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Identifying patterns of healthcare use and exploring indicators of quality of care among people with dementia nearing the end of life using routine data

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Identifying patterns of healthcare use and exploring indicators of quality of care among people with dementia nearing the end of life using routine data

A thesis incorporating publications submitted to King's College London for the degree of Doctor of Philosophy

February 2024

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Lay summary

People with dementia can use many healthcare services during their lives after diagnosis. However, healthcare services for people with dementia can be expensive, bring them little benefit, and not be what they would choose. If we want to improve the quality of care for the growing number of people with dementia, we need to develop a better understanding of how people use multiple services.

There are elements of care that we can measure to help us understand how good the care we are providing to a group of people is. These measures are called ‘quality Indicators’. Quality indicators can help healthcare staff and planners understand the quality of the care delivered, compared to the recommended good practice. Based on existing scientific evidence, I found 71 quality indicators that we can collect from the regular electronic information we have about people living in different care settings (e.g., home or hospital). For example, if a lot of people with dementia have unplanned admissions to hospital or intensive care towards the end of their lives, that is an indication of poor quality of care. Looking at the services people with dementia have used will help us understand how to improve the quality of care we offer.

This thesis aims at identifying and describing patterns of healthcare use; and investigate indicators of quality of care that people experience when they are near the end of life.

The thesis comprised of three parts:

i. I first looked at how patterns of unplanned hospital admissions change among people with dementia between the time they are diagnosed and when they die. I found that among 19,221 people with dementia, rates of unplanned hospital admissions were relatively low and steady after the diagnosis but increased steeply as they got near death. For example, people with dementia spent on average 20% of their last six months of life in hospital.
ii. I next explored trends in intensive care use among people with dementia. This study showed that of 19,787 people, 726 (4%) had one or more intensive care unit admissions at any time after receiving their dementia diagnosis. The use of overall intensive care decreased over the years, but an increase was observed in intensive care admissions which took place within the last year of life of people who died with dementia.
iii. Finally, I looked at people with dementia in groups according to which services they used (including community care, hospital care, and specialist mental health support) in the year after their diagnosis and in the last year of life.

> Based on data from 8,623 people who died with dementia, I identified three groups of people with dementia based on the patterns of healthcare use in the first year after dementia diagnosis: low healthcare use after diagnosis, planned and unplanned hospital use after diagnosis, and mental healthcare use after diagnosis.
>
> I Identified four groups of people with dementia based on the patterns of healthcare use in the last year of life: low healthcare use in the last year of life, moderate hospital use in the last year of life, high hospital use in the last year of life, and community mental healthcare use in the last year of life.
>
> The chance of being in each group was associated with different demographic, social and illness-related characteristics. For example, being diagnosed with dementia at an older age, being male, and having dementia diagnosis other than Alzheimer's Disease were associated with an increased possibility of being in a group characterised by high unplanned hospital use in the year after diagnosis.
>
> I looked at what sort of a person with dementia was in each group. For instance, older men whose dementia was diagnosed at a later age and those who had a diagnosis other than Alzheimer's disease were more likely to be in the group that had more unplanned admissions to the hospital in the year after their diagnosis.

This PhD thesis contributes new knowledge to the services used by people with dementia from diagnosis to the end of life. People with dementia are often in hospital towards the end of life. We need to prioritise training for hospital staff in palliative and end-of-life care for patients with dementia. The findings also show that if we want to reduce unplanned hospital admissions, we need to improve the knowledge of staff who work in the community about what services are available (e.g. post-diagnostic support) when people are at an earlier stage in their illness.

Clinicians, commissioners, and policymakers who want to improve the quality of care will benefit from knowing more about the different experiences of care for people in the end stage of life. To provide better care for people with dementia towards the end of life, we need to consider different patterns from the time of diagnosis onwards.

This thesis provides innovative examples of how electronic information from different sources and statistical ways can be used to identify how healthcare services fit together to meet the needs of people with dementia who are near the end of life. Regularly collected, clinically important information about people affected by dementia can help us understand and improve the quality of care towards the end of life.

Abstract

Background: People with dementia access multiple healthcare services. The type of care needed among people with dementia may vary significantly and change over time. Among people with dementia nearing the end of life, many may not access the services they need at the right time and place, and instead access costly emergency or unplanned healthcare services that may be of limited benefit and not in line with their preferences. Improving service planning and the quality of care for the growing number of people with dementia nearing the end of life requires a better understanding of patterns of different healthcare service use over time. By using quality indicators across care domains relevant to people with dementia nearing the end of life, a more comprehensive understanding of the overall care quality can be obtained. Routine data can provide detailed information regarding the characteristics of people with dementia and robust quality indicators about the care they receive across care settings.

Aim: To identify and describe patterns of healthcare use; and investigate indicators of care quality experienced among people with dementia nearing the end of life using routine data.

Methods: This thesis is composed of three observational studies using secondary analysis of routine data. Individuals with a dementia diagnosis (1995-2020) were assembled from the Clinical Record Interactive Search (CRIS), a de-identified electronic patient records system within South London and Maudsley (SLaM) in London, United Kingdom. The existing linkages between CRIS and the Office for National Statistics (ONS) for mortality data, and Hospital Episode Statistics (HES) datasets (inpatient hospital, adult critical care, accident & emergency (A&E) visits, and outpatient appointments) for hospital data were obtained. Three studies are considered:

Study 1: A retrospective cohort study to describe the patterns of unplanned hospital admissions among people with dementia from diagnosis to death.

Study 2: A retrospective cohort study to describe the trends in critical care admissions among people with dementia and explore the association between dementia severity and survival following discharge from a critical care unit.

Study 3: A retrospective cohort study aiming to bring together multiple measures of healthcare use and biopsychosocial factors to identify whether latent subpopulations are present within a large sample of people with dementia, characterised by different patterns of healthcare use which took place in the first year after dementia diagnosis and in the last year of life. This analysis also explores whether a relationship between group memberships in the first year after dementia diagnosis and in the last year of life may exist.

Results: Results from the studies show variability in the patterns of healthcare use among people with dementia, with an increase in unplanned hospital use in the last year of life, and potentially sub-optimal care quality experienced by a proportion of those nearing the end of life.

Study 1 is based on data from 19,211 people with dementia and 57,017 unplanned hospital admissions. This analysis shows that the cumulative incidence of unplanned hospital admissions (n=14,759) was 76.8% (95% CI 76.3% - 77.3%). Rates and lengths of unplanned hospital admissions among people with dementia remained relatively low and short in the months after the dementia diagnosis, both increasing only as people approached the end of life. Admissions in the last year of life accounted for 37.3% of all unplanned hospital admissions for the whole cohort. Over a third of decedents (38.1%, n=4,697) died in hospital and 24.5% of these people (n=1,153) died during their first admission after diagnosis. The percentage of time spent as an inpatient was <3% for people who were alive at the study end but was on average 19.6% and 13.3% for the decedents in the last six and twelve months of life, respectively. Variations in the rates of unplanned hospital admissions were observed among decedents with dementia depending on their proximity to death at the time of diagnosis.

In the second study of the thesis, which included 19,787 people diagnosed with dementia, 726 (3.7%) individuals had one or more critical care admissions at any time after receiving their dementia diagnosis. Compared to unplanned hospital admissions, critical care admissions were a rare event among the dementia cohort. The overall one-year survival of people with dementia who had a critical care admission was 47.5% (n=345). Dementia severity was not associated with one-year survival following critical care admission (mild dementia vs. moderate-severe dementia odds of one-year mortality OR: 0.90, 95% CI [0.66-1.22]). Over the 12-year period (2008-2019), overall critical care use decreased (β=-0.05; 95%CI -0.01, -0.0003; p=0.03). The consistent increase in the rates of unplanned hospital admissions in the last year of life identified in Study 1, prompted the investigation of the trends in critical care admissions in the last year of life. Critical care admissions occurring during the last year of life increased (β=0.11, 95%CI 0.01, 0.20, p=0.03).

In the final study of the thesis, based on data from 8,623 decedents diagnosed with dementia, latent class analyses revealed three distinct groups of people with dementia based on the patterns of healthcare use in the first year after dementia diagnosis (*Low healthcare use after diagnosis (n=1426, 49%), planned and unplanned hospital use after diagnosis (2,939, 34.1%),* and *mental healthcare use after diagnosis (n=1,426, 16.5%)*).

In the last year of life, four distinct groups of people with dementia were identified based on the patterns of healthcare use (*Low healthcare use in the last year of life (n=2756, 32%), moderate hospital use in the last year of life (n=3,689, 43%), high hospital use in the last year of life (n=754,* *9%), and community mental healthcare use in the last year of life (n=1,423, 17%)*). The risk of being in each group was associated with different biopsychosocial characteristics of people with dementia. Being diagnosed with dementia at an older age, being male, and having a non-Alzheimer's disease dementia diagnosis were associated with a higher risk of being in a group characterised by high unplanned hospital use in the first year after diagnosis and in the last year of life.

Conclusions: This thesis contributes new insights into the scope of services used by people with dementia by focusing on several validated quality indicators, identifying variations in the patterns of healthcare use as people live and die with dementia. Methodologically, this thesis provides innovative examples of the use of routine data linkages and structural equation modelling such as latent class analysis to identify and describe patterns of healthcare and how services fit together in the delivery of care for people with dementia nearing the end of life.

Hospitals remain a significant place of care for people with dementia towards the end of life. Embedding dementia end-of-life care training across hospitals should be prioritised to improve the quality of care for all. Unplanned hospital use (i.e., admissions and A&E visits) was more common compared to the use of other services (planned admissions, critical care admissions and outpatient visits) towards the end of life. Almost one in six people with dementia access specialist mental health services in the first year following their dementia diagnosis, and in the last year of life. Unplanned healthcare use, which is associated with burdensome care experiences and poor care quality, were observed among approximately one in ten people with dementia nearing the end of life. This has implications for improving knowledge about available services in the community earlier in the disease trajectory, and access to community services to reduce potentially avoidable hospital use.

Clinicians and policymakers may find value in being aware of the differences in the care experiences leading up to the end of life, considering different timelines and pathways from diagnosis onwards, when planning high-quality care provision for people with dementia who may be nearing the end of life. Further research is needed to understand why variations in healthcare use leading to burdensome care experiences among a subgroup of people with dementia nearing the end of life exist, and how these can be minimised. Routine collection of information about people with dementia and their care, and access to data linkages between relevant health and social care services, are needed to improve our understanding of quality indicators relevant to end-of-life across care domains, including care preferences, psychological, cultural and communication aspects of care.

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Publications and presentations

Publications in peer-reviewed journals incorporated in the thesis

Publication 1

Yorganci E, Sampson EL, Gillam J, Aworinde J, Leniz J, Williamson LE, Cripps RL, Stewart R, Sleeman KE. Quality indicators for dementia and older people nearing the end of life: A systematic review. Journal of the American Geriatrics Society. 2021 Dec;69(12):3650-60. DOI: https://doi.org/10.1111/jgs.17387

Publication 2

Yorganci E, Stewart R, Sampson EL, Sleeman KE. Patterns of unplanned hospital admissions among people with dementia: from diagnosis to the end of life. Age and Ageing. 2022 May;51(5):afac098. DOI: https://doi.org/10.1093/ageing/afac098

Publication 3

Yorganci E, Sleeman KE, Sampson EL, Stewart R. Survival and critical care use among people with dementia in a large English cohort. Age and Ageing. 2023 Sep 1;52(9):afad157. DOI: https://doi.org/10.1093%2Fageing%2Fafad157

Other related publications

Leniz J, Yi D, Yorganci E, Williamson LE, Suji T, Cripps R, Higginson IJ, Sleeman KE. Exploring costs, cost components, and associated factors among people with dementia approaching the end of life: A systematic review. Alzheimer's & Dementia: Translational Research & Clinical Interventions 2021; 7(1): e12198. DOI: https://doi.org/10.1002/trc2.12198.

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Crawley S, Yorganci E, Farnood A. A night at the museum: Engaging young people about dying with dementia. EAPC Blog. 2024 Jan https://eapcnet.wordpress.com/2024/01/16/a-night-at-the-museum-engaging-young-people-about-dying-with-dementia/

Presentations at scientific meetings and conferences

Yorganci et al., “Challenges of engaging with public about research with routine data” The London Interdisciplinary Social Science Doctoral Training Partnership (LISS DTP) Meeting 2021 – Oral Presentation

Yorganci et al. “Quality indicators for care of older people and people with dementia who are approaching the end of life applicable for use with routinely collected electronic datasets: A systematic review” Postgraduate Research Conference 2021 – Oral Presentation

Yorganci et al., “Quality Indicators for Palliative Care of Older, Frail People and People with Dementia Using Routinely Collected Electronic Datasets: A Systematic Review” European Association for Palliative Care World Congress 2021– Poster Presentation

Yorganci et al., “Patterns of Unplanned Hospital Admissions among People with Dementia: From Diagnosis to the End of Life” European Association for Palliative Care World Congress 2021– Oral Presentation

Yorganci et al. “Identifying subgroups of people with dementia who has distinct patterns of healthcare use over the course of the illness” SEMantics (invited speaker) monthly seminar at the Institute of Psychiatry, Psychology and Neuroscience, King’s College London – Oral Presentation

Yorganci et al., “Survival and critical care use among people with dementia in a large English cohort” EPA Section of Epidemiology & Social Psychiatry 20th Biennial Congress 2022 - Oral Presentation

Yorganci et al., “Identifying Distinct Profiles of People with Dementia Based on their Healthcare Use in the Last Year of Life Using Routine Data” European Association for Palliative Care World Congress 2023– Poster Presentation

Yorganci et al., “Trends in Critical Care Admissions of People with Dementia in the Last Year of Life in a Large English Cohort Using a Novel Data Linkage” European Association for Palliative Care World Congress 2023– Poster Presentation

Yorganci et al., “Empowering better end of life dementia care: The EMBED-Care programme” ECHO Hub - Palliative, End of life care and Dementia ECHO Knowledge Network Training Day 2023 – Oral Presentation (Presented findings of the three studies from this thesis)

Statement of contribution

This PhD was conducted while I was working as an ESRC PhD Training Fellow as part of the Empowering Better Dementia End of Life Care (EMBED-Care) programme at the Cicely Saunders Institute, King's College London. I was responsible for designing and undertaking the work detailed in this thesis under the supervision of Professor Katherine Sleeman, Professor Robert Stewart, and Professor Elizabeth Sampson.

