Llywodraeth Cymru
Welsh Government

An overview of mortality amongst People with a Learning Disability in Wales, 2012-2022

Appendices and References

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Glossary

PwLD	People with a Learning Disability The term "intellectual disability", instead of "learning disability" is more common outside of British English and in academic literature.
APC Ds	Admitted Patient Care Data set This data set covers all inpatient and day case activity undertaken in NHS Wales, and inpatient or day case activity relating to Welsh residents treated in English NHS hospitals. Information from the APC Ds is used to update a very similar but longer-existing data set known as the *Patient Episode Database for Wales* (PEDW). The names APC Ds and PEDW are sometimes used interchangeably. More information about the APC Ds and PEDW can be found at https://dhcw.nhs.wales/information-services/information-delivery/archived-pedw-data-online/
ICD-10	International Classification of Disease, 10th Edition This is a classification system for diseases and other health conditions – it is used to describe what health conditions, including reasons for admission, someone has while in hospital, in a structured, consistent way.
OPCS-4	OPCS Classification of Interventions and Procedures, version 4 This is a classification system for interventions and surgical procedures – it is used to describe what has been done to someone during their time in hospital in a structured, consistent way. ("OPCS" stands for the name of a UK government department that originally managed this classification system.) More information about clinical classification systems can be found at: https://digital.nhs.uk/services/terminology-and-classifications/clinical-classifications
WIMD2019	Welsh Index of Multiple Deprivation, 2019 update More information about WIMD can be found at https://www.gov.wales/welsh-index-multiple-deprivation

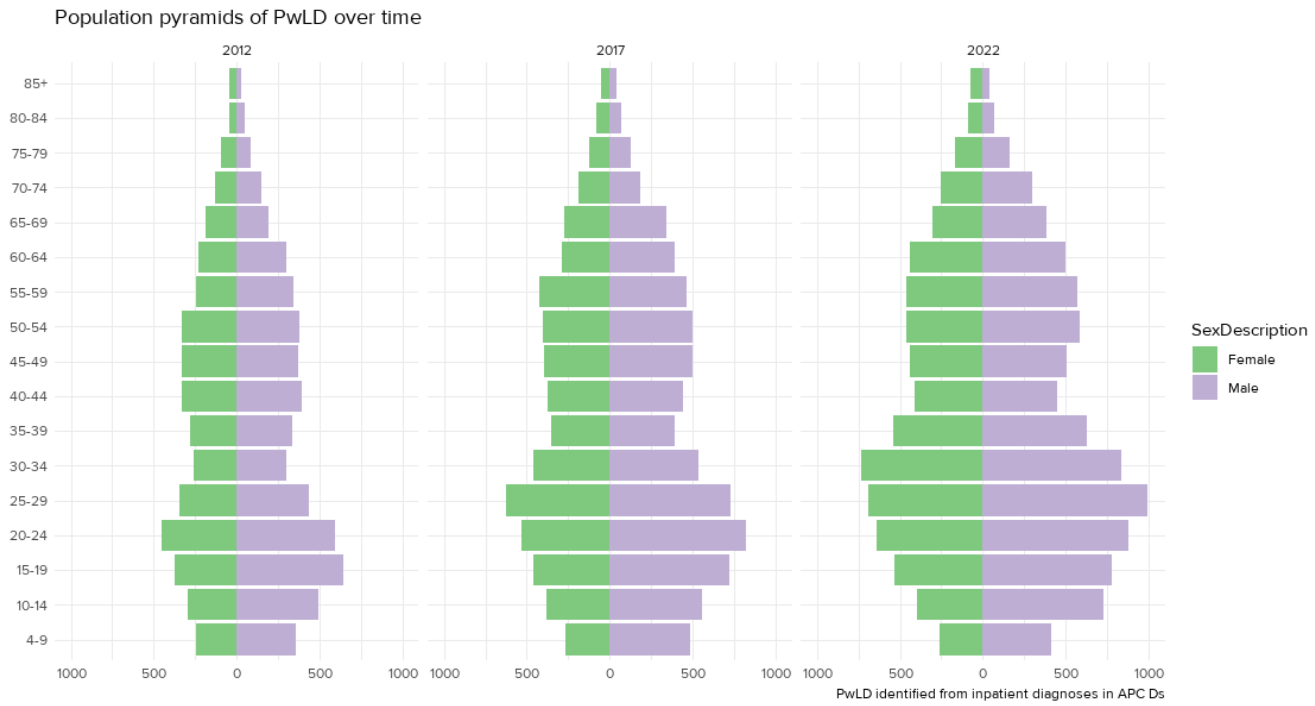
Appendix A - Stability of the set of PwLD identified over time

In order to look meaningfully at mortality rates over time, it is important to understand whether the set of PwLD identified from inpatient diagnoses is stable with respect to characteristics that might influence these mortality rates.

Changes in these characteristics over time do not necessarily invalidate looking at mortality in this group over time, particularly if they arise from changes in the actual population rather than biases in the approach to identification. Regardless, they are important context for making sense of any changes – or lack of change – in mortality.

