

The economic impact of dementia

Module 2: Dementia's contribution to health metrics

September 2024



Contents of this report

| | Section | Page |
|---|--|----------------|
| 1 | Introduction to the study | 3 – 8 |
| 2 | Executive summary | 9 – 11 |
| 3 | Methodology, assumptions and limitations | 12 – §9 |
| 4 | Healthcare utilisation across dementia and non-dementia cohorts | 20 – 34 |
| 5 | Appendices | |
| | National bed capacity | 36 – 37 |
| | DiscoverNOW cohort characteristics | 38 – 40 |
| | References | |



Introduction to the study

CF partnered with Alzheimer's Society in a programme of work split into four modules, to understand the current and future economic and healthcare impact of dementia

Presented here

MODULE 1

Overall annual cost of dementia now and projected to 2040, broken down by:

- Cost type (health care, social care, unpaid care, quality of life and economic costs)
- Dementia severity
- Regions of England and devolved nations

MODULE 2

Healthcare utilisation now and projected to 2040 of people with dementia, including:

- A&E attendances
- Inpatient admissions
- Outpatient appointments
- Primary care, community and mental health contacts
- Prescriptions

MODULE 3

Cost and outcome comparisons with other conditions (e.g. cancer, CVD)

Cost and outcome comparisons with similar countries

MODULE 4

Potential cost savings due to early and accurate diagnosis and effective treatment

The aim of the study was to quantify the economic burden of dementia, using detailed healthcare data to bring new insight into the costs of people with dementia

- The **projected rise in dementia prevalence** poses a significant **healthcare, social care and economic challenge**, and highlights the urgent **need to prioritise it as a health and care concern**
- Carnall Farrar (CF) was commissioned to **develop a body of evidence** that can **illustrate the economic impact of dementia** in the UK
- This research estimates the **present and future costs of dementia to 2040** across a broad spectrum of cost categories and conducts a deep dive into the healthcare utilisation of people with dementia
- The research identifies **valuable insights into current dementia management** and highlights key findings and strategies for future strategies

1

This is **one of the largest UK studies of healthcare resource utilisation by patients with dementia**, using a study cohort of **26,097 dementia patients** across North West London. This data **enabled identification of people with mild, moderate and severe dementia using MMSE results recorded for 2,757 patients.**

2

This study undertook a unique data-led, real-world evidence approach, leveraging **linked record-level patient data** across primary and secondary care, mental health, community and prescribing used to **identify real per person healthcare costs.**

3

This study considered the **costs associated with dementia beyond just health and social care** including **quality of life** (additional heating costs, legal costs, transport costs, police call-outs and scams) and **loss of economic consumptions. The costs were separated by payer, to provide an understanding of costs burdens on individuals and their families.**

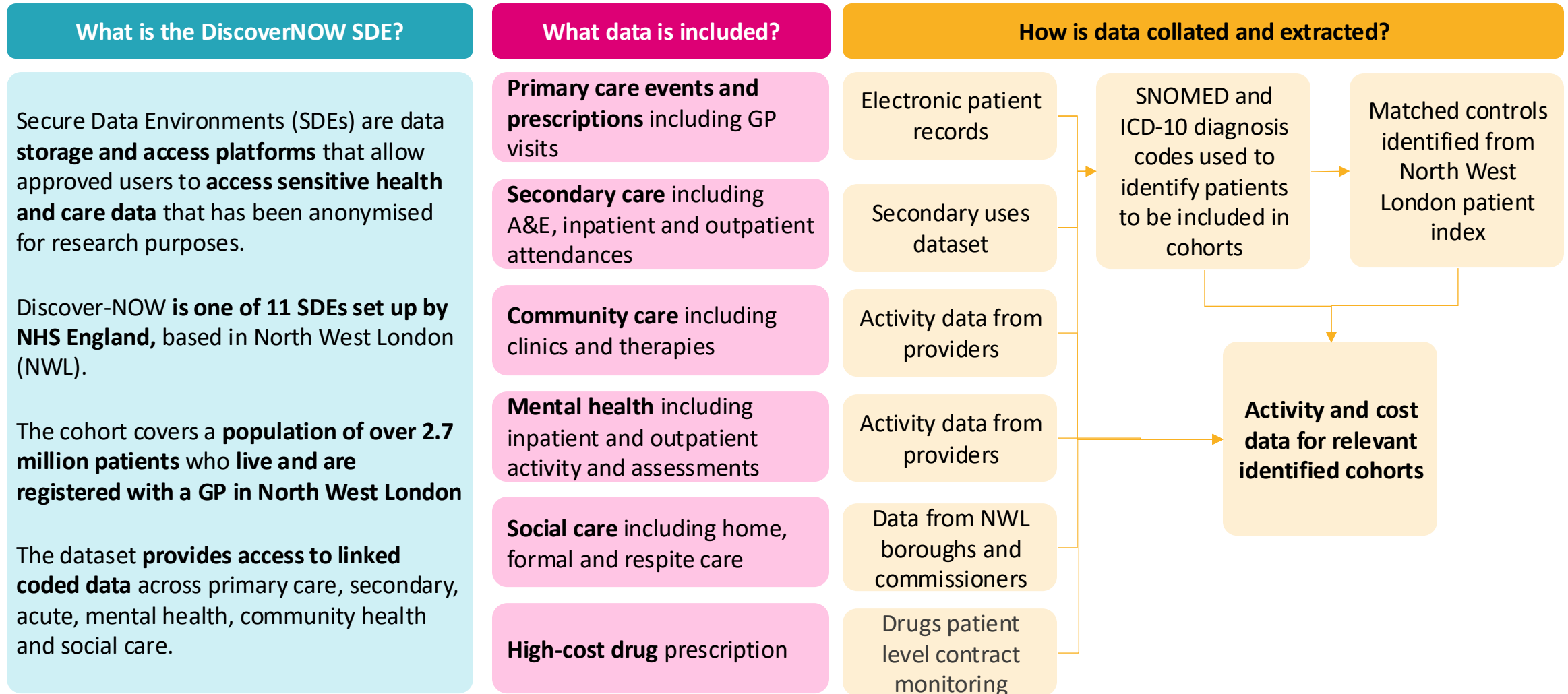
4

This study included an estimation of the **healthcare costs of undiagnosed patients compared to diagnosed patients**, by analysing two years' worth of healthcare costs pre-diagnosis.

5

The data leverages key national datasets for population forecasts and trends in real-term prices over time to **project costs up to 2040**, and health and social care statistics **extrapolate the activity and cost projections to other regions of England, and Scotland, Northern Ireland and Wales.**

The study differs from previous work as it leverages a retrospective cohort study of patient-level data to estimate healthcare costs and study healthcare utilisation



With 26,097 dementia patients, this is one of the largest UK studies of healthcare resource utilisation by patients with dementia

| Study / Cohort | Author(s) | Year | Location | Method | Cohort size |
|---|---------------------------|-------------|-------------|-----------------------------------|----------------|
| Swedish Dementia Registry (SveDem) | Religa, D. et. al | 2015 | Sweden | Internet-based quality registry | 76,747 |
| National Alzheimer's Coordinating Center's Uniform Data Set | Besser, L. et. al. | 2018 | USA | Longitudinal data set | 37,568 |
| Economic & healthcare impact of dementia | Carnall Farrar | 2024 | UK | Retrospective cohort study | 26,097* |
| MRC CFASII (Cognitive Function and Ageing Studies) | Comas-Herrera, A. et. al. | 2017 | England | Screening & diagnostic | 7,796 |
| Paquid Epidemiological Program | Dartigues, J. F. | 2004 | France | Epidemiological study | 3,777 |
| MEMENTO cohort study | Dufouil, C. et. al | 2017 | France | Cohort study | 2,323 |
| Amsterdam Dementia Cohort | Van Der Flier, W. M. | 2018 | Amsterdam | Cohort study | 1,942 |
| Prevalence and etiology of dementia in a Japanese community | Ueda, K. et. al. | 1992 | Japan | Diagnostic | 887 |
| Pain in dementia: prevalence and associated factors | Van Kooten et al. | 2017 | Netherlands | Observational study | 400 |
| Dementia cases in the Framingham Heart Study | Yuan et al. | 2021 | USA | Longitudinal cohort study | 607 |
| Prevalence of dementia in patients in Southern Brazil | Souza et al. | 2019 | Brazil | Retrospective cohort study | 256 |
| Prevalence of dementia in Egypt: a systematic review | Elshahidi, M. H. | 2017 | Egypt | Screening & diagnostic | 126 |
| Geriatric medicine led memory clinic study | Chua et al. | 2019 | Singapore | Retrospective cohort study | 72 |

*Of the 26,097 people with dementia, 2,757 people can be classified into the mild, moderate and severe stages of dementia using recorded mini mental state exam (MMSE) scores.

Clinical and academic dementia experts have been consulted throughout the work to inform development of the approach, define assumptions and validate findings

Alzheimer's Society Research Strategy Council¹

- Professor John O'Brien (Chair) - University of Cambridge
- Dr Paresh Malhotra (Vice-Chair) - Imperial College London
- Dr Joseph Butchart - University of Exeter
- Professor Nick Fox - University College London
- Professor Claire Goodman - University of Hertfordshire
- Professor Barbara Hanratty - Newcastle University
- Dr Li Su - University of Cambridge
- Rosemary Phillips – Research network volunteer and RSC lay representative
- John Major - Research Network Volunteer and RSC lay representative
- Professor Dame Louise Robinson - Professor of Primary Care and Ageing at Newcastle University

Clinical and Economic Experts

- Dr Steve Laitner - GP, Advisory Board Member and Freelance Health Consultant
- Professor Sube Banerjee – Vice-Chancellor for the Faculty of Medicine and Health Sciences, University of Nottingham
- Linda Clare – Chair, Professor of Clinical Psychology of Ageing and Dementia and PenARC Dementia Theme Lead
- Professor Linus Jönsson – Professor, Karolinska Institutet
- Dr Ross Dunne – Consultant Psychiatrist and Clinical Director, Greater Manchester Dementia Research Centre
- Michael Chard – Director of Policy & Analysis, Association of Directors of Adult Social Services
- Philippa Lynch – Partners in Care and Health (joint ADASS/Local Government Association)
- John Jackson - National Care & Health Improvement Adviser Finance
- Raiad Shahzad – Department for Health and Social Care
- Michael Jackson – Program Lead for Neurology and Dementia Intelligence, Office for Health Improvement and Disparities

Study Team

- Carnall Farrar: Ben Richardson, Dorinda Hickey, Nitasha Dhiri, Dr Bec Gray, Will Fryer, Jennifer Leigh
- Imperial College Health partners: James Payne-Gill, Moulesh Shah, Dr Benjamin Pierce

Expert Reviewers

- Professor Dame Louise Robinson – Academic GP and Professor of Primary Care and Ageing at Newcastle University.
- Annie Williamson – Research Fellow at the Institute of Public Policy Research
- Dr Mani Krishnan – Chair, Faculty of Old Age Psychiatry at the Royal College of Psychiatry, Consultant and Specialty Clinical Director at TEWV
- Professor Raphael Wittenberg – Associate Professorial Research Fellow and Deputy Director of CPEC at LSE and Deputy Director of the Centre for Health Service Economics and Organisation at University of Oxford



Executive Summary

Dementia is a major factor in the current pressures on the healthcare system. Its impact will increase sharply as prevalence grows.

