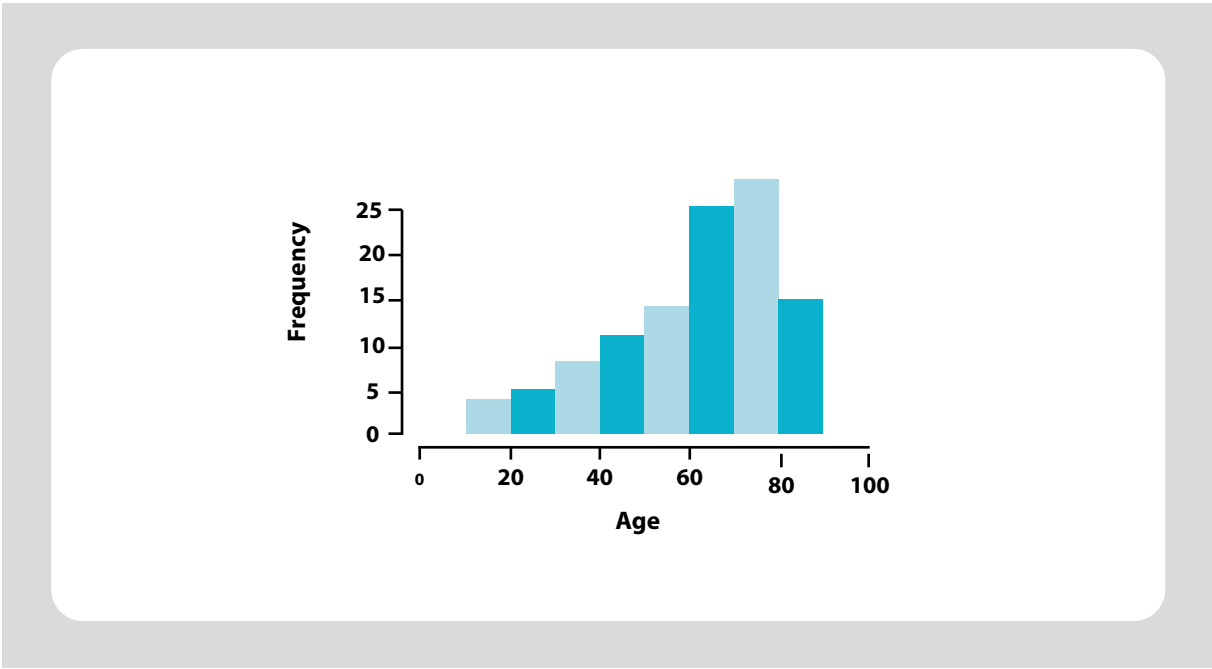


Table 2. UIC Cohort 1 (including those declining or not attending an appointment) by LCG area of residence

| Local Commissioning Group Area | Percent (%)* |
|--------------------------------|--------------|
| South Eastern | 34 |
| Northern | 23 |
| Belfast | 19 |
| Southern | 13 |
| Western | 6 |
| Outside Northern Ireland | 6 |

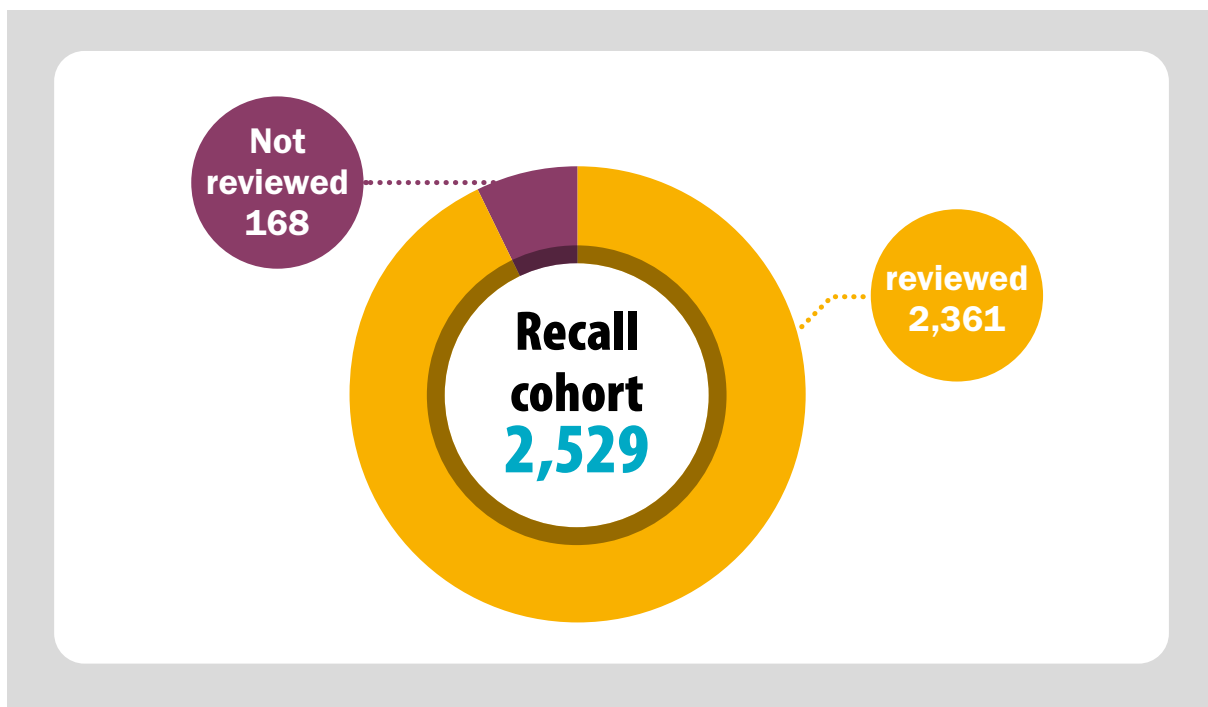
* Does not add up to 100% due to rounding.