Demographics and deprivation

The chart below shows 'population pyramids' for the set of PwLD identified in different years (only every *fifth* year is shown):

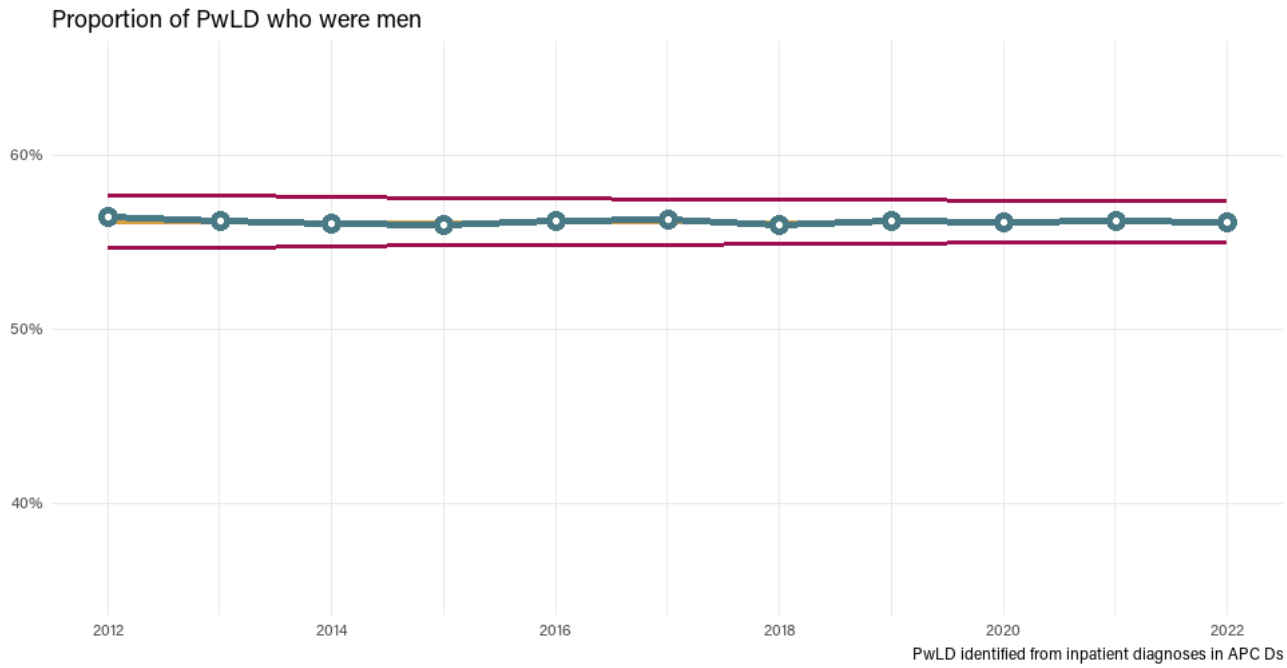


It can be seen that the size of population grows between 2012 and 2022 – we find more PwLD in later years than earlier years. This is mostly because in later years, we can look back over a longer period to find hospital admissions and associated diagnoses.

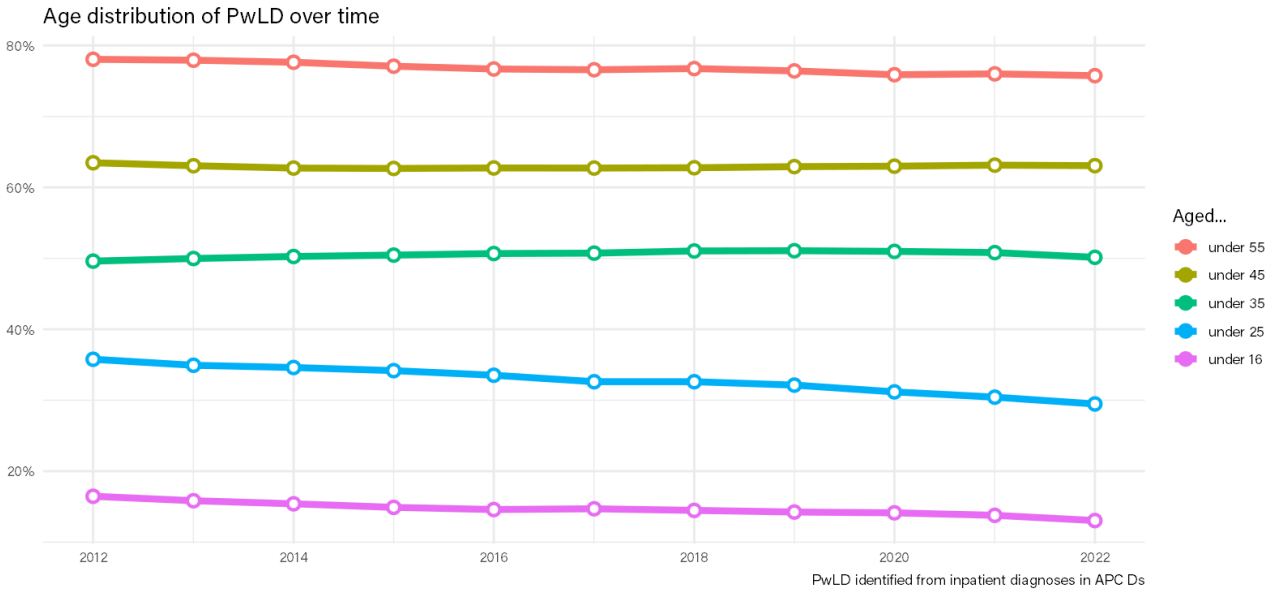
The rough "shape" of the population – the breakdown by age and gender – appears to stay fairly stable between the three points in time. We look at this in more detail below.

