Scottish Government
Riaghaltas na h-Alba

Neurological Conditions: estimating the prevalence in Scotland of selected conditions using General Practice and Hospital Admissions datasets

An Experimental Statistics publication for Scotland

HEALTH AND SOCIAL CARE

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1 Introduction

This report presents the estimated prevalence of (the number or proportion of people in the population with) 28 specific neurological conditions. The primary estimates derive from two separate data sources:

- **General Practice (GP) recorded diagnoses**: the number of registered patients with a diagnosis ever recorded for the specified condition.
- **Hospital Admissions data**: the number of people admitted to hospital with a diagnosis for the specified condition recorded in the preceding 20-year period.

This exploratory work was initiated by the Scottish Government and supported by Public Health Scotland (PHS) to address the Data Commitment in the Scottish Government's Neurological Care and Support: Framework for Action 2020-2025, published in December 2019. The Framework noted that neurological conditions account for between 10% and 20% of acute medical admissions, and 10% of the overall burden of disease in Scotland, as measured by Disability-Adjusted Life Years (DALYs). The Framework discussed the challenge in obtaining basic epidemiological data. It highlighted the need for more accurate population-level prevalence estimates to inform service planning and development. It set out the following commitment to address these issues.

> **Neurological Framework: Commitment 12**
>
> We will work with NHS Information Services Division (now part of PHS) and others to ensure a cohesive approach to capturing the needs of people with a neurological condition that will:
>
> - improve the recording of neurological conditions in people's routine health and care records, so that they are visible to appropriate services;
> - enable more accurate population-level estimates of the prevalence of neurological conditions to inform other data analysis;
> - support the development of systems and processes for service planning and workforce development, based on these improved prevalence estimates.

The purpose of this report is to address that commitment by improving our understanding of the prevalence of selected neurological conditions.

This work builds on a previous briefing paper on the prevalence of neurological conditions prepared by the Scottish Burden of Disease study team for the National Advisory Committee for Neurological Conditions (NACNC). That exploratory analysis covered eight neurological conditions and drew on a range of Scottish and global data sources to show comparisons with findings from other studies. This report adds to that work by:

- Expanding the number of neurological conditions for which estimates are provided.
- Including for the first time general practice recorded diagnoses of specified neurological conditions, provided by the PHS Scottish Primary Care Information Resource (SPIRE) team.
- Including complementary hospital admissions data for most of those specified conditions, provided by the PHS Scottish Burden of Disease (SBoD) study team.
- Including comparisons with other studies, where available and considered robust, for some conditions on the expanded list.

This is new and exploratory work which is intended to start a discussion about how the availability of data about people with neurological conditions could be further improved. Strengths and limitations of the data are presented later in the report.

2 Methodology

The neurological conditions included in this work were identified by members of NACNC. A list of the conditions for which data were requested and provided is shown in Annex C, with explanations for some data gaps.

General practice and hospital admissions data for the specified conditions were obtained from PHS. Full details of the methodology are available at Annex D and a process map is available at Annex E.

The general practice dataset comprises total counts of currently registered patients with a diagnosis ever recorded for each specified condition as of 8 April 2022. Data are not available for two of the 14 NHS Boards, and for 21 general practices from the other 12 NHS Boards. This dataset therefore covers general practices representing 72.7% of registered patients at the time of the data extract.

The hospital admissions dataset comprises total counts of people discharged from hospital with a diagnosis for each specified condition, recorded in any of the six diagnosis code positions, during the 20-year period prior to the end of 2019.

These datasets are not directly comparable: they derive from different data sources (SPIRE, which is sourced from general practice records, and Scottish Morbidity Records (SMR), which are sourced from hospital activity data) (see Annex D for more details). There are other differences (see Annex F for more details). However, the datasets complement each other, and together provide a broader picture of what national data can tell us about people diagnosed with neurological conditions. They also highlight where the data gaps might be, with respect to neurological conditions.

For some of the neurological conditions, comparative estimates were identified or calculated to provide additional context for the general practice and hospital admissions data. The comparative estimates included in this report derive from primary research considered robust or from specific disease registers.

Quality assurance support to inform the final version of the report was provided by PHS analysts and a neurologist member of NACNC, to whom access was granted to enable their assistance with data interpretation.

3 Findings

3.1 All Conditions

Table 1 shows the data for each condition from the two datasets. Annex C includes notes on why data is not available for some conditions.

It is important to emphasise again that the general practice dataset does not cover the whole of Scotland: the general practices whose data are included represented 72.7% of registered patients at the time of the data extract. If the general practice dataset covered 100% of registered patients, and prevalence was the same for the missing practices, the true general practice recorded diagnosis figures could be almost 40% higher.