Recall activity

Belfast Health and Social Care Trust

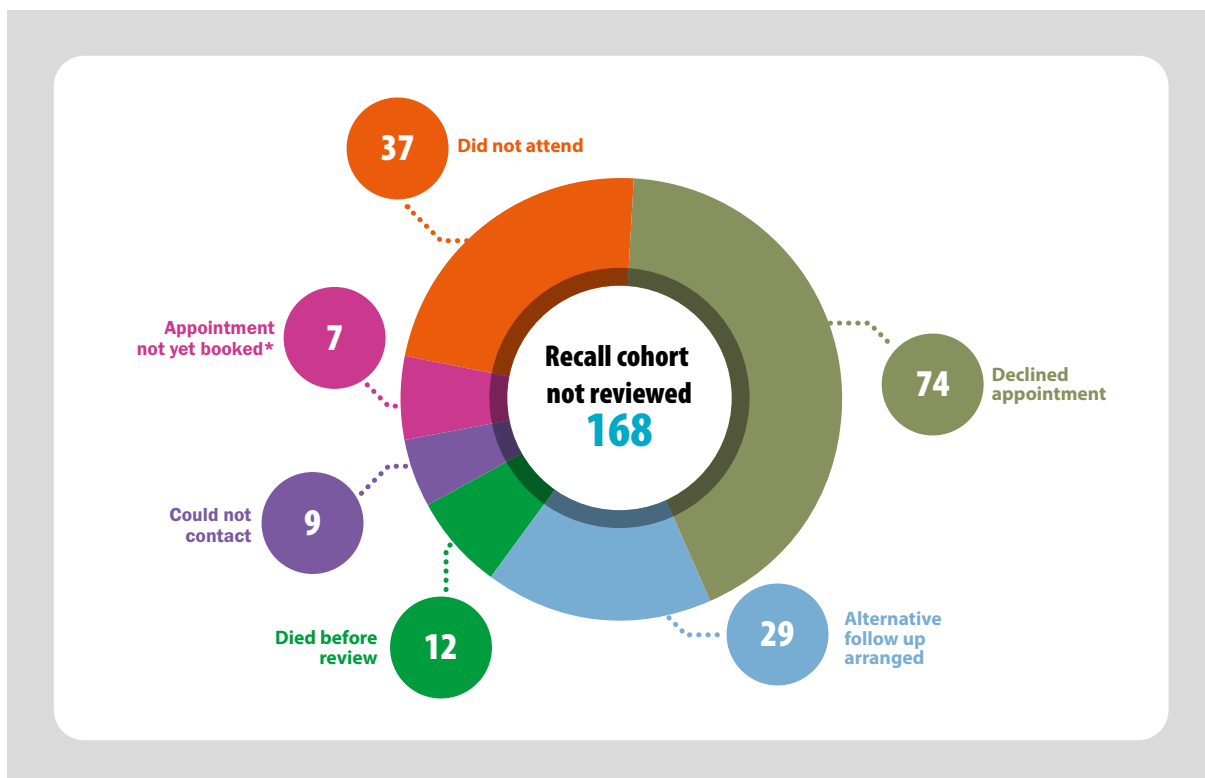
Each person in the recall cohort (2,529) was assigned a status (eg *appointment not yet booked; did not attend; reviewed at least once*) for case management and reporting purposes. Information is presented for activity up to the end of 30 April 2019, using data entered up to and including 7 May 2019.

Figure 4: Breakdown of the total number of people invited to attend a review appointment



At the end of April 2019, 168 of the original 2,529 people invited for review had not been reviewed for a variety of reasons, including declining an appointment or not attending an appointment. A breakdown of these is provided (Figure 5).