For the systematic review (Publication 1) included in the background chapter of this thesis, I was responsible for writing and registering the study protocol, the search strategy, article screening, data extraction, quality appraisal of studies, analysis and write-up of the paper. Dr Javiera Leniz Martelli, Dr Lesley Williamson, and Rachel Cripps contributed to double screening the included studies. Jesutofunmi Aworinde and Juliet Gillam contributed to the data extraction of the psychometric properties of the quality indicators.

For study 1 (Publication 2), the retrospective cohort study of unplanned hospital admissions using data linkages between clinical and administrative records from South London and Maudsley NHS Foundation Trust and national hospital and death registries, I was responsible for the protocol writing, access application, data curation, data cleaning, analysis plan, analysis, and write-up of the paper. CRIS Data Extraction team, namely Megan Pritchard, provided guidance on the data curation stage.

For study 2 (Publication 3), the retrospective cohort study of critical care admissions using data linkages between clinical and administrative records from South London and Maudsley NHS Foundation Trust and national hospital and death registries, I was responsible for the protocol writing, access application, data curation, data cleaning, analysis plan, analysis, and write-up of the paper. CRIS Data Extraction team, namely Dr Daisy Kornblum and Hitesh Patel, provided guidance on the data curation stage.

For study 3, the retrospective cohort study using multiple data linkages between clinical and administrative records from South London and Maudsley NHS Foundation Trust and national hospital and death registries, I was responsible for the protocol writing, access application, data curation, data cleaning, analysis plan, analysis and write-up of the paper. CRIS Data Extraction team, namely Dr Daisy Kornblum and Hitesh Patel, provided guidance on the data curation stage. Dr Ewan Carr provided guidance on the statistical analyses.

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This thesis is dedicated to the memory of my mother, Selma Yorgancı.

Abbreviations

A&E	Accidents and Emergency Departments
ACC	Adult Critical Care
ACSC	Ambulatory Care Sensitive Conditions
APC	Admitted Patient Care
AOR	Adjusted Odds Ratio
BRC	Biomedical Research Centre
CDLS	Clinical Data Linkage Service
CI	Confidence interval
CQC	Care Quality Commission
CRIS	Clinical Records Interactive Search
EAPC	European Association for Palliative Care
HER	Electronic health records
EMBED-Care	Empowering Better End of Life Dementia Care
GATE	General Architecture for Text Engineering
GP	General Practitioner
HES	Hospital Episode Statistics
HoNOS	Health of Nation Outcome Scales
HSCIC	Health and Social Care Information Centre
ICD-10	International Statistical Classification of Diseases and Related Health Problems 10th Revision
IMD	Index of multiple deprivation
IQR	Interquartile range
LCA	Latent class analysis
LPA	Latent profile analysis
LSOA	Lower Super Output Area
LTA	Latent transition analysis
MMSE	Mini Mental State Examination
NICE	National Institute for Health and Care Excellence
NHS	National Health Service
NLP	Natural Language Processing
OECD	Organisation for Economic Co-operation and Development
ONS	Office for National Statistics
OP	Outpatient Care
PPI	Patient and Public Involvement

QI	Quality indicator
RA	Research assistant
RI-LTA	Random-intercept Latent Transition Analysis
REC	Research Ethics Committee
RECORD	The REporting of studies Conducted using Observational Routinely-collected health Data (RECORD)
RRR	Relative Risk Ratio
SD	Standard deviation
SE	Standard error
SEM	Structural equation modelling
SLaM	South London and Maudsley NHS Foundation Trust
UK	United Kingdom
USA	United States of America
WHO	World Health Organisation

Glossary

Conceptual model	A visual representation of variables, factors, outcomes and relationships between them.
Dynamic cohort	Where the study participants can join or leave the cohort at different times. Individuals within the cohort are followed up to determine the incidence of an event.
Epidemiology	The study of the distribution and determinants of health-related states and events in specified populations.[2]
Epistemology	The nature of knowledge and how it can be acquired[3]
Exploratory research	Research which investigates questions that have not been studied in depth. The preliminary results often lay the groundwork for future analysis.
Frailty	A state of increased vulnerability to stressors, frailty is characterised by an accumulation of deficits, diminished strength and endurance, and reduced physiological function.[4]
Health and care needs	A need is something essential. Healthcare needs are related to treating, controlling, preventing, and caring for a disease, illness, injury, or disability. Social care needs are related to those which involve performing activities of daily living, remaining independent, taking a fuller part in society, being safe in vulnerable situations, managing complex relationships, and accessing a care home or other supported accommodation.[5]
Health inequality	Uneven distribution of health or health resources as a result of genetic or other unavoidable factors
Health inequity	Avoidable, unfair differences in health and distribution of health resources arising from factors such as poor governance, corruption, or cultural exclusion
Informal care	Vital, unpaid care and support provided by family members, friends for people with dementia living in the community.
Integrated care systems	Partnerships of organisations that come together to plan and deliver joined up health and care services, and to improve the lives of people who live and work in their area.[6]
Interoperability	Allowing people involved in the provision and receipt of care to seamlessly exchange and access the data they need to inform care decisions across a whole pathway.[7]

Longitudinal study	A study where researchers observe and collect data on several variables without trying to influence those variables.
Multimorbidity	The coexistence of two or more chronic conditions within one person.[8]
Ontology	The nature of the social world and what can be known about it[9]
Palliative care	An approach to care that improves the quality of life of patients and their families facing challenges associated with life-threatening illness, whether physical, psychological, social or spiritual.[10]
People affected by dementia	The term “people affected by dementia” in the thesis refers to the individuals who have dementia and their friends and family who are also affected
Quantitative research	The process of collecting and analysing numerical data. Quantitative research methods are appropriate for finding patterns, making predictions and generalising results to wider populations.
Routinely collected electronic data	Administrative data that were not predominantly collected for research purposes, those including electronic medical records, and data collected for insurance purposes such as mandated minimum datasets.[11]
Secondary research	Use of data for research gathered for other purposes.

Chapter 1: Background

This chapter begins with a broad overview of people with dementia, the changing demography and those who might be nearing the end of life, followed by an overview of the healthcare system in England, and conceptual models of healthcare systems and healthcare use. The dementia pathway followed by most people with dementia from diagnosis until the end of life is introduced, further focusing on the evidence regarding the patterns of healthcare among people with dementia. Healthcare use relevant to policy including different aspects of hospital and specialist healthcare service use among people with dementia are discussed. Finally, the quality of care, the quality indicators in relation to the care of people with dementia who may be nearing the end of life and their importance in policy are presented.

1.1 Population

1.1.1 People with dementia and demographic changes

Since the 19th century, mortality has declined, meaning that the number of people living into older ages has increased.[12] As older age is the strongest determinant of risk for dementia,[13] the prevalence and the incidence of people with dementia is also increasing, with 1.6 million people expected to be living with dementia in the United Kingdom by 2040.[14, 15] Having dementia, which is a life-limiting condition, is associated with a decreased life expectancy compared to people without dementia.[16] Differences in life expectancy among people with dementia exist and are affected by the dementia type, sex, age, cognitive problems, frailty and multimorbidities.[17, 18]

People with dementia constitute a heterogenous group in terms of dementia aetiology, comorbidities and other sociodemographic factors. Similar to many other countries, the population of England is now more diverse.[19] It is estimated that 25,000 people living with dementia are from a minority ethnic background in England and Wales, which is expected to increase to seven-fold in the next 40 years, to over 170,000.[20] Furthermore, with societal changes to family structures, more people with dementia are living alone and away from their families; currently, over 120,000 in England and, set to double by 2040, with consequent increasing demands for formal care.[21]

1.1.2 Risk factors, and health and care needs

Although no cure for dementia exists, our understanding of risk factors for developing dementia, the presentation and the management of symptoms to maintain quality of life is expanding. Along with age, genetics and family history of dementia are non-modifiable risk factors for developing dementia, accounting for around 60% of dementia incidents in the population. Around 40% of the dementia incidence on the other hand are attributable to the potentially modifiable risk factors occurring during the life course of the individuals.[22] The factors which contribute to increased dementia risk can be found across an individual’s life stages; these are education (early life), hypertension, obesity, hearing loss, traumatic brain injury, and alcohol misuse (midlife) and smoking, depression, physical inactivity, social isolation, diabetes, and air pollution (later life).[22] Dementia prevention efforts are predominantly focused on managing modifiable risk factors in effort to reduce or delay the occurrence of dementia.[22]

Yet, as people are living longer, many people will continue to live and die with dementia, and often with multimorbidities.[23] On average, people with dementia have three or more illnesses.[24] Dementia can be caused by and complicate other conditions and vice versa; chronic conditions such as hypertension, coronary heart disease, and diabetes, can exacerbate cognitive dysfunction and other symptoms, and dementia can increase the chances of further complications and lead to quicker functional decline.[24] People who have cardiovascular conditions such as heart disease and high blood pressure are at a higher risk of developing vascular dementia.[25] Conditions such as Parkinson's disease also increases the chances of dementia, where approximately one in three people with Parkinson's disease develops dementia.[26] When people with dementia experience ill-health or acute incidents requiring healthcare interventions for their other health conditions, co-occurrence of dementia often necessitates adjustments to standardised treatment and care provision.[23] Managing multimorbidities of people with dementia can lead to polypharmacy which could have more harm than benefits, if not monitored regularly.[27]

Dementia imposes a significant impact on individuals and their families.[28] Cognitive impairment and the combination of dementia and other comorbidities are associated with disability and dependency. Although multimorbidity may play a role in the association between dementia and functional disability, dementia is the main driver of disability.[29] Dementia may directly cause memory loss, executive dysfunction and impaired judgement leading to self-neglect.[30] Behavioural and psychological symptoms experienced by people with dementia, which include a spectrum of non-cognitive and non-neurological symptoms such as agitation, aggression, psychosis, depression, and apathy can influence their daily lives and relationships with others.[31] As the condition progresses, complications may occur due to management of needs with multiple medications (polypharmacy), and people may no longer be able to perform daily tasks such as bathing and dressing, often requiring assistance from relatives or formal carers. The level of disability increases as the condition progresses. The wide array of health and care needs experienced by people with dementia often necessitates input from health and social care services. To be able to tailor the care to the needs of people with dementia and deliver high quality interventions, a better understanding of the diversity among people living and dying with dementia, the complexity of their care needs, and experiences is urgently required.

1.1.3 People with dementia nearing the end of life

Dementia is the leading cause of death in the UK[32] and ranks seventh globally.[33] According to a projection model based on annual deaths which occurred in England and Wales over an eight-year period, by 2040, the number of people dying with dementia may increase to 220,000 people annually.[34] Over a quarter (27.4%) of people with dementia live until advanced stages, but many die in the early or moderate stages from diseases other than dementia.[35] For people with dementia, death is unpredictable, and uncertainty is inherent, making identification of people with dementia who are thought to be approaching the end of life complicated.[36, 37] Most people will live with dementia for many years before receiving their diagnosis (on average 2.2 for people older than 65 years old, and 4.4 years for people with dementia who are younger than 65 years old).[38]

Prediction models have been developed in sub-groups of people with dementia, such as those who live in a nursing home with advanced dementia, with good external validity to predict who might be approaching death, however, these models are rarely generalisable or used in clinical practice.[39] Attributes associated with approaching the end of life, such as where people live (e.g., living in community or institutional settings),[40] change in their health and care needs,[31] and their healthcare interactions,[41] can inform the identification of those who may be approaching the end of life among people with dementia.

Progressive decline in cognitive and physical functioning and increased health and care needs may also signal that a person with dementia may be approaching the end of life. Weight loss, pain, and behavioural and psychological symptoms, including agitation, could become more frequent towards the end of life. In a prospective cohort study of people with advanced dementia, aspiration, dyspnoea, septicaemia and pneumonia were more frequent in those who died compared to those who did not.[36] Decrease in ability to perform daily tasks such as dressing, washing, eating or walking, presence of pressure sores, falls, incontinence, and fractures are also likely to precede the death of people with dementia. However, assessing and routinely recording symptoms of people with dementia is challenging, especially at the advanced stages of the condition where verbally raising concerns may no longer be possible.[42] Despite technological developments enabling people with dementia and their family to record their health and care needs towards the end of life at home,[43] capturing the population-level healthcare use and needs relies predominantly on getting in contact with the health and care system. Understanding that these changes may lead to death often requires expert knowledge on dementia progression and an understanding of the inherent uncertainty that may occur when trying to predict mortality. Over-reliance on cognitive and functional decline may also lead to under-recognition of other complexities and unmet needs relevant to dementia and end of life.[44] Even, when the deterioration is recognised, the imminence of death for people with dementia may be difficult to establish. Understanding who are the people with dementia approaching the end of life remains challenging, despite the growing number of people dying with dementia. While the differences in needs and service provision as people with dementia approach the end of life are acknowledged, there is no consensus in defining end of life in dementia.

Dementia is common in older adults living in care homes, with a predicted prevalence of 40-70%.[45] While some care home residents will have a formal diagnosis of dementia, people's dementia might be undetected in care homes, especially among those older (≥ 90 years old), unmarried, with fewer years of education, and with less severe presentation of dementia.[46] People with dementia, family members, or care professionals may initiate the transition from community accommodation to a care home in response to increased care needs or limited ability of informal care at home. It is challenging to determine which individuals with dementia who move to a care home are nearing the end of their lives. A systematic review focusing on the factors associated with the length of stay in care homes showed that median time from care home admission to death for older people with dementia is 4.1 years (IQR 2.5 -7.6) for men and 4.6 years (IQR 2.9 – 7.0) for women, and substantially longer for those who were diagnosed at a younger age (65-69 years).[47] In the UK, between 26%[48] and 56%[49] of care home residents die within the first year of admission.