- **Dementia is a major factor in the current pressures on the healthcare system**
 - People with dementia account for over **36 million contacts** annually across community, primary and mental health care
 - People with dementia **attend A&E almost a million times a year**
 - People with dementia account for almost **one in six patients in hospital at any given time**
- **Dementia is progressive, and as the condition worsens, healthcare utilisation increases**
 - People with severe dementia have an average length of stay in hospital for unplanned admissions which is more than **three times longer** than people with mild dementia
 - Total bed day utilisation amongst people with severe dementia is **more than twice as high as both people with mild and moderate dementia**
- **However, insufficient investment and attention are paid to diagnosis and treatment**
 - **Diagnostic imaging and neuro-psychology testing** makes up just **2% of all outpatient activity**
- **A lack of dementia diagnosis risks increasing healthcare utilisation**
 - **Undiagnosed people with dementia attend A&E, on average, 1.5 times per year**, which is **more than people with a diagnosis for mild, moderate and severe cohorts**; and three times as much as people without dementia

As dementia severity progresses, healthcare utilisation increases, particularly in the non-elective setting

- **As dementia severity progresses, healthcare utilisation increases**
 - **Non-elective stays drive 85% of inpatient activity in people with dementia** and nearly a third of all dementia healthcare costs
 - Average length of stay of someone with dementia, accounting also for excess bed days¹, is **~18 days for non-elective admissions**
 - **Length of stay increases as severity increases** – people with severe dementia only account for **10% of all elective and non-elective hospital spells but drive 29% of total bed days**
 - On average, people with severe dementia stay more than **three times longer in hospital for non-elective spells than people with mild dementia** and 4 times longer than someone with similar characteristics that doesn't have dementia
- **1 in 6 hospital beds today are occupied by someone with dementia**
 - Longer average lengths of stay for people with dementia lead to many **total bed days and “excess” bed days**¹. Dementia currently accounts for **8.2million bed days annually** and the number of bed days is expected to increase over time in line with increasing dementia prevalence
 - By 2025, people with dementia will require 20.5K acute hospital beds and by 2040 this will increase to 29,400 - **without an increase in bed capacity in the system, this number will increase to 1 in 4 patients in hospitals having dementia by 2040**²
- **Diagnostic testing is currently not very widespread for dementia today, making up only 2% of all outpatient activity**
 - There are around **37,700 MRIs and 13,700 CT scans conducted each year for dementia**, over half of which are carried out on people without a diagnosis
 - **People without a dementia diagnosis are nearly three times as likely to go to A&E** than those with a diagnosis
- **Primary care only drives 8% of total dementia healthcare spend yet it accounts for 43% of all community-based activity**
 - **People with dementia visit the GP up to three times more each year than someone without dementia** and by 2040, there will be 6.9million additional primary care contacts associated with dementia, requiring an estimated **1.7 million more hours of primary care time**
 - Despite significant GP activity, only 6% of all primary care prescriptions for people with dementia today are for dementia-specific treatments, most of which are being administered to people in the mild and moderate cohorts
- **People with dementia are more likely to use community-based services and mental health community services (including therapy and treatment)**
 - People with dementia are **eight times more likely to use general community services** and **ten times more likely to use mental health community services** than people without dementia

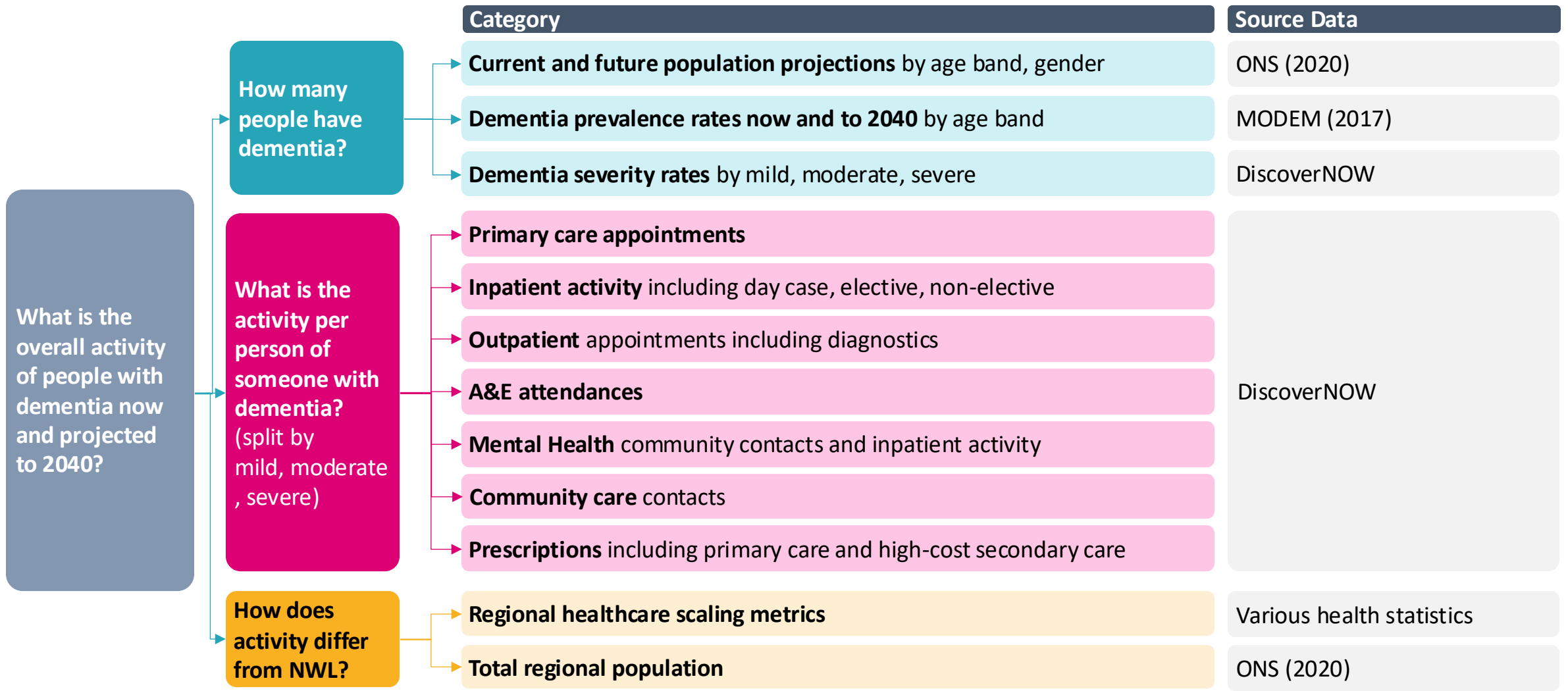
Notes: 1) patients who (for clinical reasons) remain in hospital beyond the expected length of stay (trim point) for the procedure or event they have gone in for; 2) Assuming acute bed capacity stays constant at around 119K beds

Source: CF analysis



Methodology

Patient-level data, public data and literature reviews were used to understand total health and care activity associated with people with dementia



To calculate the total prevalence of dementia, age-banded and time-varying prevalence rates from the MODEM project were applied to ONS population projections

1

Understand current population projections

- 2020-based population projections from ONS¹ were used as the projections of the UK population annually up to 2040
- The projections show annual population estimates by gender, age and local authority

2

Calculate total dementia prevalence

- Prevalence rates from the MODEM project² were applied to the population projections to calculate the estimated number of people with dementia
- The prevalence rates (shown in appendix 1) are for ages 65+; younger ages were excluded from this study due to a lack of evidence for this age group
- The prevalence rates vary by age-band and projection year, but are assumed to be constant across genders and geographical area

3

Calculating total dementia prevalence by severity

- Distribution of people across the dementia severity cohorts was estimated from the 2,757 dementia patients with MMSE scores recorded in the DiscoverNOW dataset (see appendices 2a and 2b for further detail)
- The distribution was applied to the projected dementia population to develop projections of the number of people in each stage of dementia
- The severity distribution was assumed to be constant over time

4

Calculating total dementia prevalence by diagnosis status

- Published data was gathered estimating diagnosis rates for the regions of England and devolved nations (see appendix 3)
- It was assumed that people undiagnosed were in the mild and moderate cohorts only
- The diagnosis rates were applied by geographical area to segment the mild and moderate cohorts into diagnosed and undiagnosed groups

From the population in the DiscoverNOW dataset, seven cohorts were developed to understand healthcare activity across different stages of dementia

Stage 1: Identify and classify cohorts in the data

Dementia - Mild

Dementia - Moderate

Dementia - Severe

Dementia - Unclassified

Pre-diagnosed

No dementia (Control group)

Mild cognitive impairment (MCI)

Identified using SNOMED/ICD-10 diagnosis codes and grouped into mild, moderate and severe cohorts using MMSE scores (where available)

All remaining people with dementia were identified using SNOMED/ICD-10 diagnosis codes without a recorded MMSE score

Identified by looking at people with dementia two years pre-index date

All remaining people that do not fall into the categories above

Identified using SNOMED/ICD-10 diagnosis codes, excluding anyone diagnosed with dementia later in the study period

Stage 2: Identify and classify number of comorbidities

- Patients were flagged as having long-term conditions using a pre-existing list within DiscoverNOW of common conditions
- The number of comorbidities was identified across all patients before classifying each as having **0, 1, 2-3 or 4+ comorbidities**
- The control group was matched to the dementia cohorts using age and comorbidity classification to develop differential costs

Stage 3: Extract data and use for various analyses

Used to identify annual per person healthcare utilisation of people with dementia by severity

Used to identify the healthcare utilisation of people with dementia for low-quality datasets (community and mental health)

Used as a proxy to estimate healthcare healthcare utilisation for people undiagnosed

Used as a control group to isolate dementia healthcare utilisation

Considered in unit activity metrics only - no prevalence estimated

Twelve activity metrics were then identified to explore dementia service utilisation across different settings, with data extracted from DiscoverNOW for each of the cohorts

1. People with **mild** dementia
2. People with **moderate** dementia
3. People with **severe** dementia
4. People **with dementia without a severity classification**
5. People with **mild cognitive impairment**
6. People in the **1-2 years pre-dementia** as a proxy for **undiagnosed dementia**
7. People **without dementia** (control group)

| | | Activity metrics per person | |
|----------------|--------------|---|---|
| Secondary care | Primary Care | 1 | Number of GP contacts |
| | Inpatient | 2 | Number of hospital admissions: Elective & Non-elective |
| | | 3 | Number of bed days: Elective & Non-Elective |
| | | 4 | Number of excess bed days: : Elective & Non-Elective |
| | Outpatient | 5 | Number of outpatient appointments |
| | | 6 | Number of diagnostic tests: including MRIs and CT scans |
| | A&E | 7 | Number of A&E attendances |
| Mental Health | 8 | Total contacts (therapy appointments, attendances) | |
| | 9 | Total admissions | |
| Medication | 10 | Volume of primary care prescriptions | |
| | 11 | Volume of secondary care high-cost drug prescriptions | |
| Community | 12 | Number of contacts ¹ | |

The DiscoverNOW dataset covers North West London; the outputs were scaled to other regions of England and devolved nations using the relative values of various metrics

| Care setting | Metric used | Data sources | | | |
|------------------------------|---|---|--|---|---|
| | | England | Wales | Northern Ireland | Scotland |
| A&E | A&E attendances for people aged 65+ | Hospital Episode Statistics (HES) | StatsWales Health and Social Care metrics | Information & Analysis Directorate, Department of Health: Northern Ireland Hospital Statistics | Public Health Scotland, Accident and emergency data |
| Inpatients | Spell count for people aged 65+, by spell type (day case, elective ordinary, non-elective, regular) | | Digital Health and Care Wales Admitted Patient Care statistics | Information & Analysis Directorate, Department of Health: Inpatient Activity Statistics | Public Health Scotland, Acute hospital activity and NHS beds information (annual) |
| Outpatients | Number of appointments | | Statistics Wales trends in planned care | Department of Health release of Northern Ireland Inpatient, Day case and Outpatient Hospital Statistics | |
| Primary care activity | GPs per population | ONS trends in patient-to-staff numbers at GP practices in England | British Medical Association overview of NHS pressures in Wales | Northern Ireland Statistics and Research Agency General Medical Services Annual Statistics | Public Health Scotland, General Practice Workforce survey report |
| Mental health | Mental health spend | NHS England mental health dashboard | Statistics Wales NHS expenditure | Northern Ireland Audit Office Mental Health Services report | Public Health Scotland, Scottish Health Services Cost report |
| Prescriptions | Items prescribed | NHS Business Services Authority Prescription Cost Analysis | Statistics Wales Primary Care prescriptions | Northern Ireland Statistics and Research Agency General Pharmaceutical Services Annual Statistics | Public Health Scotland, Dispenser payments and prescription cost analysis |
| Community | Insufficient data, no scaling assumed. | | | | |