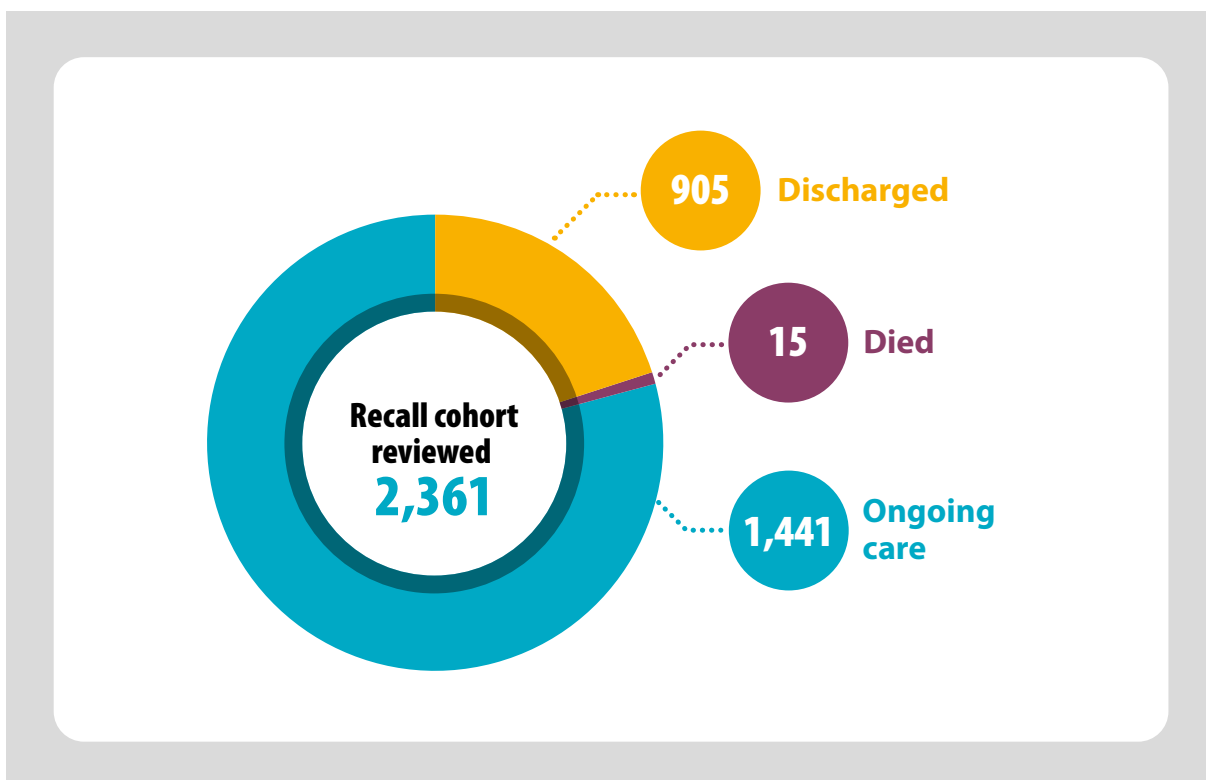
Figure 5: Breakdown of the number of people invited to attend a review appointment who were not reviewed



* These are people whose details were correct but failed to make contact for an appointment or people who were out of the country at the time of recall and are to make contact again on their return.

Of the 2,361 people who were reviewed, 905 were discharged (38.3%) and 1,441 were currently receiving ongoing care (1,343 by BHSCT clinicians and 98 were transferred or referred to clinicians in other Trusts). Fifteen people were known to have died between their review appointment and 7 May 2019. The activity data associated with people in BHSCT Cohort 1 are summarised in **Appendix 1**.

Figure 6: Categorisation of the BHSCT recall cohort 30 April 2019



Many people who attended the review had more than one appointment. The 2,361 who attended at least one recall appointment were recorded as having attended 4,170 appointments.

There were 1,882 investigations recorded as having been requested on 1,202 individuals by 30 April 2019. Of those investigations, 82 were not conducted because people declined or did not attend the investigation appointment and 1,766 (98% of the remainder) were recorded as complete by 10 May 2019 (Table 3).