Table 1: Number of people with selected neurological conditions recorded in GP practice dataset*, and estimated from hospital admissions dataset

Neurological Condition	Number of People	
	General practice: recorded diagnoses*	Hospital admissions-derived estimates
Acquired Brain Injury		
Brain Injury - Infection	24,121	n/a
Brain Injury - Other	1,803	3,185
Brain Injury - Trauma	229,255	18,749
Brain Injury - Vascular	79,830	89,198
Ataxia	2,677	3,944
Brain Tumour	7,841	7,299
Cerebral Palsy	6,416	5,936
Cluster Headache	7,312	852
Corticobasal Degeneration	32	n/a
Degenerative Spinal Disease	17,490	4,996
Dystonia	8,405	1,452
Epilepsy	57,588	40,352
Essential Tremor	10,457	1,300

Neurological Condition	Number of People	
	General practice: recorded diagnoses*	Hospital admissions-derived estimates
Functional Neurological Disorder	8,040	1,756
Huntington's Disease	519	387
Limbic Encephalitis	n/a	n/a
ME / Chronic Fatigue Syndrome	19,496	2,820
Migraine	273,598	35,052
MOG Antibody Disease	n/a	n/a
Motor Neurone Disease	523	682
Multiple Sclerosis	11,961	10,720
Multiple System Atrophy	86	191
Muscle Disorders – Dermatomyositis	482	279
Muscle Disorders - Inclusion Body Myositis	n/a	n/a
Muscle Disorders - Muscular Dystrophies	1,249	2,151
Muscle Disorders - Polymyositis	375	285
Myasthenia Gravis	1,868	1,502
Neuromyelitis Optica Spectrum Disorder	115	143
NMDAr Encephalitis	n/a	n/a
Parkinson's Disease	7,571	7,681
Peripheral Neuropathy		
Peripheral Neuropathy - due to diabetes	5,331	3,092
Peripheral Neuropathy - due to disease other than diabetes	146	485
Peripheral Neuropathy - due to Hereditary/Idiopathic	2,437	1,219
Peripheral Neuropathy - due to infection	1,712	1,322
Peripheral Neuropathy - due to mechanical causes	87,166	60,550
Peripheral Neuropathy - due to other causes	31,307	13,520
Peripheral Neuropathy - due to toxins	280	549
Post Polio Syndrome (PPS)	12	260

Neurological Condition	Number of People	
	General practice: recorded diagnoses*	Hospital admissions-derived estimates
Progressive Supranuclear Palsy (PSP)	120	123
Spina Bifida / Hydrocephalus	7,136	8,017
Tourette's (Tic Disorders)	2,932	467
* The general practice dataset does not cover the whole of Scotland: the general practices whose data are included represented 72.7% of registered patients at the time of the data extract. If the general practice dataset covered 100% of registered patients, and prevalence was the same for the missing practices, the true general practice recorded diagnosis figures could be almost 40% higher.		

Individuals are counted against each condition for which they have a diagnosis recorded. In both datasets, some individuals could have had a diagnosis for more than one condition. Therefore, the condition sub-totals should not be added up as their total will not represent the number of unique individuals with a diagnosis.

It is important to note that it is not known the extent to which the datasets for each condition overlap: this is likely to vary across conditions.

Differences between the general practice and hospital admissions data for specific conditions are likely to be attributable to where in the healthcare system people obtain a diagnosis and access care. For example, people with migraine or ME/CFS are more likely to access general practice services than to be admitted to hospital. In addition, the hospital admissions dataset does not include data from outpatient clinics, where many neurological conditions are diagnosed.

For some conditions shown above, comparisons with findings from other sources are presented below. The focus is on conditions where sources of comparative estimates are relatively robust, and where prevalence is generally used as the measure of the condition. (For some other conditions the measure generally used is incidence, or the number of new cases in a specified time period.)

Some of the comparative estimates differ from the general practice and/or hospital admissions data. The possible reasons highlight the strengths and limitations of using electronic health records as sources for prevalence estimates. For example, some differences could be attributable to different methods of case ascertainment. Other differences could reflect the complexity of clinical coding for some conditions, which makes it difficult to identify those patients in such records.

Table 1 is included in a supporting document which accompanies this publication. A full list of supporting documents accompanying this publication is shown below, and they are discussed in Annex D.

General Practice and Hospital Admissions estimates (includes Table 1 above).
General Practice recorded diagnoses.
Hospital Admissions estimates.
Primary Care Informatics: list of general practice Read codes.
Primary Care Informatics: background to list of general practice Read codes.

