The economic impact of dementia

Module 1: Annual costs of dementia
May 2024

Alzheimer's Society

CF

Contents of this report

Introduction to the study

CF partnered with Alzheimer's Society to produce a report in 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-word 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**.

Sources: CF analysis, DiscoverNOW

The study builds on previous work to estimate costs of dementia, which contributed key assumptions around dementia prevalence and use of care services

Prince, M. et. al. (2014). *Dementia UK: update.* **Alzheimer's Society.**

- This study aimed to provide an accurate understanding of dementia prevalence and cost in the UK to assist in policy development, influencing, commissioning and service design, through use of an expert Delphi consensus approach based on systematic literature review of currently available research data

Wittenberg, R. et. al. (2019a). *The costs of dementia in England.* **International journal of geriatric psychiatry, 34(7), 1095-1103.**

- This study estimated the societal costs of dementia in England for 2015, encompassing costs of health, social, and unpaid care.
- Estimates were derived from multiple sources, including ONS population projections, the Population Ageing and Care Simulation (PACSim) model[1], the Cognitive Function and Ageing Study (CFASII)[2] and the MODEM project[3]

Wittenberg, R. et.al. (2020). *Projections of care for older people with dementia in England: 2015 to 2040.* **Age and Ageing, 49(2), 264-269.**

- This study built on Wittenberg, R, et. al. (2019a) to project the cost and prevalence estimates to 2040
- People aged under 65 are not included

Wittenberg, R. et. al. (2019b). ***Projections of older people living with dementia and costs of dementia care in the United Kingdom, 2019–2040.*** **London: CPEC, LSE, 79**

- This study built on Wittenberg, R, et. al. (2019a) and Wittenberg, R, et. al. (2020) to develop prevalence and cost estimates to 2040 for the rest of the UK

Sources: 1) Kingston, A. et. al. (2018). 2) Comas-Herrera, A. et. al. (2017) 3) Matthews, F.E. et. al. (2016)

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

What is the DiscoverNOW SDE?

Secure Data Environments (SDEs) are data **storage and access platforms** that allow approved users to **access sensitive health and care data** that has been anonymised for research purposes.

Discover-NOW **is one of 11 SDEs set up by NHS England,** based in North West London (NWL).

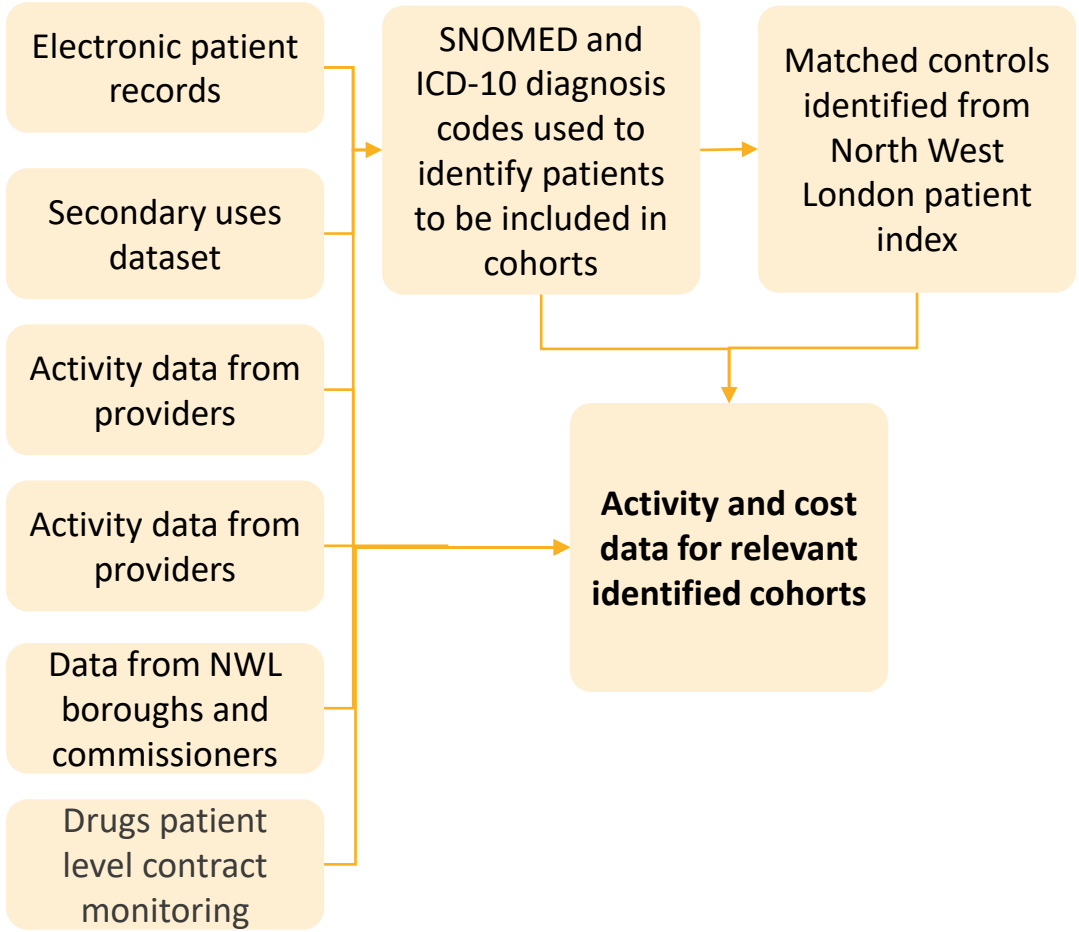
The cohort covers a **population of over 2.7 million patients** who **live and are registered with a GP in North West London**

The dataset **provides access to linked coded data** across primary care, secondary, acute, mental health, community health and social care.

What data is included?

- **Primary care events and prescriptions** including GP visits
- **Secondary care** including A&E, inpatient and outpatient attendances
- **Community care** including clinics and therapies
- **Mental health** including inpatient and outpatient activity and assessments
- **Social care** including home, formal and respite care
- **High-cost drug** prescription

How is data collated and extracted?



Source: CF analysis, DiscoverNOW

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.

Source: CF analysis, DiscoverNOW

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 Council[1]

- 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

Notes: 1) Alzheimer's Society Research Strategy Council is a panel of leading dementia experts who advise the Society on research direction and focus.

Executive summary

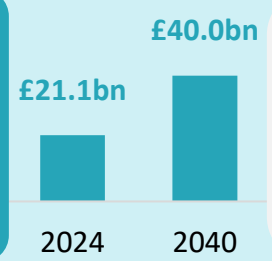
The cost of dementia is forecast to be £42 billion for 2024, increasing to £90 billion for 2040, due to a forecasted increase in dementia prevalence and cost of services

- The cost of dementia in the UK is forecast to be **£42 billion in 2024**, increasing to **£90 billion by 2040**
  - There are currently estimated to be 982,000 people living with dementia in the UK, **rising to 1.4 million in 2040**
  - The forecasted increase in dementia prevalence and cost is due to population growth, an aging population, and projected increases in the real-terms unit prices of care, especially social care
- The average per person costs associated with the mild, moderate and severe stages of dementia are estimated to be £28,700, £42,900 and £80,500 respectively, with the increase in cost by severity driven by increasing need for more complex care
- **The largest cost associated with dementia is the cost of unpaid care**, which accounts for **50% of the total** in 2024
  - Unpaid carers are a critical part of supporting people with dementia, as current needs are not fully met by social care.
  - The cost and time commitment of this care is significant, with **a third of unpaid dementia carers reporting that they spend more than 100 hours per week caring** for a dementia patient
- The second largest cost is social care, which is highly dependent on dementia severity; **the average per person cost of social care is nearly three times higher for people with severe dementia than people with mild dement**
- Diagnosis and treatment is currently a very small source of costs, with only **1.4% of all dementia healthcare costs spent on memory assessments and dementia-specific treatments**
- Analysis of people in the two years prior to their diagnosis being recorded showed that pre-diagnosis, **the average per person costs for A&E attendances and prescriptions are higher than the costs for people diagnosed with mild dementia**
- This study also highlights the **high percentage of costs of dementia that are borne by patients and their families**, estimated to be **63% of total costs**

Source: CF analysis, ONS (2020), Wittenberg, R. et. al. (2019b), Comas-Herrera, A. et. al. (2017), DiscoverNOW

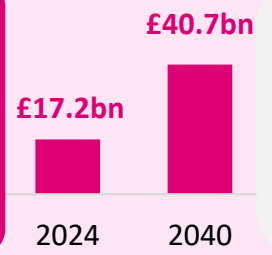
Unpaid care is the largest driver of cost, followed by social care

Unpaid care



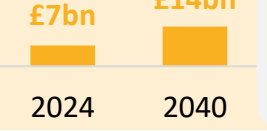
- Unpaid care costs increase with severity as patients start to require more support and caregiver surveillance, growing from £9,700 a year for people with mild dementia to £32,300 a year for people with severe dementia. These costs are exclusively borne by patients & their carers.
- By 2040, 43% more people are expected to receive unpaid care, with some carers spending up to a third of their year providing unpaid care.
- Caring places a huge burden on people - 16% of dementia carers report that they have had to give up work and nearly two thirds report they suffer from their own health conditions while providing care, with one in five reporting that they are neglecting their own health. 36.3% of unpaid dementia carers also reportedly have caring responsibilities for more than one person.
- Despite these figures only 14% of carers receive some form of respite care today.

Social care



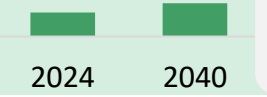
- Social care costs are driven largely by residential care - an additional 76,000 people are projected to be living in a residential home and 30,000 in a nursing home in 2040 compared to today.
- The number of people receiving domiciliary care is expected to increase by 43%, with many people with moderate dementia requiring care
- Nearly 50% of people fully fund their own social care. Social care is also the highest per person cost across all care settings – steps taken to reduce the need for social care are therefore important, not only for quality of life but also for more effective cost management.
- Despite growing demand, dementia patients face a social care system that is largely underfunded & over-stretched, leading to increasing reliance on unpaid carers, many of whom remain unidentified and feel like they do not have the support they need.

Health care



- Healthcare costs only make up 14% of total dementia costs, with almost half (£3.5billion) attributed to secondary care.
- Non-elective inpatient attendances drive the majority of hospital spend, followed by mental health services in the community.
- Diagnostic imaging, including MRI, CT, PET and neuropsychology tests, currently only makes up a very small fraction of total healthcare cost at 1.1%
- Only 3.3% of total prescribing costs relate to dementia-specific medications (AChE inhibitors or memantine) and anti-psychotics medicines

Quality of life, economic losses



- Six dementia costs linked to quality of life and economic wellbeing have been calculated in this study: additional heating costs for people confined to their homes; legal costs associated with power of attorney, transport costs resulting from reduced mobility; police call-outs; the cost of scams; a loss of consumption. These costs are often borne directly by patients, causing additional burden on top of social care and unpaid care commitments.

Charity sector

National associations and other third-party organizations play a huge role in raising awareness of dementia, providing services to those living with dementia and their families and pushing for greater political commitment. National associations are often the strongest drivers of change, with the greatest ability to influence the development or expansion of a national plan. This comes at a cost, which is difficult to quantify and therefore hasn't been included in the analysis but should be considered when thinking about the wider costs of dementia.

Sources: CF analysis, Jakobsen, M. et. al. (2011), Wimo et al (2001), Moore, M. et. al. (2001), NHS Digital. (2022)

There is variance in the total cost of dementia calculated across leading dementia studies as a result of differing prevalence estimates and population projections used

Comparison of leading dementia studies

£Billions

	Region	2013	2015	2019	2020	2021	2025	2030	2040	2050
Carnall Farrar (2024)	UK						**44.6** (43.6 – 65.9)	**57.2** (56.0 – 85.1)	**90.6** (89.0 – 136.7)	
Wittenberg, R. et. al. (2019b) *Adjusted to 2024 prices*[1]	UK			45.4	48.1		60.6	77.4	123.1	
Wittenberg, R. et. al. (2019b)	UK			34.7	36.7		46.3	59.2	94.1	
Wittenberg, R. et.al. (2020)	England		23.0	24.2		-		-	80.1	-
Prince, M. et. al. (2014)	UK	26.3								
Luengo-Fernandez, R. et. al. (2018)	UK					24.6		30.3	38.7	47.3

This study differs from previous work in a few ways

- One of **the largest UK studies of healthcare resource utilisation by patients with dementia**
- **Linked patient data** across healthcare, social care, mental health, community and prescribing used to **identify real per person healthcare costs incurred by the system**
- **Additional costs considered** associated with quality of life and lost economic output
- Assessment of the **cost of undiagnosed patients and diagnosed patients**
- Most **recently updated population projections**

Source: CF analysis

Notes: 1) Used 3.6% inflationary rate based on Bank of England statistics

Study findings suggest a pressing need to influence policy and drive change across five areas

1 Improve early and accurate diagnosis

Less than 65% of people with dementia are diagnosed, most without confirmatory testing.

- Improve screening to identify more cases earlier
- Increase the use of imaging and cerebrospinal tests for confirmation
- Enable earlier action by families and readiness for available treatments

2 Adopt existing and emerging therapies

It is estimated less than 6% of dementia patients are on NICE-approved medications.

- Support patients and families to make lifestyle modifications
- Ensure full uptake of NICE approved medicines – today and in future

3 Support unpaid care

By 2040, over half a million people will need unpaid care, with 70% of carers seeking more support.

- Increase funding for respite, support and carer training
- Adopt a strategic focus in local areas to proactively identify and support carers

4 Improve social care

Social care is of variable quality and can be a financial burden on self-funders.

- Focus on enabling and providing high quality domiciliary care
- Ensure adequate funding and workforce now and in the future to meet unmet need
- Enable collaborative working across health and care organisations

5 Improve dementia data capture

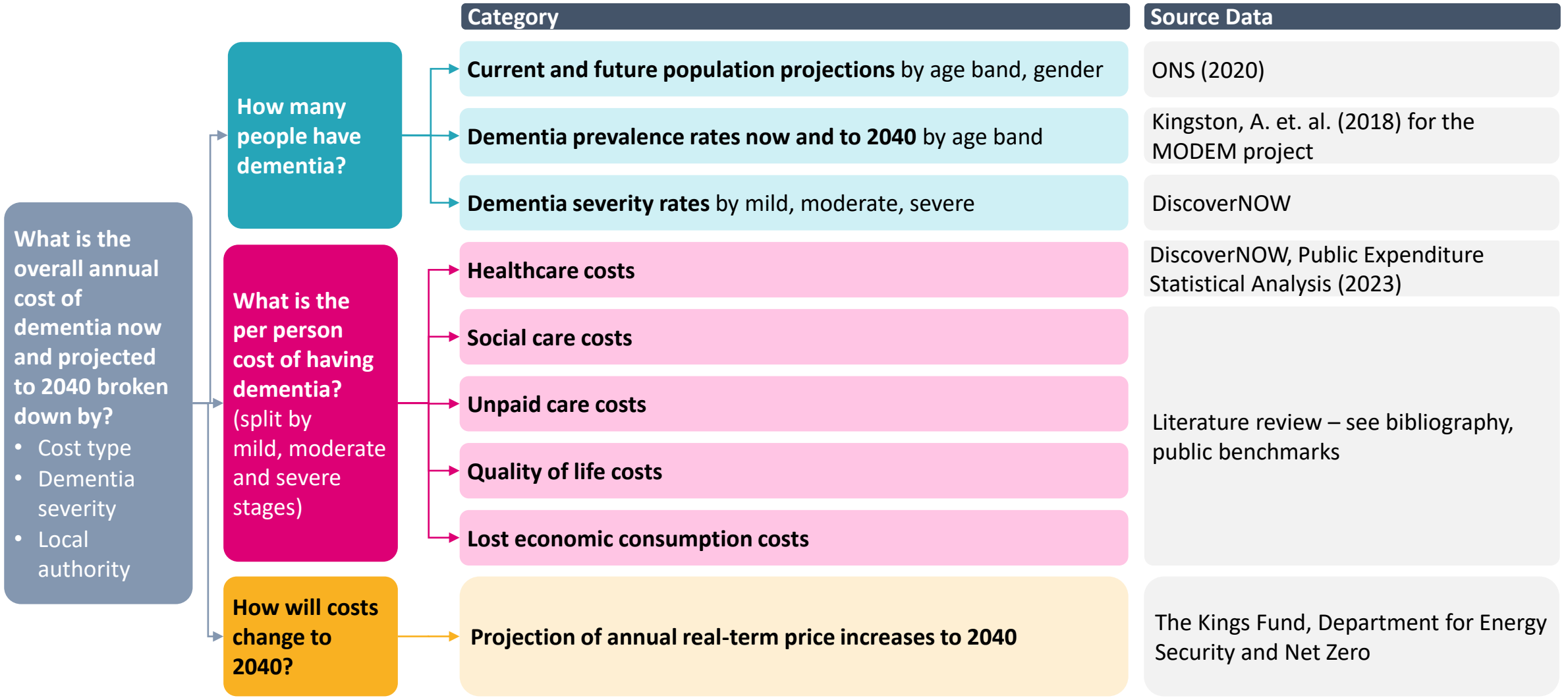
There are significant gaps in critical data collections, including records of social and unpaid care provided.

- Improve data capture of disease progression and care provision – including informal care
- Create cohort datasets to measure the impact of new treatments and initiatives

Sources: CF analysis, ONS (2020), Wittenberg, R. et. al. (2019b), Comas-Herrera, A. et. al. (2017), NHS Digital. (2024), Public Health Scotland, Alzheimer's Research UK

Methodology, assumptions and limitations

Patient-level data, public data and literature reviews were used to calculate total prevalence and subsequently total cost of dementia across different settings



Source: CF analysis

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 ONS[1] 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 project[2] were applied to the population projects 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 low prevalence
- 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 undiagnosed patients 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 patients

Sources: 1) ONS. (2020) 2) Comas-Herrera, A. et. al. (2017), CF analysis

To develop total cost estimates, prevalence projections were combined with per person cost estimates across five cost types

Healthcare	Social care	Unpaid care	Quality of life costs	Economic costs
Costs associated with: • Primary care activity • Secondary care activity • Community care • Mental health services • High-cost and primary care-based prescriptions	Costs associated with: • Residential care • Nursing care • Domiciliary care • Caregiver respite	Unpaid care costs were calculated by splitting care activities provided by unpaid carers into: • Activities of daily living (ADLs) e.g. bathing and eating • Instrumental activities of daily living (IADLs) e.g. cleaning and managing finances	Costs associated with • Transport costs associated with reduced mobility • Legal and financial costs (e.g. power of attorney) • Increased energy costs • Criminal justice costs (e.g. police callouts) • Vulnerability to scams	Taking account of the reduced spending by people with dementia, a negative cost is included.
The study utilised a real-world evidence approach, leveraging the DiscoverNOW record-level healthcare data.	Cost estimated were developed from a literature review to provide cost estimates and combined with best practice assumptions on patient volumes from previous studies.		These were new cost categories not previously explored. Appropriate assumptions were developed based on literature review.	

