The economic impact of dementia

Module 2: Dementia's contribution to health metrics September 2024



Contents of this report

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







Introduction to the study





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

	Presented here		
MODULE 1	MODULE 2	MODULE 3	MODULE 4
Overall annual cost of dementia now and projected to 2040, broken down by: • Cost type (health care,	Healthcare utilisation now and projected to 2040 of people with dementia, including: • A&E attendances • Inpatient admissions • Outpatient	Cost and outcome comparisons with other conditions (e.g. cancer, CVD)	Potential cost savings due to early and
 care, quality of life and economic costs) Dementia severity Regions of England and devolved nations 	 appointments Primary care, community and mental health contacts Prescriptions 	Cost and outcome comparisons with similar countries	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



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.



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.**



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.



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

5

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



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

What is the DiscoverNOW SDE?	What data is included?	How is data collated and extracted?			
Secure Data Environments (SDEs) are data storage and access platforms that allow	Primary care events and prescriptions including GP visits	Electronic patient records	SNOMED and ICD-10 diagnosis codes used to North West		
approved users to access sensitive health and care data that has been anonymised for research purposes.	Secondary care including A&E, inpatient and outpatient attendances	Secondary uses dataset	identify patients to be included in cohorts		
Discover-NOW is one of 11 SDEs set up by NHS England, based in North West London (NWL).	Community care including clinics and therapies	Activity data from providers			
The cohort covers a population of over 2.7 million patients who live and are	Mental health including inpatient and outpatient activity and assessments	Activity data from providers	Activity and cost data for relevant identified cohorts		
registered with a GP in North West London The dataset provides access to linked coded data across primary care, secondary,	Social care including home, formal and respite care	Data from NWL boroughs and commissioners			
acute, mental health, community health and social care.	High-cost drug prescription	Drugs patient level contract monitoring			



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

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

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



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

Alzheimer's Society Research Strategy Council¹

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

Clinical and Economic Experts

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

Study Team

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

Expert Reviewers

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



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

CF

Executive Summary





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

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



As dementia severity progresses, healthcare utilisation increases, particularly in the nonelective setting

- As dementia severity progresses, healthcare utilisation increases
 - Non-elective stays drive 85% of inpatient activity in people with dementia and nearly a third of all dementia healthcare costs
 - Average length of stay of someone with dementia, accounting also for excess bed days¹, is ~18 days for non-elective admissions
 - Length of stay increases as severity increases people with severe dementia only account for 10% of all elective and non-elective hospital spells but drive 29% of total bed days
 - On average, people with severe dementia stay more than three times longer in hospital for non-elective spells than people with mild dementia and 4 times longer than someone with similar characteristics that doesn't have dementia
- 1 in 6 hospital beds today are occupied by someone with dementia
 - Longer average lengths of stay for people with dementia lead to many total bed days and "excess" bed days¹. Dementia currently accounts for
 8.2million bed days annually and the number of bed days is expected to increase over time in line with increasing dementia prevalence
 - By 2025, people with dementia will require 20.5K acute hospital beds and by 2040 this will increase to 29,400 without an increase in bed capacity in the system, this number will increase to 1 in 4 patients in hospitals having dementia by 2040²
- Diagnostic testing is currently not very widespread for dementia today, making up only 2% of all outpatient activity
 - There are around 37,700 MRIs and 13,700 CT scans conducted each year for dementia, over half of which are carried out on people without a diagnosis
 - Per person, people with undiagnosed dementia had the highest number of A&E attendances
- Primary care only drives 8% of total dementia healthcare spend yet it accounts for 43% of all community-based activity
 - People with dementia visit the GP up to three times more each year than someone without dementia and by 2040, there will 6.9million
 additional primary care contacts associated with dementia, requiring an estimated 1.7 million more hours of primary care time
 - Despite significant GP activity, only 6% of all primary care prescriptions for people with dementia today are for dementia-specific treatments, most of which are being administered to people in the mild and moderate cohorts
- People with dementia are more likely to use community-based services and mental health community services (including therapy and treatment)

 People with dementia are eight times more likely to use general community services and ten times more likely to use mental health community services than people without dementia

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



CF

Methodology





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

		Category	Source Data
	How many	Current and future population projections by age band, gender	ONS (2020)
	people have	Dementia prevalence rates now and to 2040 by age band	MODEM (2017)
	dementiar	Dementia severity rates by mild, moderate, severe	DiscoverNOW
		Primary care appointments	
	What is the	Inpatient activity including day case, elective, non-elective	
What is the overall activity	activity per person of	Outpatient appointments including diagnostics	
of people with dementia now	someone with dementia?	A&E attendances	DiscoverNOW
and projected to 2040?	(split by mild, moderate	Mental Health community contacts and inpatient activity	
	, severe) Community care cont	Community care contacts	
		Prescriptions including primary care and high-cost secondary care	
	How does	Regional healthcare scaling metrics	Various health statistics
	from NWL?	Total regional population	ONS (2020)