Table 3. Investigations requested and completed on BHSCT patients by 10 May 2019

| Test type | Requested (excluding declined or DNA) | Completed number | Completed % |
|-----------------------------|---------------------------------------|------------------|-------------|
| Neurological investigations | 1,625 | 1,598 | 98 |
| Cardiac investigations | 103 | 102 | 99 |
| Vascular investigations | 19 | 18 | 95 |
| Other investigations | 53 | 48 | 91 |
| Total | 1,800 | 1,766 | 98 |

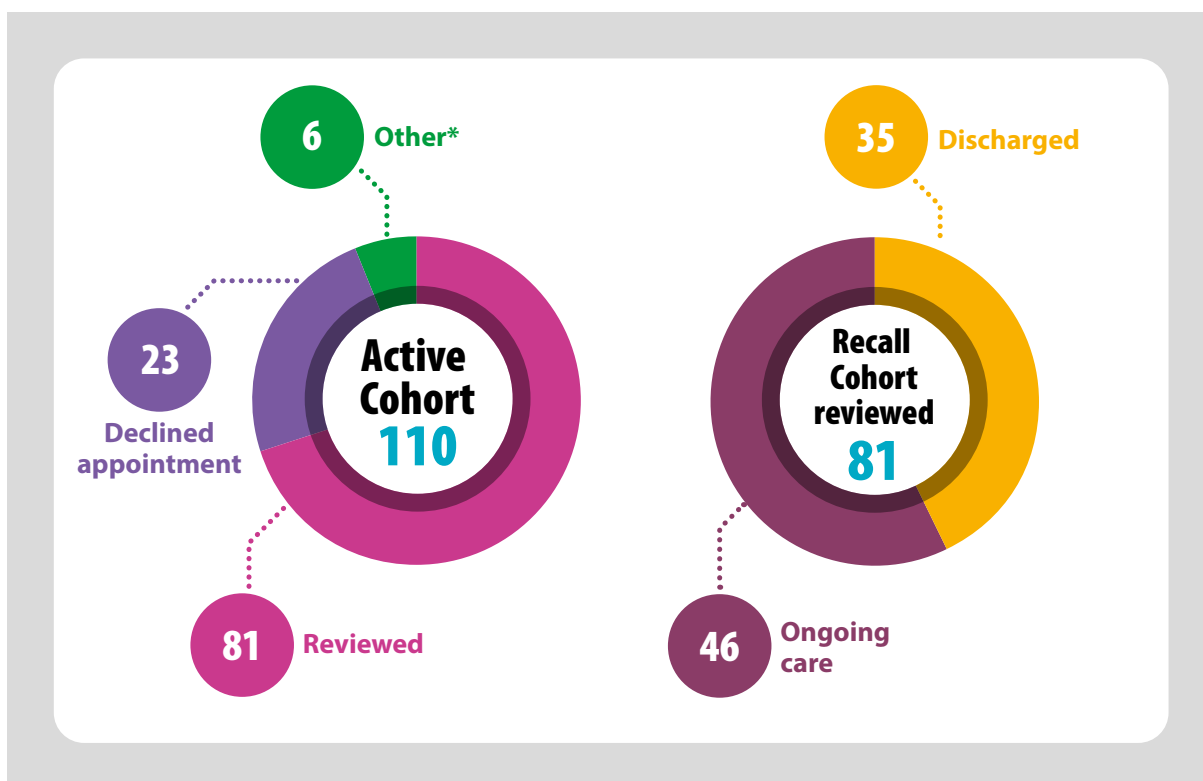
A more detailed breakdown by test name is shown in **Appendix 2**. To avoid additional demand on investigation services, most investigations were conducted in the independent sector, although a small number of specialist investigations were only available as part of HSC services.

By 12 June 2019, 223 people from Cohort 1 had been cared for by the BHSCT clinical psychology service as part of the recall.

Ulster Independent Clinic

Of the 110 people recalled by the UIC, 81 were reviewed and 29 were not reviewed for a variety of reasons described in figure 7. Of the 81 who were reviewed 43% (35) were discharged.

Figure 7. Breakdown of the active cohort and categorisation of the recall cohort of people in UIC Cohort 1 on 30 April 2019



* Other category includes: people with an alternative follow-up, people who could not attend, people who died after the recall commenced and people still to be reviewed – individual counts of people are not shown due to the risk of disclosure associated with a small cell count in one cell.

Twenty nine percent of the people reviewed had at least one clinical investigation requested. There were 28 investigations recorded as having been requested on 24 individuals by 10 May 2019. A breakdown of the investigations is shown in Table 4.

Table 4: Investigations requested and completed on people in UIC Cohort 1 by 10 May 2019

| Test type | Test name | Requested (excluding declined or DNA) | Completed % |
|-----------------------------|---------------------|---------------------------------------|-------------|
| Neurological investigations | MRI | 17 | 100 |
| | Other neurological* | 11 | 100 |
| Total | | 28 | 100 |

* Magnetic Resonance Imaging; Electroencephalography; DaTscan; Nerve Conduction Studies; Electromyography.

Core neurology activity in BHSCT

The recall clinics for Cohort 1 were additional to the core neurology outpatient clinics. The BHSCT is contracted to deliver 13,781 neurology outpatient appointments per year. Over the one year period from 1 May 2018 until the 30 April 2019 it delivered 14,457 clinics thus maintaining the core contracted activity.