The proportion of identified PwLD who were men remains steady over time, as shown more clearly in the chart below.

The chart below is a "control chart". A brief discussion of control charts can be found in Appendix F, but in this context the red lines show the limits of expected variation from year to year if there is no change in the underlying proportion of people with a learning disability who were men.

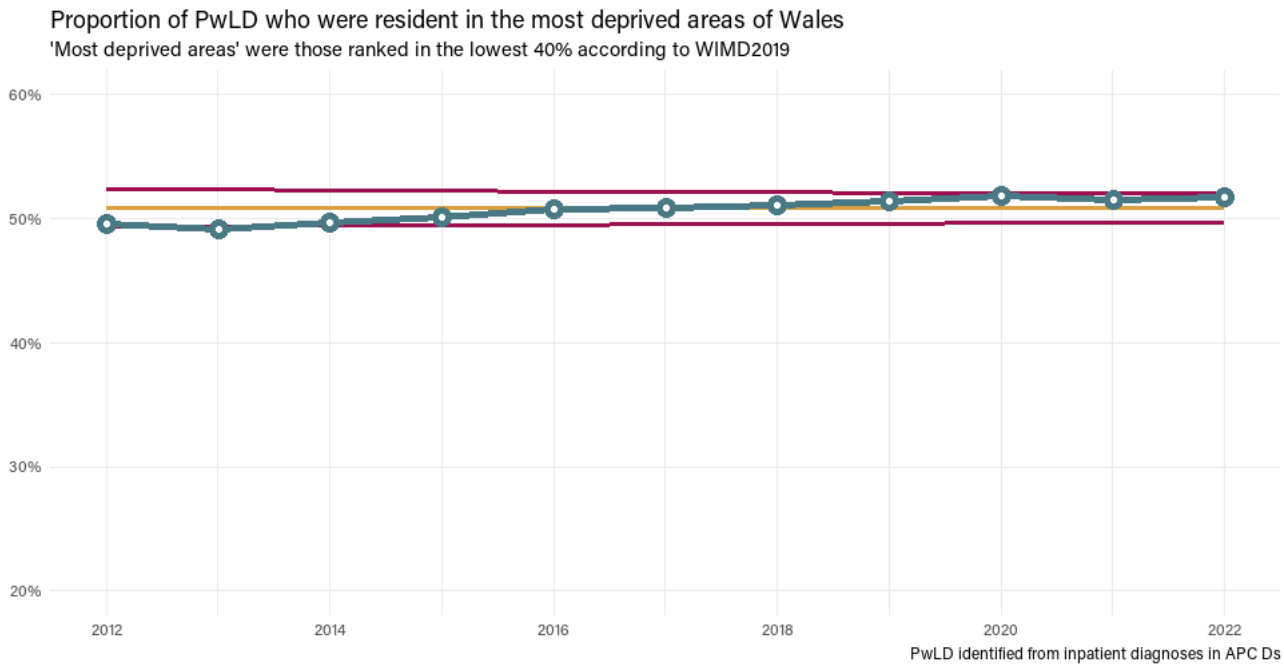


The population of identified PwLD is slightly older in later years, The change in age distribution is concentrated amongst under-35s, with the proportion of under-25s dropping considerably from more than 35% to less than 30%. This can be seen in the chart below, in the blue line:



This might partly reflect the changing age distribution of the underlying population (and indeed the population of Wales more broadly) but it may also reflect a greater preparedness to identify and record the presence of a learning disability in adults of a particular age. Future analysis might be able to differentiate these effects.

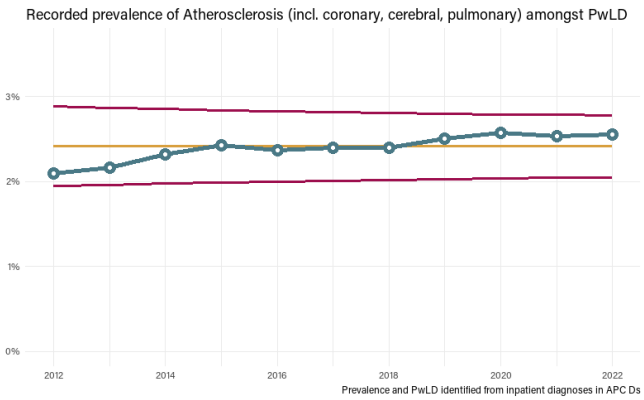
The proportion of identified PwLD who were resident in the most deprived areas of Wales (as described by WIMD2019) increases slightly over time, as shown in the chart below.