The following assumptions are made as part of this study

| Ref. | Assumption type | Assumption description |
|------|---------------------------------------|---|
| 1 | Population projections | <ul style="list-style-type: none">Used ONS projections¹ for population growth, from the 2020-based publication |
| 2 | Prevalence rates | <ul style="list-style-type: none">Used prevalence rates from the MODEM project² which vary by age band and projection yearAssumed same prevalence rate across all devolved nations and regions, and across all genders |
| 3 | Severity distribution | <ul style="list-style-type: none">Developed severity distribution from the DiscoverNOW dementia cohortsAssumed constant over time and do not vary by age |
| 4 | Care received ratios | <ul style="list-style-type: none">The study assumes that the ratios of people receiving each type of care remain constant over time |
| 5 | Diagnosis and treatment | <ul style="list-style-type: none">The study assumes that the diagnosis and treatment approaches remain unchanged throughout the projected time period |
| 6 | Care funding | <ul style="list-style-type: none">The study assumes continuation of the current funding systems for provision of care |
| 7 | Unpaid care supply | <ul style="list-style-type: none">The study assumes that there will be sufficient supply of these care streams and has not considered the impact of a potential future shortfall |
| 8 | Cost of an undiagnosed patient | <ul style="list-style-type: none">The study assumes that the healthcare cost and activity of someone undiagnosed can be estimated from the average healthcare costs recorded for the dementia cohort in the two years pre-diagnosisThe study assumed all non-healthcare related costs for someone undiagnosed are the same as someone with a diagnosis |

The approach taken has the following limitations

| Ref | Limitation |
|-----|--|
| 1 | The DiscoverNOW SDE, containing healthcare data for North West London (NWL), offers a level of data richness not found elsewhere, However, the population is not fully representative of national demographics. NWL's population skews slightly older, is less deprived than national average, with a much larger percentage of minority populations. This dataset also doesn't represent rural, coastal and remote regions. This has been controlled for by scaling activity using a range of public healthcare activity metrics. However, this implicitly assumes that activity for people with dementia is proportional to the population described by each metric. |
| 2 | MMSE scores have been used to classify severity but coverage is only 11% today – with so many missing MMSE scores there are some data irregularities in projected costs for mental health and community – the cost of unclassified patients has been used in these instances. |
| 3 | The activity totals calculated for this study are the total activity of people with dementia rather than the marginal extra activity for people with dementia in comparison with people not experiencing dementia. This is due to the challenges associated with disaggregating the healthcare utilisation impact of dementia itself with other co-morbidities. This approach is in line with other studies that have also explored the total healthcare utilisation of people with dementia . |

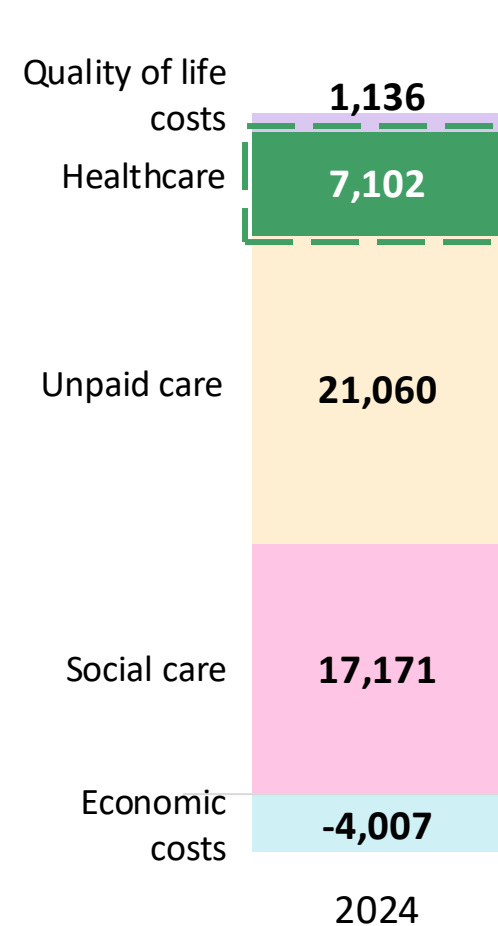


Healthcare utilisation across dementia and non- dementia cohorts

From Module 1: Healthcare costs make up only 14% of total dementia costs, with a third of this cost attributed to inpatient stays in hospital

Total cost by cost type

£millions



Total and average per person costs by severity

2024, UK average

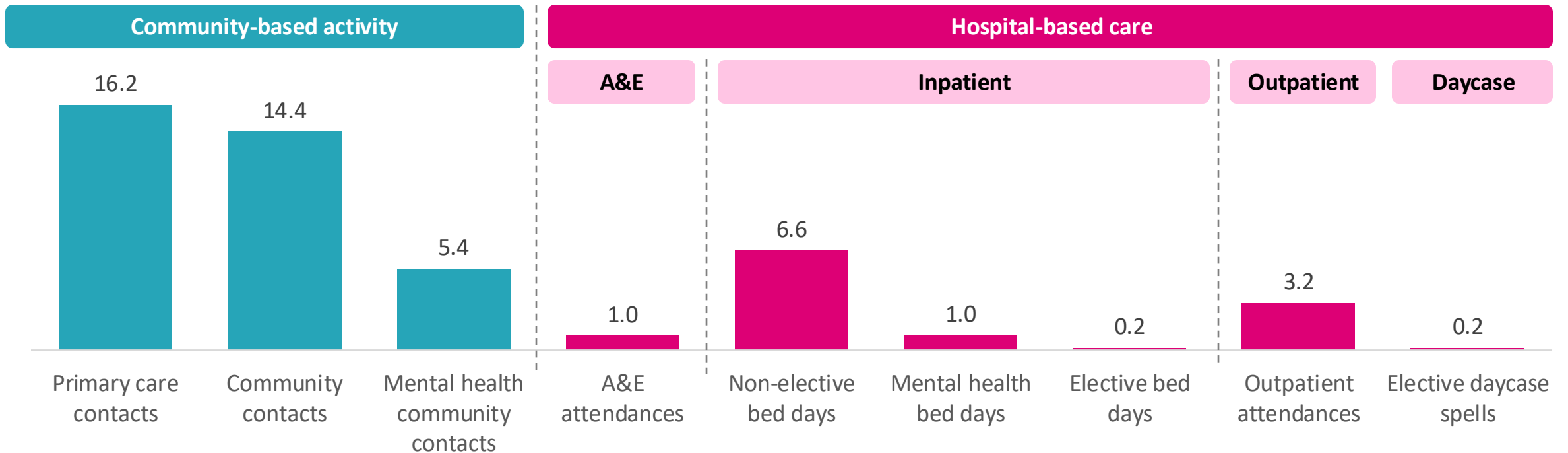
| Cost type | Total cost (billions) | Category | Category cost (billions) | Per person cost (000s) | | | | |
|----------------|-----------------------|-------------------------------------|--------------------------|------------------------|-------------|-------------|---------------|--|
| | | | | Mild | Moderate | Severe | Pre-diagnosed | |
| Secondary care | £3.3 | Inpatient activity | £2.8 | £2.9 | £2.8 | £3.7 | £2.5 | |
| | | Outpatient activity | £0.3 | £0.3 | £0.2 | £0.1 | £0.4 | |
| | | A&E attendances | £0.2 | £0.2 | £0.2 | £0.2 | £0.3 | |
| Mental health | £1.6 | Community activity | £1.2 | £1.4 | £1.4 | £1.4 | £1.0 | |
| | | Inpatient activity | £0.4 | £0.5 | £0.5 | £0.5 | £0.1 | |
| Community care | £0.9 | Community care | £0.9 | £1.0 | £1.0 | £1.0 | £0.7 | |
| Medicines | £0.7 | General primary care prescriptions | £0.6 | £0.6 | £0.5 | £0.5 | £0.6 | |
| | | Dementia primary care prescriptions | £0.02 | £0.04 | £0.03 | £0.03 | £0.01 | |
| | | High-cost drugs | £0.1 | £0.15 | £0.16 | £0.04 | £0.16 | |
| Primary care | £0.6 | Contacts | £0.6 | £0.6 | £0.6 | £0.5 | £0.6 | |
| Total | £7.1 | | £7.1 | £7.8 | £7.5 | £8.0 | £6.5 | |

Notes on data & methodology: The pre-diagnosed cohort is patients in the two years before a diagnosis is recorded. For mental health and community care costs, data quality did not allow per person costs by severity cohort, so the unclassified dementia cohort was used.

Non-elective care accounts for 86% of all inpatient dementia activity, while primary care accounts for 45% of all community-based activity

Healthcare activity: comparison of total estimated activity by setting

Millions, 2024



- **Non-elective bed days are the largest driver of inpatient activity**, with a relatively small amount of elective activity in comparison
- If a contact, attendance and bed day are equated, **primary care contacts are the largest share of healthcare activity**, almost triple that within mental health community and 16 times more than in A&E, **despite only driving 8.5% of healthcare costs**
- Contacts are defined **as any type of formal interaction a patient** has with a healthcare professional in each setting

As dementia severity progresses, healthcare utilisation increases, particularly in the non-elective inpatient, primary care and community care settings

Healthcare activity per person per year by setting

2024

| | | Control (without dementia) | Mild cognitive impairment | Pre-dementia | Mild | Moderate | Severe |
|----------------------------------|-----------------|----------------------------|---------------------------|--------------|------|----------|--------|
| Emergency | A&E attendances | 0.5 | 0.6 | 1.5 | 0.9 | 1 | 0.7 |
| Primary care | Contacts | 7.0 | 11.9 | 16.9 | 17.2 | 14.8 | 12.5 |
| Non-elective | Bed days | 0.7 | 1.5 | 5 | 5.7 | 6.7 | 14 |
| | Excess bed days | 0.1 | 0.1 | 1 | 0.5 | 1.5 | 4.1 |
| | Spells | 0.1 | 0.2 | 0.5 | 0.6 | 0.5 | 0.5 |
| Elective | Day case | 0.3 | 0.3 | 0.2 | 0.2 | 0.2 | 0.1 |
| | Bed days | 0.2 | 0.2 | 0.3 | 0.2 | 0.1 | 0 |
| | Excess bed days | 0 | 0 | 0.1 | 0.1 | 0 | 0 |
| | Spells | 0 | 0.1 | 0 | 0 | 0 | 0 |
| Outpatient appointments | CT scans | 0 | 0 | 0.01 | 0.02 | 0.01 | 0.02 |
| | MRI (Head) | 0.01 | 0.01 | 0.06 | 0.03 | 0.02 | 0.01 |
| | Other | 3.1 | 3.8 | 4.2 | 3.2 | 2.4 | 1.3 |
| Mental Health¹ | Contacts | 0.6 | 0.5 | 4.3 | 4.4 | 4.5 | 2.2 |
| | Inpatients | 0.1 | 0.0 | 0.4 | 1.5 | 1.5 | 1.5 |
| Community¹ | Contacts | 1.9 | 4.7 | 12.2 | 16.4 | 16.4 | 16.4 |