Section 2. Outcomes

This section provides an analysis of the outcomes for people in Cohort 1 who attended a review appointment as part of the recall exercise (people recalled) or who had already been seen by another consultant neurologist before the recall started (already reviewed). It is important to emphasise that 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.

Method for data collection and validation

Belfast Health and Social Care Trust

Data about the cohort eligible for review, and their investigations and appointments, were managed in a database held by BHSCT.

During or after review clinic appointments, a paper form (**Appendix 3**) was completed by a consultant neurologist answering questions about each person's care, and these data were added to the database. The form completed by the consultant neurologist asked the following questions.

1. Having reviewed this patient do you consider their diagnosis to be secure?
2. Do you think that the proper management plan is in place?
3. Do you think that prescribing is appropriate?

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

In April 2019, BHSCT neurology staff reviewed all records in the database. They checked that all information about appointments and investigations was recorded, that there was a valid discharge or follow-up decision recorded, that consultants' forms had been correctly transcribed, and that the correct people had been recorded as having died, declined or not attended.

Ulster Independent Clinic

Data about the people eligible for review was managed in a database held by UIC. During or after clinic appointments, the form at **Appendix 3** was completed by a consultant neurologist answering the three questions about each person's care.

Hillsborough Private Clinic

During or after review clinic appointments, a paper form (**Appendix 3**) was completed by a consultant neurologist. The responses to the three questions were tallied and recorded. Everyone in this cohort had a valid discharge or follow up decision recorded.

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.

Analysis of outcomes

Introduction

Information about the outcomes of people seen by Dr A is shown for BHSCT and UIC combined (a breakdown by provider organisation is shown in **Appendix 4**). Information about people who had attended HPC is not included because of the risk of disclosure from small numbers.

The analysis of outcomes is limited to those who attended a review appointment as part of the recall in BHSCT (2,361 people who were recalled) or who had already been seen by another neurologist before the recall began (622 people already reviewed), and the 81 people who attended a review appointment at UIC. Therefore the total number included in the analysis is 3,064. Questionnaires were completed for 2,952 people in regard to question 1, 'Having reviewed this patient do you consider their diagnosis to be secure?', and question 2, 'Do you think that the proper management plan is in place?'. Questionnaires were completed for 2,911 people in regard to question 3, 'Do you think that prescribing is appropriate?' (Table 5). No assessment for the three 'outcome' questions was made for a small number of people (112), the majority of whom had been identified for inclusion in the recall as a result of his/her attendance at a stroke and transient ischaemic attack (TIA) clinic, but who had been cared for by a different doctor, and were not deemed to be under the care of Dr A.

Some people who were not on any medicines for a neurological or thromboembolic condition had a 'Not Applicable' response to the prescribing question.

Completeness

Table 5. Completeness of questionnaire responses

| Question | Complete | Not Applicable | Total |
|--------------------|----------|----------------|-------|
| 1. Diagnosis | 2952 | 112 | 3064 |
| 2. Management Plan | 2952 | 112 | 3064 |
| 3. Prescribing | 2911 | 153 | 3064 |

In addition to data on the responses to the three questions, the reviewing consultant neurologist was asked to indicate whether there had been a change in diagnosis.

There are a number of reasons why the diagnosis may have changed. These include: that the original diagnosis was incorrect; or the person's clinical presentation changed over time and the clinical assessment at review indicated a different diagnosis.

Questionnaire responses:

In response to question one, 2,006 (68.0%) of the 2,952 people who had this question answered were considered by the reviewing neurologist to have a secure diagnosis. In 329 (11.1%) people the reviewing neurologist was uncertain if the diagnosis was secure and in 617 (20.9%) people the diagnosis was considered not to be secure (Table 6).

Table 6. Question 1. Having reviewed this patient do you consider their diagnosis to be secure?

| Diagnosis Secure | Number | % |
|------------------|--------------|------------|
| Yes | 2,006 | 68 |
| Uncertain | 329 | 11.1 |
| No | 617 | 20.9 |
| Total | 2,952 | 100 |

In response to question two, 2,095 (71.0%) of the 2,952 people who had this question answered were considered by the reviewing neurologist to have a proper management plan in place. In 258 (8.7%) people the reviewing neurologist was uncertain that the proper management plan was in place and in 599 (20.3%) people the proper management plan was not considered to be in place (Table 7).

Table 7. Question 2. Do you think that the proper management plan is in place?

| Proper Management Plan | Number | % |
|------------------------|--------------|------------|
| Yes | 2,095 | 71 |
| Uncertain | 258 | 8.7 |
| No | 599 | 20.3 |
| Total | 2,952 | 100 |

In response to question three, 2,034 (69.9%) of the 2,911 people who had this question answered were considered by the reviewing neurologist to have appropriate prescribing. In 332 (11.4%) people the reviewing neurologist was uncertain that prescribing was appropriate and in 545 (18.7%) people the reviewing neurologist considered that prescribing was not appropriate (Table 8).