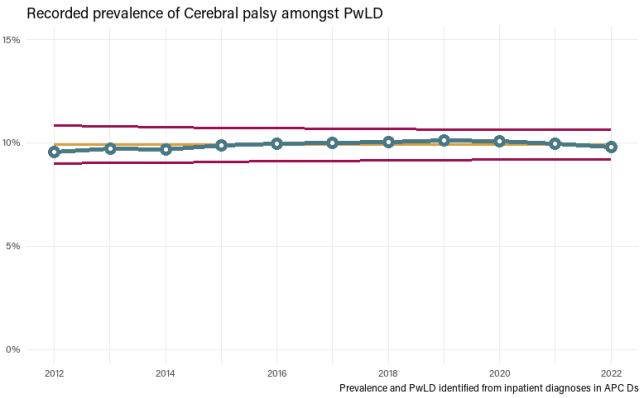


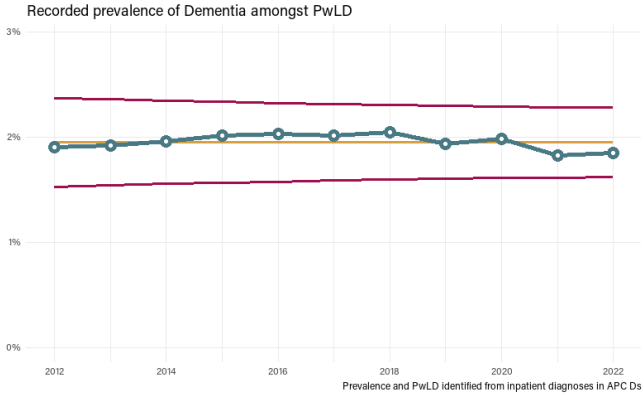
Comorbidities

Comorbidities, specifically co-occurring chronic conditions, can also be determined on the basis of coded inpatient diagnoses. The recorded prevalence of a selected set of conditions has been described below accordingly.

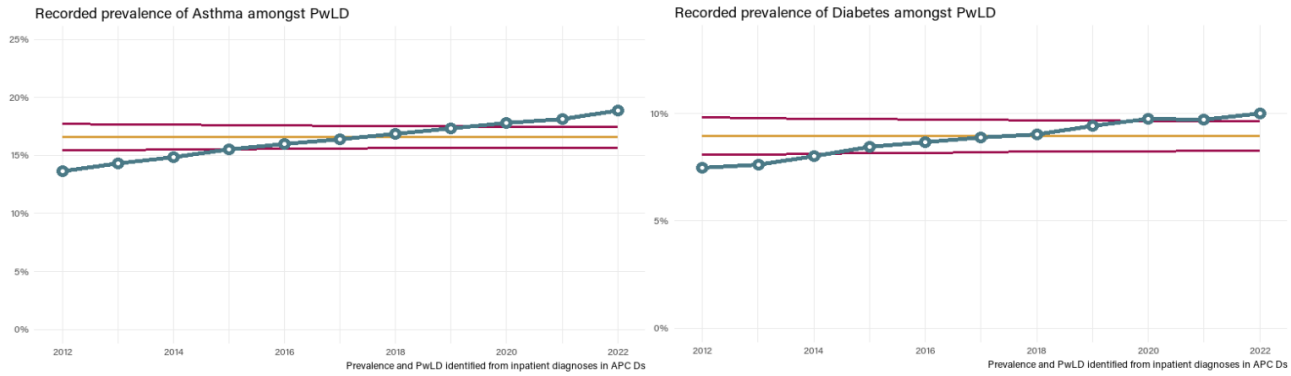
Some comorbidities show a relatively stable level of recorded prevalence amongst identified PwLD, including cerebral palsy, dementia, and atherosclerosis. The charts below show this:







Some comorbidities, by contrast, show a fairly steady rise in recorded prevalence over the last decade or so, including asthma, diabetes, hearing impairment, scoliosis and obesity. The charts below show the first two of these:



There are various possible reasons for this observed rise:

- The rise reflects a genuine underlying rise in the prevalence of these conditions amongst the PwLD identified over time.
- The rise is a product of the identification and recording of these conditions being unreliable. In later years, PwLD with a condition will have had a longer period in which to accrue inpatient stays and, consequently, more opportunities for that condition to be recorded.
- The rise is a product of changing fashions in the identification, recording and coding these conditions, amongst all inpatients.