Source: CF analysis

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

Stage 1: Identify and classify cohorts in the data		Stage 2: Identify and classify number of comorbidities	Stage 3: Extract data and use for various analyses
Dementia - Mild	Identified using SNOMED/ICD-10 diagnosis codes and grouped into mild, moderate and severe cohorts using MMSE scores (where available)	• 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	Used to identify annual per person costs of dementia patients by severity
Dementia - Moderate			
Dementia - Severe			
Dementia - Unclassified	All remaining dementia patients identified using SNOMED/ICD-10 diagnosis codes without a recorded MMSE score		Used to identify the costs of dementia patients for low-quality datasets (community and mental health)
Pre-diagnosed	Identified by looking at dementia patients two years pre-index date		Used as a proxy to estimate healthcare costs for undiagnosed patients
No dementia (Control group)	All remaining patients that do not fall into the categories above		Used as a control group to isolate dementia costs
Mild cognitive impairment (MCI)	Identified using SNOMED/ICD-10 diagnosis codes, excluding anyone diagnosed with dementia later in the study period		Not used in the analysis but removed from the control group for this study

Source: CF analysis

To calculate total healthcare cost, the per person costs derived from the DiscoverNOW data were scaled to other areas of the UK and combined with prevalence projections

1 Calculated annual per person cost from NWL data

- For the identified cohorts, data describing the healthcare activity and costs across the various care settings was retrieved from the DiscoverNOW database for the period between 2015 and 2022
- Historical costs were adjusted for inflation, and activity in 2020 and 2021 was excluded due to the impact of COVID-19
- An annual per person cost in current prices was developed for each dementia cohort and the pre-diagnosed cohort

2 Scaled per person cost to each English region and devolved nation

- The per person cost for each cohort group was extrapolated from North West London to each English region and the devolved nations, using an index based on public healthcare spend (see appendix 4 for more details)
- This assumes spending on dementia patients is consistent with overall spend, and the scaling applies equally across healthcare resource type

3 Applied scaled per person costs to prevalence projections

- The adjusted per person costs across each care setting were multiplied by the corresponding prevalence rates by region and dementia cohort
- For the community and mental health care settings, costs were not segregated by severity due to low data quality
- The pre-diagnosis costs were used for the undiagnosed cohort

Source: CF analysis

The residential and nursing care costs were developed using a combination of assumptions around the unit costs and distribution of care across the dementia cohorts

1 **Calculate volume of patients receiving social care**	• Estimates from Wittenberg, R. et. al. (2019a) of the number of people in each dementia cohort receiving residential or nursing care were converted to percentage of the total cohort (see appendix 5) • These percentages were applied to the dementia prevalence projections by cohort to determine the expected number of people receiving residential and nursing care
2 **Calculate volume of patients who receive state funding**	• Statistics from the ONS report "Care homes and estimating the self-funding population, England: 2022 to 2023" were used to estimate the percentage of people with dementia in care homes who are self-funding • Due to lack of available data for other countries, this estimate was applied to all the devolved nations and was held constant across all age bands and severity cohorts
3 **Identify a unit of cost for self-pay vs state-funded care**	• A literature review was conducted to determine unit costs for residential and nursing care for self-funded and state-funded residents • The costs vary by geographical location (see appendix 6) but do not vary by age or dementia severity
4 **Calculate total cost**	• The total cost of residential and nursing care was developed by combining the number of patients receiving residential and nursing care, either self-funded or state-funded by the respective unit costs

Source: CF analysis

To calculate costs for domiciliary and respite care, estimates were developed by combining assumptions around the unit costs, uses of these services and intensity of use

Domiciliary care

Domiciliary care was defined as domestic home care, community nursing care and specialist nursing care. The method for estimating the total annual cost is described below, with assumptions developed from literature review (see appendix 5 for further details)

Total hours per week	=	Dementia prevalence by severity	x	Percentage of cohort receiving care[1]	x	Visits per day by severity	x	Visit time for each setting	x	Assumed: seven day working week
Annual cost	=	**Total hours per week**	x	Unit costs per hour	x	Assumed: 52 week year				

Respite care

Respite care is providing temporary formal care for someone who receives unpaid care, to provide a respite for their carer. The method for estimating the total annual cost is described below, with assumptions developed from literature review (see appendix 5 for details):

Total number of unpaid carers	=	Dementia prevalence by severity	x	Percentage of cohort receiving unpaid care[1]	x	Percentage of carers who receive a respite				
Annual cost	=	**Total number of unpaid carers**	x	Percentage self-funded or state-funded	x	Unit costs per week	x	Assumed: one respite week per year		

Source: CF analysis

Notes: 1) Based on estimates in Wittenberg, R. et. al. (2019a)

Unpaid care costs were calculated taking into account both the replacement cost of hiring a professional carer and the opportunity cost of hours of work foregone

1 Calculate volume of patients receiving unpaid care

- Estimates from Wittenberg, R. et. al. (2019a) of the number of people in each dementia cohort receiving unpaid care were converted to percentage of the total cohort (see appendix 5)
- These percentages were applied to the dementia prevalence projections by cohort to determine the expected number of people receiving residential and nursing care

2 Calculate volume of unpaid care hours each patient receives per year

- Unpaid care activities consist of two types of activities:
  - Activities of daily living (ADLs) such as bathing and eating; these costs were estimated using the replacement cost of a formal caregiver providing this care
  - Instrumental activities of daily living (IADLs) such as cleaning and managing finances; these costs were estimated as opportunity costs of foregone income for hours where an individual is instead engaged in providing unpaid care
- We conducted a literature review to identify the daily time unpaid carers spent on these three activities across each of the severity cohorts *(*see appendix 7*),* it was assumed that unpaid carers work 51 weeks per year, with one week of respite

3 Assign a cost for each of the three activities

- The replacement cost of an hour of formal care was valued at £24 per hour
- The opportunity cost of an hour of foregone income care was valued at £11.44

4 Calculate total cost

- We then applied the relevant volumes of patients receiving unpaid care with the respective yearly hours per person and cost per hour to calculate a total annual cost for unpaid dementia care

Source: CF analysis

Costs for six categories of quality of life and economic costs were estimated. Appendices 8a – 8c summarise the detailed assumptions to calculate costs for each category

Additional heating costs	Legal costs	Transport costs resulting from reduced mobility
• Heating costs are expected to be higher for dementia patients, due to more hours spent in the home and an increased likelihood of forgetting to turn the heating off • It is assumed that all dementia patients incur this cost	• Dementia patients will eventually be unable to make financial decisions due to advanced cognitive decline. • As a result, it is assumed that 22% of patients will transfer Lasting Powers of Attorney to (at a uniform rate of around one in five each year reflecting the expected lifespan of a patient with dementia[1])	• Due to cognitive and physical impairments, dementia patients will eventually need to give up driving • While many patients will have support from friends and family, those living alone without informal care support will need to pay for transport to attend appointments or for other transport needs
Police call-outs	**Scams**	**Lost economic consumption**
• Some dementia patients living at home will wander away or get lost while out – families may in turn call the police to report a missing person • Police are also regularly called out to deal with vulnerable dementia patients in care homes that are exhibiting behavioural problems or violence • It is assumed that 5% of severe and moderate dementia patients occur will require these callouts	• Dementia patients (and older people more generally) are susceptible to scams that impose a significant financial cost. • The assumption is that 1%, 5% and 1% of mild, moderate and severe dementia patients respectively are in danger of being scammed by the average amount of £5000	• Dementia patients will eventually change their spending patterns and reduce consumption of goods and services across the economy, which will have an impact on economic output overall • It is assumed that all dementia patients will experience a drop in economic consumption of between £2,500 - £7,500 depending on severity • This is modelled as a negative cost, as it represent less money spent in the economy

Sources: CF analysis, 1) Xie, J. et. al. (2008) 2) Seaton's Solicitors (n.d.) 3) Canada Life. (2023, August 15)

Historical data was used to develop estimates for the annual percentage increase in real-terms prices across the different cost categories

Cost type	Cost category	Annual percentage increase	Source
Economic costs	Drop in consumption	0.0%	Assumed to be in line with inflation
Formal care	Domiciliary care	1.8%	The Kings Fund (2024). Social care 360: expenditure. Data range: 2015/16 – 2022/23
	Nursing care	3.4%	
	Residential care	3.4%	
	Respite care	1.8%	
Unpaid care	Unpaid care	1.8%	
Healthcare	Community care	1.8%	The Kings Fund (2023). The NHS budget and how it has changed. Data range: 2010/11 – 2022/23
	Mental health care: Community activity	1.8%	
	Mental health care: Inpatient activity	1.8%	
	Primary care: Contacts	1.8%	
	Primary care: Prescriptions	1.8%	
	Secondary care: A&E attendances	1.8%	
	Secondary care: High-cost prescriptions	1.8%	
	Secondary care: Inpatient activity	1.8%	
	Secondary care: Outpatient activity	0.6%	
Quality of life costs	Additional energy costs	0.0%	Department for Energy Security and Net Zero (2024). Domestic energy price indices. Data range: 1990 – 2023
	Police callouts	0.0%	Assumed to be in line with inflation
	Power of attorney costs	0.0%	
	Transports costs	0.0%	
	Vulnerability to scams	1.8%	

- As in previous studies, the costs in this report are presented in 2024 prices, but projected costs are adjusted for an expected real-terms price increase
- Using historical data, an average annual percentage change in real-terms price was developed
- The annual percentage increase was applied the projected costs to adjust for real-terms price increases in unit costs

Source: CF analysis

The following assumptions are made as part of this study

Ref.	Assumption type	Assumption description
1	**Population projections**	• Used ONS projections[1] for population growth, from the 2020-based publication
2	**Prevalence rates**	• Used prevalence rates from the MODEM project[2] which vary by age band and projection year • Assumed same prevalence rate across all devolved nations and regions, and across all genders
3	**Severity distribution**	• Developed severity distribution from the DiscoverNOW dementia cohorts • Assumed constant over time and does not vary by age
4	**Care received ratios**	• The study assumes that the ratios of people receiving each type of care remain constant over time
5	**Expenditure projections**	• The study assumes that unit costs will rise between 0 – 3% across all five cost categories based on an annual percentage change in real-term prices developed from historical data
6	**Diagnosis and treatment**	• The study assumes that the diagnosis and treatment approaches remain unchanged throughout the projected time period
7	**Care funding**	• The study assumes continuation of the current funding systems for provision of care
8	**Unpaid care supply**	• The study assumes that there will be sufficient supply of these care streams and have not considered impact of a potential future shortfall
9	**Cost of an undiagnosed patient**	• The study assumes that the healthcare cost and activity of an undiagnosed patient can be estimated from the average healthcare costs recorded for the dementia cohort in the two years pre-diagnosis • The study assumed all non-healthcare related costs for an undiagnosed dementia patient are the same as a diagnosed patient

Sources: 1) ONS (2020) 2) Comas-Herrera, A. et. al. (2017)

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 cost using public health expenditure as an index for regional spend. However, this implicitly assumes that dementia spend is proportional to general healthcare spend.
2	MMSE scores have been used to classify severity but coverage is only 11% today – with this level of unknown 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	Social care and unpaid care data is difficult to obtain – care hours, care activities, costs and utilisation data is not captured in a systematic way. Provider and carer surveys give some insights into care but individual perceptions of care often vary - as such, assumptions are difficult to estimate and highly variable across studies. The total costs of unpaid and social care are therefore both very sensitive to the assumptions used in the study. To control for this, assumptions have been taken from reputable surveys commissioned by ONS and NHS England, dementia experts have been consulted on the work and figures have been compared to existing literature to ensure assumptions are robust and in line with expectations.
4	There is very little empirical evidence on quality-of-life costs – assumptions, based on literature reviews, are sensible estimates where data is not available
5	National associations and other third-party organizations play a role in raising awareness of dementia, providing services to those living with dementia and their families and pushing for greater political commitment. National associations are often the strongest drivers of change, with the greatest ability to influence the development or expansion of a national plan. This comes at a cost, which is difficult to quantify and therefore hasn't been included in the analysis but should be factored in when thinking about the wider costs of dementia.
6	The costs calculated for this study are the total costs of patients with dementia rather than the marginal extra costs for people with dementia in comparison with people not experiencing dementia. This is due to the challenges associated with disaggregating the cost impact of dementia itself with other co-morbidities. This approach is in line with other studies that have also explored the total cost of dementia

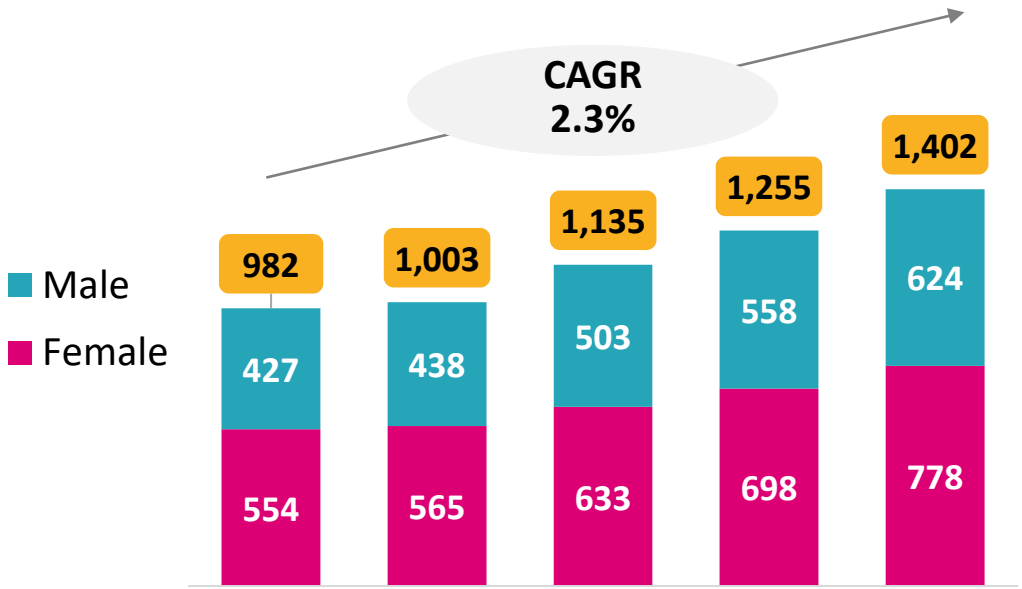
Source: CF analysis

Dementia prevalence now and by 2040

The number of people living with dementia is expected to grow from 1.4% of the total UK population in 2024 to 1.9% by 2040, representing a 40% increase

Total UK dementia prevalence for people aged 65 and over

Number of people with dementia in the UK, 000s



	2024	2025	2030	2035	2040
Prevalence: All ages	1.42%	1.44%	1.58%	1.71%	1.87%

- The increase is driven by **an aging population**, a general **increase in life expectancy**
- **More women are expected to live with dementia** than men, reflective of overall population dynamics
- Dementia is predicted to affect 0.1% of the population aged under 65[2]. **Patients with young onset dementia have been excluded** from this analysis and **further research is needed** into the specific challenges faced by people living with young onset dementia.
- **NHS England currently underestimates dementia prevalence for those aged 65 and overl** the NHS primary care dementia dataset estimates prevalence for this age group at 4.1% but this study has found prevalence is closer to 7%

Data & methodology summary:

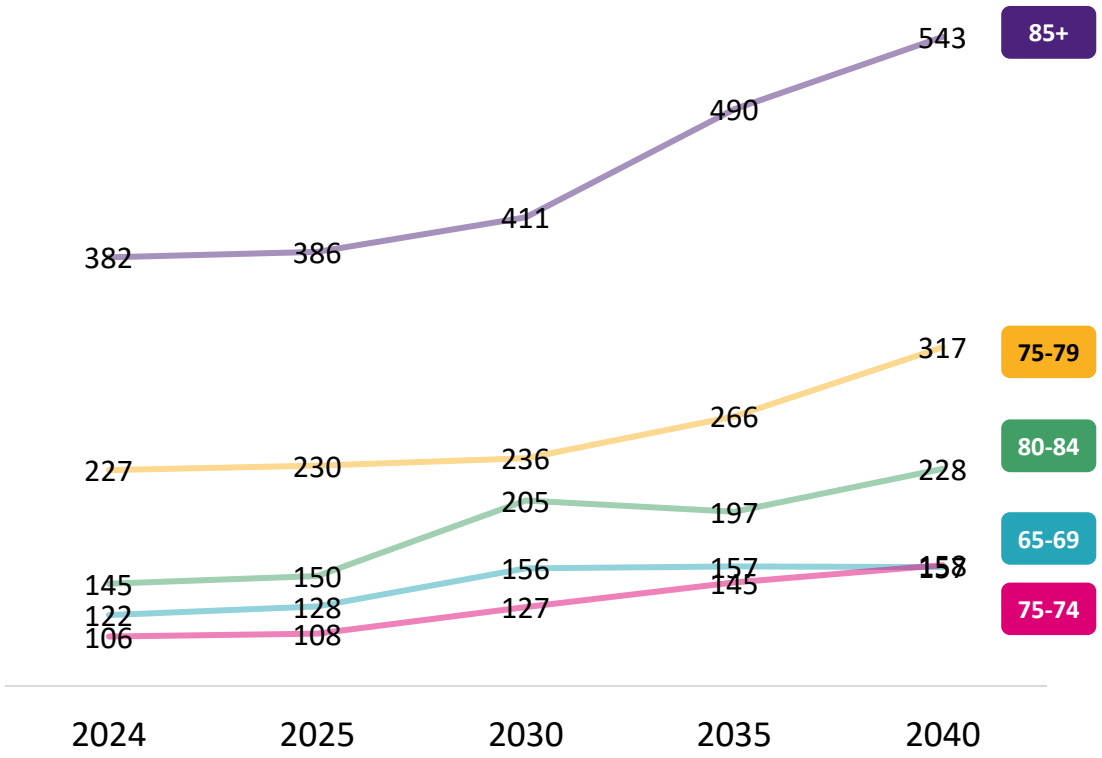
This projection is calculated through application of the age-banded prevalence rates from the MODEM project[1], which change over time, to the 2020 ONS age-banded population projections[2] by gender. Prevalence rates can be found in appendix 1.

Sources: 1) Comas-Herrera, A. et. al. (2017) 2) ONS. (2020), CF analysis

Dementia primarily affects the very elderly, with 39% of people with dementia in 2024 and 2040 aged 85 and over

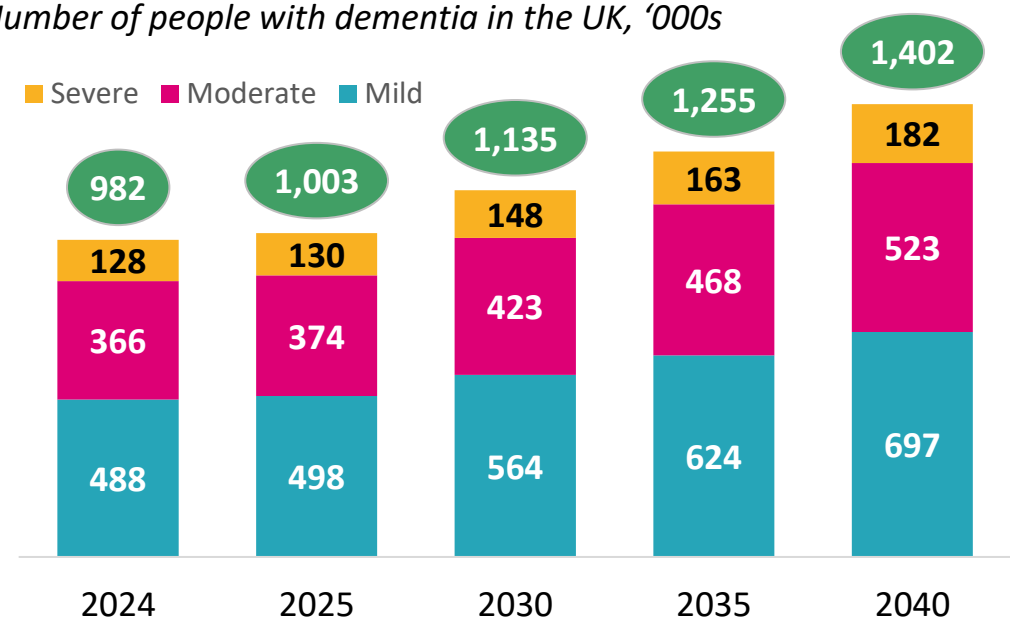
Total UK dementia prevalence of 65+ by five-year age band

Number of people with dementia in the UK, '000s



Total UK dementia prevalence of 65+ by dementia severity

Number of people with dementia in the UK, '000s



Data & methodology summary: *Percentage estimates of people with dementia in each severity cohort were developed from the DiscoverNOW data and applied to the prevalence projections, as a constant over time.*

