

Neurology Recall Cohort 1, 2 and 3 Summary Report

April 2023 (revised)

Background

This paper provides a brief, high level summary of the activity and outcomes of each of the three cohorts of people involved in the neurology recall.

Following receipt of a report from the Royal College of Physicians which related to the work of an individual consultant neurologist (Dr A), who was employed by the Belfast Health and Social Care Trust (BHSCT), a recall of neurology patients was announced on 1 May 2018. This announcement commenced the recall of a first cohort of patients, which was subsequently followed by a further two cohorts. The Permanent Secretary Neurology Regional Assurance Group (PSNRAG), chaired by the Department of Health's (DoH) Permanent Secretary and the Neurology Regional Co-ordination Group (RCG) co-chaired by the Health and Social Care Board (HSCB) Director of Commissioning and the Public Health Agency (PHA) Director of Public Health were established to oversee and report on the activity and outcomes of the recall.

The outpatient and clinical investigation activity associated with the review of people who were patients under the active care of (or had been discharged from the care of) Dr A between June 1996 and May 2018 is summarised in this report. Dr A was appointed to the post of consultant neurologist within the BHSCT in June 1996 and worked in BHSCT, the Ulster Independent Clinic (UIC) and Hillsborough Private Clinic (HPC), before being restricted from clinical practice in July 2017.

The purpose of the recall was to assess patients and former patients of Dr A to ensure they were receiving the care and treatment they required. 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 patient recall process was not designed as an assessment or audit of the consultant's practice.

Each review appointment was supported by a form, completed by a consultant neurologist, answering specific questions about each individual's care which were based on recommendations by the Royal College of Physicians, 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".

Cohort 1

A recall of people who were identified as being under the active care of Dr A was announced by BHSCT on 1 May 2018. 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 UIC and HPC. This group is referred to as Cohort 1.

Cohort 1 comprised of two groups of people – the first included people who were invited to be reviewed by another consultant neurologist (i.e. were recalled) and the second included people that had already been seen by another neurologist before the recall began (i.e. those who had already been reviewed). 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.

2,639 people were included in this active cohort and offered recall appointments; of which 2,442 individuals attended recall appointments.

A subsequent report relating to the findings of this cohort - the Activity and Interim Outcomes Report for the Active Caseload (Cohort 1) - was published by the Department of Health on 19 December 2019.

Based on the learning from the Cohort 1 patient recall, it was agreed that a further cohort of people should be recalled. This group of people is referred to as Cohort 2 and is described in further detail below.

Cohort 2

A recall of people who were identified as having been discharged from the care of Dr A was announced by the Department of Health on 30 October 2018. This group of people is referred to as Cohort 2. It comprised of two sub-groups (Cohorts 2a and 2b) which are described below.

Cohort 2a consisted of people who were discharged by the consultant back to the care of their General Practitioner (GP) 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.

424 people were included in Cohort 2a and were offered recall appointments; of which 344 individuals attended recall appointments.

Cohort 2b consists of people who were identified from HSC information systems as having been under the care of Dr A 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 was reported up to 13 October 2019.

1,044 people were included in Cohort 2b and were offered recall appointments; of which 730 individuals attended recall appointments.

The Activity and Outcomes Report for the Active Caseload (Cohort 2) was published by the Department of Health on 19 April 2021.

Based on the learning from the review of people in Cohort 2, it was 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 were still receiving specific medicines would need to be further analysed and invited for review.

Cohort 3

A recall of people who were identified as having been discharged from the care of Dr A was announced by the Department of Health on 20 April 2021. This group of people is referred to as Cohort 3.

Cohort 3 comprises those people who had been under the care of Dr A between June 1996 and March 2012 (inclusive) who had been subsequently returned to the care of their GP, had not been subsequently under the care of another consultant neurologist and had recently been prescribed one or more specific medications.

Cohort 3 further included those people who had been under the care of Dr A for stroke related conditions, who had not been seen in the previous cohorts and, due to the extension of the age range within the 'young stroke' category in line with relevant NICE guidelines, were now identified as falling into the 'young stroke' category.

768 people were identified as being potentially eligible for recall in Cohort 3. After further stratification, 602 people were included in Cohort 3 and were offered recall appointments, of which 495 individuals attended.

Summary of Cohort 1, 2 and 3 Data and Outcomes

The numeric activity and outcomes for those people reviewed as part of the Cohorts 1, 2 and 3 recall is summarised below.

Breakdown of data by Cohort

In the tables that follow, both in regard to activity and outcomes, the data is presented for each of the three cohorts of people reviewed as part of the recall. In considering these data it must be emphasised that each of the three cohorts were different, specifically the criteria for reviewing people differed for each of the cohorts as reflected in the three detailed reports. There are a number of limitations in the analysis and caution should be exercised when drawing up any potential conclusions.

Table 1 - Demographics per cohort

Combined average figures for each Cohort rounded to the nearest whole number^{*1}	Average age of people included in Cohort	Number of females included in Cohort %	Number of males included in Cohort %
Cohort 1 Combined Average	53 years	61%	39%
Cohort 2 Combined Average	59 years	61%	39%
Cohort 3 Combined Average	66 years	56%	44%
All Cohorts Combined Average	59 years	59%	41%

In the totality of the recall, the mean age of those included in the cohort was 59 years. 59% of people were female and 41% of people were male.