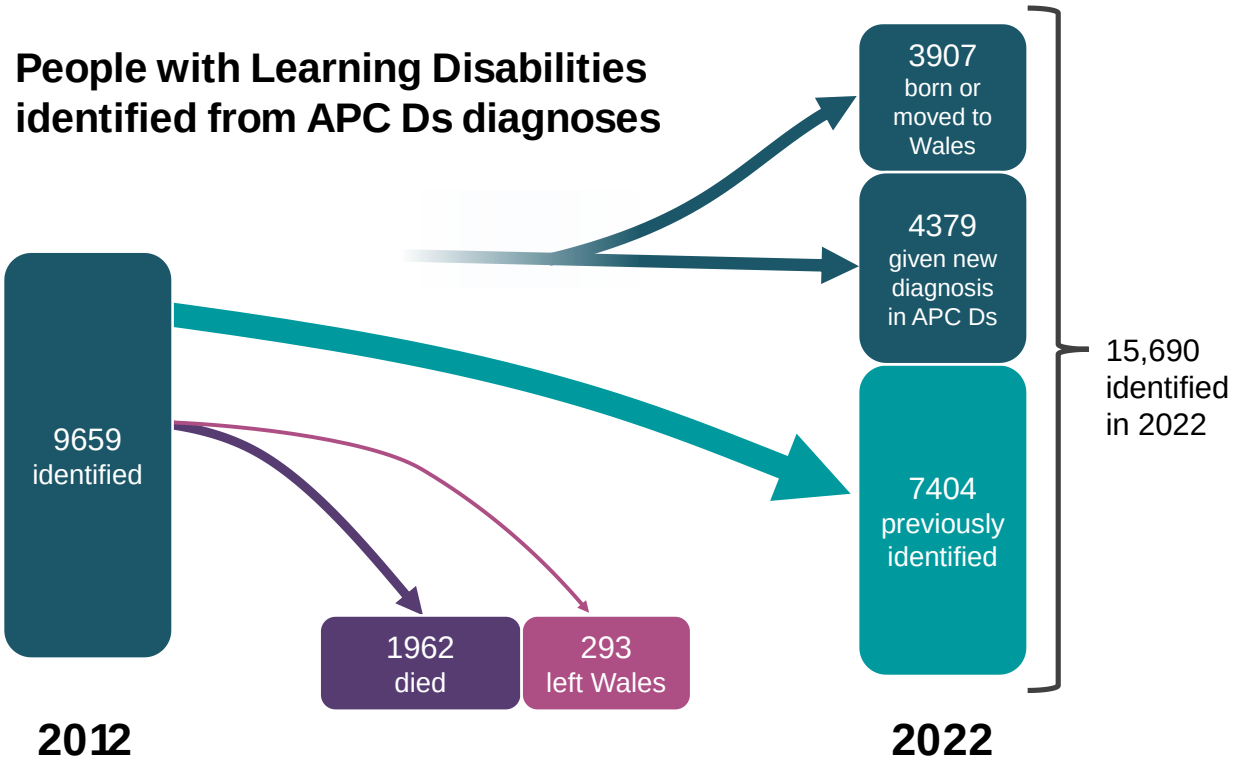
The overall rise may well be a combination of the above. Future analysis might be able to go some way towards teasing out the relative impact of each of these effects.

Epilepsy shows a small but steady decrease in recorded prevalence over the period of interest. As before this might reflect changes in the underlying presence of the condition or in broad fashions for the identification and recording of certain conditions. However, in this case, it might also reflect better management of epilepsy in the community and fewer admissions where epilepsy was considered sufficiently relevant to warrant recording in the medical record (and subsequent coding). Future analysis might be able to describe the extent of this effect.

Flows and turnover

Another way to consider the stability of the set of PwLD identified over time is to consider the "turnover" of the set from year-to-year. Each year approximately 5-8% of the set of PwLD identified are newly discovered, with the rest of the set for that year being people carried over from the previous year.

77% of the PwLD identified in 2012 were also found in the set of PwLD identified in 2022. These people – who were identified both in 2012 and 2022 – made up just half of all the people identified in 2022. The diagram below shows the flows between, and in and out of the sets identified in 2012 and 2022.



Discussion

There are some issues described above that might raise concerns about the stability and comparability of the set of PwLD identified over time – in more recent years the population identified is older and has a greater recorded prevalence of some comorbidities. All else being equal we might expect the population identified in later years to have a slightly higher all-cause crude mortality rate, for example, because of these differences.

Appendix B – ICD-10 diagnosis groups

Where a description is show in *italics*, the description is not taken from the ICD-10 itself; in these cases an alternative description has been provided for greater legibility.