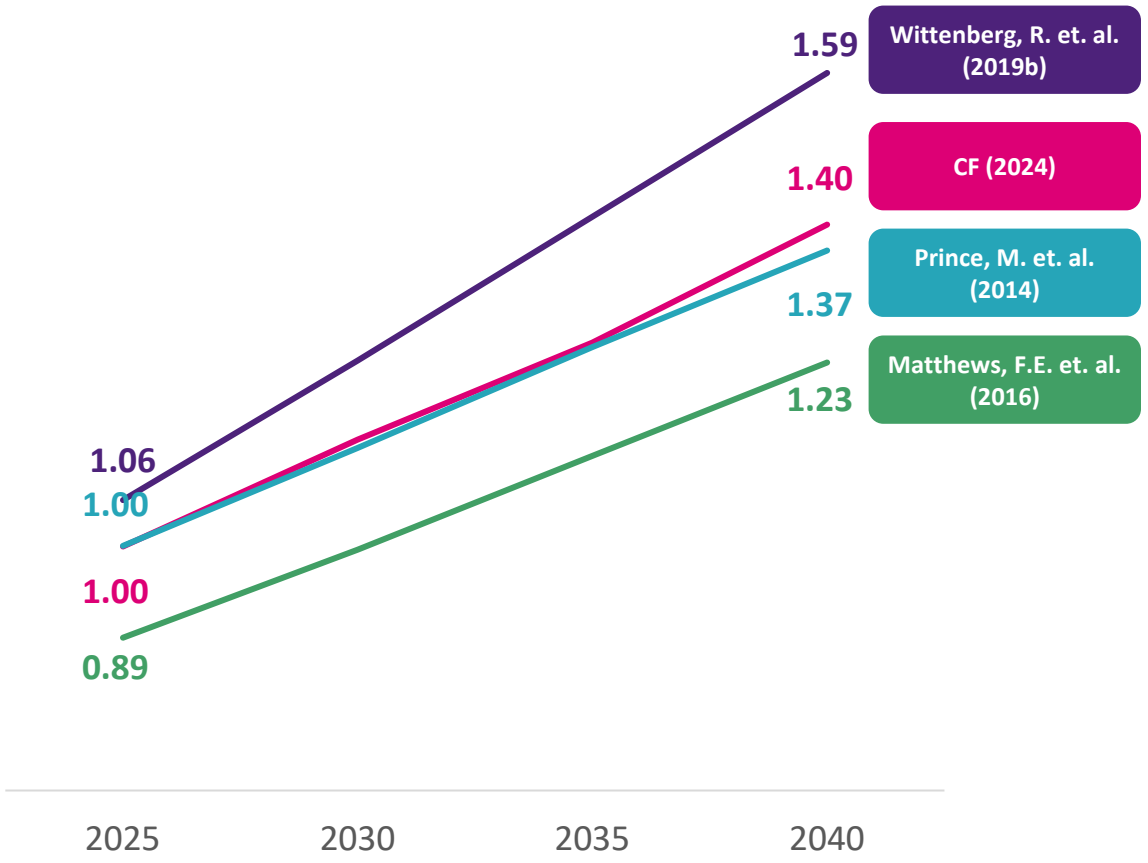
- Dementia prevalence increases with age, with 39% of people with dementia aged 85 and over in 2024
- The number of people in each severity cohort decreases with increasing severity

Sources: CF analysis, Comas-Herrera, A. et. al. (2017), ONS. (2020)

The projected dementia prevalence in this study of 1.4million by 2040 is is 0.2million lower than previous estimates in leading dementia studies

Comparison of UK total dementia prevalence projections across studies

Number of people with dementia in the UK, millions



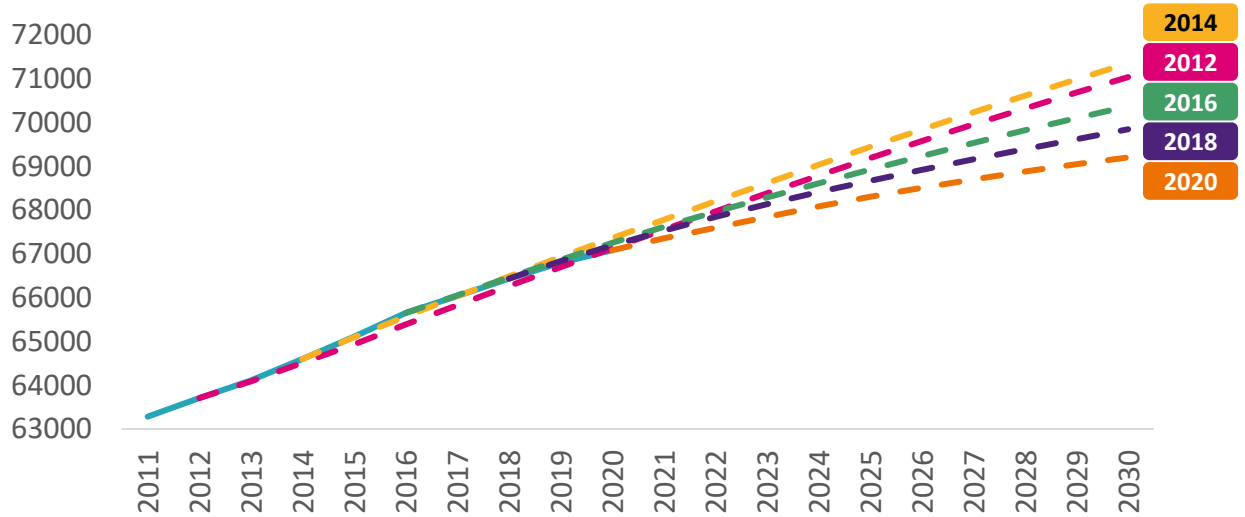
- Wittenberg, R. et. al. (2019b) uses 2014-based population projections which predicted a **larger overall population by 2040**
- This study uses 2020-based population projections which predict that there will be **1.2m fewer people aged 65 and over by 2040**
- As a result, although **prevalence rates have not changed**, total projected prevalence has **decreased from previous estimates**
- It is important to note that despite a downward adjustment, there is **still significant growth expected in the population aged 65 and over** leading to a **long-term upward trajectory in the prevalence of dementia**
- This study combines the most up to date estimates of dementia prevalence and population growth to generate estimates of the projected dementia population

Source: CF analysis

This reduced prevalence estimate is a result of decreases in ONS population projections between 2014 and 2020, including in the 65 and over age range

Reduction in ONS population projections between 2012 and 2020

Number of people in the UK, '000s



Reduction in ONS population projections in 2020 versus 2014

Number of people, '000s

Age band	2020	2025	2030	2035	2040
65-69	-5	-9	-10	-1	15
70-74	-10	-29	-40	-49	-41
75-79	-29	-65	-84	-104	-123
80-84	-44	-96	-156	-173	-203
85+	-85	-245	-438	-674	-871
Total	-173	-444	-728	-1,001	-1,223

- Since 2014, the ONS **population projections have decreased,** while still maintaining an overall projected growth in the population
- In 2016, it was estimated the total UK population would be **71.3m by 2030** but in 2020 this projection had **decreased to 69.2m**, a 3% decrease
- In the 65 and over age group there are **1.2m fewer people aged 65+ by 2040** in the 2020-based projections compared to the 2014-based projections
- ONS have described that more recent projections suggest slower population growth because of **lower assumptions both about future levels of fertility and mortality improvements**
- The most recent adjustment between 2018 and 2020 may also have been impact by excess deaths from COVID-19

Sources: CF analysis, ONS

In line with the projected population distributions, 84% of dementia patients are estimated to live in England, with the highest concentration based in South East England

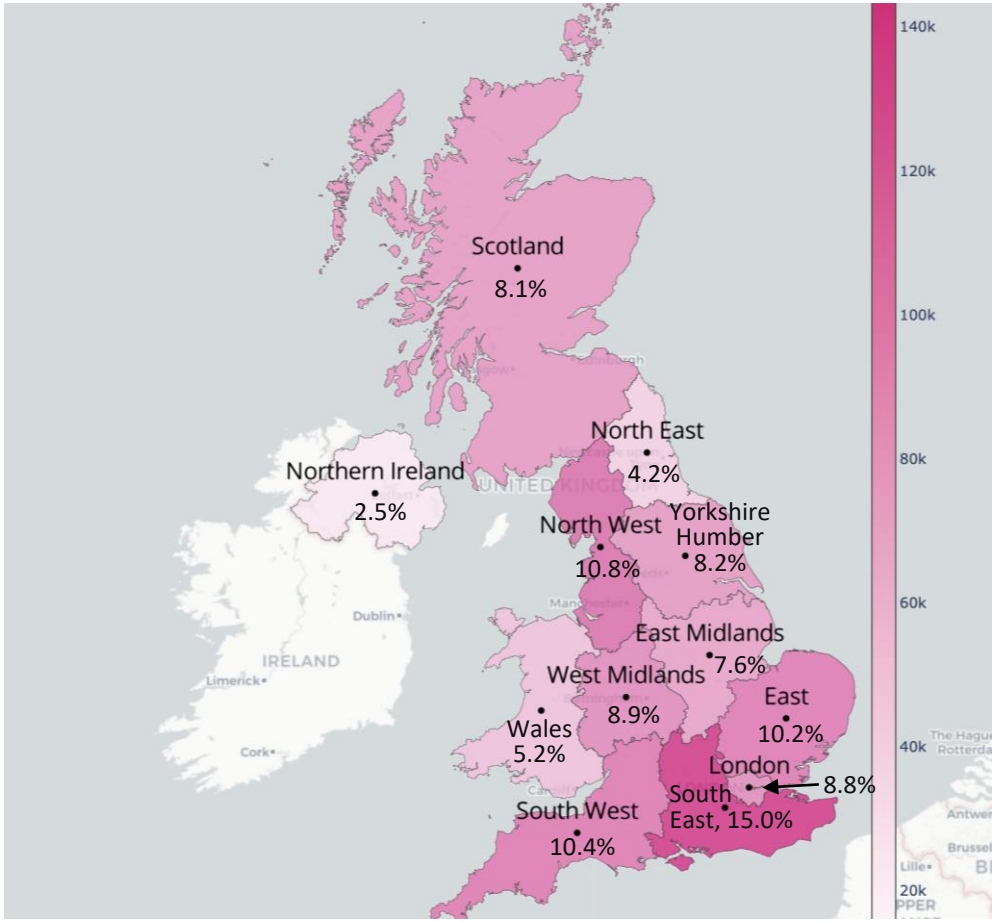
UK dementia prevalence by region

Number of people with dementia

	2024	2040	% change 2024-2040
England	825,860	1,183,126	43%
South East	147,211	211,298	44%
North West	106,343	147,899	39%
South West	101,595	147,822	46%
East of England	100,287	142,201	42%
London	87,303	133,956	53%
West Midlands	87,189	121,286	39%
Yorkshire and The Humber	80,574	112,609	40%
East Midlands	74,300	108,687	46%
North East	41,059	57,367	40%
Scotland	79,789	111,493	40%
Wales	51,226	69,982	37%
Northern Ireland	24,700	37,409	51%
UK	**981,575**	**1,402,010**	**43%**

UK dementia prevalence by region

Prevalence distribution for 2024



Source: CF analysis, Comas-Herrera, A. et. al. (2017), ONS. (2020)

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 population with diagnosed dementia in North West London, December 2023

High deprivation ↓ Low deprivation

IMD Decile	60 - 64	65 - 69	70-74	75-79	80-84	85-89	90+
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%**

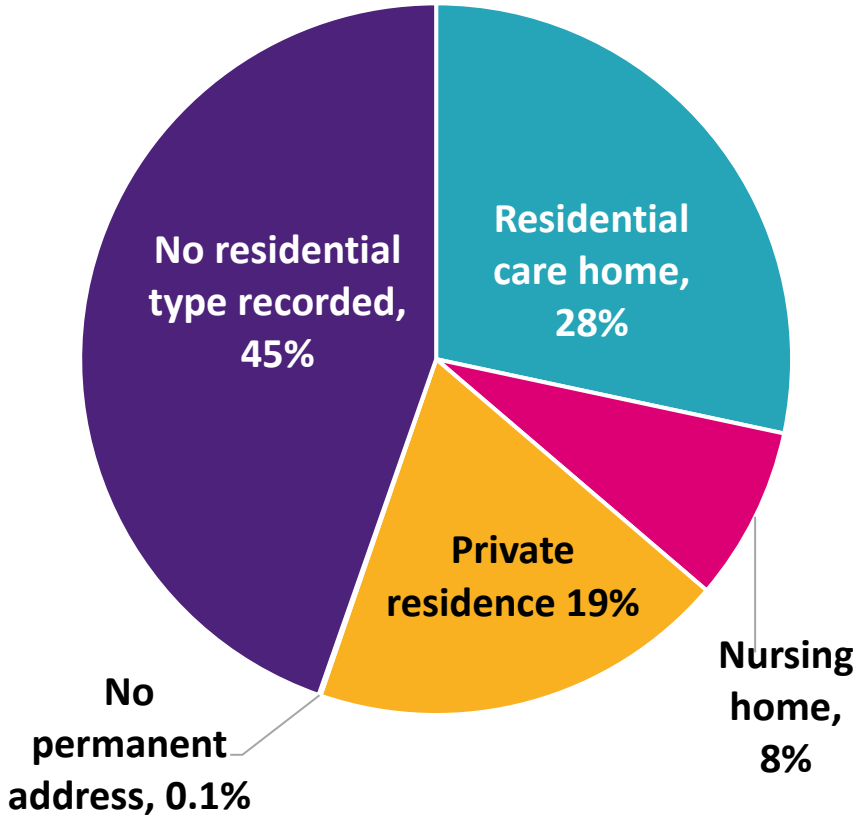
- Prevalence of diagnosed dementia is **higher for people living in more deprived areas in North West London**
- While it's difficult to extrapolate this nationally, expert opinion would suggest that there are **links between dementia prevalence and deprivation across the country**
- It's important to 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 quantify using current data

Source: CF analysis, DiscoverNOW

There are large gaps in NHS data with regards to the residential setting that diagnosed dementia patients currently live in, which makes it difficult to provide targeted care

Recorded dementia diagnosis by residential type

England, January 2024



	Number of recorded diagnoses
Residential care home	136,492
Nursing home	38,087
Private residence	91,516
No permanent address	440
No residential type recorded	214,923

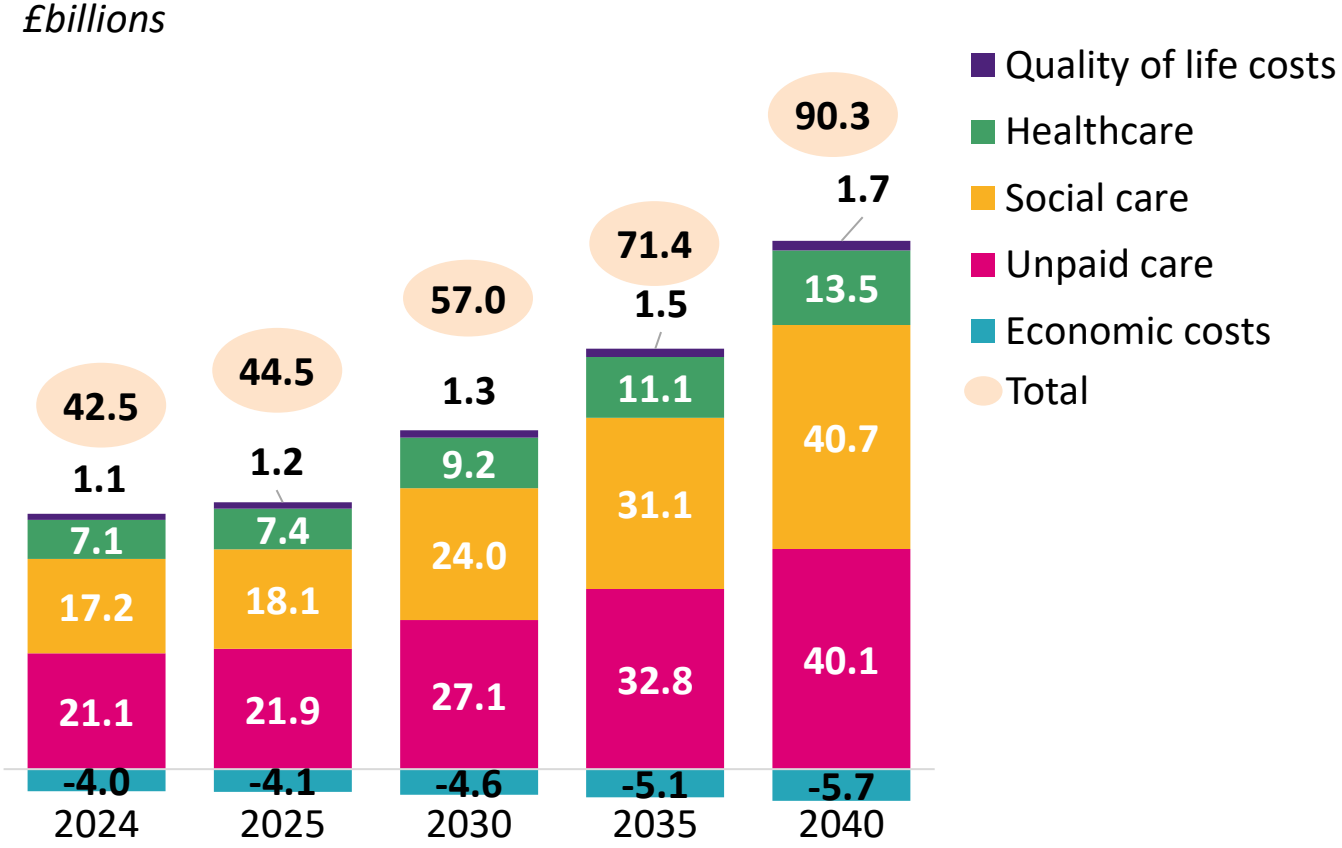
- Data has been collected on the **number of patients on the GP practice dementia registers** by type of residence since April 2023
- **Over 45% of patients do not have their most recent residential type recorded**, which makes it difficult to provide comprehensive analysis and care
- Of those that are recorded, **65% are in institutional care**
- A very **small number have no permanent address**

Source: CF analysis, NHS Digital. (2024)

Dementia costs now and by 2040

The study estimates that the total cost of dementia in UK in 2024 is £42.5billion, with 77% spent on social and unpaid care. This is expected to grow to £90.3billion by 2040.

Estimated costs of dementia in the UK by cost category



- This analysis shows the total cost of dementia in UK is estimated to be **£42billion today**, and is **projected to rise to £90billion by 2040.**
- In 2024, it is anticipated that **unpaid care and social care** accounts for **50% and 40% of the total cost spent** respectively.
- A **greater number of quality of life costs** have been considered in this work than in previous studies. These costs are **incurred as patients lose their independence** and include loss of mobility, increased energy costs, vulnerability to scams, police call outs and power of attorney. While these costs are relatively small, they place an **added burden on those living with dementia.**
- Economic costs account for a **reduction in consumption**, following changes in behaviors and spending patterns that come with the disease, these have been applied as a negative effect.