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

1 Understand current population projections	 2020-based population projections from ONS¹ were used as the projections of the UK population annually up to 2040 The projections show annual population estimates by gender, age and local authority
2 Calculate total dementia prevalence	 Prevalence rates from the MODEM project² were applied to the population projections to calculate the estimated number of people with dementia The prevalence rates (shown in appendix 1) are for ages 65+; younger ages were excluded from this study due to a lack of evidence for this age group The prevalence rates vary by age-band and projection year, but are assumed to be constant across genders and geographical area
3 Calculating total dementia prevalence by severity	 Distribution of people across the dementia severity cohorts was estimated from the 2,757 dementia patients with MMSE scores recorded in the DiscoverNOW dataset (see appendices 2a and 2b for further detail) The distribution was applied to the projected dementia population to develop projections of the number of people in each stage of dementia The severity distribution was assumed to be constant over time
4 Calculating total dementia prevalence by diagnosis status	 Published data was gathered estimating diagnosis rates for the regions of England and devolved nations (see appendix 3) It was assumed that people undiagnosed were in the mild and moderate cohorts only The diagnosis rates were applied by geographical area to segment the mild and moderate cohorts into diagnosed and undiagnosed groups



Izheimer's

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

Stage 1: Iden	tify 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		 Patients were flagged as 			
Dementia - Moderate	codes and grouped into mild, moderate and severe cohorts using MMSE scores (where available)	having long-term conditions using a pre-existing list within DiscoverNOW of common	Used to identify annual per person healthcare utilisation of people with dementia by severity		
Dementia - Severe	All remaining people with demontia	conditionsThe number of comorbidities			
Dementia - Unclassified	were identified using SNOMED/ICD-10 diagnosis codes without a recorded MMSE	was identified across all patients before classifying each as having 0, 1, 2-3 or 4+	Used to identify the healthcare utilisation of people with dementia for low-quality datasets (community and mental health)		
Pre-diagnosed	Identified by looking at people with dementia two years pre-index date All remaining people that do not fall into the categories above	 comorbidities The control group was matched to the dementia cohorts using age and comorbidity classification to 	Used as a proxy to estimate healthcare healthcare utilisation for people undiagnosed		
No dementia (Control group)			Used as a control group to isolate dementia healthcare utilisation		
Mild cognitive impairment (MCI)	Identified using SNOMED/ICD-10 diagnosis codes, excluding anyone diagnosed with dementia later in the study period	develop differential costs	Considered in unit activity metrics only - no prevalence estimated		



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

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

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





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

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



Alzheimer's

Societ

The following assumptions are made as part of this study

Ref.	Assumption type	Assumption description
1	Population projections	 Used ONS projections¹ for population growth, from the 2020-based publication
2	Prevalence rates	 Used prevalence rates from the MODEM project² 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 do 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	Diagnosis and treatment	 The study assumes that the diagnosis and treatment approaches remain unchanged throughout the projected time period
6	Care funding	The study assumes continuation of the current funding systems for provision of care
7	Unpaid care supply	 The study assumes that there will be sufficient supply of these care streams and has not considered the impact of a potential future shortfall
8	Cost of an undiagnosed patient	 The study assumes that the healthcare cost and activity of someone undiagnosed can be estimated from the average healthcare costs recorded for the dementia cohort in the two years pre-diagnosis The study assumed all non-healthcare related costs for someone undiagnosed are the same as someone with a diagnosis



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

The approach taken has the following limitations

Ref Limitation

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

- 1 much larger percentage of minority populations. This dataset also doesn't represent rural, coastal and remote regions. This has been controlled for by scaling activity using a range of public healthcare activity metrics. However, this implicitly assumes that activity for people with dementia is proportional to the population described by each metric.
- 2 MMSE scores have been used to classify severity but coverage is only 11% today with so many missing MMSE scores there are some data irregularities in projected costs for mental health and community the cost of unclassified patients has been used in these instances.

The activity totals calculated for this study are the total activity of people with dementia rather than the marginal extra activity for people with dementia in comparison with people not experiencing dementia. This is due to the challenges associated with disaggregating the healthcare utilisation impact of dementia itself with other co-morbidities. This approach is in line with other studies that have also explored the total healthcare utilisation of people with dementia.