Table 8. Question 3. Do you think that prescribing is appropriate?

| Prescribing Appropriate | Number | % |
|-------------------------|--------------|------------|
| Yes | 2,034 | 69.9 |
| Uncertain | 332 | 11.4 |
| No | 545 | 18.7 |
| Total | 2,911 | 100 |

These three tables show the responses to the three questions independently.

While the data above in each table should be considered separately, the analysis did explore, for the 2,006 people with a secure diagnosis, how many were also considered to have a proper management plan in place and appropriate prescribing. This indicated that of those with a secure diagnosis, 1,816 (90.5%) were also considered to have a proper management plan in place and appropriate prescribing.

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.

Of the 2,006 people whose diagnosis was considered to be secure, none had a change in diagnosis.

Of the 617 people whose diagnosis was considered not secure, almost all had their diagnosis changed.

Of the 329 people for whom the security of diagnosis was considered to be uncertain after their review (recall) appointment, the diagnosis after the review was either uncertain or unchanged. These individuals continued to have uncertainty regarding the security of their diagnosis and the majority were still receiving investigations or care.

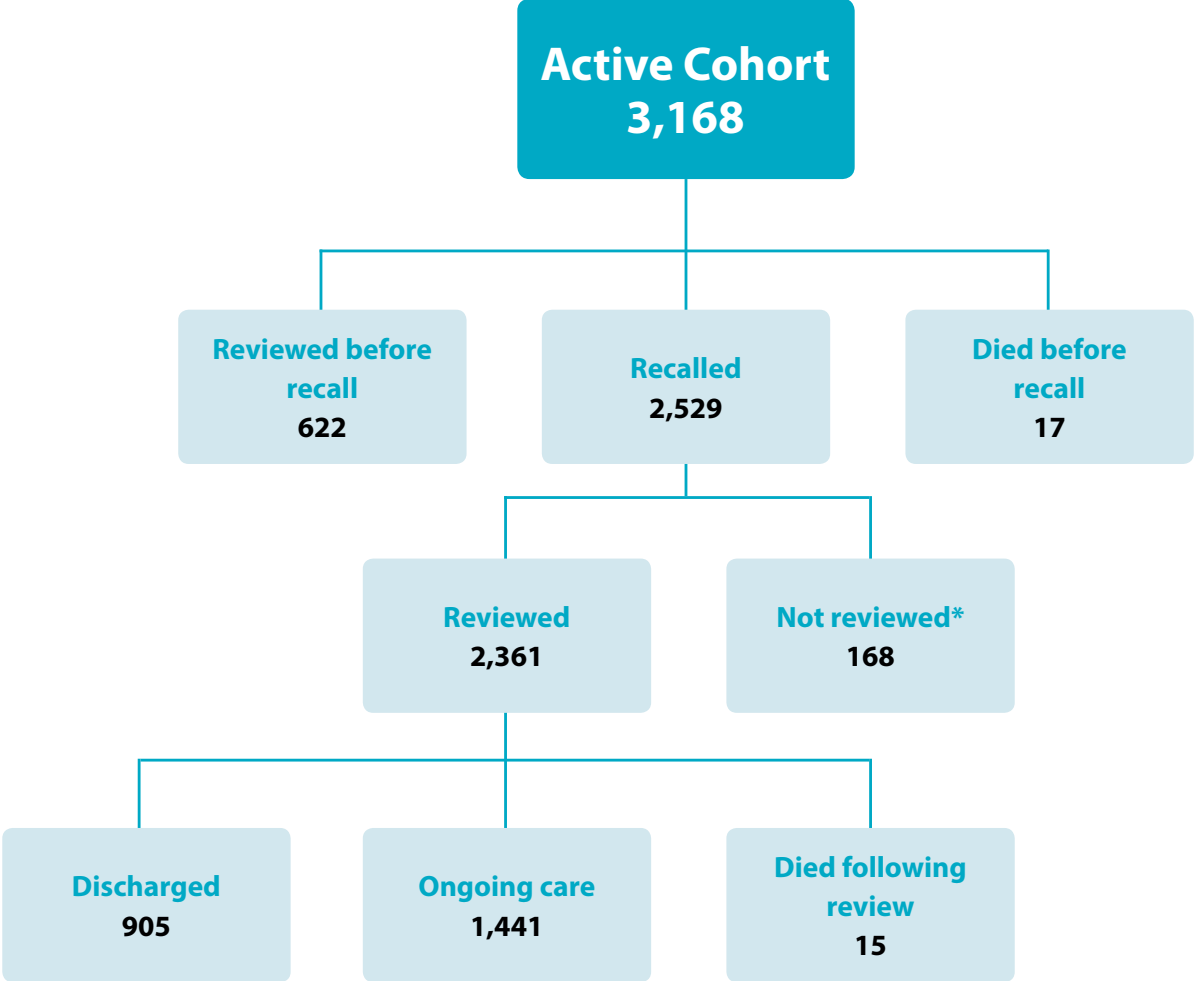
Next steps

This report provides high level outcome data for people who were in Dr A's active caseload (Cohort 1).