Sources: CF analysis, ONS (2020), Wittenberg, R. et. al. (2019b), Comas-Herrera, A. et. al. (2017), DiscoverNOW
Note: Prices expressed in real terms, in 2024 prices

Costs are distributed in line with dementia prevalence, with 84% of costs in 2024 occurring in England

Estimated cost of dementia by country: 2024 to 2040

Millions	2024	2040
England	**£35,785**	**£76,453**
Social care	£14,595	£34,760
Healthcare	£5,886	£11,258
Quality of life costs	£956	£1,462
Unpaid care	£17,719	£33,803
Economic costs	-£3,372	-£4,830
Scotland	**£3,408**	**£7,047**
Social care	£1,299	£3,005
Healthcare	£630	£1,173
Quality of life costs	£92	£138
Unpaid care	£1,712	£3,185
Economic costs	-£326	-£455
Wales	**£2,273**	**£4,626**
Social care	£928	£2,104
Healthcare	£396	£721
Quality of life costs	£59	£86
Unpaid care	£1,099	£1,999
Economic costs	-£209	-£286
Northern Ireland	**£997**	**£2,217**
Social care	£349	£869
Healthcare	£191	£386
Quality of life costs	£29	£46
Unpaid care	£530	£1,069
Economic costs	-£101	-£153

Estimated cost of dementia by region: 2024

Sources: CF analysis, ONS (2020), Wittenberg, R. et. al. (2019b), Comas-Herrera, A. et. al. (2017), DiscoverNOW
Note: Prices expressed in real terms, in 2024 prices

The costs identified in this study are slightly lower than previous estimates, driven by lower prevalence projections and a different severity distribution

Comparison of total cost by setting across key literature

Carnall Farrar (2024). The economic burden of dementia.		
£billion	**2024**	**2040**
Healthcare	7.1	13.5
Social care	17.2	40.7
Unpaid care	21.1	40.1
Other costs	-2.9	-4.0
Total costs	**42.5**	**90.6**

Wittenberg, R. et. al. (2019b). *Projections of older people living with dementia and costs of dementia care in the United Kingdom, 2019–2040*. London: CPEC, LSE, 79		
£billion	**2025**	**2040**
Healthcare	6.3	12.5
Social care	21.6	45.4
Unpaid care	18.2	35.7
Other costs	0.3	0.6
Total costs	**46.3**	**94.1**

Differences in cost across studies are largely due to:

1. This study uses 2024 adjusted prices, while Wittenberg, R. et. al. (2019b) uses 2015 based prices
2. This study uses more recent population projections, which are lower than previous estimates
3. This study uses severity distributions developed from the DiscoverNOW dataset while Wittenberg, R. et. al. (2019b) uses severity distributions from the CFASII study[1], the latter estimates more people in the severe stage, with higher associated costs
4. This study includes more quality of life costs and economic losses, which previous studies do not appear to include
5. This study likely uses different underlying assumptions on unpaid care hours, social care and domiciliary care

Sources: 1) Matthews, F.E. et. al. (2016), CF analysis

Average cost per patient increases significantly as patients progress through disease stages, with mild dementia costing £28,700 but severe dementia costing £80,500 per year

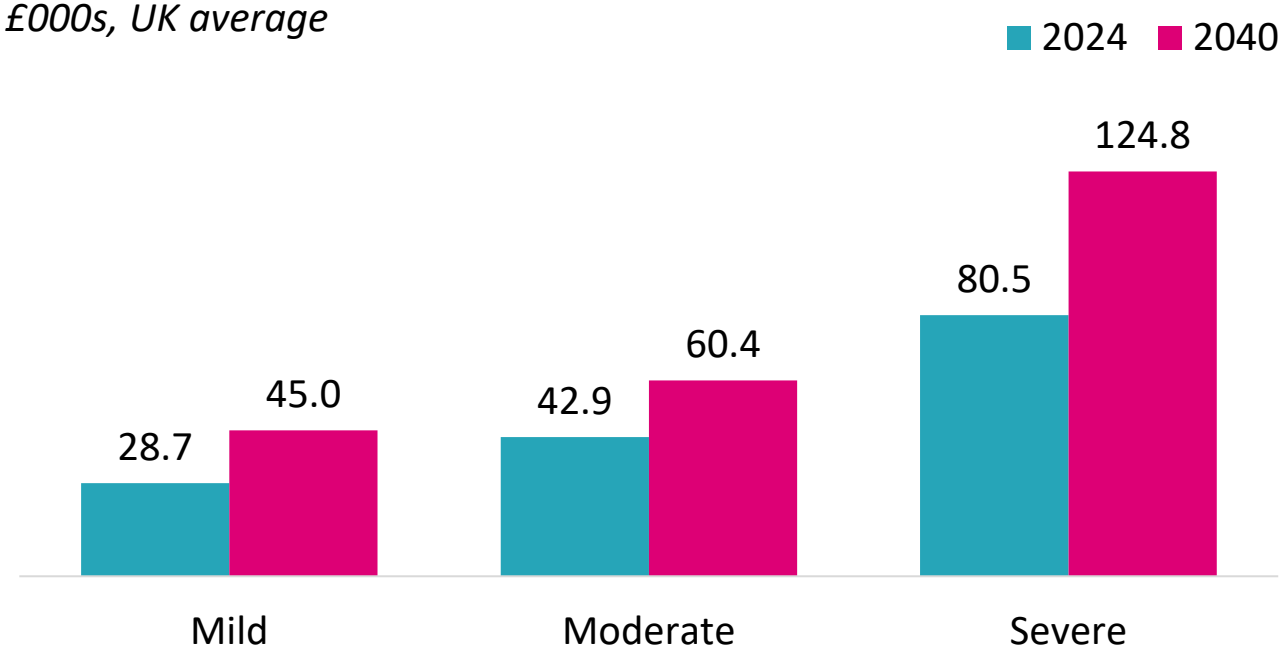
Per person costs of dementia by cost type

UK average

	2024
Total cost	**£43,259**
Healthcare	£7,235
Social care	£17,493
Unpaid care	£21,456
Economic cost	-£4,083
Quality of life	£1,157

Per person costs of dementia by severity

£000s, UK average



- The cost of care increases at a faster rate as patients progress through disease stages - a **moderate patient is 1.5 times more costly than a mild patient** but a **severe patient is nearly two times more costly than a moderate patient**

Sources: CF analysis, ONS (2020), Wittenberg, R. et. al. (2019b), Comas-Herrera, A. et. al. (2017), DiscoverNOW
Note: Prices expressed in real terms, in 2024 prices

The increase in the average per person costs with increasing severity is largely driven by an increase in the average cost per person of social care

Estimated per person costs of dementia by severity and setting: 2024

£000s, UK average

	Mild	Moderate	Severe	Pre-diagnosed
All costs	**28,727**	**42,942**	**80,499**	**0**
Social care	16,306	8,708	47,236	0
Unpaid care	9,688	33,369	32,265	0
Healthcare	7,766	7,468	7,976	6,480
Economic costs	-2,500	-5,000	-7,500	0
Quality of life costs	910	1,709	522	0

- **Average per person costs increase with severity across all care settings,** excluding quality of life costs which decrease, likely due to people becoming bed-bound and therefore being less likely to need transport or fall victim to scams
- **Social care has the highest per person cost across cost types for mild and severe dementia**, while unpaid care is the highest cost for moderate dementia
- **Delaying the onset of severe dementia symptoms and care needs** represents a cost-effective approach to the management of this patient population – this will be explored more in Module 4
- **Pre-diagnosed patients have slightly lower overall healthcare costs** per person than diagnosed patients

Sources: CF analysis, ONS (2020), Wittenberg, R. et. al. (2019b), Comas-Herrera, A. et. al. (2017), DiscoverNOW

The average per person costs developed in this study are comparable with previous work, with differences due to new cost categories and estimates for social and unpaid care

Average per person costs across studies by severity

£000s, UK average

	Carnall Farrar (2024)	Wittenberg, R. et. al. (2019b)		Prince, M. et. al. (2014)	
	2024	2020 (expressed in 2015 prices)	2020 (expressed in 2024 prices[1])	2013 (expressed in 2013 prices)	2013 (expressed in 2024 prices[1])
Mild	**28.7**	24.4	33.5	26.2	38.7
Moderate	**42.9**	27.5	37.8	39.3	58.0
Severe	**80.6**	46.1	63.4	41.2	60.8

- The estimated average per person costs are **comparable with results from other studies**
- The **biggest difference is for the severe dementia cohort**, which is due to several factors:
  - The real-term price of social care has risen above inflation by an average percentage change of 3.4% (see slide 25), meaning unit costs are higher
  - This study estimates more cost for unpaid care than previous estimates
  - New cost types have been incorporated which were not studied in previous work

Source: CF analysis

Notes: 1) Used 3.6% inflationary rate based on Bank of England statistics

Differences between this study and previous include additional costs across all cost types, uplifted prices to 2024 and a larger cohort used to identify healthcare costs

		Wittenberg, R. et. al. (2019b)	Carnall Farrar (2024)
Healthcare	Inclusions	• Primary care • Secondary care • Community	• Primary care • Secondary care • Community • **Mental Health** • **Prescribing**
	Data sources	• NHS Reference Costs in 2015 prices • MODEM cohort data	• Costs calculated using real patient-level data from NWL expressed in 2023 prices
Social Care	Inclusions	• Residential care • Nursing care • Homecare	• Residential care • Nursing care • Homecare • **Respite care**
	Data sources	• PSSRU Unit Costs, 2016 • MODEM cohort data	• Literature review, Laing & Buisson, Lottie.org (retrieved 2024) • Care homes and estimating the self-funding population, England (2022) • Personal Social Services Survey of Adult Carers in England (June 2022)
Quality of life	Inclusions	• None	• **Transport costs (reduced mobility)** • **Power of attorney costs** • **Increased energy costs** • **Police callouts** • **Vulnerability to scams**
Economic	Inclusions	• None	• **Reduced economic output (GVA)**
Cohort		• 318 people with clinically diagnosed dementia and their main carers	• **26,097 patients with clinically diagnosed dementia**
Data coverage		• Populations served by Sussex Partnership NHS Foundation Trust.	• Patient-level data from over 2.7m people, extrapolated nationally using an index of cost based on public health expenditure

Source: CF analysis

Difference in cost is also driven by large differences in the unit costs of social care between studies and differences in the distribution of time spent on unpaid care

Percentage of people with dementia receiving care

Wittenberg, R. et. al. (2019b)

		Percentage of cohort		
		Mild	Moderate	Severe
Community	No care	34%	31%	3%
	Unpaid care only	26%	44%	20%
	Homecare	7%	4%	2%
	Both	7%	12%	9%
Social Care	Residential care	19%	6%	47%
	Nursing care	8%	2%	19%
Total		100%	100%	100%

Comparison of social care & unpaid care unit costs

2024, UK average

	Social care				Unpaid care	
	Self-funded		Local Authority			
	Residential	Nursing	Residential	Nursing	Replacement cost	Opportunity cost
Carnall Farrar (2024)	£1,299	£1,503	£957	£1,037	£24	£11.44
Wittenberg, R. et. al. (2019b) *(inflation adjusted)*	£518 *(£738)*	£701 *(£999)*	£782 *(£1,114)*	£701 *(£999)*	*£18 (£25)*	*£7.20 (£10.30)*
Cost difference, % (inflation adjusted)	**76%**	**50%**	**-14%**	**4%**	**-4%**	**11%**

- The proportion of people with dementia in each care setting is consistent across studies, but social care unit costs are much higher in this study compared to assumptions used in Wittenberg, R. et. al. (2019b), this is reflective of the increase in real-terms prices for social care since 2015
- Unpaid care costs are comparable with those used in Wittenberg, R. et. al. (2019b) but the assumed number of care hours are higher (see appendix 7)

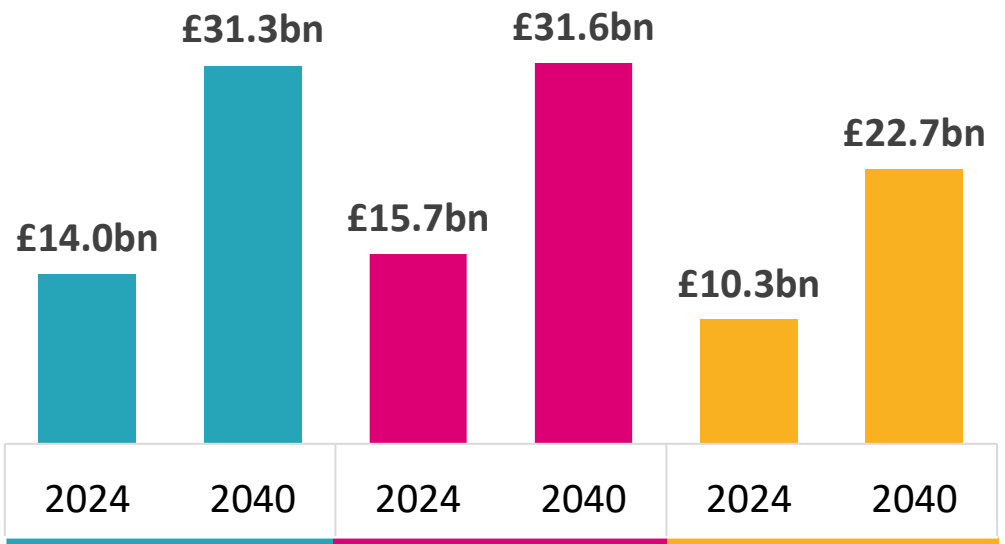
Source: CF analysis

Notes: 1) Based on data table S1

The total cost of dementia by severity is similar across mild, moderate and severe cohorts

Estimated total costs of dementia by severity

2024 – 2040



		Mild	Moderate	Severe
Cohort size, *000s*	2024	488	332	127
	2040	697	523	182
Average per person costs, *000s*	2024	£28.7	£42.9	£80.5
	2040	£45.0	£60.4	£124.8

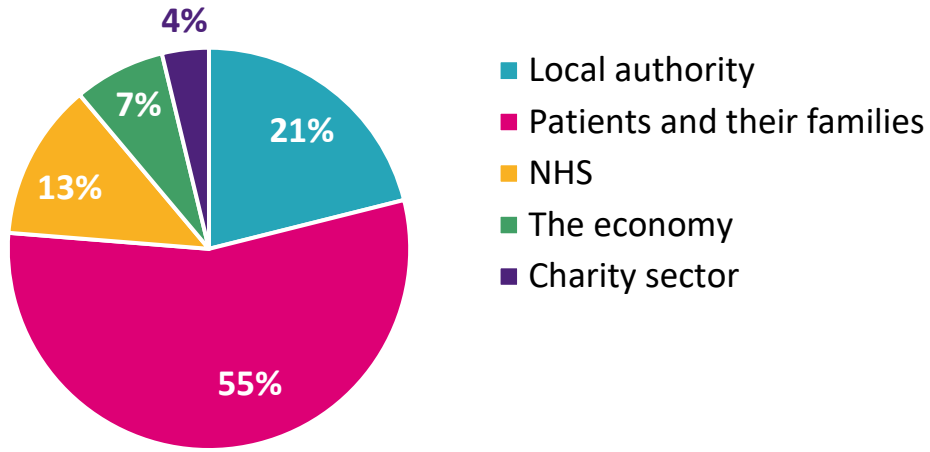
- While average per person costs increase with increasing severity, the number of people in the cohort decreases, meaning **total costs are similar**
- If opportunities exist to increase the time spent in earlier stages, or decrease the length of time for which people require more extensive care, **the total costs of dementia could be reduced**
- There are currently several treatments that aim to alter the course of disease progression and reduce its substantial impact (known are disease modifying treatments or DMTs) in varying stages of development and regulatory approval
- In Module 4 of this study, we analyse the potential impact of increased use of existing treatments to reduce the time for which more expensive care is required

Sources: CF analysis, ONS (2020), Wittenberg, R. et. al. (2019b), Comas-Herrera, A. et. al. (2017), DiscoverNOW

It is estimated that 63% of dementia costs are funded by patients and their families, with 41% of people reporting that this has caused them financial difficulties

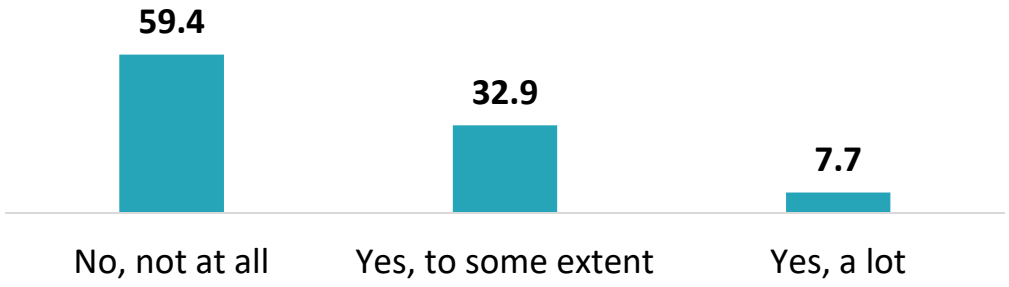
Percentage of costs paid by funding source[1]

2024, England



In the last 12 months, has caring (for a dementia patient) caused you any financial difficulties?[2]

N = 14,460



Total costs by funding source and cost type for this study

2024, £billions

	Self-funded	Local authority	NHS	Total
Unpaid care	**21.1**			**21.1**
Social care	**8.8**	**8.4**		**17.2**
Residential care	4.7	5.5		10.2
Nursing care	2.2	2.6		4.8
Domiciliary care	1.9	0.4		2.3
Healthcare			**7.1**	**7.1**
Quality of life	**1.1**	**0.02**		**1.1**
Additional heating	0.7			0.7
Criminal justice		0.02		0.02
Legal	0.1			0.1
Scam	0.1			0.1
Transport	0.1			0.1
Economic cost	**-4.0**			**-4.0**
Total cost	**26.8**	**8.7**	**7.1**	**42.5**

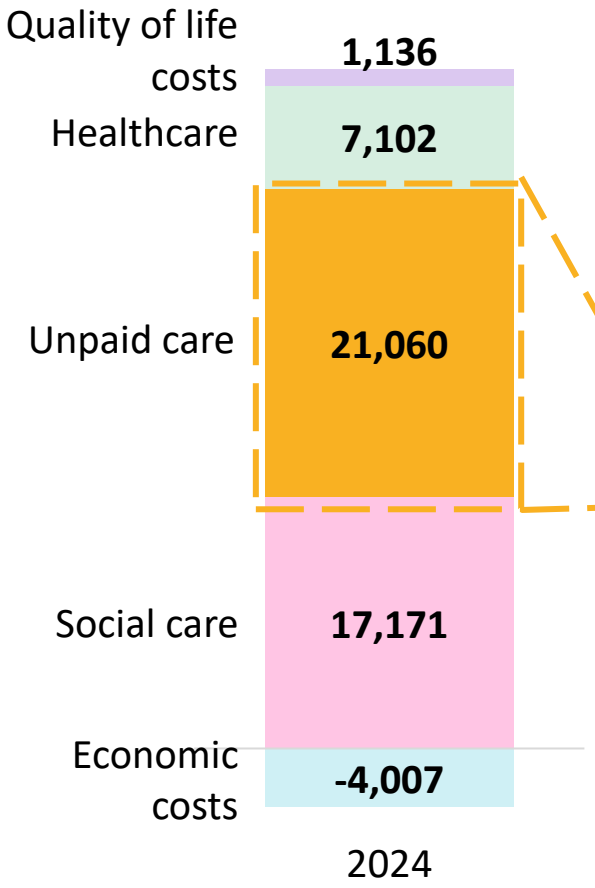
Note: The percentage of social care costs that self-funded or state-funded were estimated based on ONS data for England[1], as limited data was available for other devolved nations. The distribution may differ in Northern Ireland, Wales and Scotland.

Sources: 1) ONS. (2023) 2) NHS Digital. (2022), CF analysis

Unpaid care is the largest component of cost, borne directly by patients & their carers. Costs increase more than three times as patients move from mild to moderate dementia.