Healthcare utilisation across dementia and nondementia cohorts



 Module 2: Dementia's contribution to health metrics



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





CF

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



Healthcare activity: comparison of total estimated activity by setting



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



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

Healthcare activity per person per year by setting

2024	2024						
2024		Control (without dementia)	Mild cognitive impairment	Pre- dementia	Mild	Moderate	Severe
Emergency	A&E attendances	0.5	0.6	1.5	0.9	1	0.7
Primary care	Contacts	7.0	11.9	16.9	17.2	14.8	12.5
	Bed days	0.7	1.5	5	5.7	6.7	14
Non-elective	Excess bed days	0.1	0.1	1	0.5	1.5	4.1
	Spells	0.1	0.2	0.5	0.6	0.5	0.5
	Day case	0.3	0.3	0.2	0.2	0.2	0.1
Floating	Bed days	0.2	0.2	0.3	0.2	0.1	0
Elective	Excess bed days	0	0	0.1	0.1	0	0
	Spells	0	0.1	0	0	0	0
0	CT scans	0	0	0.01	0.02	0.01	0.02
Outpatient	MRI (Head)	0.01	0.01	0.06	0.03	0.02	0.01
appointments	Other	3.1	3.8	4.2	3.2	2.4	1.3
Mental	Contacts	0.6	0.5	4.3	4.4	4.5	2.2
Health ¹	Inpatients	0.1	0.0	0.4	1.5	1.5	1.5
Community ¹	Contacts	1.9	4.7	12.2	16.4	16.4	16.4

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

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



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



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

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



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

Average length of stay per hospital spell by severity

Days, 2024

			Mild	Moderate	Severe
Elective	Average length of stay	4	7	7.6	0.1
Elective	Excess length of stay	0.6	3	2.1	0
Non Floativo	Average length of stay	6.6	9.3	12.7	27.7
Non-Elective	Excess length of stay	0.7	0.9	2.7	8.1

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



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



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

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



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



• Bed capacity hasn't increased over time – until COVID-19, the number of beds in the system was in decline

- The most recent statistic show that there are over 132,000 acute hospital beds in UK (104,000 in England², 9,000 in Wales³, 6,000 in Northern Ireland⁴ and 13,000 in Scotland⁵)
- Assuming a bed occupancy of 92%, one in six hospital beds today are occupied by someone with dementia

Sources: 1) NHS England. (2023) 2) NHS England. (2024) 3) StatsWales (2024) 4) Department of Health (Northern Ireland). (2023) 5) Public Health Scotland. (2023), CF analysis



27

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



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



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



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

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



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



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

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



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



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

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



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



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

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



Despite significant primary care activity, only 6% of all prescriptions are for dementiaspecific treatments

Total prescriptions for dementia patients per year



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

Millions, 2024								
		Moderate	Severe	Undiagnosed dementia	Tota			
AChE inhibitors	1.3	0.8	0.4	0.1	2.6			
Memantine	0.5	0.4	0.2	0.03	1.1			
Antipsychotics	0.2	0.2	0.1	0.2	0.6			
High-cost drugs	0.1	0.04	0.03	0.1	0.3			

21.0

22.4

10.8

11.5

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

Per person prescriptions for all patients per year

30.5

32.6

Millions, 2024

Other prescriptions

Total

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

47.9

48.4

110.4

114.9



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



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





Appendices



CF

Bed capacity





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



Northern Ireland: Acute bed Availability³



Wales: Acute bed Availability²



Scotland: Acute bed Availability⁴



2013/14 2014/15 2015/16 2016/17 2017/18 2018/19 2019/20 2020/21 2021/22 2022/23





Sources: 1) NHS England. (2024) 2) StatsWales (2024) 3) Department of Health (Northern Ireland). (2023) 4) Public Health Scotland. (2023)

CF

Dementia cohort characteristics



 Module 2: Dementia's contribution to health metrics



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



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



39

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

Dementia prevalence by IMD decile and age

Percentage of people with diagnosed dementia in NWL, December 2023

	IMD Decile	60 - 64	65 - 69	70-74	75-79	80-84	85-89	90+
High deprivation	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 comorbidities in lower deciles than in upper deciles
- There may also be inequalities in diagnosis rates, but these are difficult to study using current data



CF

References





References (1/2)

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

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

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

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

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

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

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

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

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

NHS England (NHSE). (2024). Bed Availability and Occupancy Data – Overnight. Retrieved from <a href="https://www.england.nhs.uk/statistics/stat



References (2/2)

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

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

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

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

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

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

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

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