3.2 Specific Conditions

Epilepsy

GP-recorded diagnoses dataset: 57,588
Hospital admissions dataset: 40,352

Comparative data. In 2015 SIGN (the Scottish Intercollegiate Guidelines Network) published a guideline on the diagnosis and management of epilepsy in adults. This stated that there were 54,000 people with active epilepsy in Scotland. This figure derived from a 2011 publication by the Joint Epilepsy Council of the UK and Ireland on epilepsy prevalence and incidence. This statistics publication reviewed a variety of data sources to estimate, for each UK nation and for Ireland, the number of people with a diagnosis of epilepsy and a prescription of anti-epileptic drugs.

The higher GP figure could reflect that people are less likely to be admitted to hospital if their seizures are mild or their condition is well-managed.

Huntington's Disease

GP-recorded diagnoses dataset: 519
Hospital admissions dataset: 387

Comparative data. A 2013 study explored the prevalence of adult Huntington's disease in the UK based on diagnoses recorded in general practice records. It reported, for the period 1990-2010, an average prevalence rate for Scotland of 16.1 cases per 100,000 population aged 21 and over. If this rate was applied to the current population estimate (aged 21 and over, using the Mid-2021 Population Estimates for Scotland), it would give a figure of 689 people.

Migraine

GP-recorded diagnoses dataset: 273,598
Hospital admissions dataset: 35,052

Comparative data. In 2020 the Migraine Trust commissioned an independent rapid research review about who is living with migraine in the UK. The review cites a number of UK and international studies, including the Global Burden of Disease Study in 2016, which surveyed people from several countries including the UK. It stated that, based on the information available, around one in five adults in the UK may be living with migraine or migraine-like symptoms (23%). If this 23% rate was

applied to the current adult population estimate (aged 18 and over, using the Mid-2021 Population Estimates for Scotland), it would give a figure of 1,024,631 people.

This variation in numbers is likely to reflect the different methods of case ascertainment, and where people are most likely to access healthcare. A population survey will identify people who report migraine but are not seeking healthcare. Many people with migraine will not seek GP care; and most will never require hospital treatment.

Motor Neurone Disease (MND)

GP-recorded diagnoses dataset: 523
Hospital admissions dataset: 682

Comparative data. A national register for MND integrates clinical care, audit, research and evaluation to provide ongoing comprehensive monitoring of every person living with MND in Scotland. A study on the Changing epidemiology of motor neurone disease in Scotland, drawing on this register and other data sources, found that, in 2017, there were 422 people living with MND in Scotland. In 2021, MND Scotland evidence to the Scottish Parliament Health & Sport Committee's Inquiry into Technology and Innovation in the NHS stated that MND Specialist Nurses were supporting over 450 people with MND in Scotland.

Further work would be needed to explore why the GP and hospital admissions figures are higher than those derived from the national register, which research shows has a high coverage of the population with MND.

Multiple Sclerosis (MS)

GP-recorded diagnoses dataset: 11,961
Hospital admissions dataset: 10,720

Comparative data. There is a national register for MS in Scotland whose aim is to improve the care of people with MS through systematic and comprehensive audit of their diagnosis and early management. The register collects data on MS incidence (the number of new cases). The latest national report from this register states that, since the register was established in 2010, data have been collected on 5,878 people with a confirmed diagnosis of MS, 578 of whom received a diagnosis in 2021. (Patients who choose not to be contacted by an MS Specialist Nurse and paediatric patients are excluded from these data.) A 2019 study drawing on findings from this register suggested that, in the light of the high incidence rates it shows, previous estimates of prevalence in Scotland were likely to be under-estimates.

The MS register does not set out to measure prevalence. Further work would be needed to explore the relationship between its data and the higher GP and hospital admissions figures.

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)

GP-recorded diagnoses dataset: 19,496
Hospital admissions dataset: 2,820

Comparative data. A Scottish Good Practice Statement on ME-CFS published in 2010 stated that epidemiological evidence for Scotland is lacking but that a population prevalence of at least 0.2-0.4% is widely accepted, and that over 20,000 people in Scotland may be affected by ME/CFS. This figure would represent a prevalence rate of approximately 0.4%. The 2021 NICE guidance on ME and CFS cited data for England and Wales which would also represent a population prevalence rate of 0.4%. If this 0.4% rate was applied to the current population estimate (all ages, using Mid-2021 Population Estimates for Scotland), it would give a figure of 21,920 people.