A 'one-size-fits-all' approach to dementia care from the moment of diagnosis to the end of life, which relies on clear stages of dementia progression is not suitable. There is great clinical heterogeneity in how health and illness trajectories of people with dementia progress. Dementia is a condition which often requires input from multiple care professionals across various settings. Exploring the heterogeneity of experiences among people with dementia nearing the end of life is crucial for informing the adaptation of the healthcare services to address complex and varying needs efficiently and equitably as they approach the end of their lives. To be able to understand how people with dementia might be accessing healthcare services in England, and where disparities may arise, the next sections will introduce the healthcare system and where it sits among wider systems which support health and care.

1.2 Healthcare

1.2.1 Health and social care system in England

Dementia care is provided by health and social care services, private and informal caregivers. Although this thesis will solely focus on healthcare, gaining a wider understanding of the health and social care system is necessary. The primary aim of health care is to provide high quality of care to its recipients.[50] Health care is defined as systems and actions to improve health or well-being.[51] In England, health and social care systems are often managed separately, while in some instances delivered in an integrated way, such as at care homes. People can access the National Health

Services (NHS) based on clinical needs, free of charge at the point of delivery.[52] The healthcare ecosystem includes primary care, secondary care, tertiary care, and community health services, and is supported by wider systems including social care and care provided by family members and other carers (Figure 1-1). Primary care services include access to doctors, predominantly general practitioners (GPs), nurses and other allied-health professionals, and links to community groups. Primary care is available to all residents of England and it is the first point of contact for non-urgent health concerns. Secondary care refers to hospital care, including emergency services and mental health care mostly accessed via referrals. Finally, tertiary care services, which are rarely relevant to people with dementia, include more specialist services (e.g., renal dialysis, transplants) often prescribed to those with chronic conditions are only accessed via referrals.

Community health services are increasingly preferred by people with long-term health conditions, addressing their complex health and care needs via services delivered mainly at people's homes, primary care, community hospitals and care homes. Care providers within the healthcare ecosystem do not operate in isolation, but as part of an integrated care system where patients can be referred from one provider to the other as needed.[53] Community health services play an essential role in addressing the needs of people with dementia at their usual place of care.

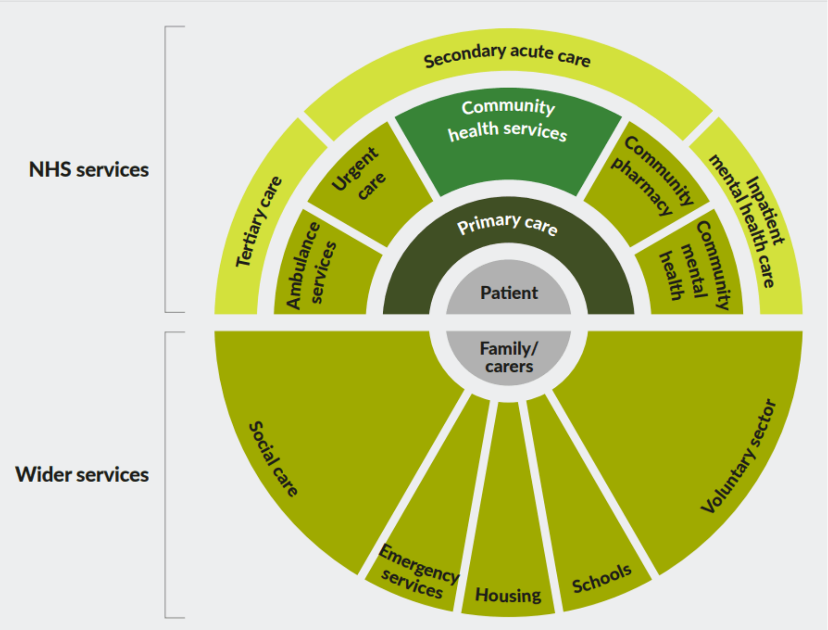

Figure 1-1. NHS services and wider systems that support health and care (*reprinted with permission*).[54]

Although not a formal part of the health care structure, the social care system is likely to affect the healthcare use of people with dementia, especially towards the end of life.[55] Social care provides a wide range of services to care for and support people to live independently while protecting vulnerable individuals. Access to social care is not necessarily free. Access is means-tested, and some people with dementia may be eligible for free provision (e.g., through NHS Continuing care). Adult social care is commissioned and provided by the local councils. All residents of England are eligible to have a needs assessment which helps social care professionals determine the appropriate social care services for the individuals. The Department of Health and Social Care oversees all health and social care services.[a]

However, accessing health and social care services can be challenging and inequitable for people with dementia and their families. People affected by dementia may experience situational, psychological, interpersonal, structural and cultural barriers (e.g., knowledge about available services, availability of suitable services for the needs of people with different dementia diagnoses, and trust in the system) when trying to access services.[55] Having inequitable access to health and social care can result in unmet needs and receiving sub-optimal or inappropriate care, which may lead to poorer outcomes for people affected by dementia. Health inequities among people with dementia can be exacerbated due to lack of appropriate, evidence-based, and easy-to-use services.[56, 57] [58] Conceptual models of healthcare and the healthcare use can inform our understanding of how people with dementia might be accessing and using the existing health and social care services.

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[a] Health and care systems in England went under major reconfigurations (e.g., the introduction of integrated care systems, the establishment of the Department of Health and Care, and the merging of NHS England and NHS Digital) during the conception of this thesis. However, the information provided in this section reflects the health and care systems relevant to this thesis.

1.2.2 Conceptual models of healthcare and healthcare use

Conceptual models are often a representation of a system, providing a summary of its main components, and variables which can contribute to an outcome of interest and the presumed relationship between them. Models can aid the accumulation of knowledge and understanding, and highlight key areas for policy change.[59]

Healthcare systems are inherently complex due to the social, biological and political nature of health.[60] Conceptualising healthcare as a “complex adaptive system” and viewing the interactions within the parts of the system as more important than the individual parts is useful for understanding how healthcare can meet complex needs of people with dementia.[61] The complexity theory of healthcare systems focuses on optimising the performance of the whole system to meet the population needs. It acknowledges both the unpredictability and possibility of emergencies as part of the healthcare system. Viewing healthcare as a complex adaptive system also helps with recognising the warranted and unwarranted variations in healthcare delivery.[62] However, the application of the complexity theory to healthcare research is criticised for having unclear definitions and difficult to implement solutions.[60] Adapting the healthcare system to achieve desirable variations and reduce unwarranted variations in patterns of healthcare use requires an understanding of how individuals interact with the healthcare system to meet their needs.[63]

The experiences of people with dementia with healthcare services can be explored by theories about how and why people seek healthcare.[1, 59, 64-67] The most widely used model developed and revised by Andersen [59, 64] called the “Behaviour Model of Health Services use” proposes environmental factors, population characteristics and health behaviour and outcomes to explain people’s interactions with health services. However, this theory primarily aims to explain the healthcare use of the general population. As the patterns of healthcare use vary drastically for different populations, models which were developed for the healthcare use of the general population have been further developed and adapted for people who may be experiencing life-limiting conditions and those who may be approaching the end of life. Until recently, models of healthcare use of people who may be approaching the end of life were focused on people with terminal cancer. A model developed to explain factors influencing dying at home for patients with terminal cancer[67] was further developed and adapted for non-malignant conditions.[1] The model developed by Murtagh et al. encompasses personal and demographic, disease-related factors and specific symptoms, illness burden and trajectories, and environmental factors to explain what might influence place of care and death (Figure 1-2). This is a comprehensive model which includes factors that have been shown to affect healthcare use of people with dementia towards the end of life.[41, 68] Addition of the “specific symptoms, illness burden and trajectories” component to Gomes and Higginson’s model is relevant to the healthcare use of people with dementia, especially those who may be approaching the end of life, whose disease trajectory is uncertain and the burden of the illnesses varying depending on the type of dementia and other conditions they have.

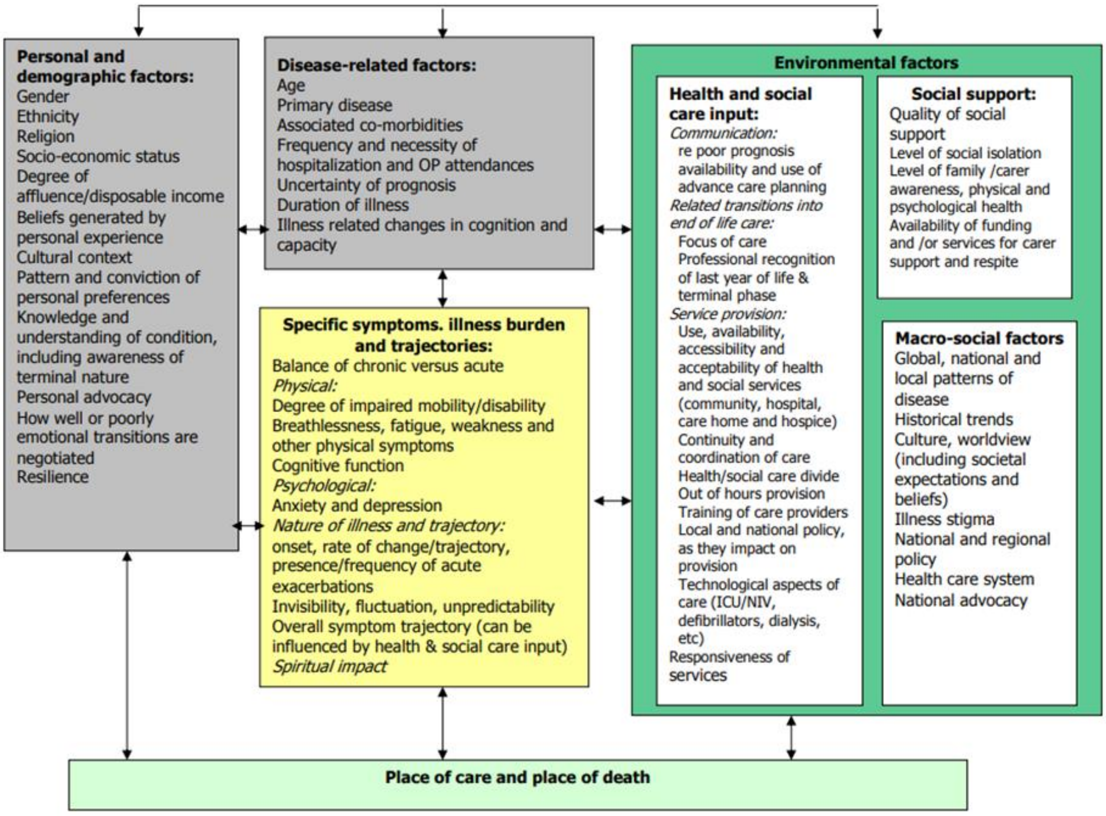

Figure 1-2. Murtagh et al 2012 [1] model of factors affecting place of care and death in non-malignant conditions *(reproduced with permission)*

These conceptual models of healthcare and healthcare use informed the design of this thesis and the interpretation of how people with dementia may interact with the healthcare system to address their needs throughout their illness trajectory. Of note, the models of factors associated with healthcare use are often used to understand the use of singular healthcare service or outcome for people with dementia. There is a need to examine how these factors are related to the use of multiple healthcare services and assess each outcome in context with one another.

1.2.3 Patterns of health and care use among people with dementia from diagnosis until the end of life

Conceptual models discussed above demonstrated how individuals affected by dementia may have varying interactions with the health and care services. To be able to interpret these variations in these interactions meaningfully, an understanding of standards for providing dementia care from diagnosis until the end of life is required. The following sections will provide (i) an overview of the health and care services involved in receiving a dementia diagnosis, post-diagnostic, and dementia end-of-life care services in England, (ii) recommended care pathways, and (iii) the evidence on the patterns of health and care use among people with dementia.

1.2.3.1 Diagnosis and post-diagnostic care

For most people, the journey that leads them to receive a formal dementia diagnosis begins with a visit to their GP. Primary care providers can be approached by the relatives or friends or the individuals themselves about concerns regarding dementia. People who are suspected to have dementia are referred to a dementia specialist (e.g., old age psychiatrist, geriatrician, neurologist).[69] The dementia specialist could be in a memory clinic as part of a team specialised in diagnosing, caring for, and advising people with dementia and their families.[70] Where this community surveillance and referral system has failed, some people might be diagnosed with dementia for the first time at a later stage in the context of a hospital admission or in long-term care facilities.[71] The most recent national target is to ensure that people are seen at a memory service for a dementia diagnosis assessment within six weeks.[72] In reality, for most people, there are delays between the time when a person or family members start having a concern about dementia, when they reach out for support and when they receive a diagnosis.[73] As outlined in the models of how people access healthcare previously, factors such as poor recognition of dementia symptoms, especially in groups where dementia remains stigmatised,[74] and geographical variations in resources[72] could act as barriers to getting a timely dementia diagnosis.

According to national dementia strategies,[69, 72] post-diagnostic support must include a named care coordinator as a first point of contact, who can facilitate person-centred care and treatments, provide information on local services, and develop a care plan. At this stage, depending on the health and care needs of people with dementia, community mental health teams can provide support to manage dementia symptoms, support other mental health diagnoses, and improve their outcomes. However, most people are discharged from specialist services following their diagnosis back to their GP and offered a brief period of post-diagnostic support. Factors such as over-reliance on informal carers to manage and facilitate healthcare appointments, poor recognition and management of comorbidities, and variance in dementia training of the healthcare professionals could impact the quality of the post-diagnostic support people with dementia receive.[69, 75]

UK Dementia Strategies and the Quality and Outcomes Framework[76] also endorse an annual dementia review in primary care, which should include an assessment of dementia progression, medications, physical illnesses and weight.[69] Annual reviews can potentially benefit people with dementia and their families and have wider impact on their care such as reducing the risk of unplanned hospital admissions, and long-term care home placement following an admission.[77] However, multiple studies have shown that only around 50% of people with dementia had an annual review.[78, 79] Considerable inequalities exist in annual review receipt in terms of people's gender, and dementia type. Despite guidance on what should be included in people's annual dementia review, the content and the quality of the reviews varies. Consistent evidence from people with dementia and their families reporting lack of post-diagnostic support and care suggest that their needs may not be adequately addressed.[80]

An accurate and early diagnosis can benefit people with dementia when accompanied by post-diagnostic services that are responsive to their needs. As people get diagnosed with dementia at different stages of the condition, and deteriorate at different rates, it is often difficult to understand when they may be approaching the end of their lives following their diagnosis.[44] For some people with dementia, the care they receive after diagnosis may also be close to their death. However, the guidance on post-diagnostic care predominantly focuses on living well with dementia,[69] and end-of-life care tends to treated be separately. Similarly, evidence on the patterns of healthcare use among people with dementia predominantly focuses on a select period of care such as the year after diagnosis or the last year, months or days of life. The care needs of people with dementia are likely to shift from mental health to physical health in more advanced stages, requiring input from other services.