Total cost by cost type

£millions



Total and average per person costs by severity

UK average

	Total cost (billions)	Per person cost (000s)		
		Mild	Moderate	Severe
2024	£21.1	£9.7	£33.4	£32.3

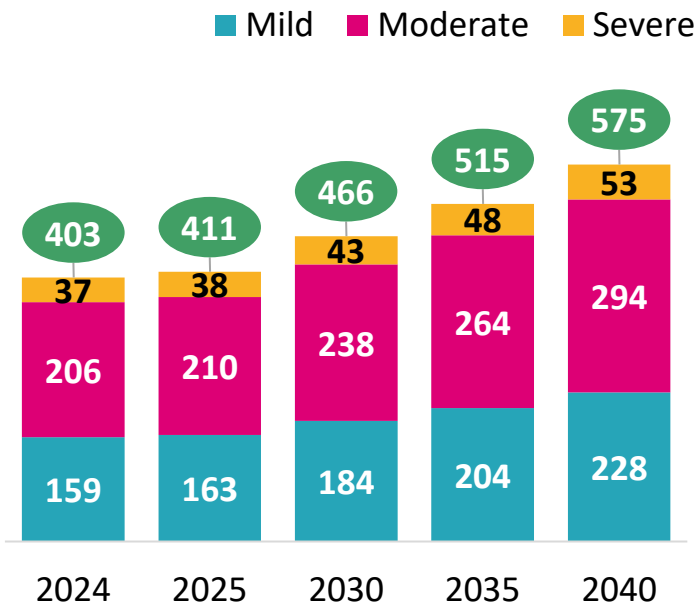
- There is **increasing dependence and need for care** over time as cognitive and functional impairment progresses with disease stage
- Those living with dementia eventually reach a level of disability that **requires constant care and supervision, increasing the number of unpaid hours spent on care** and the burden on patients and their loved ones
- Given that **most dementia patients are cared for in the community by family and friends**, this cost is significant but can often be underrepresented
- Supporting these individuals should be a **key consideration for policymakers going forward**

Sources: CF analysis, Jakobsen, M. et.al (2011), Wimo, A. et. al. (2001), Moore, M. et. al. (2001)

By 2040, 43% more people are expected to require unpaid care, reaching a total of over half a million people

Estimated number of unpaid care recipients

000s

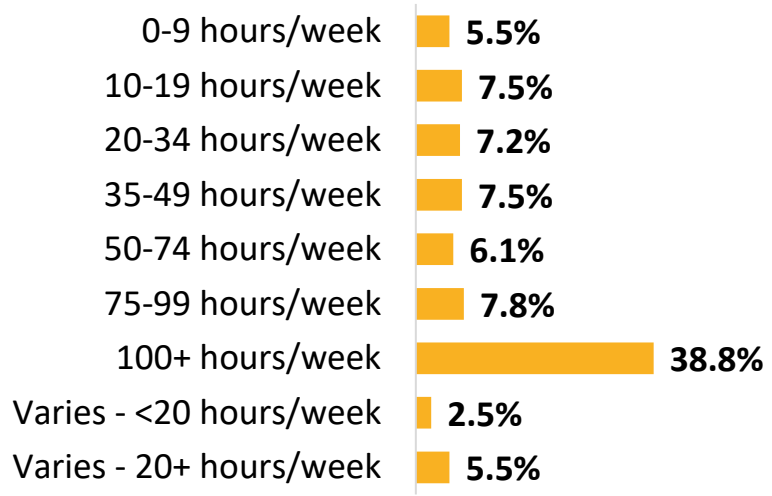


Average annual hours/days of unpaid care

	Average care hours per patient per year	Days spent on unpaid care	% of the year spent on unpaid care
Mild	1,826	76	**21%**
Moderate	3,329	139	**38%**
Severe	5,728	239	**65%**

Distribution of care hours reported by unpaid dementia carers[1]

Q22: About how long do you spend each week looking after or helping the person you care for?
N = 14,085



- 36.3% of unpaid dementia carers reportedly have **caring responsibilities for more than one person**[1]
- Around a **third of unpaid dementia carers** also report that they **spend more than 100 hours per week** caring for a dementia patient – it is assumed that hours of care increase as the condition progresses

Sources: 1) NHS Digital. (2022), CF analysis

Unpaid care is having a significant impact on carer wellbeing and the majority of carers report that they are neglecting their needs, with 70% of carers wanting more support

Dementia carers: unpaid carer impact and sentiment[1]

Which of the following statements best describes how you spend your time? *N=14,435*	
I'm able to spend my time as I want, doing things I value or enjoy	12.3%
I do some of the things I value or enjoy with my time but not enough	66.8%
I don't do anything I value or enjoy with my time	21%

Which of the following statements best describes how much control you have over your daily life? *N=14,570*	
I have as much control over my daily life as I want	18.1%
I have some control over my daily life but not enough	63.3%
I have no control over my daily life	18.6%

Thinking about how much time you have to look after yourself, sleep or eating well, what best describes your situation? *N=14,605*	
I look after myself	47.4%
Sometimes I can't look after myself well enough	30.4%
I feel I am neglecting myself	22.2%

Thinking about how much social contact you've had with people you like, which of the following best describes your social situation? *N=14,585*	
I have as much social contact as I want with people I like	23.5%
I have some social contact with people but not enough	53.6%
I have little social contact with people and feel socially isolated	22.8%

Thinking about encouragement and support in your caring role, which of the following best describes your present situation? *N=14,390*	
I feel I have encouragement and support	30.9%
I feel I have some encouragement and support but not enough	50.5%
I feel I have no encouragement and support	18.6%

Sources: 1) NHS Digital. (2022) – data restricted to unpaid carers, CF analysis

While most carers are retired, 16% report that they have had to give up work and nearly two thirds reportedly suffer from their own health conditions while providing care

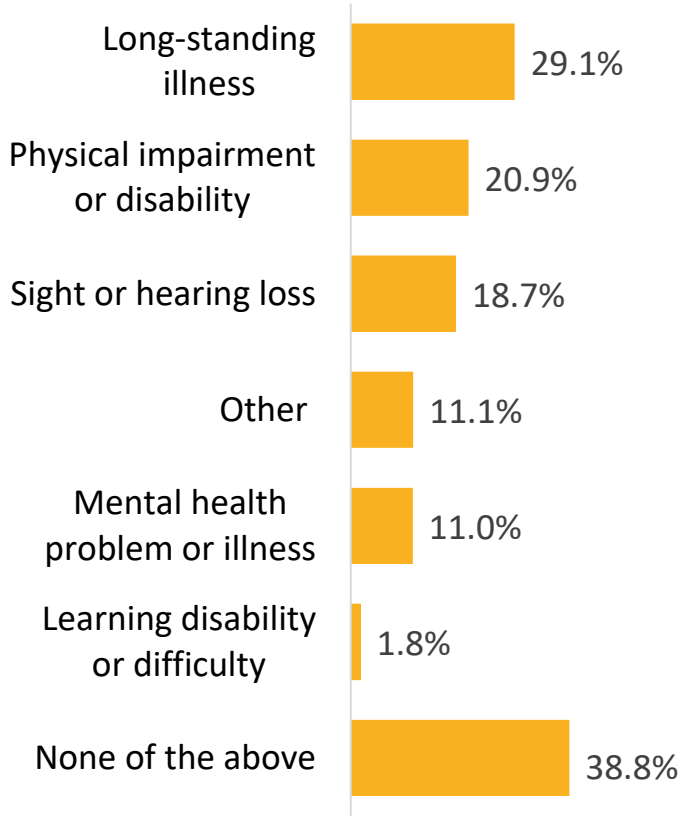
Unpaid dementia carer employment and support

Q20: Thinking about combining paid work and caring, which of the following statements best describes your current situation? N = 13,995

Given up employment	I am not in paid employment because of my caring responsibilities	**16.1%**
Employed but require support	I am in paid employment but don't feel supported by my employer	**3.2%**
	I am self-employed but I am unable to balance my work and caring	**2%**
Employed and feel supported or don't need help	I am in paid employment and I feel supported by my employer	**10.3%**
	I am in paid employment and do not need support from my employer to combine work and caring	**3%**
	I am self-employed and I am able to balance my work and caring	**2.6%**
Not employed	I am not in paid employment for other reasons (e.g. retired)	**62.8%**

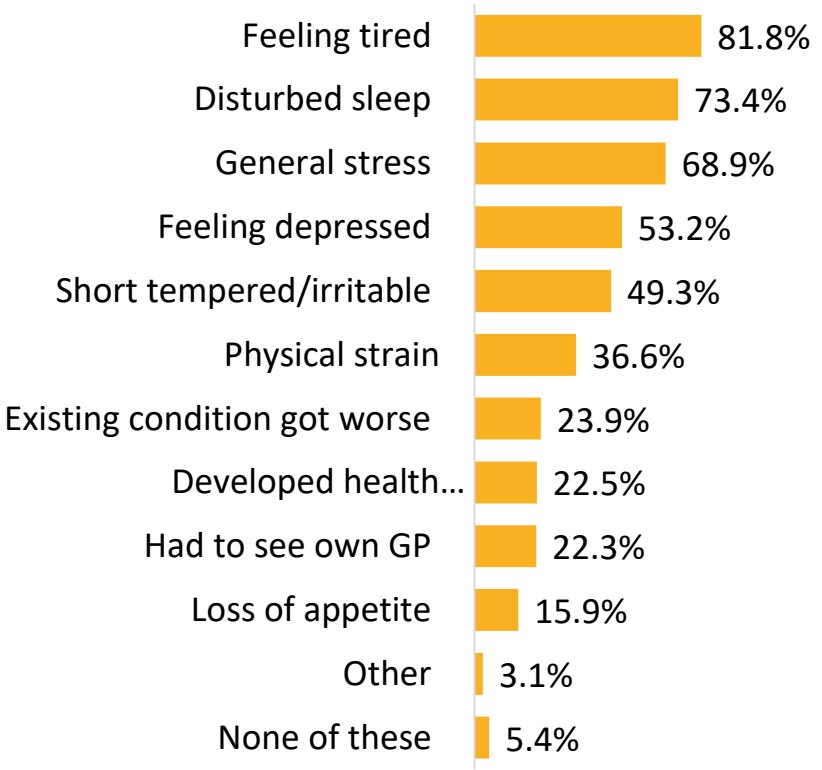
Unpaid dementia carer health conditions

Q24: Do you have the following?
N = 13,885



The impact on unpaid dementia carers

In the last 12 months, has your health been affected by your caring role in any of the ways listed below? N = 14,635

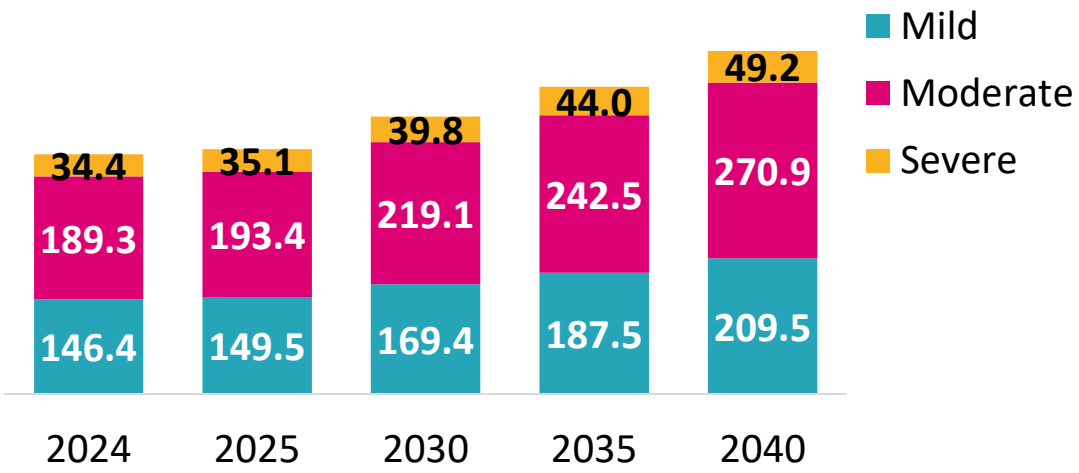


Sources: NHS Digital. (2022), CF analysis

Despite the large care burden falling on unpaid carers, over 70% of report that they feel unsupported with only 14% estimated to have some form of respite care

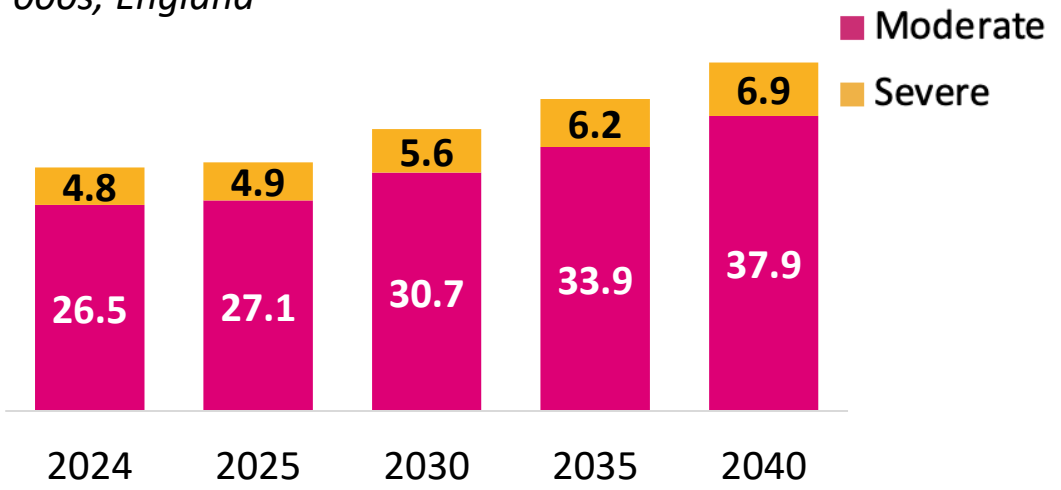
Estimated patients with unpaid carers

000s, England



Estimated respite breaks for carers: 2024 – 2040

000s, England



- **Many carers are not identified by their GP** or other health services interacting with the person needing care, meaning **caring work can go unacknowledged.** Based on survey responses**, only 14% of dementia carers are taking a respite break** each year – for around a week[1]
- **Over 70% of carers** report that they **feel unsupported**
- Given the huge burden of unpaid care and the level of stress and lack of support these carers reportedly feel, **policy makers must ensure carers are identified, an assessment is carried out (as per Care Act) and that appropriate support is subsequently made available**

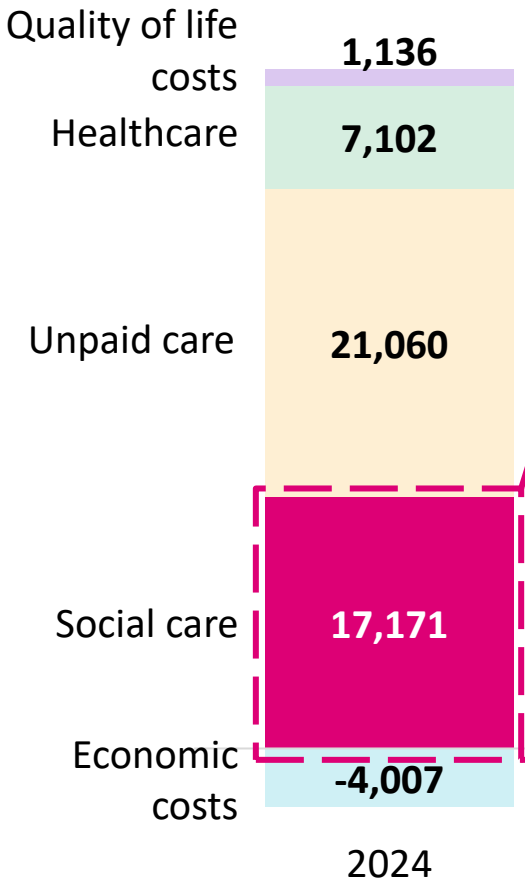
Sources: 1) NHS Digital. (2022), CF analysis

Notes: Average cost of respite is recorded as £750 per week - assumed that only carers looking after moderate and severe patients take respite.

Social care is the second largest component of cost, driven primarily by residential care costs, with severe patients accounting for the majority of all costs

Total cost by cost type

£millions



Total and average per person costs by severity

UK average

	Total cost (billions)	Per person cost (000s)		
		Mild	Moderate	Severe
Residential	£10.1	£11.0	£3.6	£27.3
Nursing	£4.8	£5.1	£1.7	£12.8
Domiciliary	£2.3	£0.2	£3.4	£7.1
Respite	£0.03	£0.0	£0.07	£0.04
All	**£17.1**	**£16.5**	**£8.8**	**£47.6**

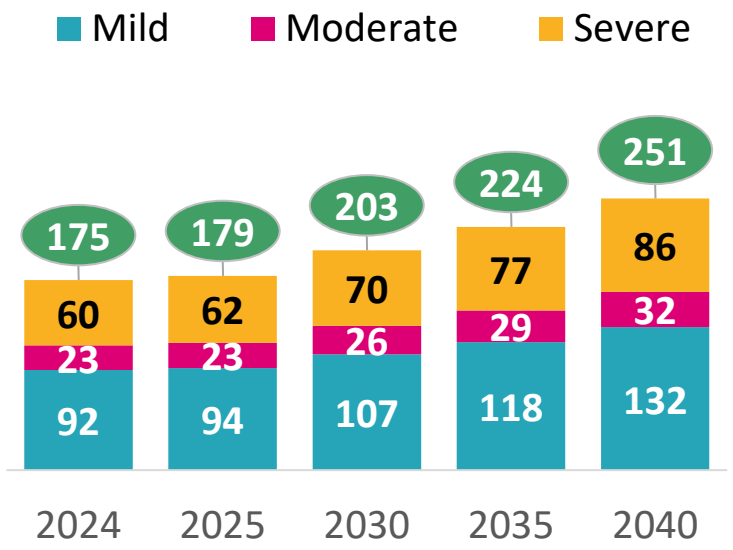
- Social care costs **increase significantly as dementia severity progresses** and are very high for people living with severe dementia
- Respite care costs are relatively low as **only 14% of unpaid dementia carers[1] self-report that they take respite breaks each year** – there is a significant lack of support for carers in this space
- There is a **lack of consistent and reliable data captured across the social care sector** – estimates have been developed using the best publicly available data

Sources: 1) NHS Digital. (2022), CF analysis, ONS (2020), Wittenberg, R. et. al. (2019b), Comas-Herrera, A. et. al. (2017), DiscoverNOW

By 2040, 76K more people are projected to live in a residential home and 30K more in a nursing home relative to today, with nearly 50% funding this care themselves

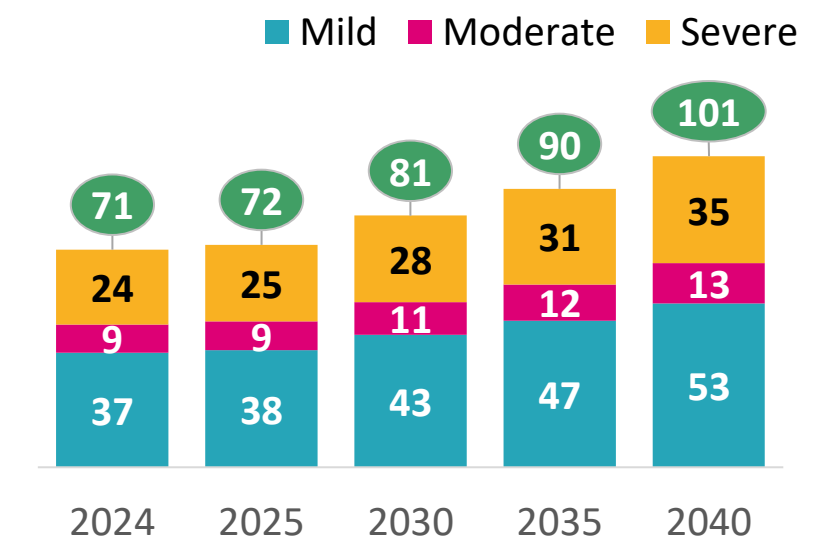
Dementia population in residential care

000s



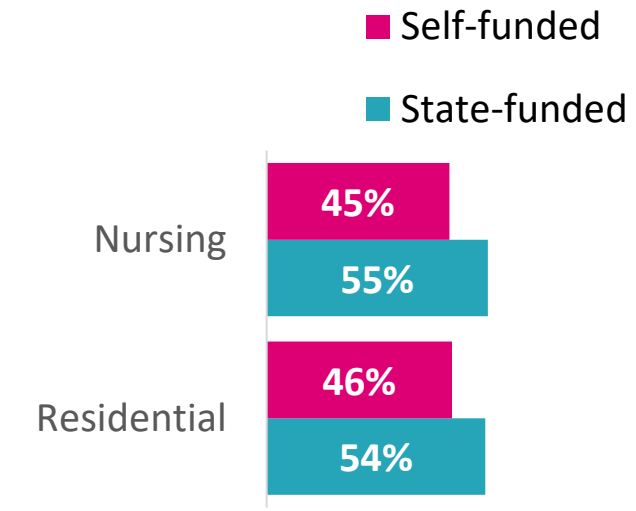
Dementia population in nursing care

000s



Care home funding arrangements

2024



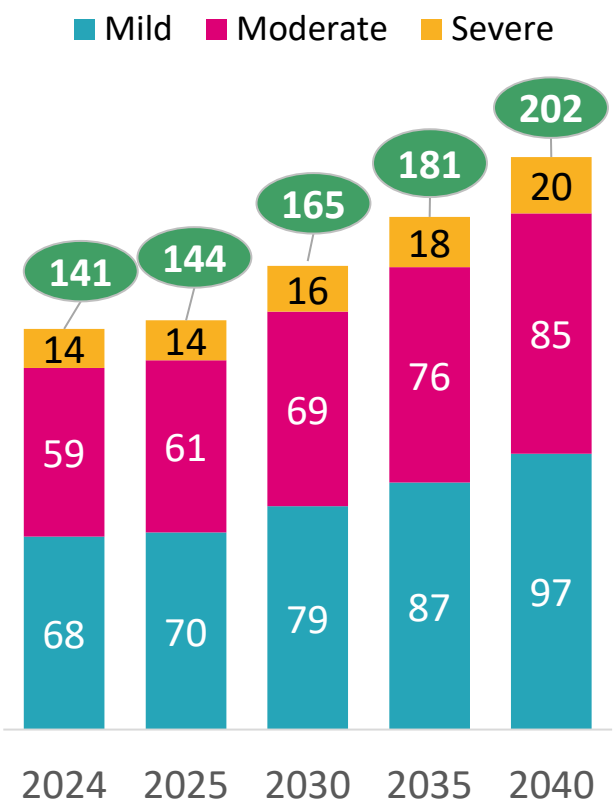
- The number of **residential and nursing home residents is expected to grow in line with increasing prevalence** and severity
- Local authority funding for any type of care is subject to strict eligibility criteria and **stringent means testing;** individuals are expected to contribute what they can towards the cost of their care home if they are above the savings threshold
- While some people will receive top-up funding, **nearly half of patients have to fund all of their care**