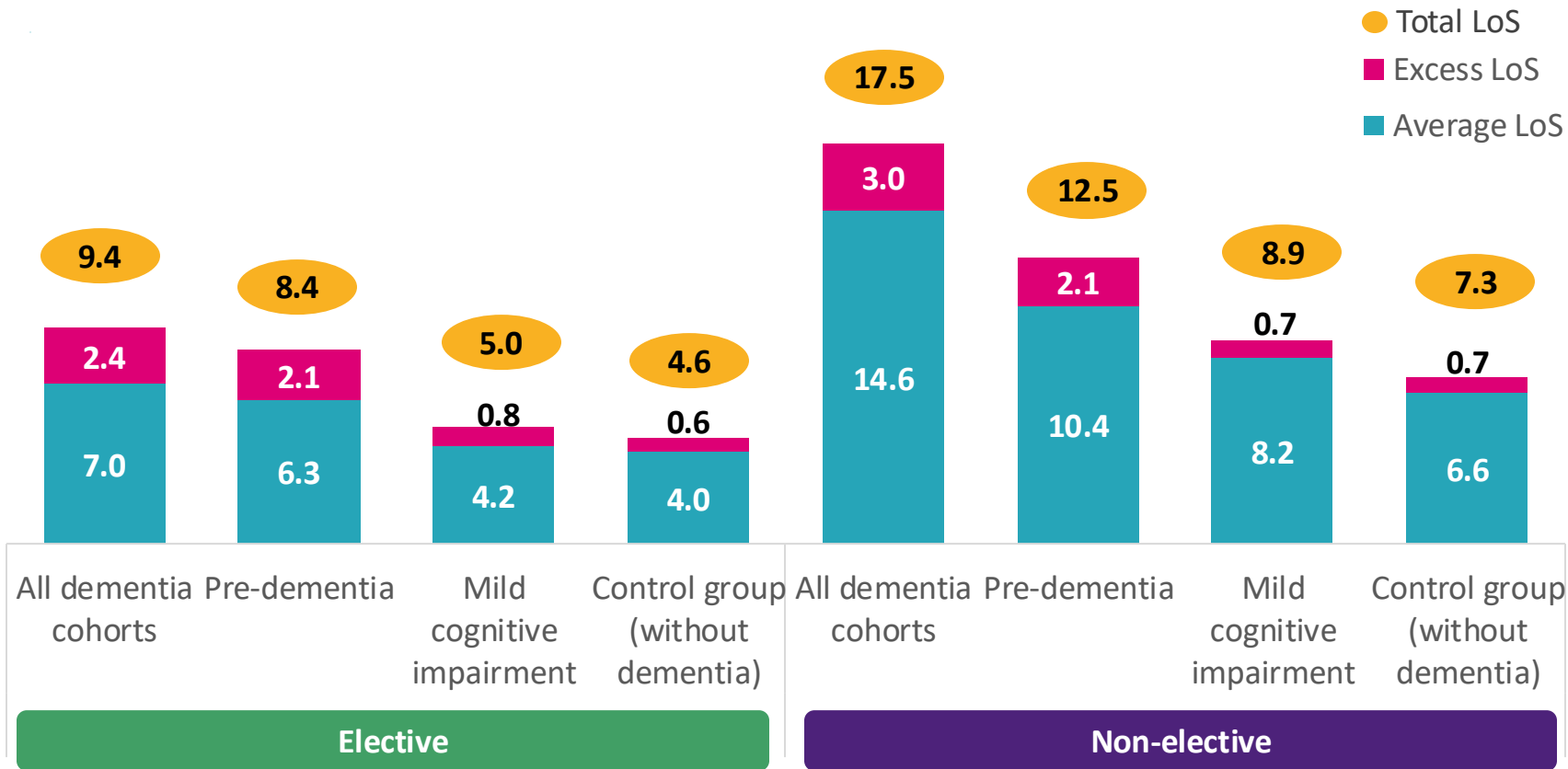
- Healthcare utilisation is higher for all dementia cohorts across most metrics, especially for primary and community care and non-elective hospital bed days
- On average, each year a person with severe dementia stays 20 times longer in hospital for a non-elective admission than someone without dementia and three times longer than someone with mild dementia
- A&E activity is highest for the pre-dementia and mild cohorts, which could be driven by an increase in accidents and falls or behavioural abnormalities that the family doesn't understand

Note on data & methodology: For mental health and community care costs, data quality did not allow per person costs by severity cohort, so the unclassified dementia cohort was used.

People with dementia stay significantly longer in hospital than people without dementia for non-elective admissions, staying over 2 weeks on average each time they are in hospital

Average and excess length of stay (LoS) per hospital spell

Days, 2024



- People with dementia stay over twice as long for acute inpatient care compared to patients with similar characteristics that don't have dementia, particularly for unplanned admissions
- People with dementia are also more likely to experience excess stays in hospital

Note on data & methodology: An excess bed day is recorded for patients who (for clinical reasons) remain in hospital beyond the expected length of stay (trim point) for the procedure or event they are admitted for. The trim point is set by NHSE based on analysis of length of stay statistics by Healthcare Resource Group (HRG) and admission type.

For non-elective activity the average length of stay increases as dementia severity increases – on average, a person with severe dementia will be in hospital for around one month

Average length of stay per hospital spell by severity

Days, 2024

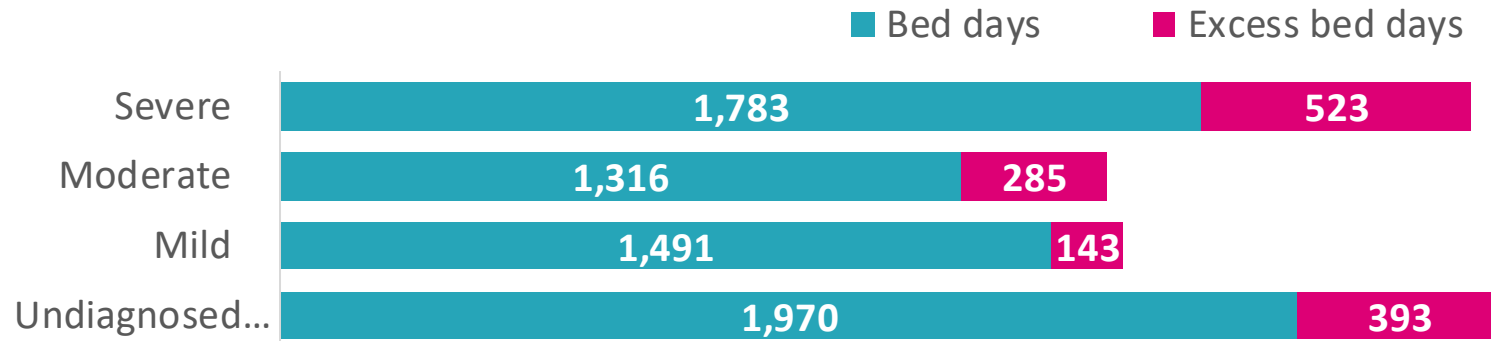
| | | Control group (no dementia) | Mild | Moderate | Severe |
|--------------|------------------------|--------------------------------|------|----------|-------------|
| Elective | Average length of stay | 4 | 7 | 7.6 | 0.1 |
| | Excess length of stay | 0.6 | 3 | 2.1 | 0 |
| Non-Elective | Average length of stay | 6.6 | 9.3 | 12.7 | 27.7 |
| | Excess length of stay | 0.7 | 0.9 | 2.7 | 8.1 |

- Average length of stay for non-elective spells is more than three times higher for **people with severe dementia** than for people with mild dementia, and four times longer than the control group
- A **person with severe dementia** will be in hospital for around **one month on average** for an unplanned admission
- People with mild or moderate dementia also have a higher number of excess bed days per spell for elective activity

Longer average lengths of stay for people with dementia leads to a large number of total bed days; dementia accounts for 8.2million bed days annually

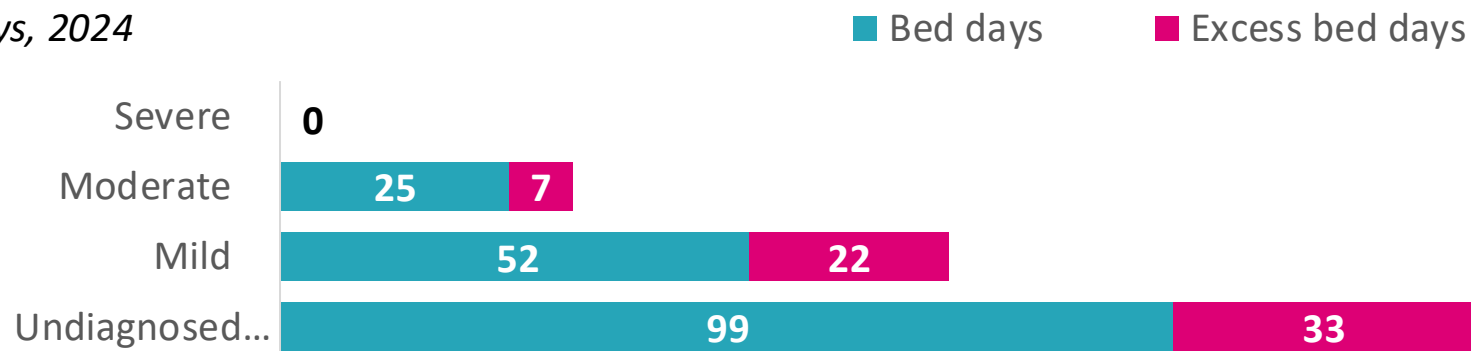
Total number of hospital bed days for each severity cohort: Non-elective spells

000s days, 2024



Total number of hospital bed days for each severity cohort: Elective spells

000s days, 2024



- People with dementia, with a diagnosis, account for **5.5million bed days each year**, while pre-dementia patients account for a further **2.5million of all bed days**
- **People with severe dementia** account for **10% of all elective and non-elective hospital spells** but **29% of total bed days for dementia**

Note on data & methodology: The healthcare utilisation for undiagnosed patients has been estimated by using the per person activity of people in the two years pre-diagnosis and multiplying this by the estimated number of undiagnosed dementia patients based on published diagnosis rates.

One in six hospital beds today are occupied by someone with dementia, a high figure for a condition with a relatively low prevalence rate

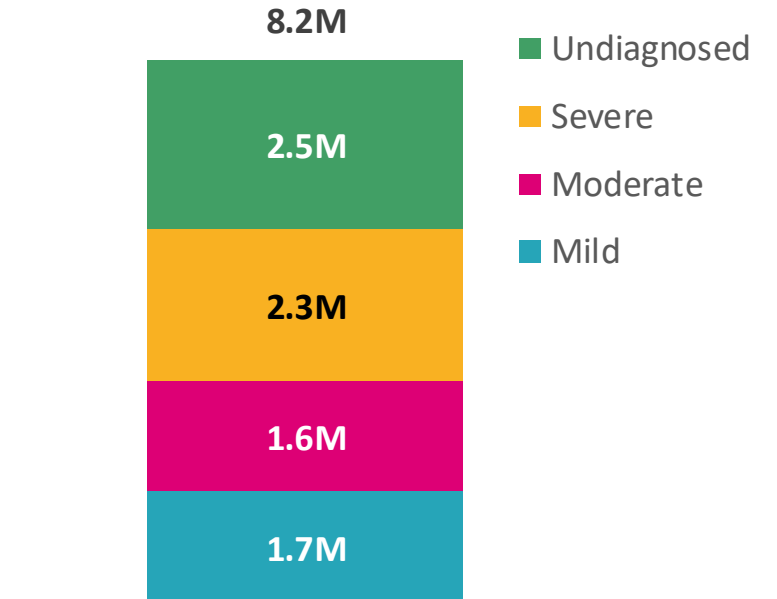
Prevalence and prevalence rates for major conditions

2022/23, England and Wales

| Condition | Prevalence millions | Prevalence rate ¹ |
|---------------------------------------|---------------------|------------------------------|
| Hypertension | 9.8 | 14.4% |
| Depression | 9 | 13.2% |
| Obesity | 7.7 | 11.4% |
| Diabetes melius | 5.1 | 7.5% |
| Asthma | 4.4 | 6.5% |
| Chronic kidney disease | 2.8 | 4.2% |
| Cancer (aggregated) | 2.4 | 3.5% |
| Ischaemic heart disease | 2.0 | 3.0% |
| Atrial fibrillation | 1.4 | 2.1% |
| Stroke and transient ischaemic attack | 1.3 | 1.8% |
| Chronic obstructive pulmonary disease | 1.3 | 1.8% |
| Dementia | 0.9 | 1.4% |