1.2.3.2 Specialist care

People with dementia can experience chronic pain, complex issues due to comorbidities, and psychiatric symptoms that may persist over prolonged periods, which can benefit from specialised input. Healthcare professionals, including mental health teams, old age psychiatrists, geriatricians, and palliative care specialists can provide the expertise needed to support care for people with dementia in the community and hospitals. Having access to clinical experts in dementia care for complex issues can reassure and empower care staff to make changes and improve care.[81] However, active input from dementia specialists to care of people with dementia is limited in the UK.[36] Differential referrals to mental health services [82] and limited specialist input to the care of people with dementia in hospitals, care homes and people's homes can impair the quality of life of people with dementia and their experiences.[36, 83] As dementia progresses, the input from palliative and end-of-life care specialists to dementia care may be beneficial and have an impact on reduction of potentially costly and burdensome healthcare use (e.g., A&E visits, unplanned hospital admissions).[68, 84, 85] However, access to dementia, palliative and end-of-life care specialists for care of people with dementia in community settings and hospitals is limited.[86-88]

1.2.3.3 Health and social care of people with dementia towards the end of life

End of life as a time period is defined by NHS England as the last year of life.[89] In line with this NHS definition, dementia end-of-life care can be defined as care and support provided to people with dementia who are thought to be in their last year of life. A number of professionals can provide care to people with dementia towards the end of life. This section will focus on the places of care for people with dementia, and key dementia end-of-life health and social care providers.

1.2.3.3.1 Place of care

Where people with dementia live can impact the quality, type, and frequency of healthcare they receive in their last year of life. Towards the end of life, two-thirds of people with dementia live at home (i.e., in their own home or with relatives). People with dementia and their families can access social care services (e.g., provision of meals, carer visits, access to day centres) to address their care needs in the community by undergoing a needs assessment.

As dementia progresses, it may not be possible for an individual with dementia to live at home, and a care home may be a more appropriate place of care. In England, there are two types of care homes: residential care homes without nursing care, and nursing homes where qualified nurse input is available on-site. Some people with dementia with particularly complex needs may be eligible for free social care/care home placement through NHS continuing healthcare and NHS-funded nursing care. Financial and practical (e.g., availability of a care home close to where family lives) constraints often play an important role in the transition of individuals with dementia to a care home. Factors such as not having sufficient support at home and in the community in the face of a crisis may also lead to a transition of care to long-term care facilities for the person with dementia.[90] However, the optimal time for moving to a care home for people with dementia is unclear.[90] In England, care homes are the most common place of death for people with dementia.[86]

A tiny proportion of people with dementia in England die in a hospice (0.4%).[86] Although people with dementia can benefit from hospice care (including hospice at home services which provide specialist palliative care),[91] their access to hospice care in England is inequitable compared to people with cancer.[92] People from ethnic minority backgrounds were also shown to find some of the healthcare services such hospice and as end-of-life care services less accessible.[93]

2.2.3.3.2 Palliative care

The role of palliative care for people with dementia is implied due to the life-limiting nature of the condition, especially towards the end of life. Palliative care can be delivered from a generalist (*an approach, which involves all healthcare workers practising palliative care principles as a core skill, supplemented by some healthcare workers who are not engaged full-time in palliative care but have* *had additional training and experience in palliative care*[94]*)* or a specialist approach (*services whose core activity is the provision of palliative care to individuals with more complex and demanding care needs*[94]).

The integrated model of palliative care proposes the introduction of a palliative care approach to coexist with disease-modifying treatments.[95] The integrated model of palliative care highlights the continuum of care needed from diagnosis to end of life, and how people's care needs may increase as the disease progresses. Despite the role of palliative care in managing symptoms and improving the quality of life, people with dementia seldom access palliative care prior to the last months or weeks of life. People with dementia have inequitable access to specialist palliative care and other specialist care providers such as dementia clinical nurse specialists and Admiral nurses who are specialist dementia nurses aiming to support families affected by dementia.[36, 92]

1.2.3.3.3 Primary and community care

People with dementia often receive care from multiple generalist health and care professionals, including their GPs, psychiatrists, and other allied healthcare professionals towards the end of life. In England, the primary care staff provide the majority of end-of-life care and are central in providing and coordinating palliative and end-of-life care for people with dementia in community settings (including care provision to those living in care homes).

Community care facilities and professionals are central for people with dementia who live at home and their families, and involve multidisciplinary care from health and social care professionals, encompassing specialist dementia nurses, day care centres, and other allied healthcare professionals, and paid carers to name a few. In conjunction with the care received from multiple professionals and across care settings, some circumstances, such as complex symptoms, increased healthcare use, and unmet carer needs, may call for episodic specialist palliative care involvement.[94, 96] Although most people affected by dementia would prefer to receive care closer to home, care in the community may not always be possible, necessitating a visit to hospital. Hospital use by people with dementia towards the end of life has an array of implications on individuals, the economy and the overall health and social care system, warranting a detailed exploration in pursuit of reducing the associated burdens. The next section will describe hospital care for people with dementia, specifically towards the end of life.

1.2.4 Hospital care of people with dementia

People with dementia are more likely to be admitted to the hospital compared to those without dementia from the same age groups, having 1.4 to 4 times more hospital admissions.[97-100] A systematic review and meta-analysis including data from 277,432 people with dementia has shown that an increased risk of hospitalisation remains even after adjusting for age, sex, and physical comorbidities (RR 1·4, 95% CI 1·2–1·7).[97] The mean length of stay in hospital during admission among people with dementia can vary nationally and internationally ranging between 2 to 37 days with factors such as discharge planning, the medical reasons for hospitalisation and comorbidities impacting the length of hospital stay.[101] In secondary care settings, people with dementia could experience hospital care in various ways:

(i) at specialist services, such as at a specialist mental health hospital;
(ii) as an outpatient where they receive care without an admission;
(iii) during a planned admission, when an elective hospital admission is scheduled for a health condition which requires advanced treatment and hospital care;
(iv) in an unplanned manner, as an emergency, by a visit to an Accident & Emergency (A&E) department or by experiencing a non-elective, unplanned hospital admission.

Ideally, when hospital care is necessary, people with dementia should be in the hospital as briefly as possible and, where possible, their visit or admission should be planned.[102] As dementia progresses, and towards the end of life, most people prefer to avoid hospital visits.[103] Going to a hospital can be harmful and stressful for people with dementia; they may not receive adequate pain relief,[104] may experience delirium, may receive potentially harmful medications,[102] and may experience cognitive and functional decline following their hospital admissions.[102, 105] Despite potential harms associated with hospital care, planned care at hospital can be preventative to improve quality of life, and can thus be seen as proactive management of health.[106] On the other hand, unplanned care is often caused by a crisis, and may be an indication of dysfunctions in other parts of the care system. It is therefore important to make a distinction between different healthcare services which can be experienced in a hospital.

1.2.4.1 Unplanned hospital use

For people with dementia, hospitals are a common place of care. In the UK, approximately one in four people staying in hospitals have a dementia diagnosis. Among hospital admissions in people with dementia, the majority were unplanned.[98] In England, unplanned hospital admission rates for people with dementia are higher than for those without.[98] The high incidence of hospital visits and admissions among people with dementia are of interest to researchers and policymakers, as the benefit to people with dementia remains unclear, while the associated high costs cannot be ignored. For people with dementia, hospitalisation may reflect a lack of alternative care provision in the community.[107] Most medical reasons for the A&E attendances and hospitalisations among people with dementia are ambulatory care sensitive conditions (ACSCs), implying conditions that could have been treated in the community if detected early enough.[108] People with dementia and their families also often visit A&Es due to non-medical emergencies including social crises.[109] People with dementia may visit A&E departments as it may be the path of least resistance, with 82.6% experiencing at least one A&E visit in the last year of life.[110] The number of A&E visits increases towards death.[110] People with dementia who visit an A&E may also subsequently experience an unplanned hospital admission.

Evidence from large retrospective cohort studies conducted in England showed that around 50% of people with dementia were hospitalised within a year of receiving their diagnosis, and that individuals with more severe dementia had longer hospital stays.[98, 111] Evidence from the US and the UK show that hospital use in individuals with dementia increases during the year of death.[112, 113] Evidence from England revealed that multiple unplanned hospital admissions in the last 90 days of life of people with dementia are associated with factors such as being male, from a deprived area, depressed mood and presence of physical illness.[114] Having comorbidities and the type and severity of dementia diagnosis further influence people's risk of hospitalisation.[37, 115] The number of socioeconomic risk factors a person has is associated with the higher likelihood of hospitalisation.[116] People with dementia who live in highly deprived areas have a significantly higher risk of unplanned hospital admissions and a lower probability of elective admissions.[117] On the other hand, primary care providers' identification of palliative care needs and being seen by the same GP in the last year of life are associated with fewer unplanned hospital admissions in the last three months of life.[118]

Apart from people's personal characteristics, and interactions with other health and social care services, the characteristics of healthcare services themselves may also impact their unplanned hospital admissions. For instance, GP practice level factors such as the age and location (urbanicity) of the practice, the demographic make-up of the GP catchment area, and the Clinical Commissioning Group's budget allocated to mental health have been found to be associated with the rates of unplanned hospital admissions of people with dementia.[119] Evidence shows that people with dementia living in a care home were less likely to have unplanned hospital admissions in the last year of life.[114, 118] Also, at an area level, living in a care home with nursing staff (i.e., nursing home) was associated with lower likelihood of attending an A&E department among people with dementia in the last year of life.[41] Dementia care in the community, including care home placements, can be costly and commonly it is subsidised by self-funders, further exacerbating the urgent need for hospital care.[87] Evidence from England and other countries demonstrates variability in unplanned hospital use experiences among people with dementia. Further evidence is needed to enhance our understanding of when in relation to formal recognition of people's dementia diagnosis these events start occurring more frequently and for whom.

1.2.4.2. Critical care admissions

During a hospital admission, people with dementia can spend time in different parts of the hospital, preferably on 'dementia-friendly' wards, which are designed and organised to minimise distress experienced of people with dementia as much as possible.[120] Admissions to critical care units, on the other hand, can exacerbate likelihood of having delirium, further cognitive decline, and mortality among people with dementia. Critical care is provided when people with potentially recoverable conditions or who have had accidents or injuries may benefit from detailed observation, organ support, and invasive treatments.[121] Although sometimes essential, the benefits of a critical care admission may be outweighed by its burden for people with dementia, especially if they are nearing the end of life.[122] Hence, a high incidence of critical care admissions among people with dementia towards the end of life may signal potentially inappropriate and burdensome care provision. Further to the potential burdensome interventions and experiences of people with dementia and their families, critical care admissions are costly. Further research is needed for understanding the use of critical care admissions among people with dementia, due to a potentially negative impact of critical care admissions on the quality of life of people with dementia, especially towards the end of life, and associated high costs to the individuals and the healthcare system.

Deciding who should be admitted to a critical care unit can be a difficult task; it requires weighing up the potential benefits and possibility of recovery with risks for each patient, considering the dementia severity and physical frailty of the person, patient and family expectations and limited resources such as bed availability in and out of the critical care units.[123] A critical care admission for a person with dementia who may be approaching the end of their life may not be appropriate.[124] The rates and the nature (e.g., treatments, length of stay, palliative care provision) of critical care admissions of people with dementia vary across countries[125, 126] and are impacted by cultural factors, funding of the healthcare systems, and systemic factors such as bed availability.[121] Increases in critical care admission rates among people with dementia in the last month and year of life has been identified in the US and Belgium.[127, 128] On the other hand, in some countries, such as Taiwan, a decrease in critical care use among people with dementia towards the end of life was observed following the introduction of home palliative care provision.[125] The incidence and the nature of critical care admissions among people with dementia in England remain unexplored.

1.2.4.3 Hospital deaths among people with dementia

Among the existing dementia end-of-life care policies, one of the most common quality indicators (QIs) for measuring the success of implemented actions is the place of death.[129] Although care homes are the most common place of death for people with dementia, England has one of the highest rates of hospital death in dementia among European countries.[86, 130] People with dementia who are older, live in more affluent areas, with more care home provision are less like to die in a hospital and more likely to die in a care home.[86] A high proportion of people with dementia dying in hospitals is accepted to be an indicator of poor care quality and a pointer to lack of community resources which may inhibit people with dementia from dying outside of hospitals.[86, 131, 132] Place of care and death are often used as quality indicators as they are easy to measure.[133] However, focusing on where people die is a simplistic approach to quantifying the quality of care received by people with dementia who may be approaching the end of life. It only provides a snapshot of where people died and implies that all hospital deaths are undesirable and not in line with people's preferences. Changing societal structure and expectations, e.g., cultures becoming more individualistic, older people living alone or away from their families who may support them may result in a shift of preference towards being in a hospital rather than at home.[134] To get a better understanding of the quality of care received by people with dementia who may be approaching the end of life, their journey preceding death including their other interactions with health and social care must be explored.