Myasthenia Gravis

GP-recorded diagnoses dataset: 1,868
Hospital admissions dataset: 1,502

Comparative data. A study of the prevalence and incidence of neuromuscular conditions in the UK between 2000 and 2019 using primary care (GP) data showed, for 2019, a rate of 33.7 cases per 100,000 population. If this rate was applied to the current population estimate (all ages, using the Mid-2021 Population Estimates for Scotland), it would give a figure of 1,847 people.

Parkinson's Disease

GP-recorded diagnoses dataset: 7,571
Hospital admissions dataset: 7,681

Comparative data. A 2017 study of the prevalence and incidence of Parkinson's Disease using primary care (GP) data was undertaken by Parkinson's UK with advice from clinical experts. It projected that, in 2018, 12,184 people in Scotland aged 20 and over would have Parkinson's Disease. The study assessed that its prevalence and incidence estimates were consistent with findings from other studies which it reviewed.

It is not known to what extent the GP and hospital admissions data shown above overlap; and whether both figures represent an under-estimate of prevalence in the population.

Progressive Supranuclear Palsy (PSP)

GP-recorded diagnoses dataset: 120
Hospital admissions dataset: 123

Comparative data. A 2022 systematic review of prevalence studies of Progressive Supranuclear Palsy and Corticobasal Syndrome found that the best three prevalence

studies (two undertaken in the UK) gave a pooled rate of 7.1 people per 100,000 population per year. If this rate was applied to the current population estimate (all ages, using the Mid-2021 Population Estimates for Scotland), it would give a figure of 389 people.

3.3 Strengths and Limitations

General Practice Dataset

- **Innovation.** This is the first general practice extract of this kind for neurological conditions in Scotland. It offers a starting point for potential future work to analyse variation between NHS Boards, regional inequalities and comparisons with other countries.
- **Incomplete dataset**. The general practice data presented in this report does not include data for the whole of Scotland. Two out of the 14 NHS Boards did not participate in the data extract, and data from 21 general practices from the other 12 NHS Boards were removed following a PHS quality assurance process. Data from 653 general practices were extracted and retained for analysis. These general practices had a total population of 4,260,960 registered patients, representing 72.7% of the 5,858,622 registered patients at the time of the data extract. Annex D shows details of excluded data. While it would be possible to obtain crude estimates of the true national figures based on the proportion of registered patients covered by the general practice dataset, PHS analysts advise against doing so. Further work with clinical and statistical input would be required to produce robust estimates.
- **Clinical coding**. Whether general practice datasets of this kind are comprehensive depends on the extent to which the conditions are diagnosed and recorded using the appropriate Read codes. This Primary Care Informatics guidance for general practices in Scotland highlights the benefits of accuracy, completeness and consistency in the coding of patient records.

Hospital Admissions Dataset

- **Mapping of Read codes to ICD codes.** SBoD used an in-house mapping file to map Read codes used by general practices across to ICD10 codes used for hospital admissions. In addition, the PHS Terminology Services team provided a full list of ICD10 codes for each specific condition, which were used to supplement the codes mapped from the Read codes. ICD codes are less granular and in larger groups than Read Codes. As a result, for some neurological conditions, the hospital admissions dataset may be capturing patients with a broader diagnosis.
- **The potential of hospital records to under-estimate the prevalence of disease.** Estimates drawing on hospital inpatient/daycase data only could under-estimate the prevalence of disease in the population. This will vary according to the condition. For some conditions, people diagnosed are more likely to be supported by GPs, or in outpatient clinics from which detailed data are not available. They might never require hospital admission, or only very late in the progression of the condition.

- **Timeframe**. Using a 20-year lookback will not capture those discharged from hospital with one of the listed neurological conditions before the year 2000 and who subsequently did not have a hospital admission until the end of the observation period (31 December 2019). This will result in an under-estimate of prevalent cases. Creating a longer lookback, such as 30 or 40 years, is possible. However, this would require additional mapping work to be undertaken between ICD10 and ICD 9 (the previous ICD version), which is beyond the scope of the present work.

Recovery from Neurological Conditions

General practice electronic records include data from as far back as the 1940s. For this data extract it was decided to set no date limits for when a relevant Read code was entered into the clinical system. Therefore, a patient would be identified in the search if their record included one of the relevant Read codes, regardless of when the Read code had been entered in the system. This approach was taken in order to identify patients who could have been diagnosed with progressive or lifelong conditions a long time ago.

However, for some neurological conditions, such as brain injury, migraine and epilepsy, recovery from or management of the condition is possible. Therefore, the presence of a relevant code in either of the general practice or hospital admissions datasets might not indicate a current or chronic condition. As such the estimates could overstate current prevalence and future healthcare need.