Total dementia patient bed days

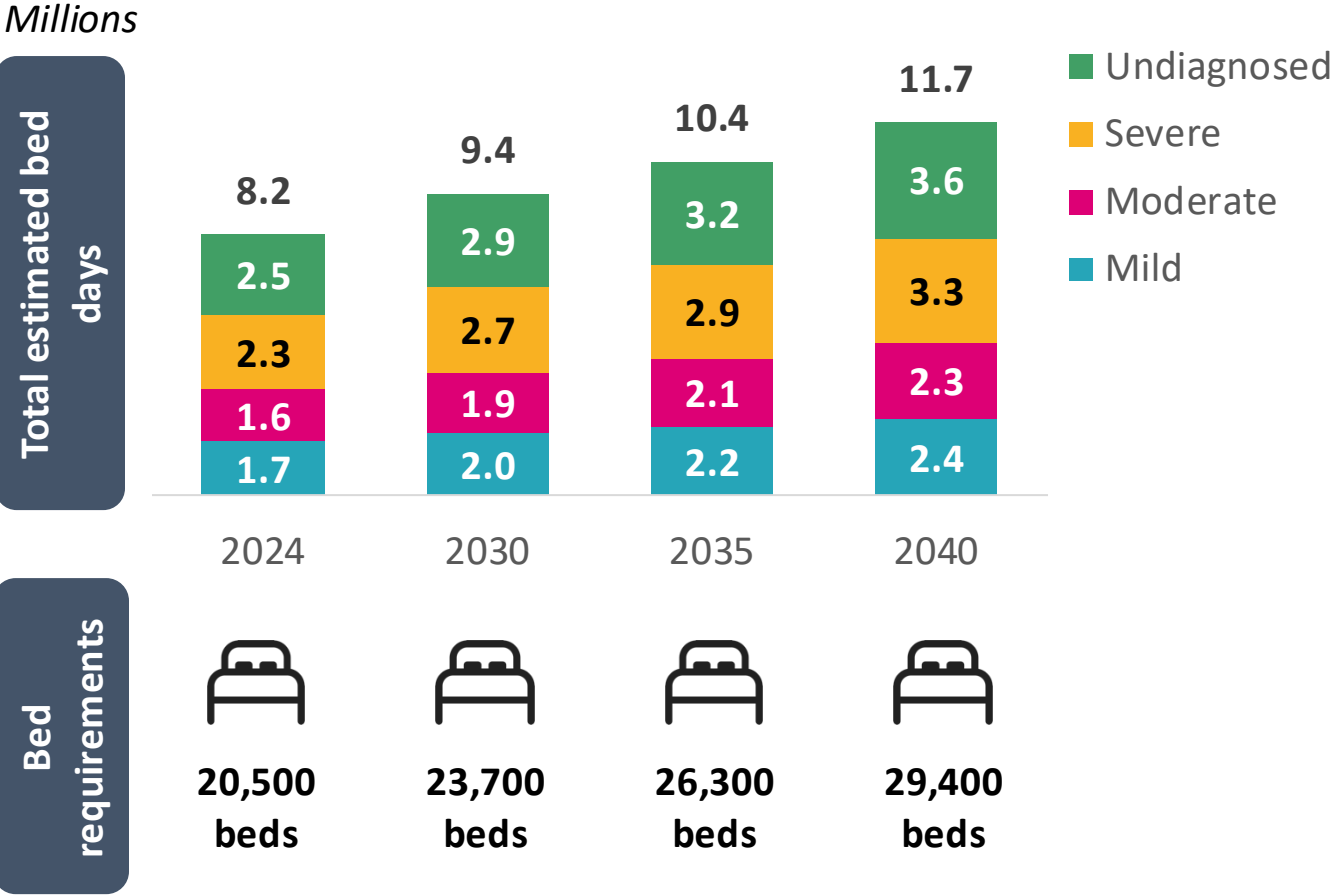
2024, UK



- **Bed capacity hasn't increased over time** – until COVID-19, the number of beds in the system was in decline
- The most recent statistic show that there are **over 132,000 acute hospital beds in UK** (104,000 in England², 9,000 in Wales³, 6,000 in Northern Ireland⁴ and 13,000 in Scotland⁵)
- Assuming a **bed occupancy of 92%**, **one in six hospital beds** today are occupied by someone with **dementia**

In our projections of healthcare utilisation, the number of bed days for people with dementia is expected to increase over time, growing from 20,500 beds in 2024, to 29,400 by 2040

Bed days and bed requirements for people with dementia

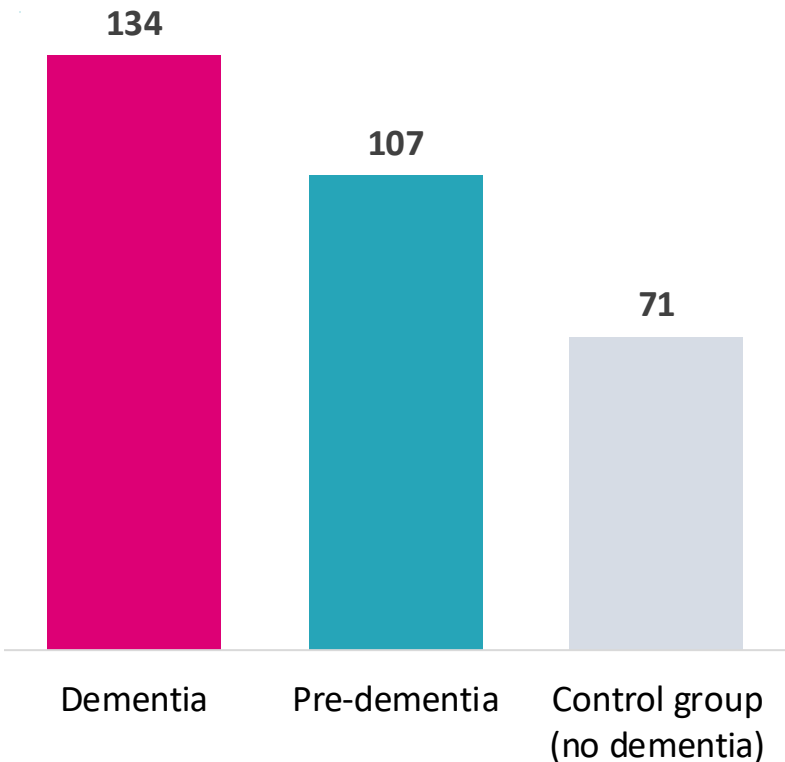


- Total **hospital inpatient bed days** are expected to **increase over time**, in line with increasing dementia prevalence
- In 2040, people with dementia will have an estimated **11.7million bed days**
- By current estimates, **one in six hospital beds** are occupied by a person with dementia today
- If this ratio is maintained, the UK will require **an additional 8,900 beds by 2040, an increase of 43%**
- If the current number of beds does not increase, **by 2040 people with dementia will occupy one in four beds**

Length of stay is even higher in the mental health setting, with people staying nearly five months for each inpatient admission

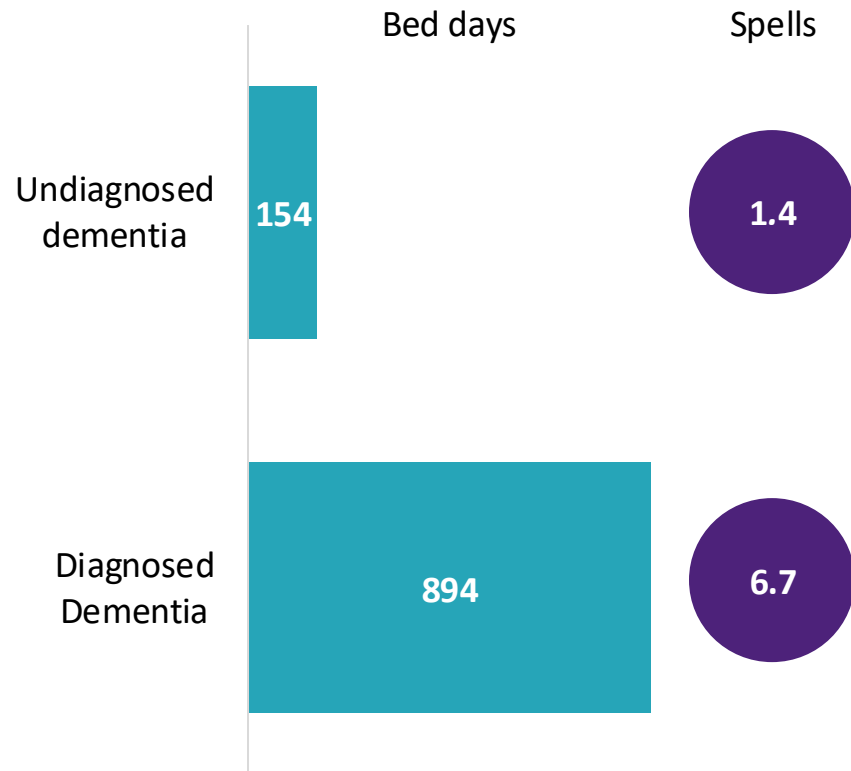
Mental health: average length of stay

2024



Mental health: total bed days and spells

000s, 2024



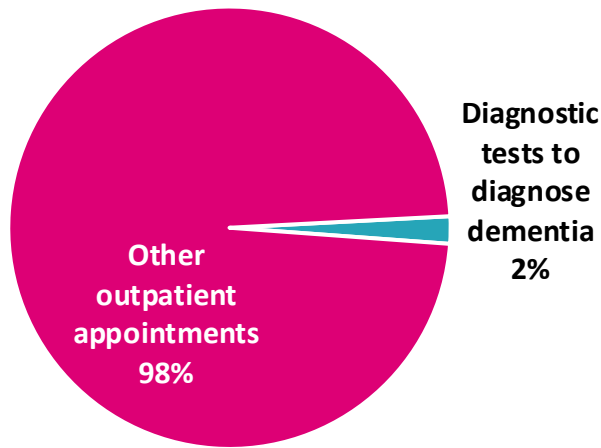
- There are around **1million inpatient bed days each year** in the mental health setting
- People with dementia admitted to a mental health hospital **stay twice as long as those who are admitted with similar characteristics but don't have dementia**, staying almost **five months on average**

***Note on data & methodology:** The total healthcare utilisation for undiagnosed patients has been estimated by using the per person activity of people in the two years pre-diagnosis and multiplying this by the estimated number of undiagnosed dementia patients based on published diagnosis rates.*

Diagnostic imaging and neuro-psychology testing makes up 2% of all outpatient activity, with undiagnosed patients accounting for almost half of all this diagnostic activity

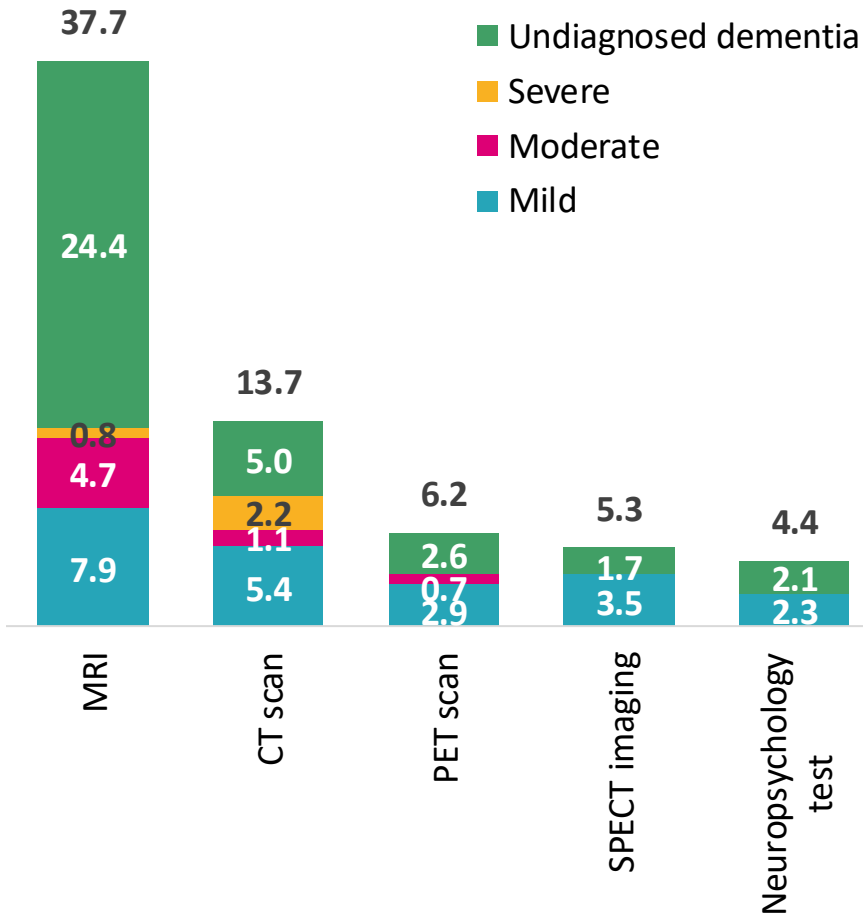
All outpatient activity by type

2024



Dementia-related diagnostic testing volumes

000s, 2024



- The volume of diagnostic tests that are used to diagnose dementia is very small compared to the total number of outpatient appointments, at less than 2% of the total
- Based on the estimates in this study, a total of 37,000 MRI scans of the head will be administered to people with dementia or in the two years pre-diagnosis in 2024 in the UK, compared to a total of 4.1million MRIs in England in 2023