1.2.5 Dynamic patterns of multiple healthcare use

People with dementia often receive multidisciplinary care from separate services across the healthcare system to meet their changing care needs so that they can live well and independently for as long possible and to manage potentially complex symptoms as they approach the end of their lives. As demonstrated above by evidence of how different characteristics affect healthcare use and outcomes, every person with dementia will likely have different needs and experiences. People with dementia may experience regular appointments, monitoring of their medications, when necessary, social, and nursing support, community visits from dementia specialists, and hospital care at different time points while living with dementia. Studies of healthcare use among people with dementia predominantly focus on the use of one healthcare service, and for limited periods of time, consequently identifying incomplete healthcare use and trajectories.

Focusing on a single healthcare process or outcome (e.g., annual review post-diagnosis or place of death) is common in research and policies. However, this information only provides a snapshot of the care received by the person and does not tell us about the care received throughout their time living and dying with dementia, and importantly how different services complement or substitute each other. Important gaps exist in our knowledge about the interplay between multiple healthcare services when the use of healthcare services is examined in silos. Varying trajectories of functional decline and morbidity among people with dementia are likely to be reflected in dissimilar patterns of healthcare use. Increasing diversity among the dementia population, and their needs also necessitate a greater understanding of which services people with dementia are using, which services they need and who may not be receiving optimal care.

While policies and service configuration err towards a “one size fits all” approach when describing people with dementia and the services they need, the research evidence is growing in support of multiple dementia care pathways. Gaining understanding of clusters of healthcare use would enable understanding the care quality, and delivery of effective interventions to address care needs, improve access to beneficial services, and care planning to prevent unnecessary use of services.

There is growing evidence from studies conducted in other countries analysing healthcare use and expenditure trajectories towards the end of life, that healthcare use patterns observed among people approaching death may be affected by events occurring long before the last year of life.[135] [136-138] For instance, a person with dementia may receive care from community dementia specialist nurses for several years, yet may experience an unplanned hospital admission, and die in hospital. On the other hand, another person with dementia might visit A&E multiple times, prior to their transition to a care home and die outside of the hospital. Provision of high-quality care to people who may be approaching the end of life may benefit from understanding the experiences of people with dementia before their end-of-life care needs come apparent. This is particularly relevant for people with dementia whose prognosis is difficult to predict. Experts opinions on early introduction of interventions aiming to improve end-of-life of people with dementia vary.[139] A better understanding of healthcare use and identifying associated potentially modifiable factors in the run up to death can inform policies aimed at reducing costs while not compromising the quality of care. Identifying appropriate population-based quality indicators for dementia end-of-life care could inform which aspects of healthcare use should be prioritised for exploration.

People with dementia who may be approaching their end of life are disadvantaged compared to people with other terminal conditions such as cancer.[88, 140, 141] Variations in care quality in terms of experiencing unfair and avoidable differences in care persist within care and within the population living with dementia.[140, 142] Previous sections have highlighted where and how people with dementia receive care from the point of their diagnosis to the end of life, their patterns of healthcare use and the recommended dementia care guidelines. To make informed judgements on quality of the healthcare use among people with dementia, an understanding of how the quality of care can be conceptualised and measured is needed.

1.3 Quality of care

1.3.1 Defining quality of care

With the growing demand for health care, rise in multimorbidities, associated costs and variations in clinical practice, assessing the quality of care provided at a population-level has become necessary for many countries. Formal care received can be further defined as care delivered by any health or social care professional when an individual accesses an institution within the formal healthcare system. To assess, monitor and improve areas of care, what is meant by quality of healthcare should also be clarified.

Quality of care has been defined in many ways. First, a system-based framework was proposed by Donabedian, widely accepted as the basis for defining the quality of health care.[143] Within this framework, quality can be categorised into structures (*organisational factors that define health system*), processes (*the actual care given; interactions between users and the health care structure; in essence, what is done to or with user*), and outcomes (*consequences of care; structure, as well as processes, may influence the outcome, indirectly or directly*).[51, 143] While defining quality of care, it is crucial to consider the context. Contextual factors at local and national levels will impact the quality of care, and are generally out of healthcare providers' control. For instance, Stewart et al. [144] built on Donabedian's concept of care quality in their model of care for dying persons, which puts more prominence on the environment of care, and satisfaction with care. Additionally, while structures and processes are components of care, outcomes are not a component but potentially consequences of the structures and processes (e.g., interventions, interpersonal communication) received by the individuals.[51] It is tempting to focus on the outcome category of quality of care. Yet, it could be challenging to determine causal links between the processes and structures and the outcomes experienced. This framework has been adopted in definitions and measurements of care quality. In England, the NHS uses the following definition for care quality:

> *"Care that is effective, safe and provides as positive an experience as possible by being caring, responsive and personalised. Care should also be well-led, sustainable and equitable, achieved through providers and commissioners working together and in partnership with, and for, local people and communities."*[50]

The quality of care experienced by a population can be assessed with references to various domains such as timeliness, access, effectiveness, safety and cost-effectiveness to name a few (Appendix 1). Priorities and measurements relevant to each quality of care domain for a population might differ and at times conflict with each other. Nevertheless, definitions of the quality of care often include multiple care domains, and lack of attention to one may influence the other.

At the population level, quality of care could be defined as *"the ability to access effective care on an efficient and equitable basis for the optimisation of health benefit/well-being for the whole population"* (p.1617).[51] From the definition mentioned earlier, having access to care is crucial. Without equitable and timely access to care, the other domains, such as effectiveness, safety and person-centredness of care become redundant. Access does not equate to healthcare use. However, supply factors and structures of healthcare systems are strong determinants (e.g., In the US, uninsured people are unlikely to have access and hence utilise many aspects of care). In theory, England's healthcare system (NHS) provides equal access to effective care for all users (horizontal equity) as healthcare is free, but people may experience barriers to access. Timeliness of access to effective care when needed and whether greater access is there for those who have more needs (vertical equity) are harder to ensure even within a free healthcare system.

As people with dementia approach the end of their lives, supporting health, independent living, and improving health in long-term become less of a priority, whereas improving person-centred care experiences, in a safe and timely manner take precedence. From a policy and service planning perspective, certain aspects of the quality of care such as value for money, and capacity of the appropriate services often take precedence. However, as described in the previous chapter regarding the patterns of healthcare use among people with dementia, understanding the quality of care received by people with dementia from one service may require considering the quality of other available services.

1.3.2 Measuring quality of care

Assessing the quality of care is a challenging and an inherently iterative process, where assessments lead to maintenance or improvements where needed. The quality of care can be explored by measuring the individual-level care experiences: patient-reported outcome measures and patient and carer experience measures, and the overview of quality at a population level with quality indicators (QIs). QIs are explicitly defined, measurable items of practice performance that, alongside (review) criterion and performance standards, can be used to judge the quality of care provided by healthcare organisations, governments, researchers and other non-governmental organisations such as the Care Quality Commission (CQC), the World Health Organisation (WHO), and the Organisation for Economic Co-operation and Development (OECD).[145, 146] QIs enable the identification of services that deliver excellent care as well as those that require improvement, and the effectiveness of new interventions and services.[147]

Studies analysing existing datasets have focused on various aspects of access to care, treatments, and survival for people with dementia approaching the end of life. However, the lack of credible QIs often makes the interpretation of their findings and what they indicate about the quality of care received by people with dementia approaching the end of life difficult. To be credible, QIs should be based on empirical evidence (or combine best available evidence with professional consensus), be scientifically sound, feasible and easy to collect for the healthcare systems and be acceptable to key stakeholders.[148, 149]

Historically, QIs were developed predominantly for measuring healthcare aspects of preventative public health initiatives and those aiming to improve or eradicate diseases.[147] Additionally, as up until recently, palliative and end-of-life care was deemed to be appropriate solely for care of people with cancer, measuring the quality of palliative care practices, provided to people with other terminal conditions such as dementia and frailty was not a priority. Evidence-based practices for older, frail and dementia populations approaching the end of life are increasing, yet if the QIs are not psychometrically robust and applicable to the existing systems, the interpretations of this quality measurement will be inevitably problematic. To improve the quality of care provided to people with dementia approaching the end of life, population-based, valid, and reliable quality indicators are needed. Studies recommending population-based quality indicators and outcomes for use with routine data for people with dementia approaching the end of life have been mostly based on expert opinions.[148] Additionally, for people with life-limiting conditions such as cancer, QIs often take into account patient preference, whereas in dementia, people may not be able to express what they want or have capacity to make decisions. Suitability of available population-based quality indicators for the evaluation of end-of-life dementia care is relatively unexplored. Identifying appropriate population-based quality indicators for dementia end-of-life care could inform which aspects of healthcare use should be prioritised for exploration.

1.3.3 Quality of quality indicators

The development and testing of QIs is a resource-intensive and time-consuming process. To be able to inform health and social care professionals, researchers and policymakers on the choice of appropriate QIs, it is more efficient to assess the properties of existing QIs, which could be applied efficiently rather than develop new QIs. To be credible, QIs should be based on empirical evidence (or combine best available evidence with professional consensus), be scientifically sound, and be acceptable to key stakeholders.[148, 149] The systematic review presented in Chapter 3 seeks to inform choices of the robust quality indicators for classification of people with dementia approaching the end of life.

1.4 Policy priorities for the care of people with dementia towards the end of life

For dementia care, European and global policies commonly include raising awareness, early diagnosis with person-centred, integrated care, fiscal investment, further research, training and education for the workforce, and increased involvement of people with dementia, and care and support for living at home.[150] The absence of end-of-life care-focused recommendations is noticeable. On the other hand, WHO's global action plan on dementia [151] acknowledges the role of dementia palliative and end-of-life care from the point of diagnosis. However, whilst palliative and end-of-life care is mentioned among dementia care policy documents,[152] it is seldom prioritised,[153] and dementia palliative and end-of-life care in policies are rarely coupled with concrete implementation plans or resource allocation.[153] The momentum for improving access to a timely dementia diagnosis in policies and practice has not yet translated to efforts for better end-of-life care.

Policies which include plans on improving end-of-life dementia care have a clear focus on reducing the unnecessary use of secondary care (i.e., hospitals). The NHS Long Term Plan proposes personalised care to improve the quality of end-of-life care, reducing avoidable hospital admissions and enabling people to die in their preferred place of death.[154] The NHS Five Year Forward View, which sets out a vision for the future of the NHS, focuses on dementia diagnosis and post-diagnostic support to reduce crises and avoid unnecessary hospital admissions.[155] However, these policies lack references to the need or effectiveness of proposed interventions. Finally, integrated care systems in England, which are "*partnerships bringing together NHS organisations, local authorities and others to take collective responsibility for planning services, improving health and reducing inequalities across geographical areas*" were formalised as legal entities during this PhD, with the passage of 2022 Health and Care Act.[6, 156] Concepts of integrated dementia care and integration of palliative care into dementia care have been previously explored, but with limited exploration of the patterns of healthcare use in current practice.[28, 85, 157] This legal change in the delivery of care in England, reiterated the need for exploring how multiple services deliver care concurrently to meet the complex needs of people with dementia until the end of life. A better understanding is needed of who might need these interventions the most, of the best timing for interventions, and of the professionals to involve. These policies and the research evidence lack findings related to the timing of increased use of potentially burdensome and inappropriate care, and its distribution among people with dementia. Lack of this information makes it difficult to implement interventions which may minimise the receipt of inappropriate care. Hence, it may be informative to understand what may have been happening earlier on in the disease trajectory, and whether events occurring near the time of diagnosis have an impact on the events occurring towards the end of life.

1.4.1 The role of routine data in dementia care and policy

Routine datasets are self-evidently important resources for quantifying the quality of care provided to people with dementia around the end of their lives, a necessary step towards developing and evaluating improvement and equity, and policy formulation. There are ongoing national and international efforts in place to improve the research access to broad (*relating to the number of individuals represented in a dataset*) and deep (*an indication of the number of measures and granularity of those measures related to each individual*) data regarding dementia care.[158, 159] Evidence highlighted throughout this chapter include numerous routine data and linkage studies, with a focus on the role of routine data in assessing care quality. To maximise the benefits of routine data research in improving care, there is a strong argument for the role of governments in supporting the role of the routine data in dementia policies. Governments can support the infrastructure, trust-building, access and linkage of data required for assessing dementia care and align the different relevant policy areas such as health and social care, or labour and economic domains to meet the needs of people affected by dementia. Inclusion of the role of routine data in dementia care and dementia care research policies is becoming more common with promising national and international initiatives to improve access and the quality of routine data.[160] [151, 161]

Routinely collected data (e.g., insurance claims, electronic health records, hospital records, disease registries, population census, and death certificates) are increasingly used in healthcare research.[127, 162, 163] The turn of the century (2000s) marked an increase in the use of routine datasets to identify issues in access to and quality of care,[164] in addition to mapping healthcare pathways of people with dementia.[165] With more and more healthcare organisations moving towards fully digitalised healthcare records, large amounts of information can be retrieved safely and analysed appropriately using advanced analytic software at a limited cost.[166] Since then, various areas of dementia care and support (e.g., health and social care interactions,[167] economic evaluations,[138] mortality,[168] medications and other interventions,[169] disease progression[170]) have been investigated. For conditions such as cancer and heart disease, more relevant clinical measures than those available for dementia are embedded in data collection at national and international levels, and established disease registries encompassing all stages of the disease progression have been in operation for longer periods than more recent dementia registries (e.g., the National Cancer Registration Dataset which includes information from multidisciplinary team meetings, pathology reports, and treatments).[171-173] However, the quality, reproducibility and comparability of dementia studies using routinely collected data are improving.

1.5 Summary

The background chapter provided an overview of the changing dementia population, healthcare provision and healthcare use of people with dementia from diagnosis until the end of life, and the policy context. Growing acknowledgement of the complexity of experiences of dementia and interactions with healthcare necessitates a comprehensive exploration of and how the quality of care can be assessed using routine data, patterns of healthcare use and judgements regarding the quality of care received by people with dementia who may be approaching the end of their lives.