Re-diagnosis of Neurological Conditions

This work could not take account of re-diagnosis: for example people initially diagnosed with one condition (such as Parkinson's Disease) who are subsequently re-diagnosed with a different one (such as Progressive Supranuclear Palsy (PSP). As noted earlier, in both datasets individuals could appear more than once if they have a diagnosis for more than one condition.

See also Annex F which describes differences between the two datasets on issues such as timeframe and mortality.

4 Comments including Data Improvement Plans

The data commitment in the Neurological Framework is ambitious. It requires improvements in gathering and extracting reliable data on neurological conditions. Developing reliable estimates of the prevalence of neurological conditions in the Scottish population is an important first step to improve data. Consequently, the Scottish Government's Neurological Care and Support - Framework for Action 2020-2025: Midpoint Progress Report has prioritised the need to understand how we can collect more reliable data on prevalence. This experimental statistics report supports this aim to develop more reliable data by comparing estimates from alternative data sources.

The incompleteness of the general practice dataset is a significant limitation in this report, with the data extract covering only 72.7% of registered patients. The accuracy of future data extracts would be improved by the participation of all 14 NHS Boards, and by improving consistency in recording of general practice patient lists to avoid exclusion of data following quality assurance processes.

Public Health Scotland are undertaking a wider programme of work to expand the available analysis relating to disease prevalence as recorded in general practice, as well as providing support to improve consistency of coding across Scotland. This report will provide additional context to those discussions.

Detailed diagnostic data are not currently available from hospital outpatient clinics, where a considerable proportion of people with neurological conditions are diagnosed. Improved availability of outpatient diagnostic data would enhance our understanding of the prevalence of specific neurological conditions. Timely feedback of these diagnoses to patients' general practices would improve the accuracy of general practice data.

Work is required to address the other challenges around data set out in the Scottish Government's Neurological Framework's Midpoint Progress Report, such as data linkage, or combining two or more sets of administrative data. This work could improve the quality and accuracy of the original datasets, clarify the extent to which they overlap and improve understanding of re-diagnosis. For example, the NHS Greater Glasgow & Clyde: Scottish Epilepsy Register healthcare improvement project, funded through the Framework, is working to improve local data collection and patient safety by linking prescribing data and the use of unscheduled care and hospital admissions data. The learning from this project will be relevant for scaling up and replicating data improvement at a national level.

There would be value in a wider group of analysts, researchers and clinicians considering how data of this kind could be improved. This could include consideration of patient pathways for specific neurological conditions and in which part of the health system those patients are most likely to be seen, diagnosed and treated. Depending on the nature of disease presentation, most cases will be defined based on general practice data, whereas for other conditions some cases will be defined based on hospital admissions data. It will also be important to consider how the overlap between cases defined using both methods differs between conditions. This is potentially important in terms of comparing these prevalence estimates with those from other sources.

5 Annexes

Annex A: References

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Annex B: Acronyms and Glossary

Acronym / Term	Definition
CHI (number)	Community Health Index A register of all patients in NHS Scotland. The CHI number uniquely identifies a person on the index.
DALY	Disability-Adjusted Life Years. A composite measure of ill-health and early death.
GBD	Global Burden of Disease A tool to quantify health loss from hundreds of diseases, injuries, and risk factors.
GP	General Practice or General Practitioner
ICD codes	International Classification of Diseases. This coding system allows the systematic recording, analysis, interpretation and comparison of mortality (deaths) and morbidity (illness) data. ICD-10 is the version in use in Scotland.
NACNC	National Advisory Committee for Neurological Conditions Provides expert advice on delivery of the national framework: Neurological Care and Support: Framework for Action 2020-2025,
NRS	National Records of Scotland
PCI	Primary Care Informatics A group of GPs, general practice managers and others with a special interest in health informatics.
PHS	Public Health Scotland
Read codes	A national standard coding system used in Scottish general practices for recording clinical information (signs, symptoms, diagnoses or activities).
SBoD	Scottish Burden of Disease Study A population health surveillance system that provides national-level and local-level data on health conditions
SMR	Scottish Morbidity Records Method of collecting healthcare data for individual patients.
SPIRE	Scottish Primary Care Information Resource A system that enables PHS to request and obtain authorised information from general practice clinical systems