All outpatient activity by type and dementia cohort

000s

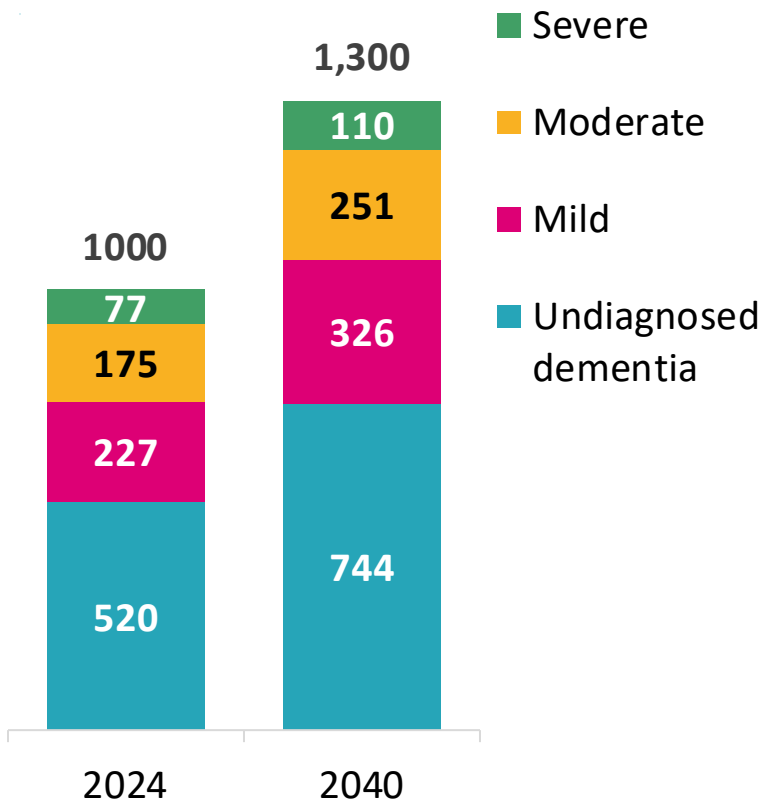
| | Mild | Moderate | Severe | Undiagnosed |
|--------------------------------------|-------|----------|--------|-------------|
| Diagnostics | 22.1 | 6.5 | 3.0 | 35.8 |
| Other outpatient appointments | 979.2 | 558.5 | 157.5 | 1591.4 |

Notes on data & methodology: The activity shown is for testing relevant to dementia that was recorded in the outpatient setting. Additional activity may have occurred in the mental health care setting that could not be analysed from the available data.

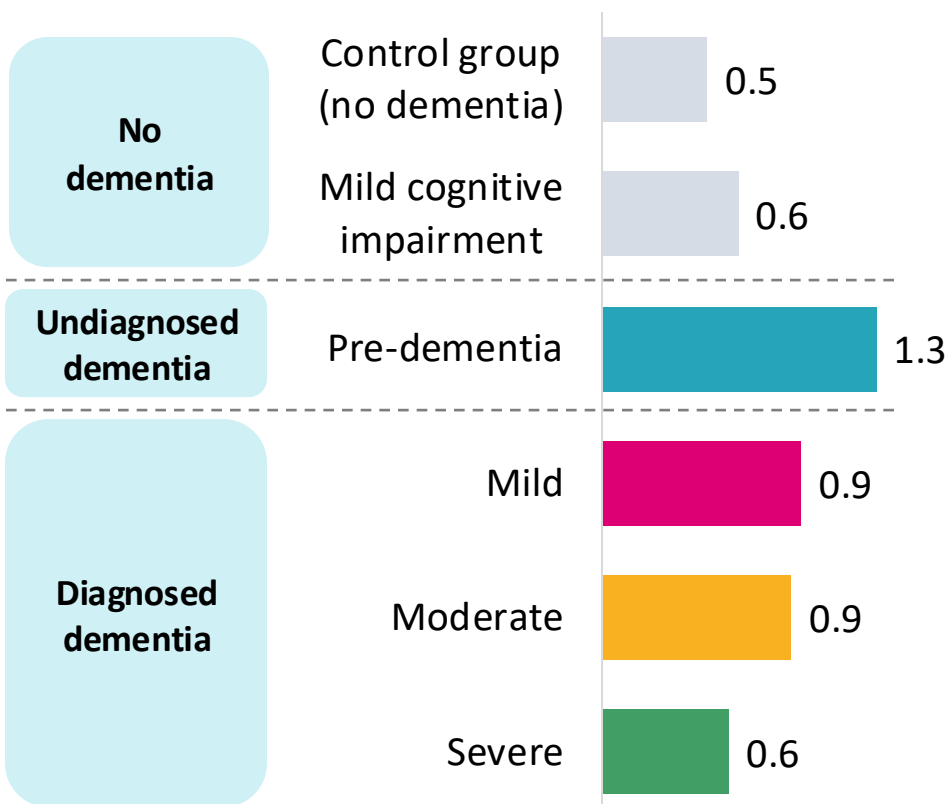
Undiagnosed people with dementia are nearly 3 times more likely to go to A&E than those without dementia

Total A&E attendances

000s



Average A&E attendances per person



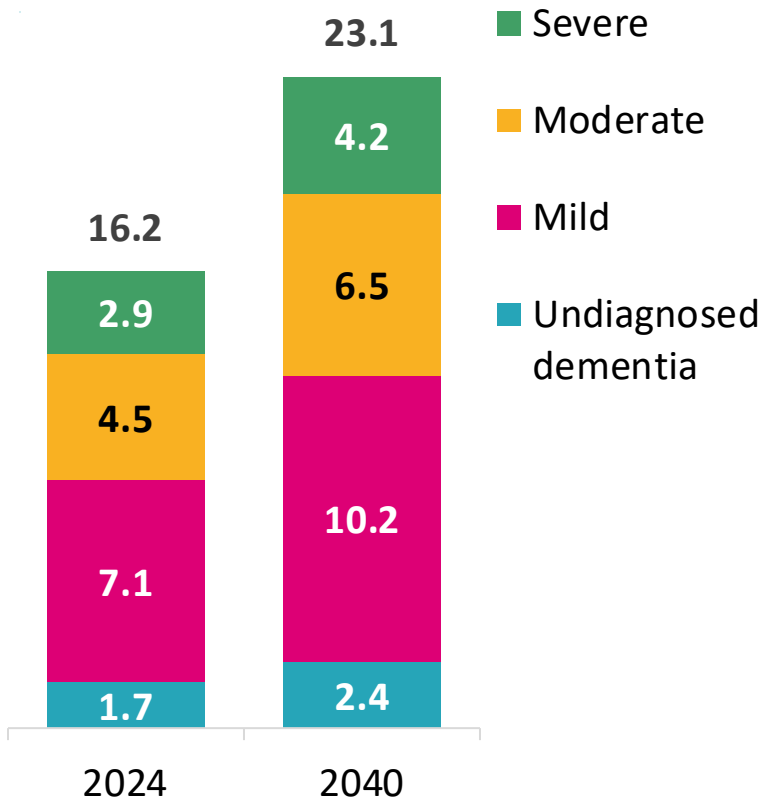
- On average, people in the dementia cohorts attend A&E more than the control cohort
- The highest number of A&E attendances per person was for the pre-dementia cohort
- These people may not receive the care they need or make the lifestyle changes required to reduce the likelihood of accidents that subsequently require hospital care

Note on data & methodology: The total healthcare utilisation for undiagnosed patients has been estimated by using the per person activity of people in the two years pre-diagnosis and multiplying this by the estimated number of undiagnosed dementia patients based on published diagnosis rates.

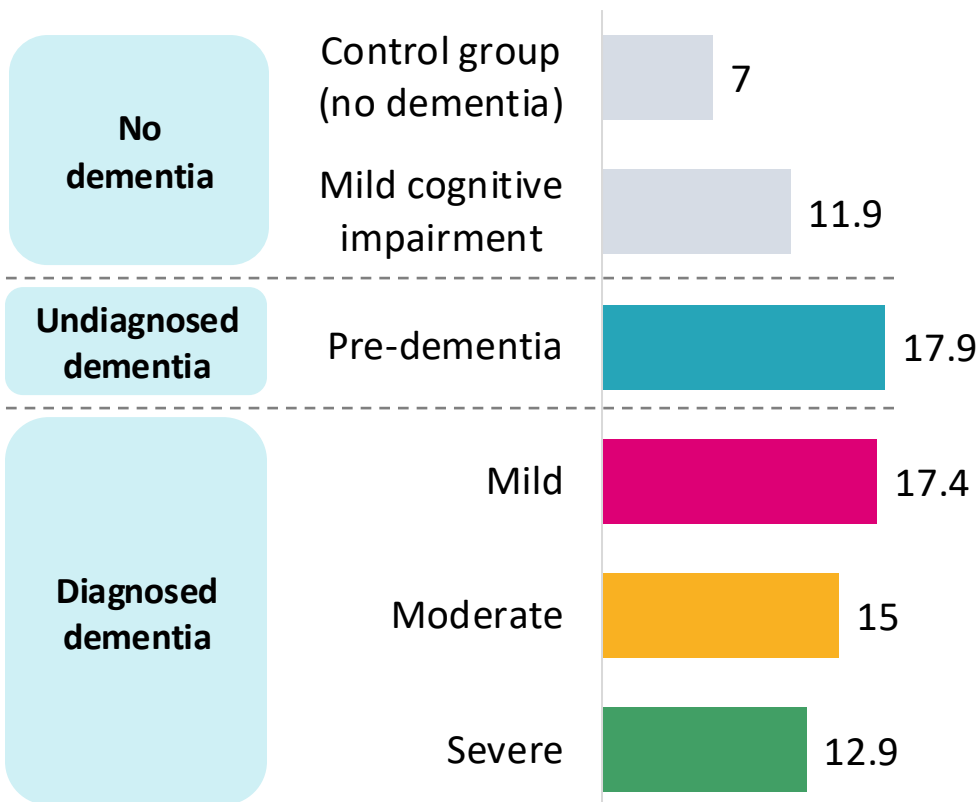
By 2040 an additional 6.9 million primary care contacts will be required each year, representing a 43% increase on the current 2024 activity

Total primary care contacts

Millions



Average primary care contacts per person

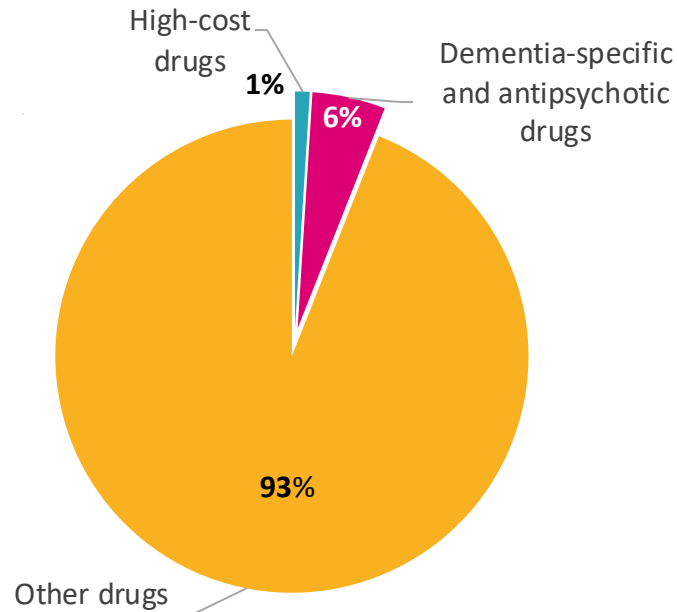


- Unlike other healthcare activity metrics, the number of primary contacts decreases with increasing severity
- People with dementia visit the GP between 1.5 and 2.5 times more each year than someone without dementia
- Assuming the average length of a GP interaction is 15 mins, GPs are spending nearly 4.1 million hours a year with dementia patients, which is expected to increase by 43% by 2040

Note on data & methodology: The total healthcare utilisation for undiagnosed patients has been estimated by using the per person activity of people in the two years pre-diagnosis and multiplying this by the estimated number of undiagnosed dementia patients based on published diagnosis rates.