For those individuals in Cohort 2, as defined on page 4, a further analysis is currently underway. A report on the outcome data for people who were in Cohort 2 is expected to be published early in 2020, at which time there will be an announcement on whether any further recall is considered necessary.

Appendix 1.

Summary of BHSCT Cohort 1 activity



*Not Reviewed

- Declined appointment 74
- Did not attend 37
- Alternative follow up arrangements 29
- Died before review 12
- Could not contact 9
- Appointment not yet booked 7

Appendix 2.

Investigations BHSCT

| Test type | Test name | Requested (excluding declined or DNA) | Completed % |
|-------------------------------|---------------------------|---|----------------|
| Neurological | CT | 32 | 100 |
| | DAT | 33 | 100 |
| | EEG | 313 | 99.4 |
| | EMG | 55 | 96.4 |
| | LP | 43 | 69.8 |
| | MIBG | 4 | 75 |
| | MRI | 876 | 100 |
| | NCS | 139 | 97.1 |
| | SER | 14 | 92.9 |
| | VEEG | 58 | 94.8 |
| | VER | 58 | 98.3 |
| Neurological Sub-total | | 1625 | 98.3 |
| Cardiac | Ambulatory BP monitoring | 19 | 100 |
| | Ambulatory ECG monitoring | 22 | 100 |
| | ECG | 34 | 97.1 |
| | Echocardiogram | 28 | 100 |
| Cardiac Sub-total | | 103 | 99 |
| Vascular | Carotid | 10 | 100 |
| | US | 9 | 88.9 |
| Vascular Sub-total | | 19 | 94.7 |
| Other | Other | 47 | 89.3 |
| | X-Ray | 6 | 100 |
| Other Sub-total | | 53 | 90.6 |
| Total | | 1800 | 98.1 |

DNA: Did Not Attend; CT: Computerised Tomography; DAT: DaTscan; EEG: Electroencephalography; EMG: Electromyography; LP: Lumbar Puncture; MIBG: iodine-131-metaiodobenzylguanidine scan; MRI: Magnetic Resonance Imaging; NCS: Nerve Conduction Studies; SER: Somatosensory Evoked Response; VEEG: Video Electroencephalography; VER: Visual Evoked Response; Ambulatory BP monitoring: Ambulatory Blood Pressure monitoring; ECG: Electrocardiography; ECHO: Echocardiography; Carotid: Carotid Doppler Ultrasound Scan; US: Ultrasound scan.

Some patients have had more than one investigation.

Appendix 3. Data Collection Form

Dear Colleague

Please complete the following information for each individual patient:

Patient Addressograph Label

Date of appointment

Having reviewed this patient on _____ do you consider their diagnosis to be secure?

Yes No Uncertain

Comments: _____

Do you think that the proper management plan is in place?

Yes No Uncertain

Comments: _____

Do you think that prescribing is appropriate?

Yes No Uncertain

Comments: _____

Any other comments: _____

Signature _____

PRINT NAME: _____

Appendix 4.

Outcomes for BHSCT and UIC separately

Questionnaire responses: BHSCT

Tables 9 to 11 provide a summary of the recorded answers to each of the three RCP questions for people in Cohort 1 reviewed in the Belfast Trust.

In response to question one, 1,965 (68.4%) of the 2,871 people who had this question answered were considered by the reviewing neurologist to have a secure diagnosis. In 304 (10.6%) people the reviewing neurologist was uncertain if the diagnosis was secure and in 602 (21%) people the diagnosis was considered not to be secure (Table 9).

Table 9. Question 1. Having reviewed this patient do you consider their diagnosis to be secure?

| Diagnosis secure | Number | % |
|------------------|--------------|--------------|
| Yes | 1,965 | 68.4 |
| Uncertain | 304 | 10.6 |
| No | 602 | 21.0 |
| Total | 2,871 | 100.0 |

In response to question two, 2,038 (71.0%) of the 2,871 people who had this question answered were considered by the reviewing neurologist to have a proper management plan in place. In 249 (8.7%) people the reviewing neurologist was uncertain that the proper management plan was in place and in 584 (20.3%) people the proper management plan was not considered to be in place (Table 10).