Asthma

ICD-10 Codes	Description
J45	Asthma
J46	Status asthmaticus

Atherosclerosis (incl. coronary, cerebral, pulmonary)

ICD-10 Codes	Description
I25.1	Atherosclerotic heart disease
I27.0	Primary pulmonary hypertension
I67.2	Cerebral atherosclerosis
I70	Atherosclerosis
I73.9	Peripheral vascular disease, unspecified

Cancer and other tumours

ICD-10 Codes	Description
C00-D48	Neoplasms

Cerebral palsy

ICD-10 Codes	Description
G80	Cerebral palsy

Chronic respiratory conditions

ICD-10 Codes	Description
J40	Bronchitis, not specified as acute or chronic
J41	Simple and mucopurulent chronic bronchitis
J42	Unspecified chronic bronchitis
J43	Emphysema
J44	Other chronic obstructive pulmonary disease

Asthma is grouped separately to the above.

Colorectal cancer

ICD-10 Codes	Description
C18	Malignant neoplasm of colon

C19	Malignant neoplasm of rectosigmoid junction
C20	Malignant neoplasm of rectum
C21	Malignant neoplasm of anus and anal canal

Dementia

ICD-10 Codes	Description
F00	Dementia in Alzheimer's disease
F01	Vascular dementia
F02	Dementia in other diseases classified elsewhere
F03	Unspecified dementia
G30	Alzheimer's disease

Diabetes

ICD-10 Codes	Description
E10	Diabetes mellitus, type 1
E11	Diabetes mellitus, type 2
E12	Malnutrition-related diabetes mellitus
E13	Other specified diabetes mellitus
E14	Unspecified diabetes mellitus

Dysphagia, aspiration pneumonitis, and choking on food or vomit

ICD-10 Codes	Description
J69.0	Pneumonitis due to food and vomit
R13	Dysphagia
W78	Inhalation of gastric contents
W79	Inhalation and ingestion of food causing obstruction of respiratory tract

Epilepsy

ICD-10 Codes	Description
G40	Epilepsy
G41	Status epilepticus

Hearing impairment

ICD-10 Codes	Description
H90	Conductive and sensorineural hearing loss
H91	Other hearing loss
Q16	Congenital malformations of ear causing impairment of hearing

Intestinal obstruction and constipation

ICD-10 Codes	Description
K40-K46	Hernia
K56	Paralytic ileus and intestinal obstruction without hernia
K59.0	Constipation

Ischaemic heart diseases

ICD-10 Codes	Description
I21	Acute myocardial infarction
I22	Subsequent myocardial infarction
I23	Certain current complications following acute myocardial infarction
I24	Other acute ischaemic heart diseases
I25	Chronic ischaemic heart disease

Learning disabilities

ICD-10 Codes	Description
F70-F79	Learning disability (specific)
F81.9	Developmental disorder of scholastic skills, unspecified
Q90	Down's syndrome
Q91	Edwards' syndrome and Patau's syndrome
Q93.3	Deletion of short arm of chromosome 4
Q93.4	Deletion of short arm of chromosome 5
Q93.5	Other deletions of part of a chromosome
Q99.2	Fragile X chromosome

The codes in F70-F79 explicitly code for a diagnosed learning disability.
F81.9 includes "learning disability, not otherwise specified".

The Q codes belong to the "Congenital malformations, deformations and chromosomal abnormalities" chapter of the ICD-10. The selected Q codes included above identify disorders that are almost always associated with the presence of a learning disability.

Lung cancer

ICD-10 Codes	Description
C33	Malignant neoplasm of trachea
C34	Malignant neoplasm of bronchus and lung

Obesity

ICD-10 Codes	Description

E66	Obesity

Respiratory infections

ICD-10 Codes	Description
B01.2, B05.2, B20.6, B25.0, J12-J18	Pneumonia
J00-J06, J30-J39	Upper respiratory infections
J09-J11	Influenza
J20-J22	Acute lower respiratory infections
U07.1, U07.2	COVID-19

These codes for respiratory infections are mostly a subset of the codes defined by Inada-Kim and others as "suspicion of sepsis" in 2016. See *Other infections* for more details.

Scoliosis

ICD-10 Codes	Description
M41	Scoliosis

Seizures and convulsions

ICD-10 Codes	Description
F44.5	Dissociative convulsions
G40	Epilepsy
G41	Status epilepticus
R56	Convulsions, not elsewhere classified

Stroke

ICD-10 Codes	Description
I60	Subarachnoid haemorrhage
I61	Intracerebral haemorrhage
I62	Other nontraumatic intracranial haemorrhage
I63	Cerebral infarction
I64	Stroke, not specified as haemorrhage or infarction

This is a broader set of codes than used in some other contexts. For example, the Sentinel Stroke National Audit Programme (SSNAP) generally exclude I60 and I62 when identifying stroke patients (as these involve different care pathways and outcomes to I61, I63 and I64).

Other infections

The ICD-10 codes used for this group were those that Inada-Kim and others defined as "suspicion of sepsis" in 2016, excluding those already covered by the *Respiratory infections* group.

Appendix C – OPCS-4 procedure groups

Surgery potentially related to intestinal obstruction

The 140 OPCS-4 codes used for this were those used by Grieve and others in the ESORT study in 2023. These can be found on page 36 of the ESORT Clinical Panel Summary Note.