Despite significant primary care activity, only 6% of all prescriptions are for dementia-specific treatments

Prescribing patterns in dementia patients



Note on data & methodology: The total healthcare utilisation for undiagnosed patients has been estimated by using the per person activity of people in the two years pre-diagnosis and multiplying this by the estimated number of undiagnosed dementia patients based on published diagnosis rates.

Total prescriptions for dementia patients per year

Millions, 2024

| | Mild | Moderate | Severe | Undiagnosed dementia | Total |
|---------------------|-------------|-------------|-------------|----------------------|--------------|
| AChE inhibitors | 1.3 | 0.8 | 0.4 | 0.1 | 2.6 |
| Memantine | 0.5 | 0.4 | 0.2 | 0.03 | 1.1 |
| Antipsychotics | 0.2 | 0.2 | 0.1 | 0.2 | 0.6 |
| High-cost drugs | 0.1 | 0.04 | 0.03 | 0.1 | 0.3 |
| Other prescriptions | 30.5 | 21.0 | 10.8 | 47.9 | 110.4 |
| Total | 32.6 | 22.4 | 11.5 | 48.4 | 114.9 |

- Prescriptions are expected to **grow by 40% over the next 20 years in line with increasing dementia prevalence**
- Only a very small share of **medicine costs relate to dementia specific treatments**
- People in the dementia cohorts receive **nearly 2-3 times the number of prescriptions** compared to the control group

Per person prescriptions for all patients per year

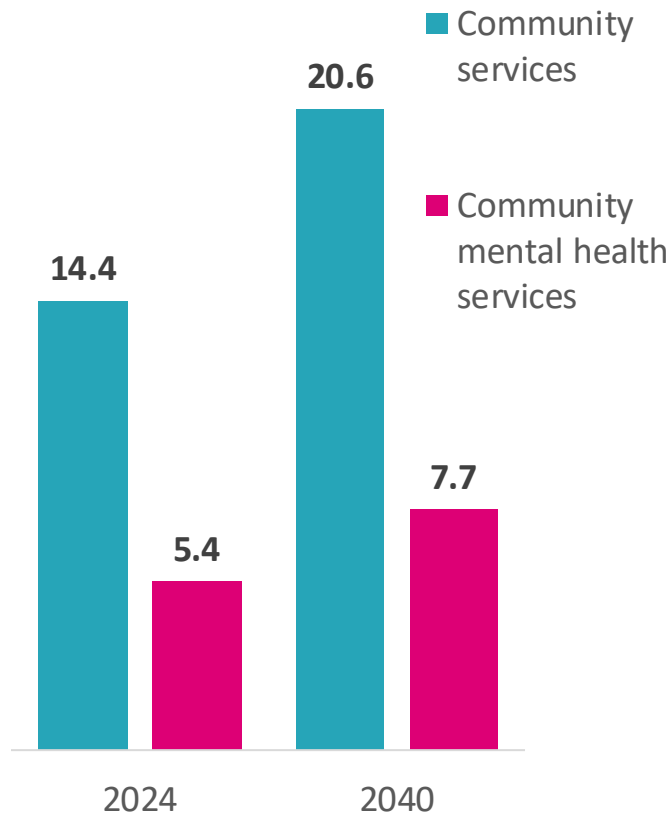
Millions, 2024

| | Control (no dementia) | MCI | Pre-dementia | Mild | Moderate | Severe |
|---------------------|-----------------------|-----|--------------|------|----------|--------|
| AChE inhibitors | - | - | 0.3 | 5.2 | 4.1 | 2.8 |
| Memantine | - | - | 0.1 | 1.9 | 2.0 | 1.5 |
| Antipsychotics | 0.2 | 0.2 | 0.5 | 0.6 | 0.8 | 0.7 |
| High-cost drugs | 0.4 | 0.6 | 1.4 | 0.9 | 0.9 | 0.6 |
| Other prescriptions | 47 | 78 | 120 | 118 | 108 | 85 |

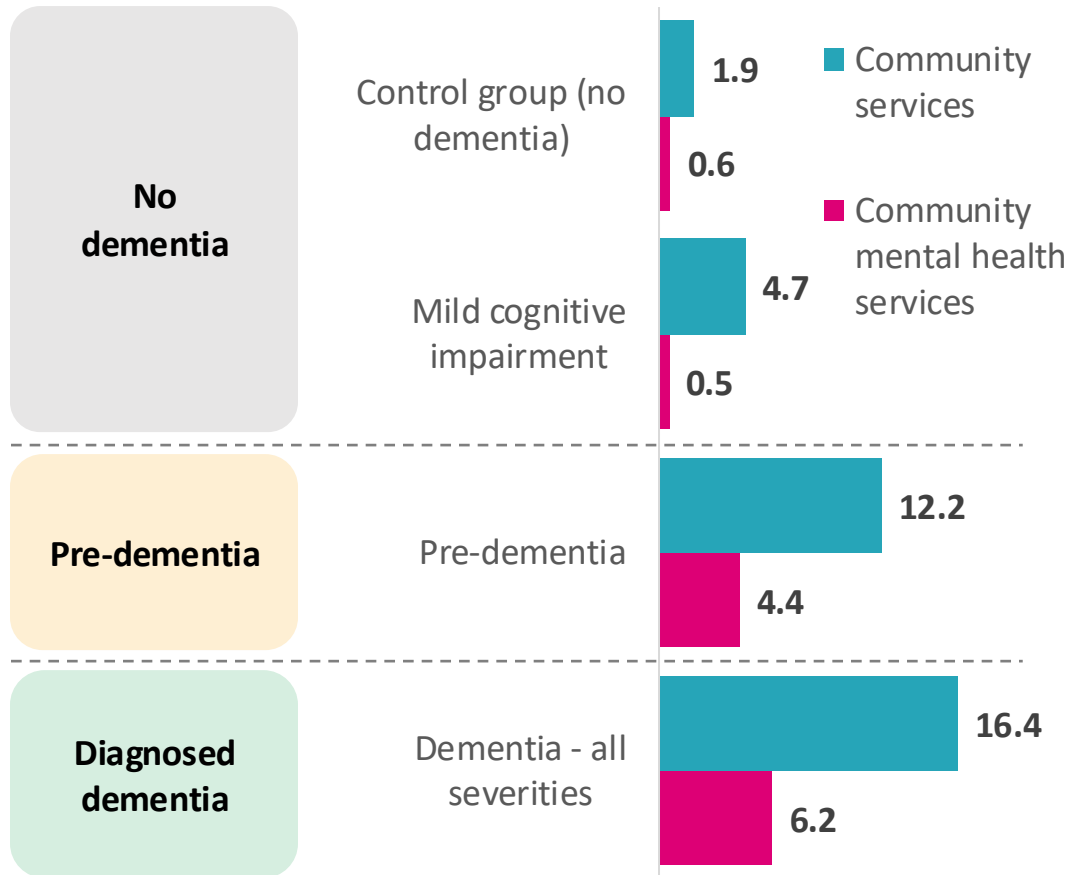
People with dementia are eight times more likely to use community-based services and ten times more likely to use community mental health services than the control cohort

Annual contacts for people with dementia

Millions



Annual contacts per head



- Community contacts include a **range of therapies and services**, including: crisis response services, diabetes services, dietician, district nursing, intermediate care, occupational therapy, palliative care, physiotherapy, podiatry, rehabilitation and specialist nursing
- Mental health community services include** psychological therapies, improved physical health care, employment support, personalised and trauma informed care, medicines management and support for self-harm and coexisting substance use.



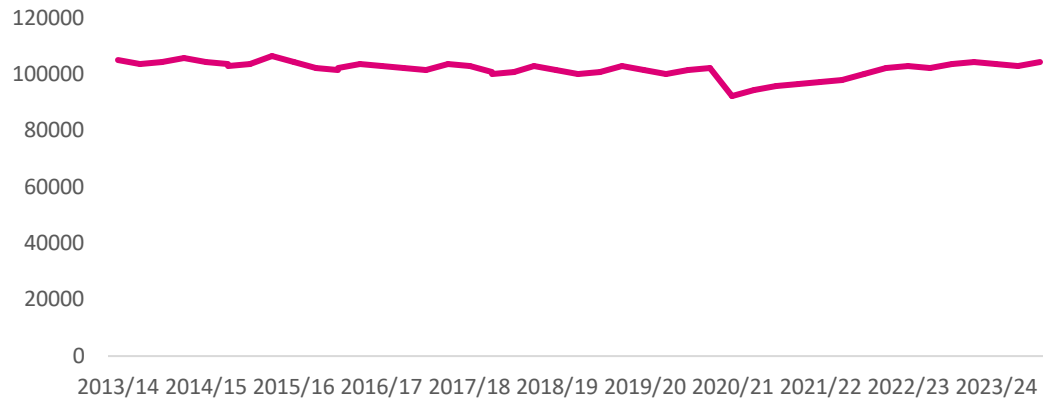
Appendices



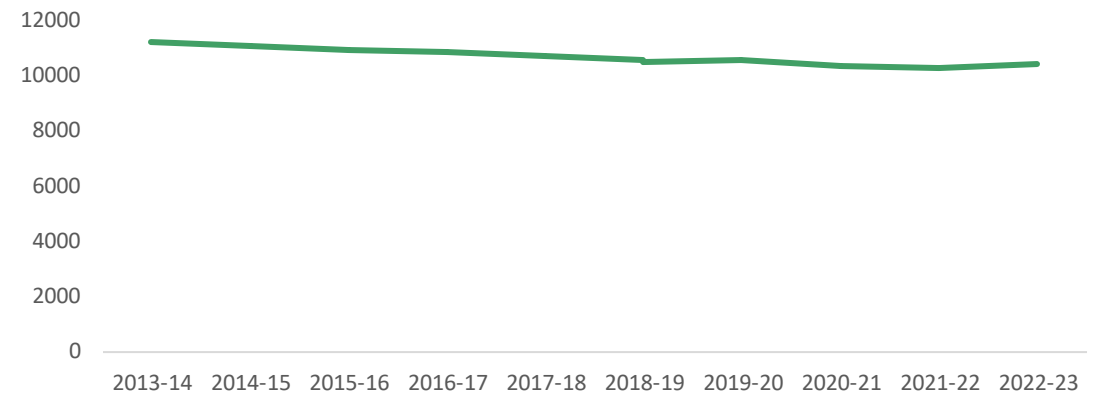
Bed capacity

Acute bed availability has been relatively unchanged in recent years, with around 132,000 beds in the UK