1 *all figures are rounded to the nearest whole number
 *Figures for cohort 2 are combined average of cohort 2a & 2b
 *Figures for cohort 3 are the combined average figures of categories 1 and 4
 *Figures for all cohorts are the combined average of all 3 cohorts average rounded figures

Table 2 - Population of Recall by LCG area

Combined average figures for each Cohort rounded to the nearest whole number*1	Belfast	Northern	South Eastern	Southern	Western	Outside Northern Ireland
Cohort 1 combined average	35%	25%	21%	11%	5%	3%
Cohort 2 combined average*2	40%	26%	22%	8%	4%	0%
Cohort 3 combined average	39%	28%	21%	9%	3%	0%
All Cohorts combined average*3	38%	26%	21%	9%	4%	1%

2 *Patient data from HPC is not included within these figures

3 *the total is less than 100 due to rounding

Table 3 - Number of people included in each Cohort by “Provider Type”

	Number of people included in recall Belfast Trust	Number of people who attended recall appointments Belfast Trust	Number of people included in recall Independent Sector	Number of people who attended recall appointments Independent Sector
Cohort 1	2,529	2,361	110	81
Cohort 2	1,124	867	344	207
Cohort 3	509	434	93	61
All Cohorts	4,162	3,662	547	349

In the totality of the recall, the total number of people included in the recall and offered appointments by BHSCT was 4,162, of which 3,662 attended recall appointments. The total number of people included in the recall and offered appointments by the Independent Sector was 547, of which 349 attended recall appointments.

Breakdown of Outcomes by Cohort

Table 4 - High Level Outcomes by Cohort

Combined average figures for each Cohort*⁴	Existing working diagnosis not secure %	Appropriate management plan not in place %	Prescribing not appropriate %	Change in diagnosis %
Cohort 1	21%	20%	19%	21%
Cohort 2 combined average	19%	18%	18%	18%
Cohort 3 Combined average	18%	22%	13%	18%
All Cohorts Combined Average	19%	20%	17%	19%

In the totality of the recall, the combined average percentage of people whose diagnosis was not assessed to be secure at the time of their recall appointment was 19%. This equates to around 1 in 5 of people seen as part of the recall.

In the totality of the recall, the combined average percentage of people for whom an appropriate management plan was not assessed to be in place at the time of their recall appointment was 20%. This equates to around 1 in 5 of people seen as part of the recall.

In the totality of the recall, the combined average percentage of people whose prescribing was not assessed to be appropriate at the time of their recall appointment was 17%. This equates to around 1 in 5 of people seen as part of the recall.

In the totality of the recall, the combined average percentage of people whose diagnosis was changed at the time of their recall appointment was 19%. This equates to around 1 in 5 of people seen as part of the recall.

4 *all figures are rounded to the nearest whole number

*Figures for Cohort 2 are combined average of Cohort 2a & 2b

*Figures for Cohort 3 are the combined average figures of categories 1 and 4

*Figures for all cohorts are the combined average of all 3 cohorts average rounded figures

Conclusion

This report reflects the totality of the neurology recall process involving people previously seen by Dr A.

BHSCT, UIC and HPC have now completed the required recalls for all cohorts of people that were under the care of Dr A.

Addendum - Additional Cohort 3 Recall

This addendum was produced by the Neurology Regional Co-ordination Group (RCG) at the request of, and in collaboration with, the Permanent Secretary Neurology Regional Assurance Group (PSNRAG). The data were provided by Belfast Trust who are responsible for the quality of the data submitted. The recall of an additional 19 patients, who were identified as falling within Cohort 3 of the Neurology Recall, was announced by Health Minister Robin Swann on 7 September 2022.

The review period for recall appointments was 12 September 2022 to 14 October 2022. In line with the process for patients involved in the previous cohorts, during or after review clinic appointments, a paper form was completed by a consultant neurologist or consultant stroke physician answering questions about each person's care, and these data were added to a database.

The form completed by the reviewing consultant asked the following questions, which were based on the recommendations of a report by the Royal College of Physicians:

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 "Uncertain" response was used in instances where the individual was currently not prescribed any medication or there was not enough information included or provided within an individual's clinical record for the reviewing clinician to establish a "Yes" or "No" response.

The reviewing consultants recorded, for each individual, 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. Data analysis was carried out using the same method as for the Cohort 3 Activity and Outcomes Report (Cohort 3 Report).

The results were combined with the results from the Cohort 3 Report. This allowed an assessment to be made as to whether the outcomes published for Cohort 3 and for the overall recall, as referred to in the Neurology Recall Summary Report, would have been different had the 19 additional patients been reviewed as part of Cohort 3.

The data analysis exercise undertaken to ascertain the outcomes of Cohort 3 was repeated to include the additional 19 patients. Given the addition of the small numbers, the results cannot be presented separately due to the risk of disclosure of information about individuals. The results were then compared with the published outcomes contained within the Cohort 3 Report and the Neurology Recall Summary Report. It was concluded that, when compared with the previous outcomes, there was no change to the published results.

In conclusion, it can be confirmed that the addition of the 19 additional patients did not have any impact on the outcome results of Cohort 3 or the totality of the recall. Had the 19 patients been reviewed as part of Cohort 3, the outcome results would have been the same. The conclusions included in the Cohort 3 Report, and in the Neurology Recall Summary Report therefore are unchanged.