Chapter 2: Systematic review – Quality indicators

The text in this chapter of the thesis is based on an article titled "*Quality indicators for dementia and older people nearing the end of life: A systematic review*"[11] which has been published in the following peer-reviewed journal:

Yorganci E, Sampson EL, Gillam J, Aworinde J, Leniz J, Williamson LE, Cripps RL, Stewart R, Sleeman KE. Quality indicators for dementia and older people nearing the end of life: A systematic review. Journal of the American Geriatrics Society. 2021 Dec;69(12):3650-60. DOI: https://doi.org/10.1111/jgs.17387

Personal contributions to the publication: I was responsible for devising the study approach, compiling the search terms, identifying suitable databases, running the searches, extracting, and screening the records. Lesley Williamson, Rachel Cripps, and Javiera Leniz were involved in the double-screening process. I designed the data extraction template for the papers and the psychometric properties of the quality indicators. I extracted the information relevant to the included papers and the quality indicators from included papers. Jesutofunmi Aworinde and Juliet Gillam were involved in the extraction of data regarding the psychometric properties of quality indicators. I completed and checked the psychometric properties of the quality indicators. I drafted the manuscript and prepared the supplementary materials. My PhD supervisors were consulted throughout and provided input on the analysis plan and review and editing of the manuscript. I would like to acknowledge Lesley Henson for her advice.

2.1 Introduction

Older people are characterized by clinical and social factors that increase their risk of poor care at the end of life.[174] With older age, the presence of multiple chronic conditions, frailty and unpredictable illness trajectories become more common, necessitating multi-faceted care provided across different services to meet various needs.[175] While dementia is not exclusively a disease of late life, older age is the strongest predictor of risk for dementia. Having a dementia diagnosis at an older age, coupled with physical needs might lead to a faster decline.[176] Older people might receive a late dementia diagnosis, with the dementia symptoms manifesting years before the diagnosis.[177] Moreover, the point at which people with dementia might start having increased care needs is unclear.[57] Identifying the end-of-life phase can be difficult, particularly for people with conditions other than cancer, including frailty or dementia.[93]

Care of older people generally has commonalities with that provided for people with dementia, such as considerations for the place of care and transitions across care settings.[176, 177] Thus, uncertainties around when dementia might require adjustments to care and treatments and the timing of diagnosis justify taking an inclusive approach which likely covers care provided to people with dementia who may not be diagnosed and those with dementia who are may be nearing the end of their lives.

People aged 85 years old or older and those with dementia are under-represented in specialist palliative care services,[92] but they are predominant users of other health and social care services towards the end of life, which also aim to address palliative and end-of-life care needs. Systemic quality monitoring is needed to learn from good care practices and improve areas of care where needed. To ensure continuity and coordination of care demands, quality of care across care settings should be assessed with robust QIs, which could be used with routinely collected information.

Measuring the quality of care provided to older people and those with dementia towards the end of life is nascent compared to relatively more established ways of the measuring quality of care provided to people with cancer who are nearing the end of life. Previous systematic reviews of palliative and end-of-life care QIs have predominantly included QIs which were developed for the care of people with cancer or those developed for general palliative care and were validated with data from cancer patients and their families.[178-180] Numerous QIs have been developed for the care of older, frail people and those with dementia who may be nearing the of life in the last 20 years. However, the quality of the previously developed QIs, and their feasibility still need to be established.

2.2 Publication 1: Quality indicators for dementia and older people nearing the end of life: A systematic review

To explore the quality of care provided to the population, it was essential to identify appropriate QIs for this population which are usable with routinely collected electronic data. Routinely collected electronic data enables measuring the quality of care provided to people over time and across different care settings while avoiding generating additional data collection tasks.[181] The psychometric properties of QIs developed for measuring the care of dementia and older people who were approaching the end of life, were assessed. Although dementia is not synonymous with old age, there are similarities between the two, especially toward the end of life, in terms of demographics, health and social care needs, and service use.[176, 177] Hence, the inclusion of QIs used for care of older people may provide opportunities to capture aspects of care which may be overlooked in dementia-specific publications. The resulting publication is presented here are presented below as the accepted manuscript for publication to ensure that figures and small text are readable. This publication reports a shortlist of robust quality indicators for the care of older people and people with people nearing the end of life, which are usable with routinely collected electronic data across all care settings (Publication 1, published in Journal of American Geriatrics Society, 2021).

The majority the supplementary material made available online with the publication presented below is provided in Appendix 2. Methodological details essential for understanding Publication 1, which are provided in the supplementary material made available online with the publication, are instead presented in the sections (Sections 2.2.1 & 2.2.2) after the publication.

Quality indicators for dementia and older people nearing the end of life: A systematic review

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Key points:

- We identified 976 quality indicators (QIs). 508 QIs were judged to be robust, 231 moderate and 237 poor in terms of their psychometric properties. The majority of the QIs were not designed for use with routinely collected electronic datasets
- Few QIs have been developed regarding the legal, ethical, spiritual, and cultural aspects of care.
- 71 robust quality indicators (QIs) for care of older people and people with dementia nearing the end of life which can be used with routinely collected electronic data, across care settings are provided

Why does this paper matter?

The use of robust quality indicators with routinely collected electronic datasets will promote monitoring and improving the care provided to older people and people with dementia approaching the end of life.

Abstract

Background: Robust quality indicators (QIs) are essential for monitoring and improving the quality of care and learning from good practice. We aimed to identify and assess QIs for the care of older people and people with dementia who are nearing the end of life and recommend QIs for use with routinely collected electronic data across care settings.

Methods: Systematic review, including five databases and reference chaining. Studies describing development of QIs for care of older people and those with dementia nearing the end of life were included. QIs were categorised as relating to processes or outcomes, and mapped against six care domains. The psychometric properties (acceptability, evidence base, definition, feasibility, reliability, and validity) of each QI were assessed; QIs were categorised as robust, moderate or poor.

Results: From 12,980 titles and abstracts screened, 37 papers and 976 QIs were included. Process and outcome QIs accounted for 780 (79.7%) and 196 (20.3%) of all QIs, respectively. Many of the QIs concerned physical aspects of care (n=492, 50.4%), and fewest concerned spiritual and cultural aspects of care (n=19, 1.9%). 315 (32.3%) QIs were robust and of those 220 were measurable using routinely collected electronic data. The final shortlist of 71 QIs came from seven studies.

Conclusions: Of numerous QIs developed for care of older adults and those with dementia nearing the end of life, most had poor or moderate psychometric properties or were not designed for use with routinely collected electronic datasets. Infrastructure for data availability, combined with use of robust QIs, is important for enhancing understanding of care provided to this population, identifying unmet needs, and improving service provision.

Keywords: End-of-life care, quality indicators, healthcare, dementia, geriatrics

Background

The number of older people and people with dementia who have palliative care needs is increasing.[1] The prevalence of dementia at death is around 30% in high-income countries, and with the aging population this number is rising globally.[2,3] Delivering high quality care to meet complex needs arising from the interaction between physical and psychological needs, polypharmacy, clinical uncertainty and care preferences can be challenging. [4,5,6,7]

Monitoring and improving healthcare of populations requires quality indicators (QIs) which can be obtained from routinely collected electronic datasets. Routinely collected electronic data can enable assessment and comparison of the care provided to people over time, across different care settings, nationally and internationally, while avoiding generating additional data collection tasks.[8] QIs enable identification of services that deliver excellent care, and those that might require improvement. At an aggregated level, QIs can also be used to assess the effectiveness of new interventions and services.[9] QIs should ideally be accessible from routinely collected electronic datasets, supported by high quality evidence, and endorsed by key stakeholders.[8,9]

Development and testing of QIs are resource-intensive and time-consuming processes. Numerous QIs have been developed to assess care of older people and those with dementia nearing the end of life. However, the properties and robustness of these QIs have not been systematically synthesised. To our knowledge, no systematic reviews have focused on QIs for the care of older people and those with dementia approaching the end of life.[10-12] Although dementia is not synonymous with old age, there are similarities between the two patient cohorts towards the end of life in terms of demographics, and health and social care needs and service use.[13,14] Most people living with dementia are older than 60 years old[15] and people with dementia comprise 40-70% of older adults living in long-term care facilities.[16,17] Older people and people with dementia follow a similar, prolonged pattern of decline towards the end of life.[18] The aims of this systematic review were: (1) to identify and assess the psychometric properties of QIs for the care of older people or people with dementia nearing the end of life; (2) to recommend QIs measurable using routinely collected electronic data across care settings.

Methods

Search strategy

We searched MEDLINE, EMBASE, PsycINFO, Web of Science, and CINAHL from inception to 14 February 2020. No study design or language limitations were applied. References of key studies and grey literature (i.e., publications produced by organisations outside the traditional academic publishing such as reports, working papers and white papers) were searched. Search terms for each database are provided in Supplementary Table S1. Definitions are provided in Table 1. Eligible studies (Supplementary Table S2) were those describing the development, review, and/or testing of QIs for the care of adults with dementia and/or those who were older, and who were nearing the end of life.

When QIs were developed and evaluated over time and/or reported across multiple papers, data were extracted from the most recent publication, considering any refinements made. Publications reporting the application of existing QIs to clinical practice were used for reference chaining but excluded from the final list of papers. We excluded studies with adults younger than 60 years old. Papers focusing predominantly on cancer and other disease-specific QIs (e.g., chronic obstructive pulmonary disease, end-stage renal failure) were also excluded. Service performance related QIs were excluded. Study authors were contacted to request additional information as required. The review was reported in accordance with Preferred Reporting Items for Systematic Reviews and Meta analyses

(PRISMA) reporting guideline (Supplementary Table S3) and the protocol was registered with PROSPERO (CRD42020170296).[19] Ethical approval was not required.

Study selection and data extraction

Identified references were downloaded into EndNote reference manager for de-duplication. Title and abstract screening was performed by one reviewer (EY), and all papers were double-screened at the full-text (EY, JL, LT, RC). Papers with ambiguous content or with discrepancies regarding eligibility were discussed with a second reviewer until a consensus was reached.

Data from the included studies were extracted (EY, JG, JA) into an Excel spreadsheet developed for the review (Supplementary link S4). Data extracted about each study included bibliographical information, aim, design, setting, country, population, and data source. Data extracted about each QI were based on a systematic review focusing on end-of-life cancer care QIs[12] and the care domains adapted from National Consensus Project's guidelines for quality palliative care (developed in the USA and used by numerous organisations).[20] Information retrieved included 1) QI type (*process: what care is given and received; or outcome: changes in health status or quality of life*[11]), 2) care domain (*'operational', 'physical', 'psychosocial', 'spiritual and cultural', 'communication, advance care planning, ethical and legal', 'other (including QIs that cover multiple care domains)'*[12,20]), 3) numerator and denominator descriptions, and 4) information on psychometric properties (*acceptability, evidence base, definition, feasibility, reliability*, and *validity*). If the information required was not available in the included paper, backward and forward reference checks were made using Google Scholar.

Data analysis

Assessment of psychometric properties of each QI were double-checked and discussed between assessors (EY, JG, JA) and other author (KES) where necessary. The six psychometric properties (acceptability, evidence base, definition, feasibility, reliability, and validity) have been shown to be important for assessment of individual QIs[21-23] and similar criteria have been used previously for assessing sets of QIs.[24] Assessment of psychometric properties was based on well-established criteria with four possible ratings: positive *(positive supporting evidence (e.g., ≥70% of an expert QI development panel (e.g., healthcare professionals, policymakers) agree that the QI is valid))*, intermediate *(doubts about the psychometric property (e.g., some but not all aspects of QI were clearly defined)),* negative *(disproving evidence about the assessed psychometric property (e.g., QI data collection, analysis or interpretation not feasible))* , and unknown *(no published information available to make a judgement about the psychometric property (e.g., reliability of QI was not reported))*.[10,12,21] Further information on the definition and assessment of psychometric properties is provided in Supplementary Table S5.

Ratings of the psychometric properties were used to classify each QI's overall usability as robust, moderate, or weak. QIs with three or more positive ratings across six psychometric categories were classified as robust. The final recommended shortlist included 1) QIs relevant across care settings (e.g., not just hospice); 2) QIs that were not reliant on a specific survey/data assessment tool; 3) robust QIs; 4) QIs measurable using routinely collected electronic data. We used reference chaining to locate if QIs had been developed or tested for use with routinely collected electronic data such as electronic health records or insurance records. Where duplicate or related QIs were identified (e.g., depression screening for people diagnosed with dementia), the QI with i) better psychometric properties, and ii) a broader denominator (greater sensitivity; applicable to more people) was chosen.[25]

Results

Studies

We identified 12,980 publications from the electronic databases, after de-duplication. An additional 19 publications were identified through reference chaining. Of these, 37 papers met the eligibility criteria (Figure 1) (Supplementary Table S6). Studies were from the USA (n=15)[26-40], Canada (n=6)[41-46], The Netherlands (n=3)[47-49], Belgium (n=3)[50,51], the UK (n=4)[52-55], Australia (n=2)[56,57], Republic of Korea (n=1)[58], Japan (n=1)[59], Sweden (n=1)[60], Italy (n=1)[61] and Spain (n=1)[61]. One paper covered QIs for Belgium, Italy and Spain[61] and one paper conducted a comparative study between the USA, Europe and Canada.[62] Of 37 papers, 11 focused on care of older people nearing the end of life, nine on dementia end-of-life care, and 17 papers focused on end-of-life care of both populations. Eight papers described QIs focusing on care provided in hospital, 12 papers focused on community-based care and 17 papers described QIs which could be applied across settings.

Quality indicators

From the 37 papers, 976 QIs (Supplementary link S4*)* were identified. Of these, 780 (79.7%) were categorised by type as 'process' QIs and 196(20.3%) as 'outcome' QIs. The distribution of QIs by care domains was as follows: physical (n=492, 50.4%); 'communication, advance care planning, and ethical and legal' (n=203, 20.8%); psychosocial (n=117, 12.0%); operational (110, 11.3%); multiple domains (n=35, 3.6%); and 'spiritual and cultural' (n=19, 1.9%). Table 2 provides a summary of topics which were covered by the QIs within each care domain. Only 65 (6.9%) QIs were coupled with a benchmark value (i.e., a standard value against which the quality of care delivered can be measured). Just over half (n=543, 55.6%)

of QIs came from one QI set[63] or adaptations of it to specific populations, care settings or countries.[29,30,35,45,59] The population of interest for 76.5% (n=747) of the QIs was people who were likely to be nearing the end of life, while 23.5% (n=229) of the QIs focused on people who had died. Data extracted about the studies and the QIs can be found in Supplementary link S4.