Appendix D – Death certificates and their coding

Introduction

The figure below presents a relatively complex example of part of a medical certificate of the cause of death (MCCD or often simply "death certificate"), including the ICD-10 coding added by the ONS, for the death of a person with Down's syndrome who died following a bowel obstruction.

			What's written on the certificate	ONS ICD-10 Coding
I	(a)	Disease or condition directly leading to death	Multi-organ failure	R68.8
	(b)	Other disease or condition, if any, leading to (a)	Ischaemic bowel	K55.9
	(c)	Other disease or condition, if any, leading to (b)	Small bowel obstruction due to volvulus and adhesion (operated)	K91.8, K56.2 Y83.9, K66.0
II		Other significant conditions CONTRIBUTING TO THE DEATH but not related to the disease or condition causing it	Down's syndrome	Q90.9

ONS-determined underlying cause of death:
K56.5 – Intestinal adhesions with obstruction

Part I of the death certificate outlines the causal route directly leading to a person's death, starting from the most immediate cause (in this case "multi-organ failure") and tracking back through the diseases or conditions that led to this.

Part II of the death certificate outlines other conditions that contributed to the person's death, but were not part of the causal chain outlined in Part I. In this case, the person completing the death certificate has chosen to include Down's syndrome.

The *underlying cause of death* is usually determined by selecting the last entry, on the lowest line, of Part I. This is broadly true of this death certificate, but the ONS's method has translated the coding of multiple individual terms ("obstruction", "volvulus", "adhesion") into a summary diagnostic code ("K56.5 – Intestinal adhesions with obstruction"). In this case, the underlying cause is an example of *Intestinal obstruction and constipation* as defined in Appendix A of this report.

This certificate *mentions*, or the death can be said to *involve*, all of the diseases and conditions shown on the certificate, whether in part I or part II, and the disease or condition determined to be the underlying cause.

Section 9 - Cause of death coding of the ONS's *User guide to mortality statistics* provides more detail about their process of coding death certificates.

Underlying cause of death identified as a learning disability or related condition

The figure below shows an example of a death certificate, including the coding added by the ONS, for the death of a person with Down's syndrome who died following pneumonia.

			What's written on the certificate	ONS ICD-10 Coding
I	(a)	Disease or condition directly leading to death	Pneumonia	J18.9
	(b)	Other disease or condition, if any, leading to (a)	Down's syndrome	Q90.9
	(c)	Other disease or condition, if any, leading to (b)		
II		Other significant conditions CONTRIBUTING TO THE DEATH but not related to the disease or condition causing it		

ONS-determined underlying cause of death:
Q90.9 – Down's syndrome

In this case, Down's syndrome was included in Part I of the death certificate, as the final entry, and has been selected by the ONS as the *underlying cause of death* based on this.

This death certificate *mentions* the pneumonia, which is an example of *Respiratory infections* as defined in Appendix A of this report.

It is not uncommon for the death certificate of a person with a learning disability to include learning disability or a related syndrome as the final entry in Part I. When looking only at underlying causes of death, this can mask preventable and/or treatable conditions – in this case, a likely respiratory infection. Future analysis could look at 'recoding' death certificates where this is the case to look at causes of death up the chain from the 'underlying cause of death' – in the example shown, from Down's syndrome to Pneumonia.

It is rarely appropriate to include "learning disability" in Part I of the certificate. "Learning disability" or long-term physical disabilities should never be listed as the *only* cause of death. In the example above, it might have been more appropriate to include Down's syndrome in Part II of the certificate as it is unlikely to have formed part of a "direct sequence of events" to having pneumonia.

For more discussion of this issue see Section 4.6 Avoid physical and mental conditions which are not fatal in themselves of the *Guidance for doctors completing Medical Certificates of Cause of Death in England and Wales* (March 2022) and *National Medical Examiner's Good Practice Series No. 3 - Learning disability and autism*.

Appendix E – Breakdown of 'Other' Underlying Cause of Death

This appendix shows underlying causes of 895 deaths grouped by ICD-10 chapter where they were otherwise ungrouped in the *Overview of mortality* in the main report.

Where there were 25 or more deaths with an underlying cause in a sub-chapter of ICD-10, these have also been shown below.