Sources: CF analysis, ONS (2020), Wittenberg, R. et. al. (2019b), Comas-Herrera, A. et. al. (2017), DiscoverNOW

The number of people in receipt of domiciliary care is expected to increase by 43%, with a large percentage of patients in the moderate cohort requiring care

Domiciliary care recipients

000s



Domiciliary care assumptions

	Mild	Moderate	Severe
Visits per day	1 visit a day	2 visits a day	4 visits a day
Average length per visit	30 mins	30 mins	30 mins
Care requirements	Low - medication and appointment reminders	Personal care, washing, ensuring patients feel comfortable at home	Intensive care with ADLs, and IADLs. Live-in care may also become an option

- The majority of home care is provided by **independent organisations** and evidence of time spent and care provided by these services is **very limited or highly variable**
- The study assumes that the **number of care visits increases over time** - in line with increasing care needs
- **Severe patients** are also assumed to receive some form of **specialist care** for at least one home visit

Source: CF analysis, Age UK: Behind the Headlines (2018)

The social care system is underfunded & overstretched which is putting vulnerable older people's health, dignity and capacity to live independently at risk

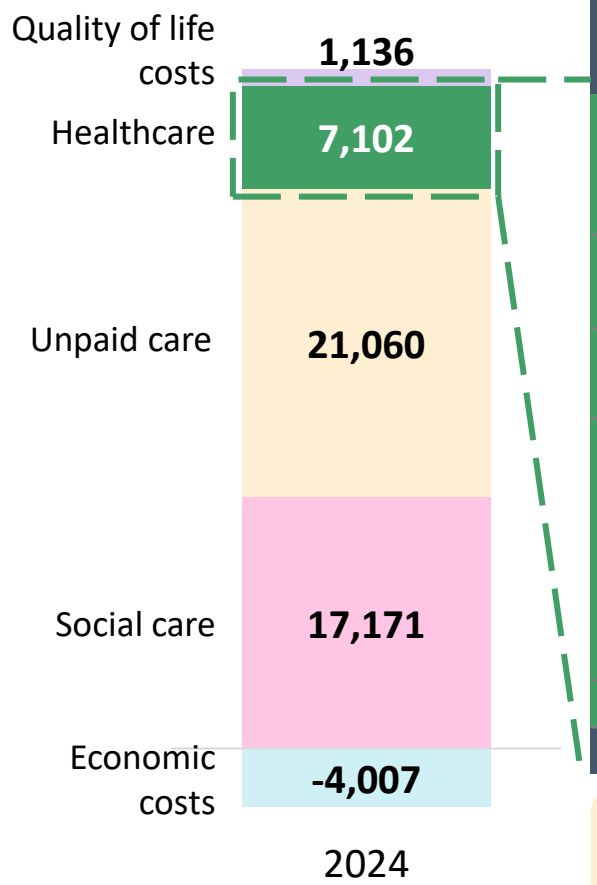
	Challenges within the social care sector
Support and services being cut back	• Local councils have seen a reduction in their budgets, leading to cuts in direct council spending on adult social care, while facing increased demand for services • There is also significant 'churn' in the home care sector - fees paid by local authorities are frequently lower than the actual costs of providing the care
Gaps in specialist care	• Local authorities have identified gaps in care for people with complex needs and those that require specialist dementia care - while there is sufficient residential care, there aren't enough nursing beds for people with more complex needs
Growing workforce crisis	• There are widespread challenges with the adult social care workforce and many care workers are leaving the sector for better paid jobs in less pressurised environments driven by low pay, high pressure and staff burnout. According to a CQC survey of adult social care providers in England: – Over half of respondents said they were having challenges recruiting new staff, with a significant lack of nursing and homecare staff – 31% of providers said they were having challenges in retaining staff – Some providers struggle to pay their staff a wage in line with inflation • Challenges in social care place added pressure on dementia patients' families and friends - even when someone is receiving formal home care, families are still usually highly involved and carry a lot of responsibility, for example, for co-ordinating care
Poor quality of care and disjointed services	• Workforce challenges are leading to a disjointed or unresponsive service – professional carers cannot spend as much time as they might want to with patients and home care patients report that their carers often do not stay for the full length of their planned visit but instead 'box tick' • Workforce constraints also lead to patients seeing multiple carers each week and a lack of continuity of care is unsettling for vulnerable patients • Poor quality of care is leading to more than one in five care home providers being rated as either inadequate or requiring improvement by the CQC
Long waiting times for a social care assessment	• Almost 250,000 people were waiting for an adult social care needs assessment in August 2023 to measure need for social care funding

Sources: CF analysis, Association of Directors of Adult Social Services. (2023)

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.*

Sources: CF analysis, ONS (2020), Wittenberg, R. et. al. (2019b), Comas-Herrera, A. et. al. (2017), DiscoverNOW

The estimated total cost of diagnosing dementia in 2024 is £80.1million, only 1.1% of the total healthcare spend and 0.2% of the total spend on people with dementia

Method

NICE guidance[1] states that a patient with suspected symptoms presenting to their GP should be referred to a memory clinic following initial assessment. From the memory clinic, NICE recommend that only if the diagnosis is uncertain then the patient should receive structural imaging testing. Activity and spend for memory assessments to diagnose dementia could not be disaggregated in the DiscoverNOW dataset. To estimate the total spend on dementia diagnosis in 2024, the following estimates were used:

Spend on memory assessments	=	Annual number of assessments in England	x	Scaling factor to rest of UK	x	Unit cost of a memory assessment	
		75,000[2]	x	1.19[3]	x	£897[4]	= **£80.1million**

Results

- The total estimate for spend on memory assessments in 2024 is £80.1million, this includes testing for people who are not ultimately diagnosed
- The total spend on memory assessments is:

1.1% of the healthcare spend for people with dementia

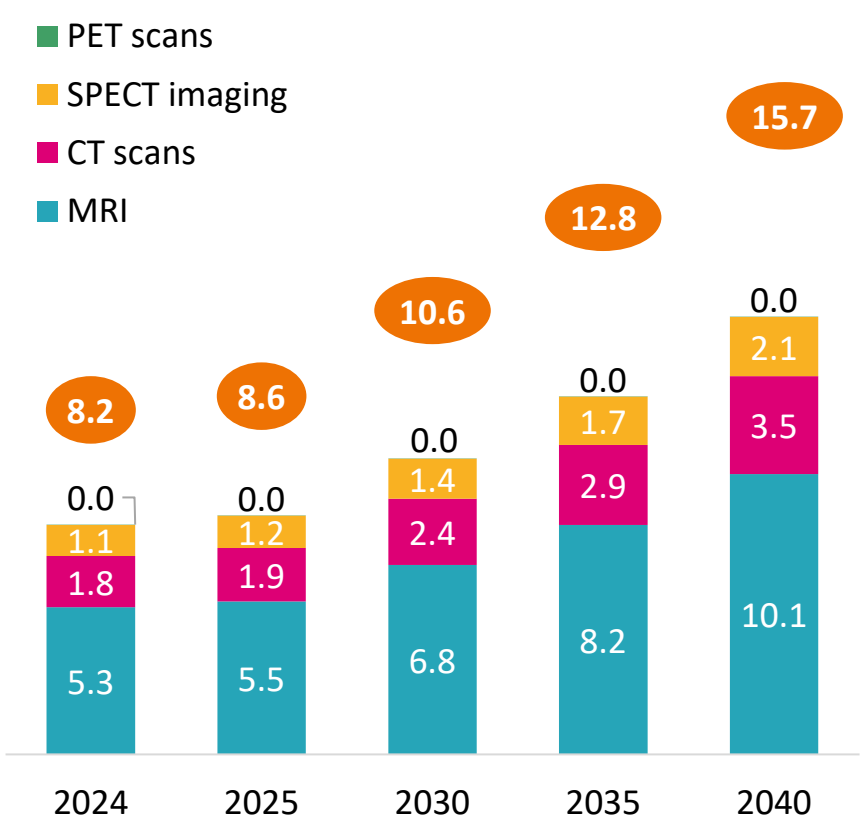
0.19% of the total spend for people with dementia

Sources: 1) NICE. (2018) 2) NHS Digital. (2024) 2) ONS. (2020) 3) PSSRU. (2023), CF analysis

Despite research highlighting the importance of timely and accurate diagnosis in dementia, diagnostic imaging costs are currently less than 0.1% of total healthcare costs

Diagnostic imaging costs by type

2024, £millions



Diagnostics costs are:

4.1%
of outpatient costs

0.12%
of healthcare costs

0.02%
of total dementia costs

- Diagnostic imaging costs are small, **£8.2m in 2024**, contributing only **0.1% of total healthcare costs**

- The average cost for an MRI scan, the most common diagnostic imaging technique for dementia, defined by the national cost collection is £219[1]
- Therefore an estimated **38,000 patients received a diagnostic scan in 2024**. When compared to the total population of 982,000 people living with dementia in the UK, it can be assumed that only 3.8% receive an imaging assessment per year
- This value includes the cost associated with non-diagnostic imaging

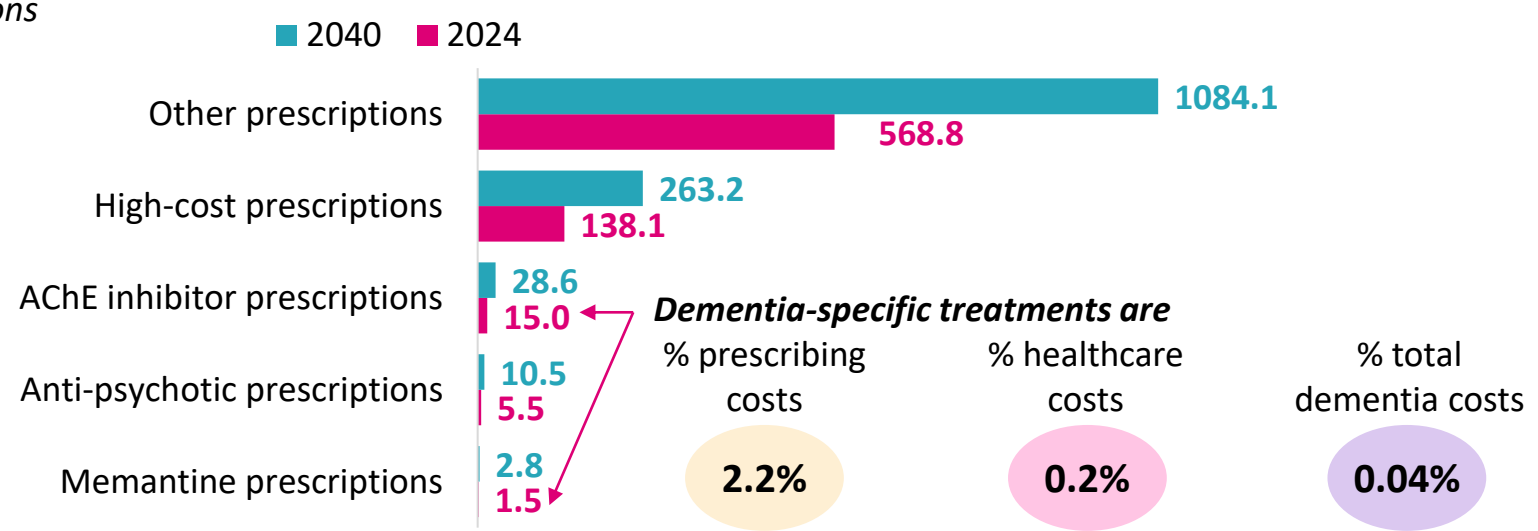
Notes on data & methodology: *The costs shown are for testing relevant to dementia that was recorded in the outpatient setting. Additional activity may have occurred in the mental health care setting that could not be analysed from the available data. Imaging could not be isolated as activity specifically to diagnose dementia.*

Sources: 1) NCC 2022/23, CF analysis, DiscoverNOW

Dementia-specific treatments (including AChE Inhibitors and memantine) as well as antipsychotics only make up 3.0% of total prescribing costs

Breakdown of prescribing costs by drug types

£millions



Breakdown of prescribing costs by drug type and severity

£millions, 2024

	Mild	Moderate	Severe	Undiagnosed
Other prescriptions	154.1	108.5	64.4	241.8
High cost prescriptions	41.1	32.9	5.0	59.0
AChE inhibitors	7.7	3.9	2.6	0.8
Anti-psychotics	1.3	0.8	0.9	2.4
Memantine prescriptions	0.6	0.5	0.3	0.1

- Dementia-specific medicines and anti-psychotic drugs **only make up 3.0% of total prescribing costs** and **0.05%** of all dementia related costs
- Based on analysis of the English Prescribing Dataset, it is estimated **less than 6%** of all people with dementia were prescribed AChE inhibitors in 2023
- Note that the study covers all types of dementia, while use of these medications is more targeted at those with Alzheimer's disease

Sources: CF analysis, DIscoverNOW

A&E costs and outpatient costs for undiagnosed patients are higher than those incurred by mild patients

Total and average per person costs by severity

2024, UK average

271,700 people | 203,800 people | 127,600 people | 378,600 people

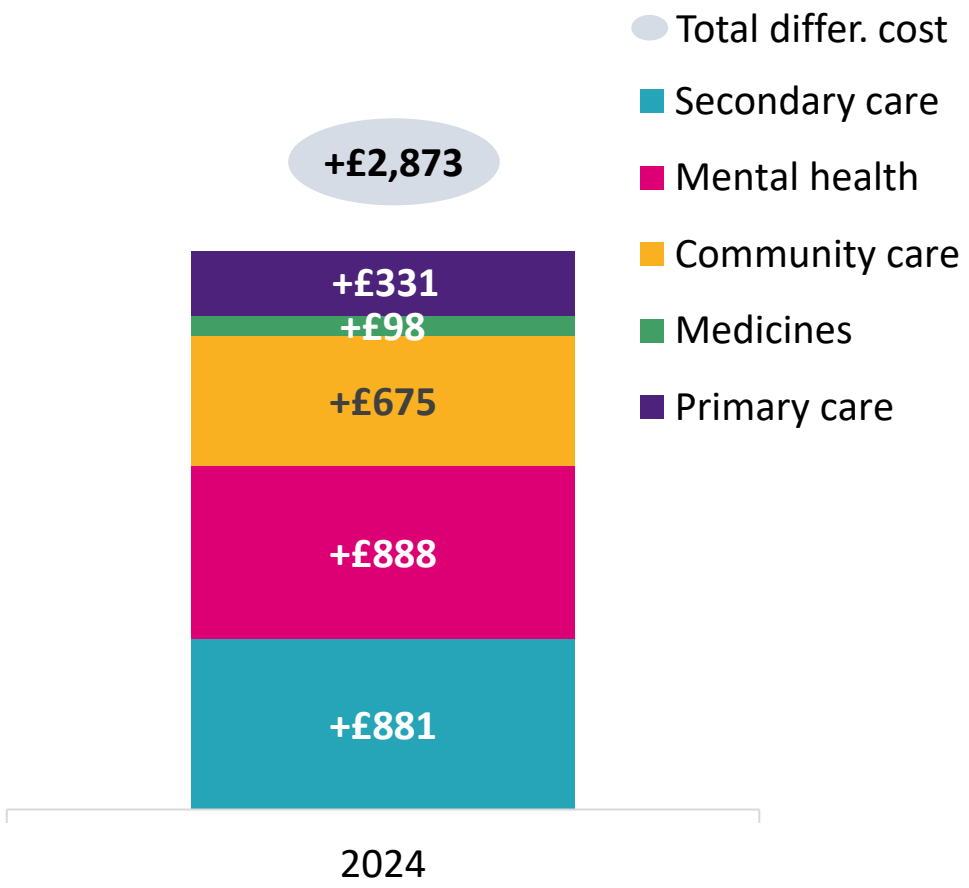
Cost type	Category	Per person cost (000s)				Total cost (millions)			
		Mild	Moderate	Severe	Pre-diagnosed	Mild	Moderate	Severe	Pre-diagnosed
Secondary care	Inpatient activity	£2.9	£2.8	£3.7	£2.5	£786.6	£568.4	£472.7	£936.8
	Outpatient activity	£0.3	£0.2	£0.1	£0.4	£84.9	£47.6	£15.9	£164.7
	A&E attendances	£0.2	£0.2	£0.2	£0.3	£57.3	£45.7	£20.2	£125.1
Mental health	Community activity	£1.4	£1.4	£1.4	£1.0	£371.4	£278.7	£174.3	£366.6
	Inpatient activity	£0.5	£0.5	£0.5	£0.1	£146.3	£109.8	£68.6	£50.7
Community care	Community care	£1.0	£1.0	£1.0	£0.7	£283.6	£212.9	£133.1	£266.9
Medicines	General primary care prescriptions	£0.6	£0.5	£0.5	£0.6	£154.1	£108.5	£64.4	£241.8
	Dementia primary care prescriptions	£0.04	£0.03	£0.03	£0.01	£9.6	£5.3	£3.8	£3.3
	High-cost drugs	£0.2	£0.2	£0.0	£0.2	£41.1	£32.9	£5.0	£59.0
Primary care	Contacts	£0.6	£0.6	£0.5	£0.6	£174.2	£112.5	£59.6	£238.4
Total		**£7.8**	**£7.5**	**£8.0**	**£6.5**	**£2,109.1**	**£1,522.2**	**£1,017.7**	**£2,453.2**

- Undiagnosed costs include the healthcare costs incurred by those living with dementia in the **two years prior to diagnosis**
- In general, **average costs per person are higher than for patients diagnosed with mild dementia**, although A&E attendances and outpatient attendances are higher before diagnosis
- These patients **may not receive the care they need or make the lifestyle changes required to reduce the likelihood of accidents** that subsequently require hospital care
- It is important to note that **this cohort naturally receive a significant amount of healthcare given their age** - the Office for Budget Responsibility found that those aged over 80 incur more than three times the amount for those under 50

Sources: CF analysis, DiscoverNOW

When matched with non-dementia patients with similar healthcare needs, each dementia patient still contributes £2,873 more in healthcare costs

Average differential cost & activity



- Alongside quantifying the total cost for dementia patients (as seen in previous studies), analysis was conducted to see how **costs for dementia compared to those for people of similar age and with a similar number of comorbidities**, showing the 'true cost' of dementia
- Patients in each cohort were **mapped to control patients**, based on **age, sex and comorbidities**, to compare similar populations
- The study used **statistical resampling** (bootstrapping) to develop statistics on the cost differences between cohorts
- **The differential cost is the difference between each cohort and its matched control group**

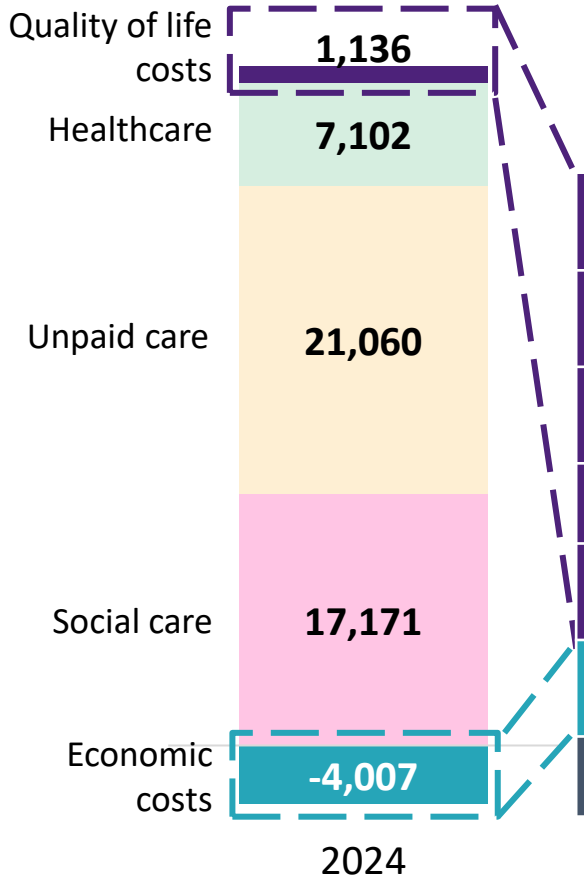
- Compared to a 'control cohort' with similar healthcare demographics, the **cost of healthcare is almost £3k higher in the dementia group**, compared with those without dementia