Assessment of psychometric properties

Most of the QIs identified were rated as 'positive' for at least one of the six psychometric properties (acceptability, evidence base, definition, feasibility, reliability, and validity) (Table 3). We were not able to make a judgement (marked as 'unknown') for at least one psychometric property in 846 (88.5%) QIs. Positive ratings of psychometric properties were as follows: acceptability (n=786, 80.5%), evidence base (n=760, 77.9%), definition (n=512, 52.5%), feasibility (n=494, 50.6%), reliability (n=170, 17.4%), and validity (n=614, 62.9%).

Overall, 508 QIs were judged to be robust, 231 moderate and 237 weak in terms of their psychometric properties. Of 508 robust QIs, 315 were unique QIs (i.e., not duplicated in other papers which developed QIs). When categorised into care domains, most of the unique, robust QIs focused on physical aspects of care (n=204, 64.8%), followed with communication (n=43, 13.7%), operational (n=29, 9.2%), psychosocial (n=28, 8.9%), other (n=6, 1.9%) and spiritual (n=5, 1.6%) aspects of care (Table 2). 220 robust QIs that could be used with routinely collected electronic data were identified.

Shortlist of recommended QIs for use with routinely collected electronic datasets

The shortlisted 71 QIs came from seven papers (Supplementary Table S7).[26,28,39,43,45,48,50] The majority (n=54, 76.1%) of these QIs referred to a process of care, while the rest (n=27,23.9%) were outcome QIs. The final recommended QIs concerned physical (n=29), operational (n=17), communication, advance care planning and legal (n=15), psychosocial (n=9) and spiritual and cultural aspects of care (n=1) (Figure 2). QIs concerning physical aspects of care varied from use of specific medications, appropriateness of medical interventions and screening of symptoms and conditions. QIs on operational aspects of care mainly related to admissions, referrals, eligibility for specific care plans or funding and place of death. QIs in the communication, advance care planning and legal category concerned communication of specific treatments to patients and their families and transfer of information between care settings. QIs relating to the psychosocial aspect of care were mainly regarding the screening and treatment of depression, people's ability to communicate and socialise with others, and included three QIs related to carers. The single QI in the spiritual and cultural aspect of care concerned availability of translators (Supplementary Table S7).

The shortlisted QIs included 35 (49.3%) which were applicable both to older people and people with dementia nearing the end of life, while 31 (43.7%) were for people with dementia, and five (7.0%) were only developed for older people. 43 QIs were designed to be used for people nearing the end of life, while 28 QIs were designed to be used for people who had died (Figure 2).

Discussion

Main findings

In this systematic review, we identified and assessed all available QIs for the care of older people and those with dementia nearing the end of life. We examined the psychometric properties of each QI, and their potential applicability at a population-level using routinely collected electronic datasets. We produced a recommended shortlist of 71 QIs with robust psychometric properties which can be used for understanding, assessing, and improving care of older people and those with dementia nearing the end of life. Of the 71 shortlisted QIs, most concerned physical (n=29) or operational (n=17) aspects of care, while only one concerned spiritual or cultural aspects of care.

This distribution is similar to findings of systematic reviews of QIs for end-of-life[10], cancer[12] or dementia care.[11] Many of the shortlisted QIs in the physical care domain focused on multimorbidities, symptoms and treatments, which reflect a biomedical approach to care of these populations.[11] These QIs tend to be rated as more robust compared to the QIs in the other care domains. QIs about the operational aspects of care, such as those relating to admissions or eligibility for financial aid, were also common. Operational QIs such as hospital admissions before death are widely used by researchers and policy makers; hence their psychometric properties may be better established.[64,65] Information needed for understanding spiritual or cultural aspects of care is also less readily available in routinely collected electronic data, but may be captured in other ways such as through patient-reported outcomes and experience surveys. Thus, combining ways of measuring quality is key to gaining a broader overview of the quality of care.[12]

Our shortlist also included a substantial number (n=24) of QIs regarding communication, advance care planning and ethical and legal, and psychosocial of aspects care. These QIs reflect receiving a diagnosis, discussion of treatments, communication of treatments to other professionals, receipt of treatment and carers' wellbeing. While application of the QIs in the communication, advance care planning and ethical and legal domain may be less straightforward to extract from electronic systems, psychometric robustness of these QIs should encourage further adaption of these QIs into practice. We identified three QIs concerning carers available from routinely collected electronic data. Personal carers often have unidentified and unmet care needs.[66] Using QIs related to carers is a promising starting point for recognising their needs at a population-level.

The smallest number of QIs (n=19) concerned spiritual and cultural aspects of care. We identified one QI from this care domain for use with routinely collected electronic data, which referred to the availability of interpreters and translated materials. More QIs in the spiritual and cultural care domain have been developed in recent years.[47,59] Their implementation into practice is currently limited. Spirituality and cultural beliefs are intrinsic aspects of person-centred end of life and palliative care and have been highlighted as one of the priority areas for palliative care of people with dementia.[20,67] Building the evidence base and incorporating information regarding spiritual and cultural aspects of care in routinely collected national datasets may support development of robust QIs in this area.

Characteristics of quality indicators

Over three quarters (79.7%) of the total identified QIs concerned processes of care, while 20.3% concerned outcomes. This may be because processes of care are often easier to measure and improve.[9] Policy makers and health and social care providers can thus be more in control of setting benchmarks and making necessary changes to improve process QI measurements. Conversely, it is harder to determine the causal relationship between the care provided and the outcome experienced by people, which may explain the smaller number of outcome QIs.

In terms of psychometric properties, more than 50% of the QIs received a ‘positive’ rating for their evidence base, acceptability, definition, and feasibility. Availability of information needed for assessing psychometric properties varied. Evidence base, acceptability, and definition of the QIs were well-documented. In comparison, information on feasibility, reliability, and validity were harder to locate among the published work, reflected in higher percentages of ‘unknown’ ratings for these psychometric properties. We also rated just 0.3% of the QIs as ‘negative’ for their validity. Scant reporting of QIs with poor validity is likely to be explained by lack of validation of the QIs after their development. However, some level of publication bias may also exist, and some validation articles might have not been retrieved from our search.

While most QIs (n=747, 76.5%) were applied prospectively to a population who were likely to be nearing the end of life, a smaller proportion (n=229, 23.5%) of QIs were designed to be used retrospectively after death. Prospectively identifying a population approaching the end of life is challenging. QIs have been developed which signal potential palliative care needs or risk of poor outcomes such as functional and cognitive impairment and caregiver distress. However, these measures may not be available in routinely collected administrative data or health records and are not collected reliably across care settings.[49] The mandate of standardised minimum datasets across settings may address this limitation in the future.[8] Development of techniques such as linking different datasets and use of text-mining could also maximise the potential of obtaining QIs covering a wider range of care domains from routinely collected electronic data.[68] Nevertheless, controls put in place for safety of patient data, organisational culture, complex governance arrangements including costs, technical barriers, and lack of transparency and communication about routinely collected electronic data may create unintended barriers for its efficient use.[69]

Strengths and limitations

The majority of systematic reviews for palliative care QIs have drawn on evidence from studies involving people with cancer [10,11]. This is the first systematic review to identify and assess QIs applicable to older people and people with dementia nearing the end of life. We used previously applied and recommended ways of assessing psychometric properties of each individual QI [12], rather than assessing the usability of overall QI sets. This approach enabled us to unpick QIs which were robust and usable within QI sets. All papers were double-screened at full-text stage, and the bibliographical data extracted and assessment of psychometric properties of each QI were also double-checked.

The evidence base for identified QIs was often unclear. In some cases, this was referred to as 'based on existing evidence and expert opinion' without any further details. There is also a chance that information on the psychometric properties of some QIs has not been published. We made efforts by frequent discussions, reference chaining and contacting the authors where needed, when making decisions on psychometric properties. QIs applicable across care settings have advantages such as comparison and continuity of measurements for a large population and are easier to apply. However, we acknowledge that setting- and condition-specific QIs have their own benefits. QIs, especially those focusing on processes and healthcare utilisation do not necessarily equate to achieving a good quality of care. Measures which may be relevant at a population level may not always translate to each individual's experience and capture issues relevant to patients and families.

Implications for policy, research, and practice

Using QIs can help deliver high quality of care.[9] The number of older people and those with dementia who are nearing the end of life is growing.[1] With advancing technology, we can retrieve more information needed for evaluating palliative and end-of-life care from routinely collected electronic datasets, while minimising data collection burden. In light of the recent COVID-19 pandemic, the value of having linked datasets across care settings has been highlighted.[8] Our findings should be used to inform the development of infrastructure needed for population level data collection. Use of the recommended QIs may provide an overview of quality of care provided to a large proportion of the population, who are in significant need of palliative care, yet may consistently experience sub-optimal care. Determining how many QIs to implement is difficult. Experts advise on being selective and having a smaller number of QIs per care domain.[9,70] QIs are often pointers for actions needed to improve or maintain the quality of care. Therefore, having fewer robust QIs (rather than many collected through routinely collected electronic datasets), combined with other quality measures is more meaningful for achieving high quality of care.[12]

Significant resource is spent developing new QIs. We suggest that instead of developing new QIs, future research should prioritise the following: (1) revising and adapting existing QIs where possible (especially for physical aspects of care); (2) developing the evidence base for psychosocial, cultural and spiritual aspects of care and further testing (feasibility, reliability, validity) of existing QIs; (3) involving patients and families in further development and selection of QIs [71]; (4) implementing shortlisted QIs into practice [72] at local, national and international population levels and (5) combining the interpretation of the QIs with other quality measures such as patient-reported outcomes for monitoring and improving quality of care and enabling learning through comparison.

Conclusions

We provide a shortlist of 71 robust QIs for older people and people with dementia nearing the end of life that are robust, which can be applicable across care settings and measurable using routinely collected electronic datasets and applied across care settings. Future research should focus on testing and developing psychometric rigour of existing QIs and implementation of robust QIs into practice, to guide our understanding of quality of care provided to these populations, to identify unmet needs, and improve service provision.

Availability of data and material

All data analysed for this review are included in this published article and its Supplementary Materials.

Abbreviations

ACP – Advance care planning

EOL – End of life

ICU – Intensive Care Unit

PRISMA – Preferred Reporting Items for Systematic Reviews and Meta Analyses

QI – Quality Indicator

UK – United Kingdom

USA – United States of America

Supplementary Materials

Supplementary Material 1 – Uploaded as “Supplementary Material 1.docx”. This file includes seven sections.

Supplementary Table S1: “*Search Terms*” used in different databases

Supplementary Table S2. *“Eligibility Criteria”*

Supplementary Table S3: “*PRISMA 2009 Checklist”*

Supplementary Link S4: “*Data Extraction Shee*t”

Supplementary Table S5: “*Assessment of psychometric categories to evaluate QIs*” which details rating criteria used to evaluate QIs

Supplementary Table S6: “*Summary of papers included in the systematic review*”

Supplementary Table S7: *“Summary of recurring topics covered in each QI category”*

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Author Contributions

Obtained funding: ELS, KES, RS. Designed the study: EY, KES, ELS, RS. Data screening, extraction, and analysis: EY, JL, LT, RC, JA, JG. Wrote the manuscript: EY. Revised the manuscript: All authors contributed to revisions, read and approved the final manuscript.

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Funders played no role in the design, methods, subject recruitment, data collections, analysis and preparation of paper.

Conflict of interests

The authors have no conflicts.

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Tables & Figures

Figure 1. PRISMA Flow Diagram

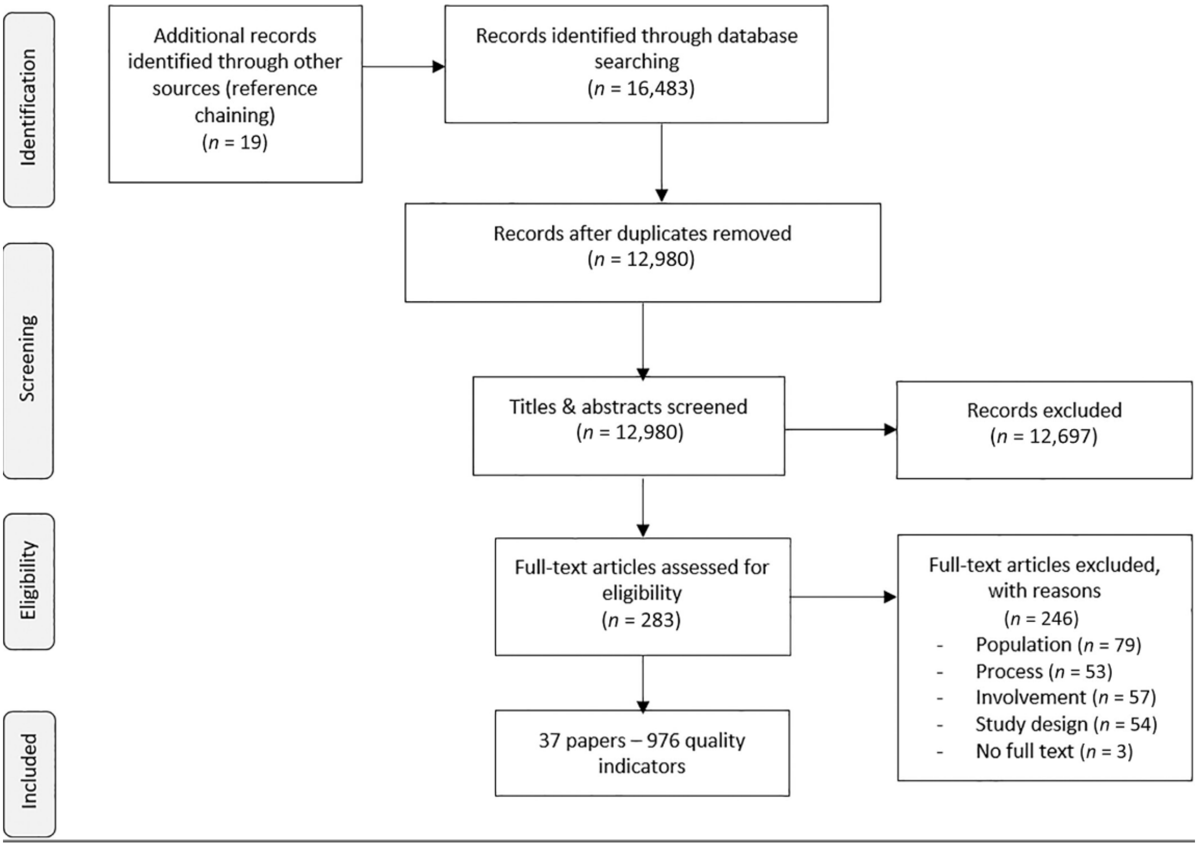

Figure 2. Shortlist of recommended QIs for use with routinely collected electronic datasets (n=71)