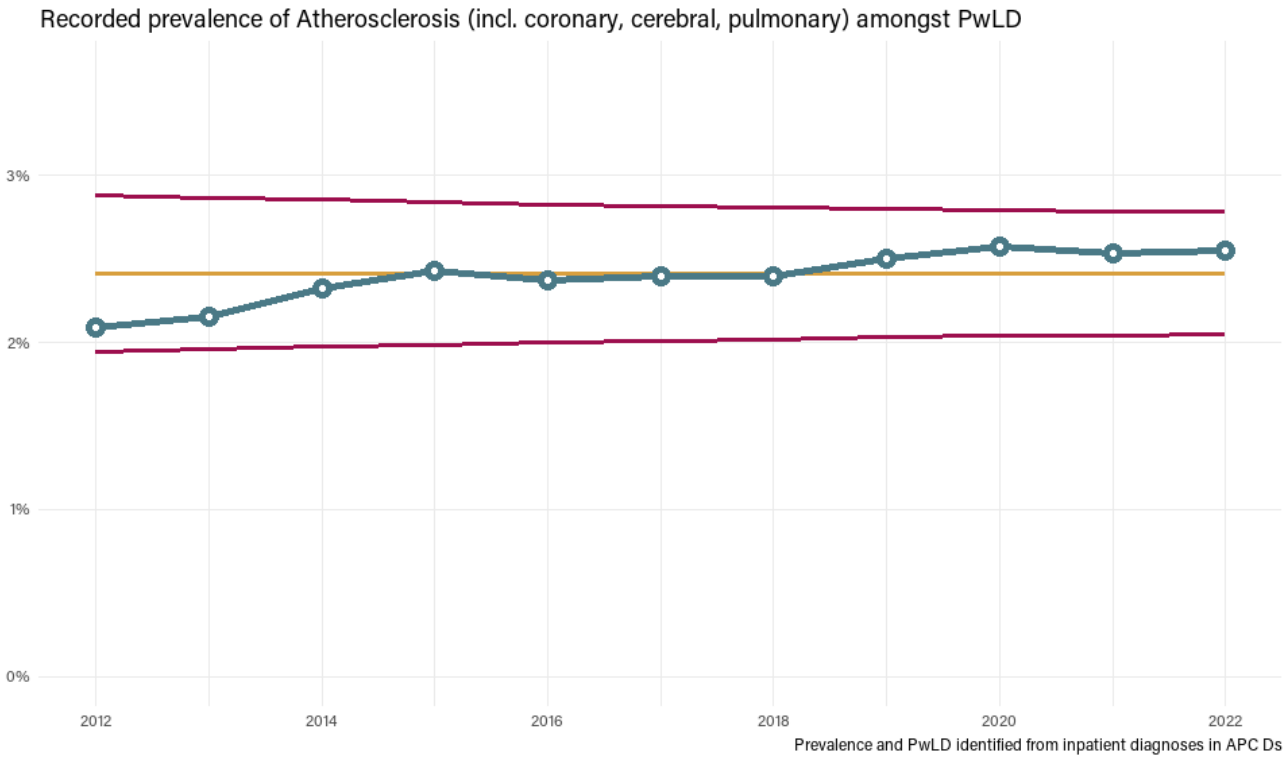
Chapter 01: Certain infectious and parasitic diseases	**17**
Chapter 03: Diseases of the blood and blood forming organs and certain disorders involving the immune mechanism	**11**
Chapter 04: Endocrine, nutritional and metabolic diseases	**84**
E10-E14 Diabetes Mellitus	52
Chapter 05: Mental and behavioural disorders	**10**
Chapter 06: Diseases of the nervous system	**109**
Chapter 09: Diseases of the circulatory system	**218**
I30-I52 Other forms of heart disease	90
I60-I69 Cerebrovascular diseases	41
Chapter 10: Diseases of the respiratory system	**88**
J40-J47 Chronic lower respiratory diseases	68
Chapter 11: Diseases of the digestive system	**97**
K70-K77 Diseases of liver	40
Chapter 12: Diseases of the skin and subcutaneous tissue	**< 5**
Chapter 13: Diseases of the musculoskeletal system/connective system	**12**
Chapter 14: Diseases of the genitourinary system	**39**
Chapter 16: Certain conditions originating in the perinatal period	**< 5**
Chapter 17: Congenital malformations, deformations and chromosomal abnormalities	**70**
Chapter 18: Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified	**36**
R50-R69 General symptoms and signs	28
Chapter 20: External causes of Morbidity and Mortality	**96**
X40-X49 Accidental poisoning by and exposure to noxious substances	25
Chapter 22: Codes for special purposes	**< 5**

Appendix F – Control charts

Some the charts presented in this report are control charts. These are sometimes known as Shewhart or Statistical Process Control (SPC) charts.

Control charts are a tool for looking at measurements over time and distinguishing between a) random or "common cause" variation, and b) systematic changes or "special cause" variation. They can help us understand whether changes in a measurement over time are indicative of a meaningful underlying change in the thing being measured (or how we're measuring it), or whether the changes are just the result of natural variation or measurement error.

The chart below is an example of a control chart. It is a "P chart" showing the recorded prevalence of atherosclerosis.



The red lines are the upper and lower "control limits". They show the limits of changes in measurement expected from "common cause" variation alone. If measurements fall outside of these limits, then this suggests that a systematic change or "special cause" event has occurred.

In this case, no measurements fall outside of these limits.

The above is an extremely brief introduction to control charts. More information on their construction and interpretation can be found elsewhere. East London NHS Foundation Trust's Quality Improvement website provides a more detailed introduction for people working in healthcare and Section 6.3.1 of the NIST Engineering Statistics Handbook provides a more through discussion from an engineering and statistical perspective.

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