Annex C: Neurological Conditions for which Data was Requested

	Neurological Condition	Data Provided?		Comment
		General Practice data	Hospital Admissions data	
1	Acquired Brain Injury			Data for sub-categories provided
	- Brain Injury - Infection	yes	no	Hospital data not included - some of the conditions listed are likely to be acute events and therefore prevalence might not be the most appropriate measure
	- Brain Injury – Other	yes	yes	
	- Brain Injury – Trauma	yes	yes	
	- Brain Injury – Vascular	yes	yes	
2	Ataxia	yes	yes	
3	Brain Tumour	yes	yes	
4	Cerebral Palsy	yes	yes	
5	Cluster Headache	yes	yes	
6	Corticobasal Degeneration	yes	no	GP Read code provided not in PHS Read code /ICD code mapping file
7	Degenerative Spinal Disease	yes	yes	
8	Dystonia	yes	yes	
9	Epilepsy	yes	yes	
10	Essential Tremor	yes	yes	
11	Functional Neurological Disorder	yes	yes	
12	Huntington’s Disease	yes	yes	
13	Limbic Encephalitis	no	no	No suitable GP Read codes identified by Primary Care Informatics
14	Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS)	yes	yes	
15	Migraine	yes	yes	

	Neurological Condition	Data Provided?		Comment
		General Practice data	Hospital Admissions data	
16	MOG Antibody Disease	no	no	No suitable GP Read codes identified by Primary Care Informatics
17	Motor Neurone Disease	yes	yes	
18	Multiple Sclerosis	yes	yes	
19	Multiple System Atrophy	yes	yes	
20	Muscle Disorders – Dermatomyositis	yes	yes	
21	Muscle Disorders - Inclusion Body Myositis	no	no	No suitable GP Read codes identified by Primary Care Informatics
22	Muscle Disorders - Muscular Dystrophies	yes	yes	
23	Muscle Disorders - Polymyositis	yes	yes	
24	Myasthenia Gravis	yes	yes	
25	Neuromyelitis Optica Spectrum Disorder	yes	yes	
26	NMDAr Encephalitis	no	no	No suitable GP Read codes identified by Primary Care Informatics
27	Parkinson's Disease	yes	yes	
28	Peripheral Neuropathy - due to diabetes - due to disease other than diabetes - hereditary/idiopathic - due to infection - due to mechanical causes - due to other causes - due to toxins	yes	yes	Data for sub-categories provided
29	Post Polio Syndrome (PPS)	yes	yes	
30	Progressive Supranuclear Palsy (PSP)	yes	yes	
31	Spina Bifida / Hydrocephalus	yes	yes	
32	Tourette's (Tic Disorders)	yes	yes	

Annex D: Methodology

General Practice Dataset

Data Request

Data for the specified neurological conditions were requested from general practices through the Scottish Primary Care Information Resource (SPIRE). SPIRE is a system that enables PHS to request and obtain authorised information from general practice clinical systems about specific health conditions. These data can then be released to inform the public and healthcare staff and other professionals about the incidence and prevalence of those conditions.

The Scottish Government analytical team requested via PHS a data extract which was approved by the SPIRE Prioritisation sub-group.

Identification of Diagnostic Codes

General practices in Scotland record patient diagnoses through the use of 'Read codes', a national standard coding system used in Scottish general practices for recording clinical information (signs, symptoms, diagnoses or activities).

The Scottish Government commissioned Primary Care Informatics (PCI) to identify the Read codes associated with each of the neurological conditions included in the data requests. PCI comprises a group of GPs, general practice managers and others with a special interest in health informatics. Their services include guidance on Read Codes.

PCI provided a set of Read codes for the majority of conditions, taking account of some advice requested and received from clinicians on the NACNC. These Read codes were used by PHS to extract the general practice data for the specified conditions. The list of Read codes and an explanatory background document are available as supporting documents accompanying this publication.

For four conditions, PCI found no suitable Read codes (see Annex C) and so data could not be extracted.

Data Extract Provided

The data provided comprise total counts of currently registered patients ever diagnosed for each specified neurological condition as of 8 April 2022, and recorded as alive as of that date (general practice electronic records include data from as far back as the 1940s.) For each condition, a breakdown by NHS Health Board, by Health and Social Care Partnership, and by sex and age are also available. The data provided are aggregate data and do not include any patient-identifiable data. The dataset is available in a spreadsheet as a supporting document accompanying this publication.

Missing and Excluded Data

The general practice data presented in this report do not include data from all NHS Boards and general practices.

NHS Ayrshire & Arran and NHS Highland did not participate in the extraction of data from SPIRE.

916 general practices were recorded on the April 2022 GP Practice Contact Details and List Sizes. 674 of these practices returned data from SPIRE.

Data from 21 practices were removed from the dataset following a quality assurance process undertaken by PHS. Reasons for removing data were as follows:

- 4 practices returned zero counts for all searches and were removed from the dataset.
- 17 practices were removed because of differences in their patient list sizes compared with published data. Practices with a difference greater than 10% of the data published on Scottish Health and Social Care Open Data for April 2022, and that also had a difference of more than 100 patients, were removed from the dataset.