Table 10. Question 2. Do you think that the proper management plan is in place?

| Proper management plan | Number | % |
|------------------------|--------------|--------------|
| Yes | 2,038 | 71.0 |
| Uncertain | 249 | 8.7 |
| No | 584 | 20.3 |
| Total | 2,871 | 100.0 |

In response to question three, 1,981 (70.0%) of the 2,830 people who had this question answered were considered by the reviewing neurologist to have appropriate prescribing.

In 321 (11.3%) people the reviewing neurologist was uncertain that prescribing was appropriate and in 528 (18.7%) people the reviewing neurologist considered that prescribing was not appropriate (Table 11).

Table 11. Question 3. Do you think that prescribing is appropriate?

| Prescribing appropriate | Number | % |
|-------------------------|--------------|--------------|
| Yes | 1,981 | 70.0 |
| Uncertain | 321 | 11.3 |
| No | 528 | 18.7 |
| Total | 2,830 | 100.0 |

These three tables show the responses to the three questions independently.

While the data above in each table should be considered separately, the analysis did explore, for the 1,965 people with a secure diagnosis, how many were also considered to have a proper management plan in place and appropriate prescribing. This indicated that of those with a secure diagnosis, 1,779 (90.5%) were also considered to have a proper management plan in place and appropriate prescribing.

Change in diagnosis: People attending recall in Belfast Health and Social Care Trust

The reviewing neurologists recorded if there was a change to any neurological diagnosis an individual had following review. The responses to any change in diagnosis were recorded as: change in diagnosis; uncertain if change in diagnosis and no change in diagnosis.

Of the 1,965 people whose diagnosis was considered to be secure, none had a change in diagnosis.

Of the 602 people whose diagnosis was considered not secure, almost all had their diagnosis changed.

Of the 304 people for whom the security of diagnosis was considered to be uncertain after their review (recall) appointment, the diagnosis after the review was either uncertain or unchanged. All of these individuals continued to have uncertainty regarding the security of their diagnosis. This analysis was not able to explore this in further detail.

Questionnaire responses: UIC

Tables 12 to 14 provide a summary of the recorded answers to each of the three RCP questions for the people in Cohort 1 reviewed in UIC.

In response to question one, 41 (50.6%) of the 81 people who had this question answered were considered by the reviewing neurologist to have a secure diagnosis. In 25 (30.9%) people the reviewing neurologist was uncertain if the diagnosis was secure and in 15 (18.5%) people the diagnosis was considered not to be secure (Table 12).

Table 12. Question 1. Having reviewed this patient do you consider their diagnosis to be secure?

| Diagnosis secure | Number | % |
|------------------|-----------|------------|
| Yes | 41 | 50.6 |
| Uncertain | 25 | 30.9 |
| No | 15 | 18.5 |
| Total | 81 | 100 |

In response to question two, 57 (70.4%), of the 81 people who had this question answered were considered by the reviewing neurologist to have a proper management plan in place. In 9 (11.1%) people the reviewing neurologist was uncertain that the proper management plan was in place and in 15 (18.5%) people the proper management plan was not considered to be in place (table 13).

Question 13. Do you think that the proper management plan is in place?

| Proper management plan | Number | % |
|------------------------|-----------|------------|
| Yes | 57 | 70.4 |
| Uncertain | 9 | 11.1 |
| No | 15 | 18.5 |
| Total | 81 | 100 |

In response to question three, 53 (65.4%), of the 81 people who had this question answered were considered by the reviewing neurologist to have appropriate prescribing. In 11 (13.6%) people the reviewing neurologist was uncertain that prescribing was appropriate and in 17 (21.0%) people the reviewing neurologist considered that prescribing was not appropriate (Table 14).

Table 14. Question 3. Do you think that prescribing is appropriate?

| Prescribing appropriate | Number | % |
|-------------------------|-----------|------------|
| Yes | 53 | 65.4 |
| Uncertain | 11 | 13.6 |
| No | 17 | 21.0 |
| Total | 81 | 100 |

These three tables show the responses to the three questions independently.

While the data above in each table should be considered separately, the analysis did explore, for the 41 people with a secure diagnosis, how many were also considered to have a proper management plan in place and appropriate prescribing. This indicated that of those with a secure diagnosis, 37 (90.2%) were also considered to have a proper management plan in place and appropriate prescribing.

Change in diagnosis: people attending recall in UIC

The reviewing neurologists recorded if there was a change to any neurological diagnosis an individual had following review. The responses to any change in diagnosis were recorded as: change in diagnosis; uncertain if change in diagnosis and no change in diagnosis.

Of the 41 people whose diagnosis was considered to be secure, none had a change in diagnosis.

Of the 15 people whose diagnosis was considered not secure, all had a change in diagnosis.

Of the 25 people for whom the security of diagnosis was considered to be uncertain after their review (recall) appointment, the diagnosis after the review remained uncertain for all of these individuals. This analysis was not able to explore this in further detail.