Source: CF analysis, DiscoverNOW

Quality of life costs drive an additional £1.1billion in cost, while economic losses from reduced economic output are estimated to reach around £4billion

Total cost breakdown: 2024

£millions



Quality of life and economic costs

UK average

	Total costs	Per person costs		
		Mild	Moderate	Severe
Additional heating	£736m	£734	£913	£118
Power of Attorney	£136m	£138	£138	£48
Reduced mobility	£139m	£0	£378	£3
Scams	£105m	£37	£231	£6
Police callouts	£20m	£0	£48	£7
Loss in consumption	-£4,007m	-£2,500	-£5,000	-£2,614
Total	-£2,871m	-£1,590	-£3,291	-£2,432

- There is an estimated £4billion drop in consumption **from dementia patients who reduce their spend,** while this represented a lower spend in the economy, we incorporated it in the total cost as a reduced cost to people with dementia
- Dementia patients, their families and the state also incur £1.0bn in annual quality of life costs as **patients' behaviours and levels of independence change**
- These costs are difficult to quantify but this study has included the additional cost to **heat homes**, an increased need for **private transportation** for those without support, increased costs for **deploying police** to deal with call outs, vulnerability to **scams** and legal costs of **lasting power of attorney**

Sources: CF analysis, Jakobsen, M. et.al (2011), Wimo, A. et. al. (2001), Moore, M. et. al. (2001)
Note: These economic costs do no include the cost of early onset dementia patients who retire due to the disease

Policy and stakeholder implications

A top priority for policy makers and healthcare providers should be improving access to early and accurate diagnosis and effective treatment

Diagnostic tests do not form a significant part of patient management

- Diagnostic testing and imaging is estimated to cost £80million in 2024, which corresponds to 1.1% of the total spend on healthcare for people with dementia
- Undiagnosed patients have higher A&E and outpatient costs than mild patients
- Early and accurate diagnosis is key to allowing people to manage their health, plan for the future and start treatment to improve their quality of life
- In particular, focus within diagnostics must shift to imaging and cerebrospinal fluid-based tests or those that best support effective treatment

Patient access to dementia specific treatments is limited

- Dementia-specific medicines and anti-psychotics make up only 3.3% of total prescribing costs
- It is estimated AChE inhibitors are prescribed to less than 6% of all dementia patient (these medicines are recommended for people with Alzheimer's disease, estimated to be 60% to 80% of all dementia patients)
- Increasing investment in disease modifying therapies that delay the onset of severe dementia symptoms represent a cost saving opportunity

Policymakers need to:

- Increase diagnostic capacity and ensure there is consistency in assessment, diagnosis and access, which is likely to require system-wide change
- Promote behavioural change in the early stages of dementia to better manage the population
- Better understand health inequalities that exist in dementia diagnosis and treatment
- Increase adoption and expenditure on dementia-specific drugs (including AChE inhibitors and memantine) to delay disease symptom progression
- Explore the real-world impact of delaying onset of severe dementia symptoms as key to cost effectiveness
- Ensure that there is sufficient budget and system readiness to cover diagnosis and uptake of new Disease Modifying Therapies (DMTs) which are anticipated to be reimbursed later this year.

Source: CF analysis

Better dementia data is foundational to supporting improvements in dementia care and patient outcomes

Data collected on diagnosis does not include disease severity	• Recording of diagnosis of dementia needs to improve as in many cases dementia diagnosis is recorded but not severity • This limits the ability to track the impact of dementia in total or progression of disease	• Clinicians, researchers and policymakers require a strong evidence-based case to invest in and approve innovative dementia medicines, such as DMTs. As such, national policymakers at NHS England should work to improve the collection of dementia data by providers.
Social care data is inconsistent and difficult to find, which makes understanding cost, activity and quality of care across the formal sector very difficult	• The number of dementia patients in residential or nursing homes is not captured • Data on self-funded or state-funded residents is also difficult to find and not consistently captured • There is no domiciliary care data recording time spent on care activities and how that varies by patient, severity and location • Where data does exist, it is often inconsistent and infrequently updated i.e. the PSSAC in England is updated every other year	• NHS England needs to encourage greater collaboration across the care system and more regular and standardised collection of data to understand utilisation, quality, cost and outcomes - electronic tools may need to be in place in order to facilitate this data capture • Surveys or provider returns should include questions on local authority-funded and self-funding patients, rectifying the current information deficit with regards to self-funding patients
There is no formal record of unpaid carers	• Both the NHS Long Term Plan and the government's roadmap for adult social care data have recognised the need for better data to identify carers and understand whether they are being supported effectively but no concrete plans exist to date	• Detailed electronic records are needed to identify carers and match them with the people they care for • Improved recording and data collection would help local authorities to identify their most vulnerable unpaid carers, develop a strategy that is aligned to their needs (and the needs of those they care for) and identify how to deliver more targeted support

Source: CF analysis, NHS Digital. (2022)

Implictions

Policymakers need to look to increase investment and support for unpaid carers to secure their commitment to caring

Demand for unpaid care is expected to increase 40% by 2040	• Unpaid carers play a vital role in supporting people with dementia, often picking up additional care responsibilities as a result of lack of capacity in the formal social care system. • Around a third of unpaid carers report that they spend more than 100 hours per week caring for a dementia patient
70% of unpaid carers report that they feel unsupported	• Many report that they lack suitable training to carry out care duties. • 16% leave the workforce due to care responsibilities and 3% feeling like their employers do not support them. • Only 14% receive some form of respite from their carer duties
Carer health is suffering due to a lack of support	• The most common effects are tiredness, disturbed sleep, general stress and depression, which has a knock-on effect on the health and care system.
Most Local Authorities need carer strategies	• The system lacks processes to identify carers and design and target interventions to reach those in need.

Policymakers need to:

- Increase funds for respite and relief support programmes and carer training

Local Authorities need to:

Adopt a strategic focus on unpaid carers, including identifying carers more proactively using co-production to understand their needs, working with employers to support carers to stay in employment, and focusing on young carers

- Design respite programmes that are targeted to reach those in greatest need
- Establish local carer groups to ensure carers have people to talk to in confidence
- Provide better training programmes for unpaid carers
- Increase signposting for information and advice to enable carers to find information about assessment and support
- Adopt a ‘culturally sensitive’ approach to encourage more people in ethnic minority groups to identify and seek support

Source: CF analysis

There is a critical need for the government to deliver on its commitment to reform social care

Social care places a huge burden on dementia patients and their loved ones	• Social care costs on average £14K per year per patient – increasing to £73K per year for severe patients • 57% of people are self-funders of social care and 2 in 5 people report that this is causing them financial burden
There are large levels of unmet need within the social care system as a result of ongoing budget reductions	• Demand for social care in the community and in care homes is set to increase yet local councils are having to cut direct expenditure on adult social care • There are large gaps in care, particularly for those that require specialist dementia care
There are widespread challenges with the adult social care workforce that are lowering the quality of care for patients	• Care workers are leaving the sector for better paid jobs in less pressurised environments driven by low pay, high pressure and burnout • Workforce constraints lead to a lack of continuity of care and a disjointed and unresponsive service. • Quality of care is variable, with more than 1 in 5 care home providers rated by the CQC as either inadequate or requiring improvement

Policymakers need to:

- Provide higher quality domiciliary care to allow people to remain in the community for longer
- Create clear workforce strategies, including ways to increase recruitment and retention
- Review how changes to the income threshold in October 2025 relieve some of the financial burden on carers
- Address social care budgets to meet needs and provide a better standard of care

Resolving these challenges also requires **effective collaboration across the system**

- Local authorities and care home providers must work as an integrated system to engage in ongoing collaboration and care planning including state and self-funded patients

Delaying dementia symptom progression with new treatments will also be a cost-effective way to manage this population.

Source: CF analysis

Appendices

Methodology supporting slides

Appendix 1 – The underlying prevalence rates used in the MODEM project were identified as the most up to date estimate of dementia prevalence

- A literature review was completed across 14 global studies to identify dementia prevalence both now and in the future by age-band, gender and severity
- The studies listed below were identified as the most reliable sources of prevalence rate estimates
- Comas-Herrera, A. et. al. (2017), which leverages the MODEM project methodology draws on data from three reputable longitudinal studies: Cognitive Function and Ageing Study II (CFAS II), ELSA (English Longitudinal Study of Ageing) and Understanding Society (the UK household longitudinal study), and leverages the PACSim model, which projects changes in prevalence rates by age band, based on detailed dynamic microsimulation of trends in cognitive function

Gender	Study	Study Year	Location	Projection Year	Prevalence by age band							
					60-64	65-69	70-74	75-79	80-84	85-89	90-94	95+
All persons	MODEM project[1]	2016	England	2020		3.1	3.1	7.8	7.8		22.1	
				2025		3.5	3.5	7.7	7.7		21.9	
				2030		3.7	3.7	8.5	8.5		19.6	
				2035		3.7	3.7	8.5	8.5		19.0	
				2040		3.9	3.9	8.9	8.9		19.7	
Male	Dementia UK: update[2]	2014	UK	-	0.9	1.5	3.1	5.3	10.3	15.1	22.6	28.8
	Dementia UK[3]	2007	UK	-		1.5	3.1	5.1	10.2	16.7	27.5	30.0
	MRC CFASII[4]	2013	England	-		1.2	3.0	5.2	10.6	12.8	17.1	
	MRC CFAS[5]	1998	England	-		1.7	2.2	5.7	14.6		19.8	
Female	Dementia UK: update[2]	2014	UK	-	0.9	1.8	3.0	6.6	11.7	20.1	33.0	44.2
	Dementia UK[3]	2013	England	-		1.8	2.5	6.2	9.5	18.1	35.0	
	MRC CFASII[4]	2007	UK	-		1.0	2.4	6.5	13.3	22.2	29.6	34.4
	MRC CFAS[5]	1998	England	-		2.0	2.9	7.4	13.9	26.5	32.3	

Sources: 1) Comas-Herrera, A. et. al. (2017) 2) Prince, M. et. al. (2014) 3) Alzheimer's Society (2007) 4) Matthews, F.E. et. al. (2016) 5) MRC CFAS (1998)

Appendix 2a - The study used severity estimates calculated from the DiscoverNOW dementia cohorts, which align with the distribution found elsewhere in the literature

Severity distribution from various sources

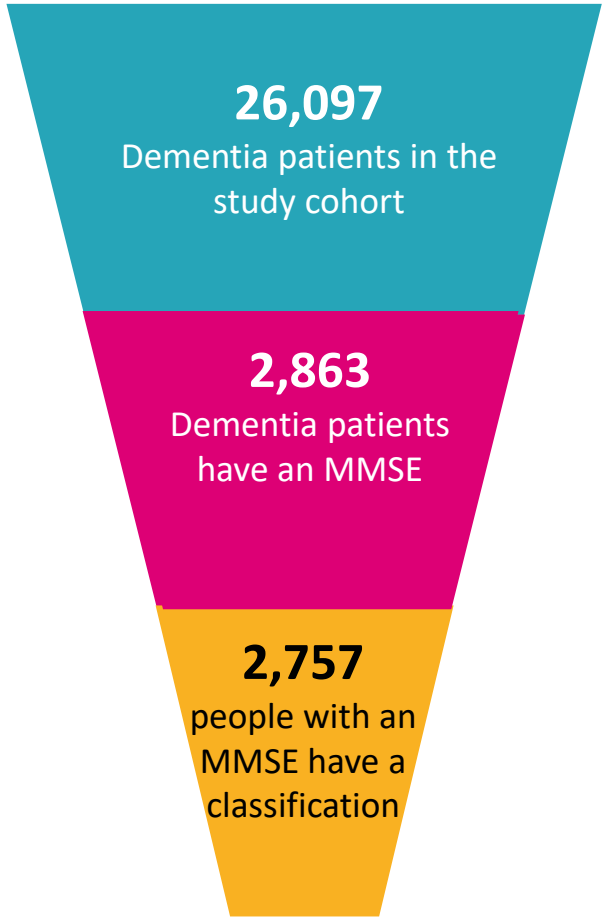
Study	Dementia severity (%)		
	Mild	Moderate	Severe
Dementia UK: update[1]	55.4	32.1	12.5
Carnall Farrar (2024)	**49.7**	**37.3**	**13.0**
MRC CFASII[2]	14.3	27.6	58.1

There does not appear to be consensus on severity distributions for dementia – results from the CFASII study (Matthews, F.E. et. al. (2016)) estimate that approximately 60% of patients are in the severe cohort, while results from Prince, M. et. al. (2014) estimate that only 12% of patients are in the severe cohort.

- A global literature review was completed and based on cohort studies across several developed countries, evidence supports the view that most patients sit in the mild cohort. MMSE scores from the DiscoverNOW cohort were also interrogated and the severity distribution aligned with Prince, M. et. al. (2014) . Based on these findings, this study therefore used DiscoverNOW dementia severity distributions for two primary reasons:
  - This is consistent with the data used elsewhere in the study
  - The distributions from the DiscoverNOW cohort are directionally consistent with the literature

Sources: 1) Prince, M. et. al. (2014) 2) Matthews, F.E. et. al. (2016), CF analysis

Appendix 2b – While only 11% of the DiscoverNOW dementia cohort had an MMSE*, there was a fairly equal spread of MMSE score volumes across the age bands



Age at Diagnosis	No MMSE	With MMSE	% of cohort with MMSE
60-64	871	80	8%
65-69	1,643	134	8%
70-74	3,198	360	10%
75-79	5,252	608	10%
80-84	5,695	754	12%
85-89	3,905	602	13%
90+	2,670	325	11%
Total	23,234	2,863	11%

Age at Diagnosis	Dementia Patients with an MMSE			
	Mild	Moderate	Severe	Un-classified
60-64	1%	1%		1%
65-69	1%	1%	1%	2%
70-74	4%	3%	2%	4%
75-79	6%	5%	3%	8%
80-84	7%	6%	4%	9%
85-89	6%	5%	3%	6%
90+	2%	4%	2%	3%
Total	26%	26%	21%	33%

IMD Decile *(1 – most deprived)*	With MMSE	% of cohort with MMSE
1	91	8%
2	253	9%
3	458	11%
4	365	10%
5	387	11%
6	457	12%
7	253	10%
8	197	13%
9	157	12%
10	174	21%
Unknown	71	8%
Total	2,863	11%

*Mini-Mental State Examination, a screening tool for cognitive impairment and dementia, that assesses various cognitive functions including orientation, memory, attention and language

Source: CF analysis, DiscoverNOW

Appendix 3 – The study conducted a literature review to identify the diagnosis rates of dementia across England regions and devolved nations

Diagnosis rate by region

Region	Diagnosis Rate
North East	70.3%
North West	68.7%
Yorkshire and the Humber	66.6%
East Midlands	67.3%
West Midlands	62%
East	62.7%
London	66.8%
South East	62.9%
South West	59.7%
Wales	53.9%
Northern Ireland	62%
Scotland	64%

- Dementia diagnosis rates for each of the regions in England were extracted from **NHS Digital, Primary Care Dementia Data** (December 2023) published on 18th January 2024

- Dementia diagnosis rates for Northern Ireland and Wales were taken from **Alzheimer's Research UK, Dementia Statistics Hub**, accessed April 2024

- The dementia diagnosis rate for Scotland were taken from **Public Health Scotland**

Source: CF analysis

Appendix 4 – A scaling factor was applied to the per person healthcare costs calculated from the DiscoverNOW data to adjust for geographical variations

UK Indexed Expenditure on health services per head

2021-22

Region	Healthcare expenditure	Total national expenditure	Healthcare ratio vs. London
England	99	97	0.84
North East	105	101	0.89
North West	106	102	0.90
Yorkshire and The Humber	96	94	0.81
East Midlands	90	88	0.76
West Midlands	98	97	0.83
East	89	91	0.75
London	118	115	1.00
South East	90	90	0.76
South West	93	91	0.79
Wales	107	113	0.91
Northern Ireland	106	118	0.90
Scotland	108	117	0.92

Adjustment of cost by region

- Data from HM Treasury was used to identify how public expenditure on healthcare varies across the UK
- Table 9.16 as part of "Public Expenditure Statistical Analyses 2023" provides an index of healthcare spend per head by region
- This was used as a proxy to adjust per person costs for London for other regions.
- A ratio of the cost in London compared to the other regions was calculated from the PESA index
- This ratio was then applied to the per person cost across different settings and cohorts to adjust spend accordingly by region
- The differences in costs between London and outside of London are likely driven through decreased unit costs but also decreased service provision which indicates a need to improve equity of access

Source: HM Treasury (2023)

Appendix 5 - The number of people presumed to be receiving care from different care settings by severity was taken from the MODEM project cost-of-illness models[1]

Estimated share of people with dementia receiving long-term care by severity of dementia and care settings in England

2015

		Percentage of cohort			Total Number of Patients: 2024 (000s)			Total Number of Patients: 2040 (000s)		
		Mild	Moderate	Severe	Mild	Moderate	Severe	Mild	Moderate	Severe
Community care	No care	34%	31%	3%	139.6	95.5	3.2	199.9	136.8	4.6
	Unpaid care only	26%	44%	20%	106.7	135.5	21.5	152.9	194.2	30.8
	Homecare	7%	4%	2%	28.7	12.3	2.1	41.2	17.7	3.1
	Both	7%	12%	9%	28.7	37.0	9.7	41.2	53.0	13.8
Social Care	Residential care	19%	6%	47%	78.0	18.5	50.5	111.7	26.5	72.3
	Nursing care	8%	2%	19%	32.8	6.2	20.4	47.0	8.8	29.2
Total		100%	100%	100%	410.5	308.0	107.4	588.0	441.3	153.8

Sources: 1) Comas-Herrera, A. et. al. (2017), CF analysis

Appendix 6 – Social care costs were calculated by estimating volumes that are self-funded or local authority funded and applying differential costs based on the care setting

Care home: Weekly cost assumptions

Region	Payer type	Dementia residential care	Dementia nursing care
East Midlands	Self-funded	£1,131	£1,360
	State-funded	£913	£1,135
East of England	Self-funded	£1,311	£1,551
	State-funded	£1,014	£1,214
London	Self-funded	£1,469	£1,702
	State-funded	£1,194	£1,416
North East England	Self-funded	£1,061	£1,099
	State-funded	£882	£1,008
North West England	Self-funded	£1,162	£1,368
	State-funded	£901	£1,110
South East England	Self-funded	£1,410	£1,645
	State-funded	£1,123	£1,347
South West England	Self-funded	£1,322	£1,555
	State-funded	£1,094	£1,316
West Midlands	Self-funded	£1,224	£1,407
	State-funded	£950	£1,148
Yorkshire and the Humber	Self-funded	£1,128	£1,335
	State-funded	£906	£1,116
Northern Ireland	Self-funded	£813	£1,118
	State-funded	£661	£882
Scotland	Self-funded	£1,346	£1,477
	State-funded	£826	£949
Wales	Self-funded	£1,309	£1,564
	State-funded	£1,028	£1,262

Care home: Funding arrangement assumptions

Region	Self-funded	State-funded
England, Northern Ireland, Scotland and Wales	40.3%	59.7%

- Unlike NHS services, social care is not free at the point of use. As it is publicly funded social care users must undergo a needs assessment and a means test.
- The distribution of patients that are self-payers or local authority funded is not well documented – the study leverages data from Provider information returns (PIR) provided to the Care Quality Commission (CQC) to estimate these figures
- There is also very little information collected on social care costs for self-funders or local authority funded patients, this study uses public benchmarks to estimate these costs
- Service users with long-term complex health needs may receive NHS continuing healthcare but most people requiring dementia care and support are ineligible for this support and continuing care packages only apply to a relatively small number of individuals (with high levels of need) – this has been excluded from our analysis
- Funding arrangements differ across the devolved nations; however, insufficient data was available to make individual assumptions

Source: ONS (2023), PSSRU (2023), Care Information Scotland. (2024)

Appendix 7 - Unpaid care costs were calculated taking into account both the replacement cost of hiring a professional carer and the opportunity cost of hours of work foregone