This left data from 653 general practices, representing 71% of the practices in operation at that time (general practices sometimes close or merge).

The 653 general practices whose data were extracted and retained for analysis had a total population of 4,260,960 registered patients, representing 72.7% of the 5,858,622 registered patients at the time of the data extract.

Hospital Admissions Dataset

Data Request

To complement the general practice prevalence dataset, the Scottish Government analytical team also requested estimates of prevalence from PHS based on hospital records. This data extract was undertaken by the Scottish Burden of Disease (SBoD) study team in PHS.

This piece of analysis drew only on hospital data used in the following Scottish Morbidity Records (SMR) datasets, to identify individuals for inclusion in the estimates:

- **SMR01 definition:** this contains general acute inpatient and daycase records. Data are derived from diagnoses made on hospital discharge.
- **SMR04 definition**: this contains mental health inpatient admissions and discharges. Data are derived from diagnoses made on both hospital admission and discharge.

It should be noted that this analysis does not include data from attendances at outpatient clinics as it is not mandatory for diagnoses to be recorded on the SMR00 Outpatient Attendance record. Therefore, patients who have attended outpatient settings only (i.e. with no inpatient/daycase admissions) will not be included in the hospital prevalence estimates.

Identification of Diagnostic Codes

Hospital admissions are coded according to the International Classification of Diseases (ICD). This allows the systematic recording, analysis, interpretation and comparison of mortality (deaths) and morbidity (illness) data.

The Read codes provided were shared with the SBoD team in order to map them across to the appropriate ICD10 codes. In addition, the PHS Terminology Services team provided a full list of ICD10 codes for each specific condition. These codes were combined with the mapped Read codes to produce a final code list. This list is available in a spreadsheet as a supporting document accompanying this publication.

Data Extract Provided

A period prevalence approach was used. Estimates cover people admitted to hospital and diagnosed with any of the specified conditions in the 20-year period up to 31 December 2019, and alive and resident in Scotland at any point in 2019. For the purpose of this analysis, it is assumed that those people still have the diagnosed condition. The data provided are aggregate data and do not include any patient-identifiable data.

SBoD used the National Records of Scotland vital events dataset ("deaths") to exclude people known to have died.

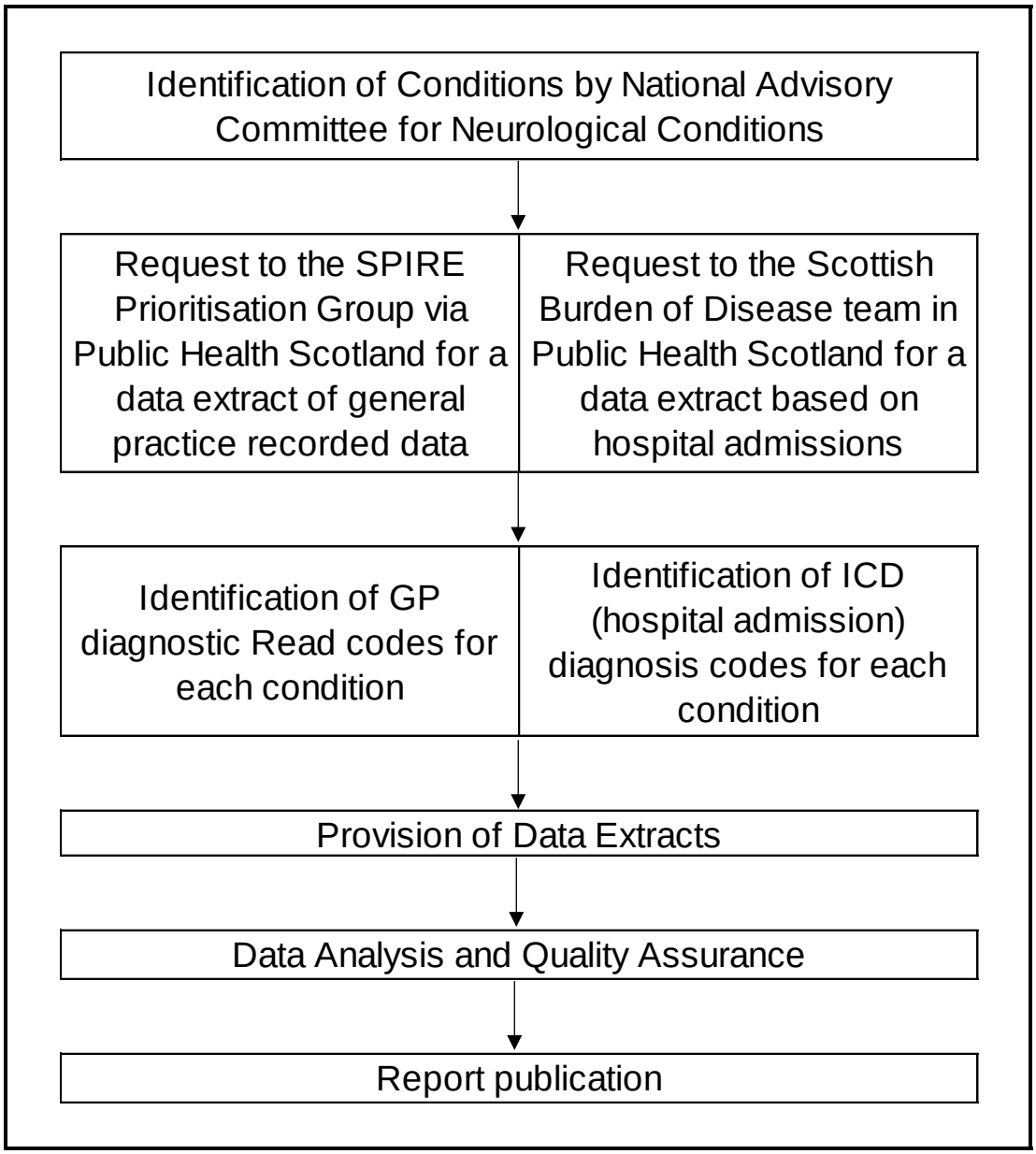
Individuals were excluded if either:

- There was no Community Health Index (CHI) number recorded (this is a unique identifier required to link to mortality data).
- They were non-Scottish residents at the time of the original hospital discharge.
- The CHI register showed that patients were no longer registered with a GP in Scotland, as at 31 December 2019, as proxy for no longer resident in Scotland. The February 2020 register was used, to allow for a lag period for updates.

The dataset is available in a spreadsheet as a supporting document accompanying this publication.

Annex E: Process Map

This diagram shows the sequence of steps undertaken during the process of developing this report.



Annex F: Comparisons Table: General Practice and Hospital Admissions Datasets

Issue	General Practice Dataset	Hospital Admissions Dataset	Comment
Source	Scottish Primary Care Information Resource (SPIRE) via PHS	Scottish Burden of Disease Study team (PHS) – Scottish Morbidity Records (SMR) data	
Scope	Data extract drew on records for 72.7% of registered patients	Data estimates drew on records for all people admitted to hospital over the specified 20 year period.	
Coding	Read codes	ICD-10 codes	Mapping of Read codes to ICD-10 codes: for some conditions ICD codes might have over-counted.
Conditions excluded from original list	For a few conditions no suitable Read codes were identified and so data could not be extracted (see Annex C).	For a few conditions no suitable Read codes were identified and so they could not be mapped across to ICD codes. Estimates were not possible for a small number of conditions for which SPIRE data were provided (see Annex C).	
Timeframe	Snapshot of patients on a specific day with a diagnosis 'ever recorded'. Coding – any time.	Patients coded at any time over a 20-year timeframe up to 31 December 2019.	This approach does not take account of any patients who recovered from their diagnosed condition.

Issue	General Practice Dataset	Hospital Admissions Dataset	Comment
	Records date back to the 1940s		
Data Source	General practice recording of patient diagnoses	Hospital coding of patient admissions	General practice recorded data are dependent on good computerised Read coding by general practices. Hospital admissions-generated estimates could under-count population prevalence for some conditions where hospital admission is not routine.
Prevalence	General practice data represent prevalence as recorded among GP- registered patients.	Hospital Admissions data represent prevalence as recorded among people admitted to hospital in the specified timeframe.	Hospital outpatients data are not available because of coding / recording issues.
Mortality / Deaths	Not known how many registered patients died recently and whose death is not yet recorded in their general practice clinical systems. There is no established approach to estimate this.	Link to National Records of Scotland (NRS) mortality data enabled exclusion of people who had died since their diagnosis.	
Population Migration	General practice recorded dataset only includes data for currently registered patients (i.e. it excludes	A linkage to the national Community Health Index (CHI) register was undertaken to exclude patients who were no longer	

Issue	General Practice Dataset	Hospital Admissions Dataset	Comment
	patients who were diagnosed in Scotland but have since migrated elsewhere).	resident in Scotland as at 31 December 2019.	

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The data collected for this publication are available in supporting documents accompanying this publication.

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