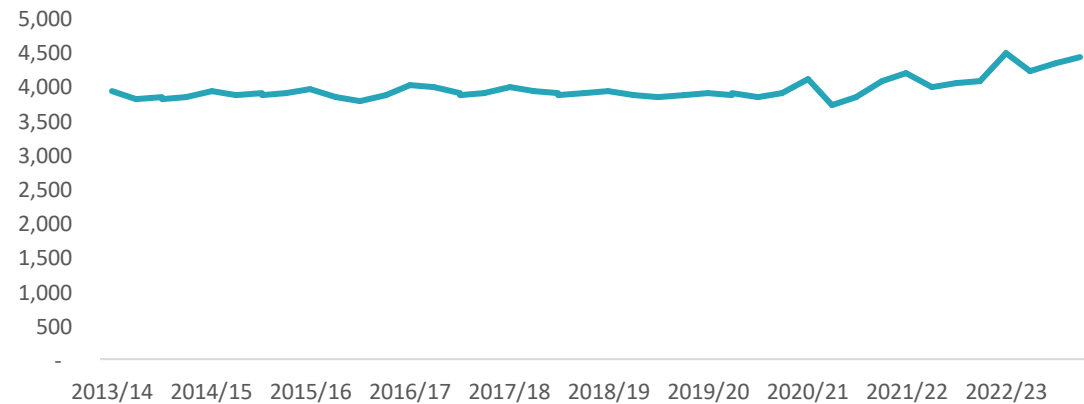
England: Acute bed Availability¹



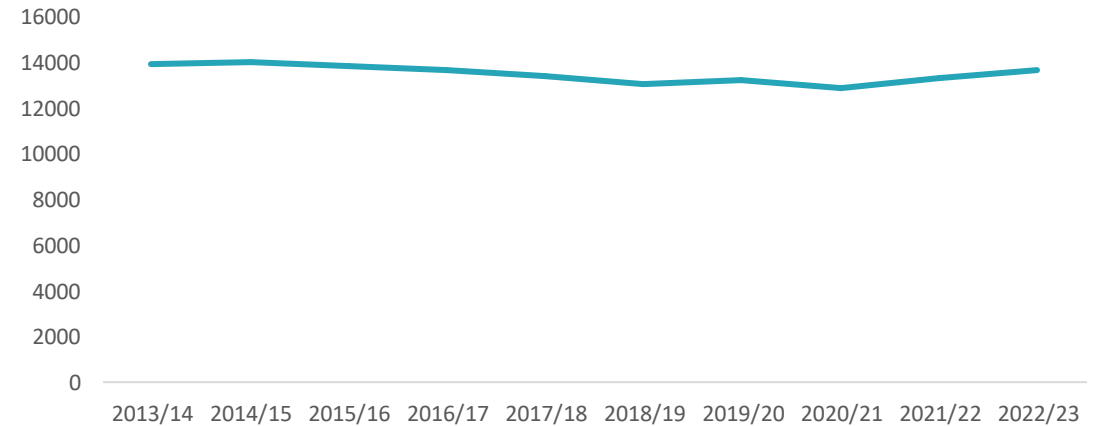
Wales: Acute bed Availability²



Northern Ireland: Acute bed Availability³



Scotland: Acute bed Availability⁴



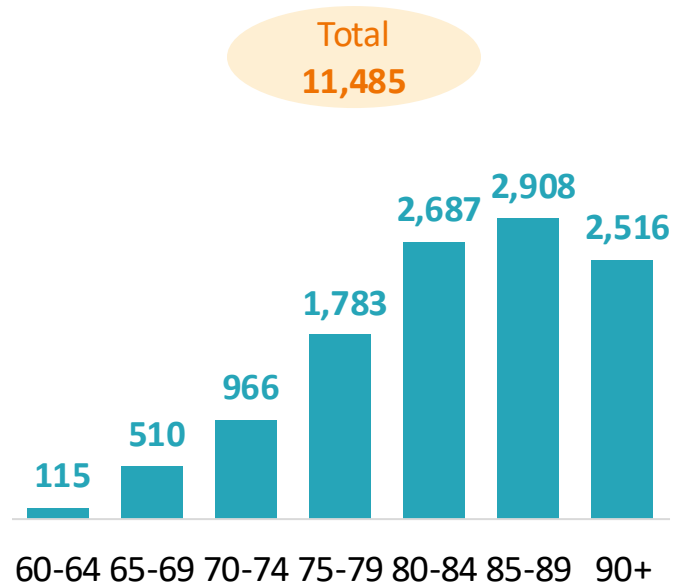


Dementia cohort characteristics

There are currently **11,500** identifiable, living people with dementia and **94,600** people with mild cognitive impairment in North West London. **70%** of people with dementia are over 80.

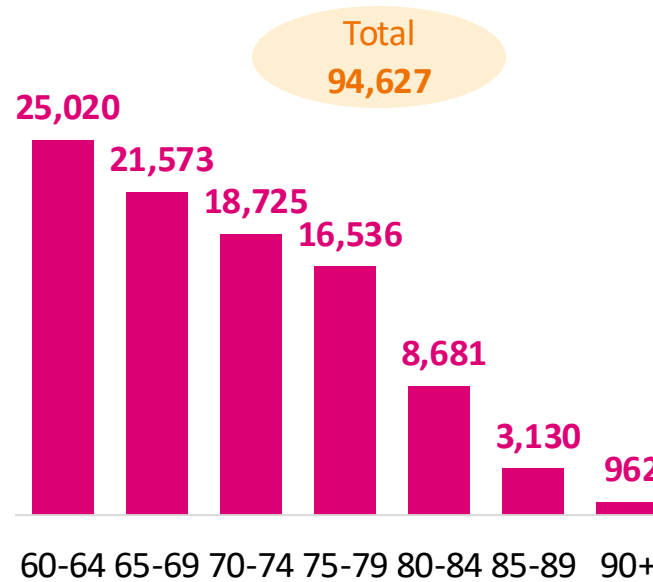
North West London (NWL) dementia caseload

Total number of current patients recorded



NWL Mild cognitive impairment caseload

Total number of current patients recorded



Percentage of cohort in age band

| | Dementia | Mild cognitive impairment |
|--------------|-------------|---------------------------|
| 60-64 | 1% | 26% |
| 65-69 | 4% | 23% |
| 70-74 | 8% | 20% |
| 75-79 | 16% | 17% |
| 80-84 | 23% | 9% |
| 85-89 | 25% | 3% |
| 90+ | 22% | 1% |
| Total | 100% | 100% |

- The dementia cohort includes people with mild, moderate and severe dementia and was identified using ICD-10/SNOMED codes in the primary care and secondary care datasets
- The mild cognitive impairment (MCI) cohort was also defined using SNOMED codes with a similar methodology, excluding the people that were diagnosed with dementia later in the study
- While over 70% of people with dementia are aged 80 and over, over 70% of people with MCI are under 75

Dementia prevalence is linked to deprivation - prevalence rates are nearly twice as high for those living in the most deprived areas compared to those in the least deprived areas

Dementia prevalence by IMD decile and age

Percentage of people with diagnosed dementia in NWL, December 2023

| | IMD Decile | 60 - 64 | 65 - 69 | 70-74 | 75-79 | 80-84 | 85-89 | 90+ |
|--|------------|---------|---------|-------|-------|-------|-------|-----|
| High deprivation ↓ Low deprivation | 1 | 0.1% | 0.5% | 2.3% | 4.0% | 13% | 24% | 41% |
| | 2 | 0.1% | 0.7% | 1.6% | 4.5% | 11% | 22% | 36% |
| | 3 | 0.1% | 0.6% | 1.8% | 4.4% | 11% | 23% | 37% |
| | 4 | 0.1% | 0.5% | 1.5% | 3.5% | 9.3% | 21% | 34% |
| | 5 | 0.1% | 0.5% | 1.4% | 3.0% | 9.7% | 19% | 32% |
| | 6 | 0.1% | 0.4% | 1.0% | 2.9% | 8.4% | 20% | 34% |
| | 7 | 0.1% | 0.4% | 0.9% | 2.9% | 7.2% | 17% | 32% |
| | 8 | 0.1% | 0.4% | 0.8% | 2.2% | 6.3% | 15% | 26% |
| | 9 | 0.1% | 0.2% | 1.2% | 2.2% | 6.7% | 16% | 27% |
| | 10 | <0.1% | 0.3% | 0.8% | 2.5% | 6.1% | 15% | 22% |
| | Unknown | 0.1% | 0.3% | 1.3% | 3.9% | 9.7% | 25% | 40% |
| | All | 0.1% | 0.5% | 1.3% | 3.2% | 8.9% | 19% | 32% |

- Prevalence of diagnosed dementia is **higher for people living in more deprived areas in North West London**
- While it's difficult to extrapolate this nationally, expert opinion would suggest that there are **links between dementia prevalence and deprivation across the country**
- It's important to also note that in general, **people are less healthy and have a greater number of co-morbidities** in lower deciles than in upper deciles
- There **may also be inequalities in diagnosis rates**, but these are difficult to study using current data



References

References (1/2)

Besser, L., Kukull, W., Knopman, D. S., Chui, H., Galasko, D., Weintraub, S., ... & Neuropsychology Work Group. (2018). Version 3 of the national Alzheimer's coordinating center's uniform data set. *Alzheimer Disease & Associated Disorders*, 32(4), 351-358.

Carers UK. (2024). Right to Carers Leave. Carers UK. Retrieved April 19, 2024, from <https://www.carersuk.org/news-and-campaigns/our-campaigns/right-to-carers-leave/>

Comas-Herrera, A., Knapp, M., Wittenberg, R., Banerjee, S., Bowling, A., Grundy, E., ... & MODEM Project group. (2017). MODEM: A comprehensive approach to modelling outcome and costs impacts of interventions for dementia. *Protocol paper. BMC health services research*, 17, 1-8.

Dartigues, J. F., Gagnon, M., Letenneur, L., Commenges, D., Sauvel, C., Michel, P., & Salomon, R. (1992). The Paquid Epidemiological. *Neuroepidemiology*, 11, 14-18.

Department of Health (Northern Ireland). (2023). Summary of Available Bed Days, Occupied Bed Days, Discharges and Deaths, and Day Cases (KH03A). Retrieved from <https://www.health-ni.gov.uk/publications/summary-available-bed-days-occupied-bed-days-discharges-and-deaths-and-day-cases-kh03a>

DiscoverNOW database. (Accessed 2024). <https://discover-now.co.uk>

Dufouil, C., Dubois, B., Vellas, B., Pasquier, F., Blanc, F., Hugon, J., Hanon, O., Dartigues, J. F., Harston, S., Gabelle, A., Ceccaldi, M., Beauchet, O., Krolak-Salmon, P., David, R., Rouaud, O., Godefroy, O., Belin, C., Rouch, I., Auguste, N., Wallon, D., ... MEMENTO cohort Study Group (2017). Cognitive and imaging markers in non-demented subjects attending a memory clinic: study design and baseline findings of the MEMENTO cohort. *Alzheimer's research & therapy*, 9(1), 67. <https://doi.org/10.1186/s13195-017-0288-0>

Elshahidi, M. H., Elhadidi, M. A., Sharaqi, A. A., Mostafa, A., & Elzhery, M. A. (2017). Prevalence of dementia in Egypt: a systematic review. *Neuropsychiatric Disease and Treatment*, 715-720.

NHS Digital. (2022). Personal Social Services Survey of Adult Carers: England 2021-22. Retrieved from <https://digital.nhs.uk/data-and-information/publications/statistical/personal-social-services-survey-of-adult-carers/england-2021-22>

NHS England (NHSE). (2024). Bed Availability and Occupancy Data – Overnight. Retrieved from <https://www.england.nhs.uk/statistics/statistical-work-areas/bed-availability-and-occupancy/bed-data-overnight/>

References (2/2)

NHS England. (2023). Quality and Outcomes Framework (QOF) 2022-23.

Public Health Scotland. (2023). Table 4: Beds 2022-23 [Data File]. Public Health Scotland. Retrieved from <https://publichealthscotland.scot/media/22033/table-4-beds-2022-23.xlsx>

Religa, D., Fereshtehnejad, S. M., Cermakova, P., Edlund, A. K., Garcia-Ptacek, S., Granqvist, N., ... & Eriksson, M. (2015). SveDem, the Swedish Dementia Registry—a tool for improving the quality of diagnostics, treatment and care of dementia patients in clinical practice. *PloS one*, 10(2), e0116538.

Souza, R. K. M. D., Barboza, A. F., Gasperin, G., Garcia, H. D. B. P., Barcellos, P. M., & Nisihara, R. (2019). Prevalence of dementia in patients seen at a private hospital in the Southern Region of Brazil. *Einstein (São Paulo)*, 18, eAO4752.

StatsWales. (2024). NHS Beds by Organisation Site. Retrieved from <https://statswales.gov.wales/Catalogue/Health-and-Social-Care/NHS-Hospital-Activity/NHS-Beds/nhsbeds-by-organisation-site>

Van Der Flier, W. M., & Scheltens, P. (2018). Amsterdam dementia cohort: performing research to optimize care. *Journal of Alzheimer's Disease*, 62(3), 1091-1111.

van Kooten, J., Delwel, S., Binnekade, T. T., Smalbrugge, M., van der Wouden, J. C., Perez, R. S., Rhebergen, D., Zuurmond, W. W., Stek, M. L., Lobbezoo, F., Hertogh, C. M., & Scherder, E. J. (2015). Pain in dementia: prevalence and associated factors: protocol of a multidisciplinary study. *BMC geriatrics*, 15, 29. <https://doi.org/10.1186/s12877-015-0025-0>

Yuan, J., Maserejian, N., Liu, Y., Devine, S., Gillis, C., Massaro, J., & Au, R. (2021). Severity distribution of Alzheimer's disease dementia and mild cognitive impairment in the Framingham Heart Study. *Journal of Alzheimer's Disease*, 79(2), 807-817.