- Dementia is a care intensive condition, especially in later stages, and **contributions are hard to translate into volumes** and economic terms.
- In order to value unpaid care, most studies chose to use one of two methods:
  - **replacement cost method:** assigns costs based on the market value that the care services would cost if sourced from a professional provider
  - **opportunity cost method:** values the cost of foregone income for hours where an individual is instead engaged in providing unpaid care
- This study follows more recent approaches taken by Wittenberg et al (2019), Prince et al (2015) and Wimo et al (2001) whereby both the **replacement cost method and opportunity cost method are used to quantify different types of activities**
- **Time spent on ADLs, IADLs and supervision** by severity was identified through **literature review**, using assumptions from questionnaires and cohort studies conducted by Ydstebø, A. E. et. al. (2020) and Schwarzkopf, L. et. al. (2001), while the **number of patients receiving unpaid care** across each severity cohort was taken from the MODEM project cost-of-illness models[3]
- Total **time spent on ADLs was valued at £24 per hour**, the replacement cost of an hour of formal home care. The **remaining portion of time spent caring was valued at a £11.44** opportunity cost (equal to the National Minimum Wage)
- **358 care days a year** (1 week respite for all carers) was assumed

Average unpaid care hours split by activity

	Mild[1] (with care needs)	Moderate[1]	Severe[2]
Total number of ADL hours per day	1.2	2.9	6.1
Total number of IADL hours per day	2.1	3.0	5.4
Total number of supervision hours per day	1.8	3.4	4.5
Total unpaid care hours per day	5.1	9.3	16
% care time spent on ADL	24%	31%	38%
% care time spent on IADL	41%	32%	34%
% care time spent on supervision	35%	37%	28%

Sources: 1) Ydstebø, A. E. et. al. (2020) 2) Schwarzkopf, L. et. al. (2001) 3) Comas-Herrera, A. et. al. (2017)

Appendix 8a – Assumptions used to quantify the cost of transferring lasting power of Attorney and the costs of people with dementia falling victim to scams

Lasting power of attorney (POA): Assumptions

	Mild	Moderate	Severe	
% of patients transferring POA in a given year	22%	22%	22%	Assumption taken from study on capacity issues and decision-making in dementia[1]
Number of patients transferring POA in a given year	112k	65k	25k	Percentage transferring PoA multiplied by cohort size
Legal costs of POA	£622	£622	£622	Based on a review of solicitors' fees[2]

Scams: Assumptions

	Mild	Moderate	Severe	
Probability of being scammed (assumption)	1%	5%	1%	Assumed probability of being scammed for dementia patients living at home
Applied to all patients living at home	73%	91%	34%	All patients living at home assumed to be at risk
Total number of people scammed each year	375k	270k	39k	
Average cost to victim of a scam[3]	£4,715	£4,715	£4,715	Based on a review of average scam cost to victims

Sources: 1) Xie, J. et al. 2008, 2) Seaton's Solicitors (n.d.), 3) Canada Life. (2023, August 15)

Appendix 8b - Dementia sufferers living at home may incur additional heating costs, while those living alone without unpaid carers may need to pay more for transport

Increased heating costs: Assumptions

	Mild	Moderate	Severe	
% of people living at home	73%	91%	34%	Based on the MODEM study cohorts used throughout
Total number of people with increased heating costs	375k	270k	39k	Assume that 100% of the cohort face increased heating costs
Average increase in annual heating costs	£1,000	£1,000	£1,000	Assumed an extra 1.5 hours of heating a day all year round, at an average of £2/hour based on published estimates from energy providers

Transportation costs: Assumptions

	Moderate	Severe	
% living at home with no unpaid care support	3%	3%	Assume that reduced mobility costs only apply to moderate and severe patients
Number of people who require transport	8.1k	1.2k	
Number of return journeys a week	4	0.25	Assumed to attend 4 appointments or outings a week
Average cost of a return journey[1]	£50	£50	Based on costs associated with services for accompanying a person to appointments, providing transportation and/or shopping etc

Drop in consumption: Assumptions

	Mild	Moderate	Severe	
Average assumed drop in consumption	£2,500	£5,000	£7,500	Hypothesised drop in consumption applied to all patients in severity cohort

Source: 1) Giebel, C. M. et. al. (2019)

Appendix 8c - Police call outs are made to deal with dementia patients who have gone missing or from care homes dealing with behavioural /and violence issues

Police callouts – people who go missing: Assumptions

	Mild	Moderate	Severe	
% of people who go missing and are reported to policed	0%	1.7%	1.7%	A report by Green et al estimates that 5% of people with dementia go missing each year but only 1/3 of those cases are reported to police
Average cost of police deployment for missing people	-	£1,000	£1,000	Based on research
Number of missing people each year	-	4,500	600	Applied to total number of people with dementia in each cohort living at home

Police callouts – call outs from care home workers: Assumptions

	Mild	Moderate	Severe	
% of patients in a care home that cause police call outs	0%	10%	10%	Based on a literature review
Average cost of answering a call	-	£9.30	£9.30	Based on Metropolitan Police Report and uplifted to 2023 prices – assumed that all call-outs are answered
Number of missing people each year	-	300	300	Based on Metropolitan Police Report – assumed that deployments are made for all call-outs
Total number of call outs from care homes	-	2,600	7,600	Calculated from MODEM projection assumptions used throughout

Sources: 1) Shalev Greene, K. et. al. (2019) 2) Metropolitan Police (2018)

Appendix 9 - The estimated total cost of memory assessments for dementia in 2024 is £80.1million, only 1.1% of the total healthcare spend and 0.2% of total spend

Method *(Memory assessments only)*

Activity and spend for **memory assessments** to diagnose dementia could not be disaggregated in the DiscoverNOW dataset. To estimate the total spend on dementia diagnosis using memory assessments in 2024, the following estimates were used:

Spend on memory assessments	=	Annual number of assessments in England	x	Scaling factor to rest of UK	x	Unit cost of a memory assessment		
		75,000[1]	x	1.19[2]	x	£897[3]	=	**£80.1million**

Results *(Memory assessments only)*

- The total estimate for spend on memory assessments in 2024 is £80.1million, this includes testing for people who are not ultimately diagnosed
- The total spend on memory assessments is:

1.13% of the healthcare spend for people with dementia

0.19% of the total spend for people with dementia

Sources: 1) NHS Digital. (2024) 2) ONS. (2020) 3) PSSRU. (2023), CF analysis

Sensitivity analysis

Most studies have found that prevalence is highest for people with mild dementia, yet recent estimates have used CFASII prevalence, which is unsupported by global literature

Study / Cohort	Author (s)	Year	Location	Method	Cohort size	Severity distribution (%)		
						Mild	Moderate	Severe
National Alzheimer's Coordinating Center's Uniform Data Set	Besser, L. et. al.	2018	US	Longitudinal cohort study	4,748	82.5	12	5.4
Swedish Dementia Registry (SveDem)	Religa, D. et. al	2023	Sweden	Longitudinal cohort study	76,747	68.7	23.5	2.26
Geriatric medicine led memory clinic study	Chua et al.	2017	Singapore	Retrospective (memory clinic records)	72	68.1	27.8	4.2
Prevalence and etiology of dementia in a Japanese community	Ueda, K. et. al.	1992	Japan	Diagnostic	887	64.2	-	35.8
Dementia UK	Alzheimer's Society	2007	UK	Literature review and Delphi Panel	-	55.4	32.1	12.5
Dementia cases in the Framingham Heart Study	Yuan et al.	2021	US	Longitudinal cohort study	607	50.4	30.3	19.3
Global status report on the public health response to dementia.	World Health Organization.	2021	Global	Meta-analysis	-	48.8	26.9	24.3
Prevalence of dementia in patients in Southern Brazil	Souza et al.	2019	Brazil	Retrospective (medical records)	256	46.5	37.1	16.4
Prevalence of dementia in Egypt: a systematic review	El Tallawy et al	2019	Egypt	Screening & diagnostic	126	41.3	43.7	15
Amsterdam Dementia Cohort	Van Der Flier, W. M.	2023	Amsterdam	Longitudinal cohort study	1,942	40.9	22.8	2.83
Paquid Epidemiological Program	Dartigues, J. F.	2003	France	Diagnostic	1,461	29.5	49.1	27.6
MRC CFASII (Cognitive Function and Ageing Studies)	Comas-Herrera, A. et. al.	2013	England	Screening & diagnostic	7,796	14.3	27.6	58.1
PACSim	Kingston, A. et. al. (2018)	2019	UK	Model-based study	-	13	24	63
Pain in dementia: prevalence and associated factors	Van Kooten et al.	2017	Netherlands	Diagnostic	679	6.1	74.2	19.5

Sources: 1) Prince, M. et. al. (2014) 2) Matthews, F.E. et. al. (2016), CF analysis

This study has conducted a sensitivity analysis to understand the range of costs associated with varying levels of dementia severity across the literature

Severity distributions and estimated prevalence across studies

UK

	Severity distribution (%)			2024 estimated prevalence (000s)			2040 estimated prevalence (000s)		
	Mild	Moderate	Severe	Mild	Moderate	Severe	Mild	Moderate	Severe
Dementia UK: update[1]	55.4	32.1	12.5	543.8	315.1	122.7	776.7	450.0	175.3
Carnall Farrar (2024)	**49.7**	**37.3**	**13.0**	**487.8**	**366.1**	**127.6**	**696.8**	**523.0**	**182.3**
MRC CFASII[2]	14.3	27.6	58.1	140.4	270.9	570.3	200.5	387.0	814.6

Total costs of dementia for each severity distribution using Carnall Farrar (2024) unit cost estimates

£Billions

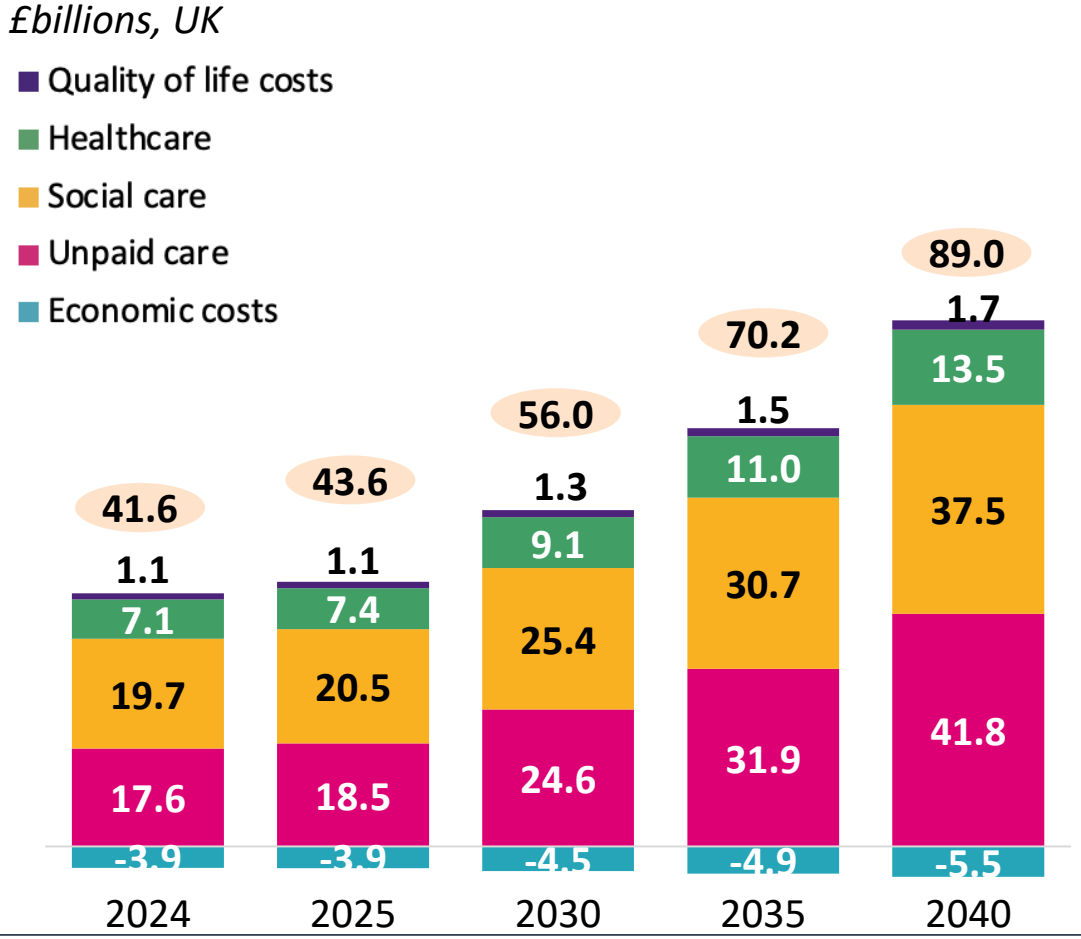
	2024	2025	2030	2040
Dementia UK: update[1]	41.6	43.6	56.0	89.0
Carnall Farrar (2024)	42.6	44.6	57.2	90.6
MRC CFASII[2]	62.4	65.9	85.1	136.7

Sources: 1) Prince, M. et. al. (2014) 2) Matthews, F.E. et. al. (2016), CF analysis

The total cost based on the Dementia UK[1] severity distribution is slightly lower, while the cost based on the MRC CFASII[2] distribution is higher due to the larger severe cohort

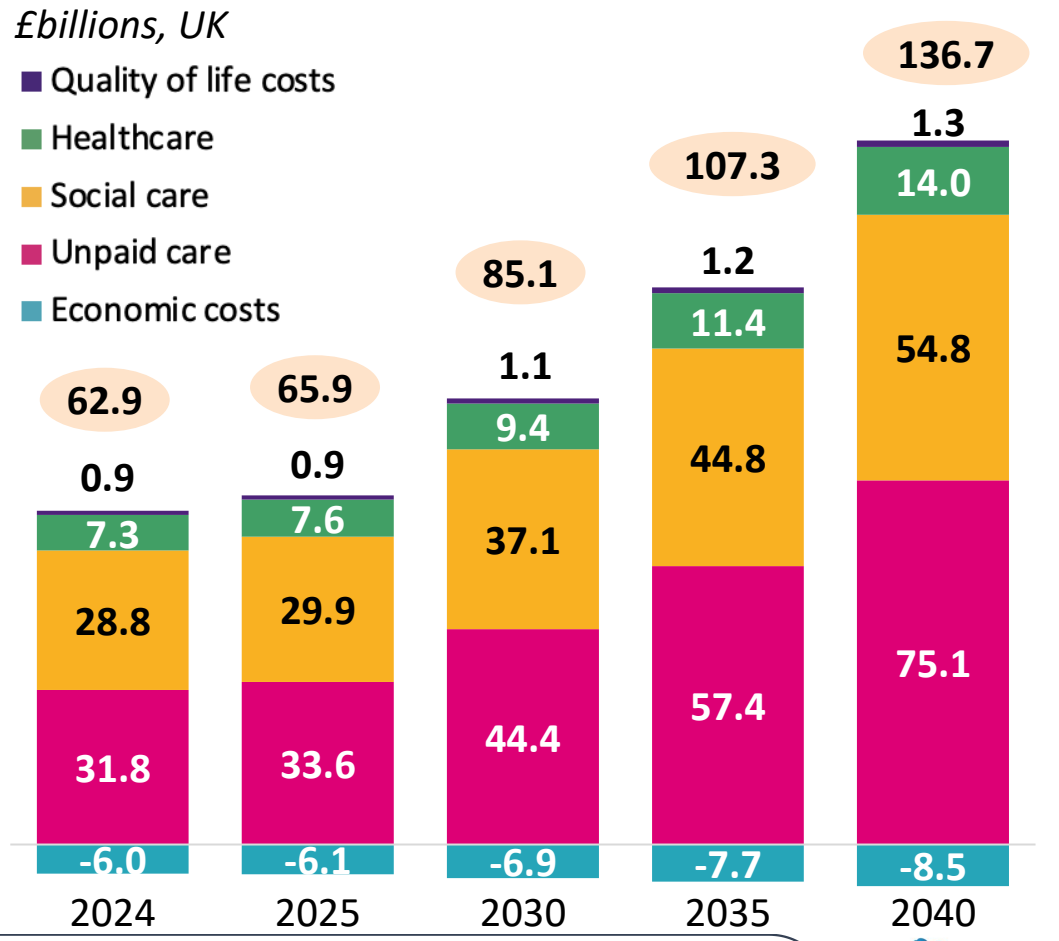
Estimated costs of dementia by cost category

Dementia UK: update severity distribution



Estimated costs of dementia by cost category

MRC CFASII severity distribution



Sources: 1) Prince, M. et. al. (2014) 2) Matthews, F.E. et. al. (2016), CF analysis

There is variance in the total cost of dementia calculated across leading dementia studies as a result of differing prevalence estimates and population projections used

Comparison of leading dementia studies

£Billions

	Region	2013	2015	2019	2020	2021	2025	2030	2040	2050
Carnall Farrar (2024)	UK						**44.6** (43.6 – 65.9)	**57.2** (56.0 – 85.1)	**90.6** (89.0 – 136.7)	
Wittenberg, R. et. al. (2019b) *Adjusted to 2024 prices*[1]	UK			45.4	48.1		60.6	77.4	123.1	
Wittenberg, R. et. al. (2019b)	UK			34.7	36.7		46.3	59.2	94.1	
Wittenberg, R. et.al. (2020)	England		23.0	24.2		-		-	80.1	-
Prince, M. et. al. (2014)	UK	26.3								
Luengo-Fernandez, R. et. al. (2018)	UK					24.6		30.3	38.7	47.3

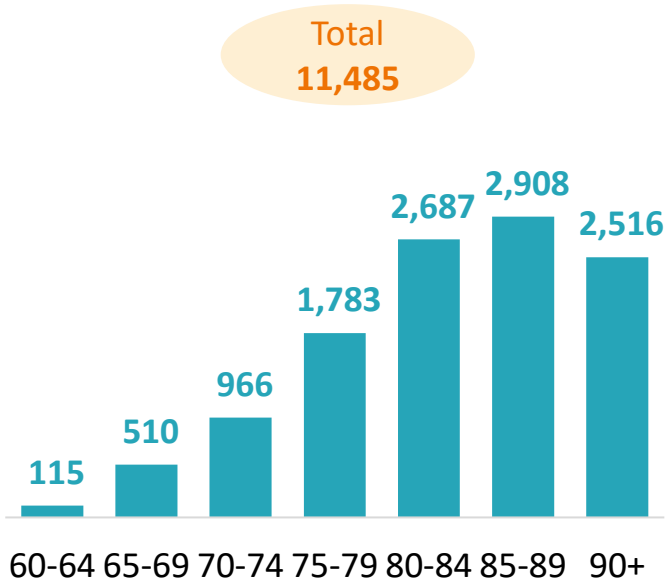
Notes: 1) Used 3.6% inflationary rate based on Bank of England statistics
Source: CF analysis

Dementia cohort characteristics

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

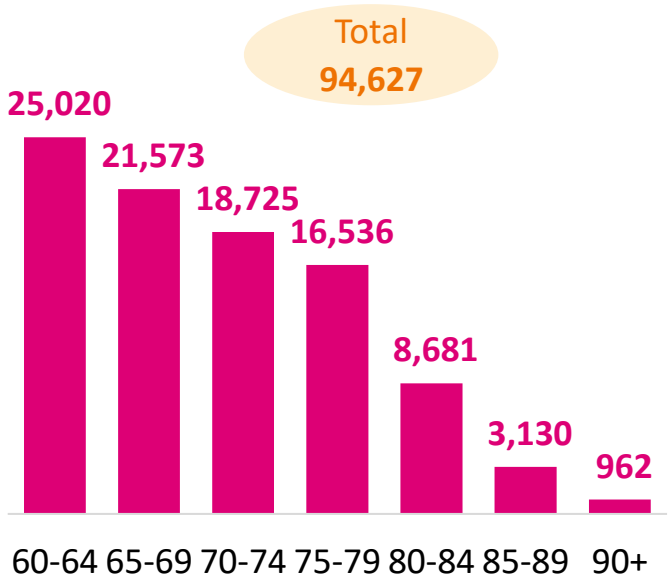
North West London (NWL) dementia Caseload

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 patients 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 patients that were diagnosed with dementia later in the study
- While over 70% of dementia patients are aged 80 and over, over 70% of people with MCI are under 75

Source: CF analysis, DiscoverNOW

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