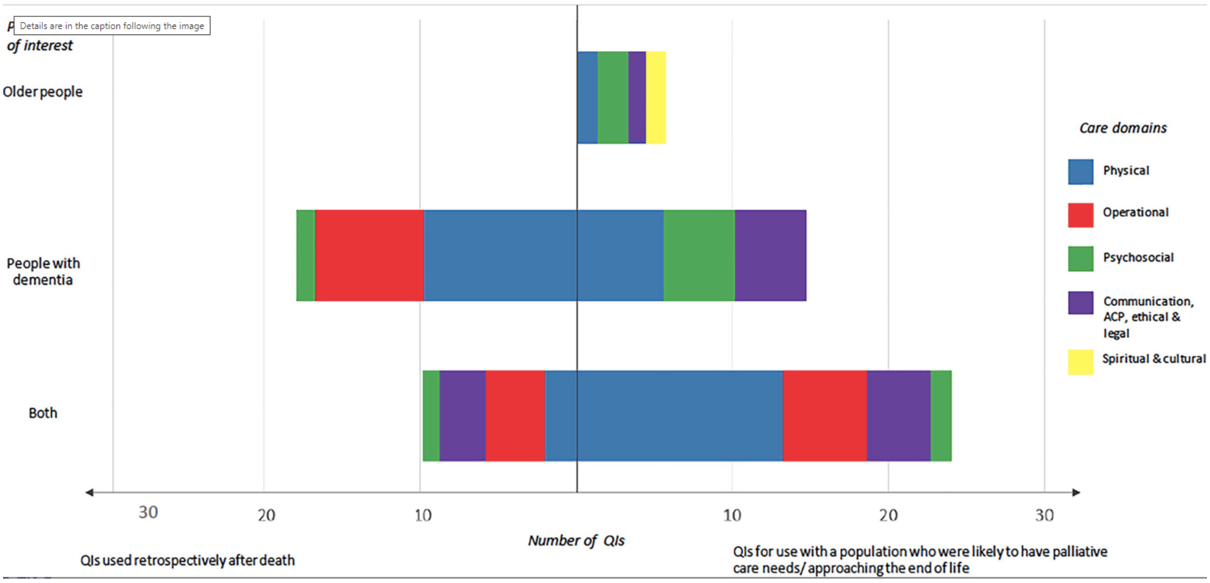

Table 1. Definitions

Quality	QIs are explicitly defined, measurable items of practice performance that, alongside

indicators (QIs)	(review) criterion and performance standards, can be used to judge the quality of care provided by a health or social care organization.[73,74] A QI requires explicit and defined components, including a numerator and a denominator. QIs can be classified by process (the quality of the care process received by the patient) and outcomes (often concerning the clinical outcomes of care).[75]
Population-level	QIs which are applicable across the patient population, and not limited to a subpopulation or a care setting. While measures such as patient-reported outcome measures concern the quality of care provided at an individual level, QIs are meaningful measurements when they are interpreted for understanding the quality of care provided at an aggregated level.
Routinely collected electronic data	Administrative data that were not predominantly collected for research purposes, those including electronic medical records, and data collected for insurance purposes such as mandated minimum datasets.

QI = Quality indicator

Table 2. Summary of recurring topics covered in each QI category and percentage of robust QIs per domain

Care domains	**Summary**
Operational (9.2%)	• involvement of specialised palliative care (e.g., involvement of specialised palliative care, late initiation of palliative care), • admissions (e.g., in-patient days Last year of life/most recent year, number of emergency admissions after the initiation of palliative care, ≥ 1 ICU admission in the last 30 days of life), • risk assessment (e.g., delirium risk assessment and documentation, assessment of dementia if the patient has cognitive impairment) • care coordination (e.g., transfer of prescription list across care settings (on and after admission)
Physical (64.8%)	• screening, diagnostic, treatments, and ongoing assessments • dementia symptoms and neuropsychiatric symptoms, • pain (e.g., new pain, ongoing pain, treatment of pain, number of people with untreated pain), • medications (e.g., use of statins, opioids, antibiotics, changing medications which are associated with mental status changes), • tube feeding, • surgery in the last year of life, • falls, • mechanical ventilation • urinary tract infections • QIs for common conditions in the older population – diabetes, hypertension, heart failure, cancer, ischemic heart disease, hearing impairments, osteoarthritis, osteoporosis, pneumonia and influenza, stroke and atrial fibrillation, vision impairment
Psychosocial (8.9%)	• screening, diagnostic, treatments, and ongoing assessments • depression (comorbid with/without dementia), • negative mood • anxiety • medications and other treatments

	caregivers' wellbeing, distress, and contact
Spiritual and cultural (1.6%)	• having translators • offering spiritual support • having a (perceived) peaceful death
Communication, advance care planning, and ethical and legal (13.7%)	• timing, nature and availability of the advance care planning, involving a multidisciplinary team in the advance care planning discussions, • discharge summaries, • preferences for life-sustaining treatments, place of care and death, having a surrogate decision maker, resuscitation status
Other/QIs covering multiple domains (1.6%)	• QIs which covered multiple domains of care (e.g., proportion of people who had a list of things which should be covered in the notes included depression assessment, transferring notes on discharge, medications, and previous admissions)

QI=Quality Indicator, ICU=Intensive Care Unit

Table 3. Summary of quality indicators by psychometric properties

Psychometric property	**Quality indicator Rating No (%)**			
	Positive	*Intermediate*	*Negative*	*Unknown*
Acceptability[a]	786(80.5)	71(7.3)	3(0.3)	116(11.9)
Evidence base[b]	760(77.9)	83(8.5)	1(0.1)	132(13.5)
Definition[c]	512(52.5)	329(33.7)	116(11.9)	19(1.9)
Feasibility[d]	494(50.6)	NA	95(9.7)	387(39.7)
Reliability[e]	170(17.4)	NA	15(1.5)	791(81.0)
Validity[f]	614(62.9)	5(0.5)	3(0.3)	354(36.3)

[a] Perception among stakeholders that a QI is agreeable, or satisfactory measured within degree of consensus [b] Availability of scientific research and expert opinion regarding the process or outcome being measured as part of the QI [c] How well a QI was defined [d] Extent to which a new QI can be successfully obtained (data collection) and analysed [e] Reliability measures (e.g., inter-rater, test-retest) relate to reproducibility of a QI [f] Extent to which a QI accurately reflects the domain of quality being assessed

2.2.1 Identification of the included papers

The eligibility criteria to identify relevant papers in line with the aim and objectives of the systematic review was developed (Table 2-1). The eligibility criteria took into account the population of interest (adults with dementia and/or those who were older, and who were nearing the end of life), the process/intervention of interest which were QIs, the involvement of the papers in the development, review or testing of the QIs and the study design of the identified papers. There were no restrictions by type of residential or geographical setting, or by written language or date.

Table 2-1. Eligibility Criteria

Eligibility criteria	**Inclusion**	**Exclusion**
Population	Adults with dementia (any type and stage) near end of life OR Frail, older (≥ 60 years old) adults near end of life ≥ 50% non-cancer	Individuals ≤ 18 years old Cancer Specific disease focus (such as COPD, ESRD)
Process/Intervention	Quality indicators Process measures Quality measures	Structure quality indicators Person-centred outcomes (*measure which may not be available in routine datasets and may not be meaningful to look at a population level)* Quality improvement projects
Involvement	Studies describing the development, review and/or testing of QIs	Application of existing QIs to clinical practice
Study design	All study types/Original research papers including: Systematic reviews of RCTs Mixed method systematic review RCTs Quasi experimental Qualitative Surveys Policy briefs	Conference abstracts Commentaries/opinion pieces Books/chapters Published protocols Thesis Case reports

Six bibliographic databases were searched from inception to February 2020. The search strategy was first developed with input from the project team, and by reviewing other published systematic reviews. Once piloted, the syntax and the subject headings were adapted for use in other databases. The electronic search strategy applied to the OVID MEDLINE database is provided in Table 2-2. The search terms applied to the other five databases are provided in Appendix 2.

Table 2-2. Electronic search strategy for OVID Medline database

	Dementia	**Terms relating to older people**	**End of life**	**Quality Indictors**
Medical subject headings	exp Dementia/	Exp Aged/ Exp Health Services for the Aged / Exp Nursing homes/ Exp Homes for the aged/ Frail Elderly	exp Terminal care/ exp Terminally ill/ Exp palliative care/	Outcome and Process Assessment (Health Care) ("Outcome and Process Assessment (Health care)" or "Quality Assurance, Health care" or "Quality Improvement" or "Quality indicators, health care" or "quality of health care").sh.
Keywords	dement*.mp alzheimer*.mp chronic* adj3 cerebrovascular.mp memory adj3 (impair* or insufficien* or complain*).mp cognit* adj2 (impair* or declin*).mp	Frail*.mp Ag?ing.tw Old* person.tw Old* people.tw Elder*.tw Old* adult*.tw Geriatric*.tw Gerontol*.tw Senior*.tw Veteran*.tw Nursing home*.tw Long term care.tw	palliat*.mp end of life.mp EOL.mp life limit*.mp terminal*.mp dying.mp end stage.mp late stage.mp advanced.mp ceiling adj3 care.mp goal* adj3 care.mp last adj4 life.mp Last year of life. mp Life's end. mp	((quality or qualities or utili?ation or performance or assurance or benchmark*) adj2 (measur* or criter* or assess* or indicator* or validat* or evaluat*)).tw.
Limit to humans				

2.2.2 Assessing the psychometric properties of the quality indicators

The six psychometric properties (acceptability, evidence base, definition, feasibility, reliability, and validity) which were assessed in understanding the quality of the QIs have been shown to be important for assessment of individual QIs.[149, 182, 183] Assessment of psychometric properties was based on well-established criteria with three to four possible ratings for each psychometric property.[149, 178, 180] Details of the assessment of psychometric properties to evaluate individual quality indicators are provided in Table 2-3.

Table 2-3. Assessment of psychometric properties to evaluate the quality indicators

Psychometric Category Rating Criteria[180]	**Measurement Property Assessment Criteria**
Acceptability	*Acceptability measures the perception among stakeholders that a QI is agreeable, or satisfactory measured within degree of consensus*[149, 182]
Unknown	Acceptability of QI not reported, or insufficiently reported for assessment, or doubt about how acceptability was assessed
Negative	As a result of a formal consensus method (e.g., Delphi or nominal group technique), <70% of panel agreed that QI is acceptable or mean score for acceptability of QI in lowest tertile of scale used
Intermediate	Using formal consensus method, mean score for QI's acceptability in middle tertile of scale used
Positive	As a result of a formal consensus method, ≥70% of panel agreed that QI is acceptable or mean score for acceptability of QI in highest tertile of scale used
Evidence base	*Evidence base measures availability of scientific research and expert opinion regarding the process or outcome being measured as part of the QI*
Unknown	Evidence base for QI not reported, or insufficiently reported for assessment, or doubt about how evidence base was obtained
Negative	QI was not evidence based
Intermediate	QI was solely based on expert opinion or clinical experience
Positive	QI was based on the integration of best research evidence available with clinical

	expertise/expert opinion
Definition	*Definition measures how well a QI was defined*
Unknown	No QI definition was provided
Negative	QI definition unclear
Intermediate	Some but not all aspects of QI were clearly defined, or QI's definition requires further interpretation
Positive	QI definition with numerator and denominator clearly reported or calculation provided
Feasibility	*Extent to which a new QI can be successfully obtained (data collection) and analysed*[149, 183]
Unknown	Feasibility not reported, or insufficiently reported to allow assessment, or doubt about how feasibility was assessed
Negative	QI data collection, analysis or interpretation not feasible
Positive	QI data collection, analysis, and interpretation reported as feasible
Reliability	*Reliability measures (e.g., inter-rater, test-retest) relate to reproducibility of a QI*[149]
Unknown	Reliability of QI was not reported, or insufficiently reported for assessment, or doubt about how reliability was assessed
Negative	As a result of using an agreement measure, <75% agreement between QI information extracted and criterion standard (e.g., patient's medical records), κ (categorial variables)<0.4, or intraclass correlation (continuous variable)<0.4
Positive	As a result of using an agreement measure, ≥75% agreement between QI information extracted and criterion standard, κ (categorial variables)≥0.4, or intraclass correlation (continuous variable)≥0.4
Validity	*Validity measures the extent to which a QI accurately reflects the domain of quality being assessed (note: A QI can be reliable (consistent in what is measure but not valid)*[2]

Unknown	QI's validity was not reported, or insufficiently reported to allow assessment, or doubt about how validity was assessed
Negative	Using formal consensus method (e.g., Delphi or nominal group technique), <70% of panel agreeing that QI is valid or mean score for validity of QI in lowest tertile of scale used
Intermediate	Using formal consensus method, average score for validity of QI in middle tertile of scale used
Positive	Using formal consensus method, ≥70% of panel agreeing that QI is valid or mean score for validity of QI in highest tertile of scale used

2.3 Discussion

The systematic review findings revealed that over the last three decades, 976 QIs were developed to assess the quality of care provided to older people and people with dementia who may be nearing the end of life. Many QIs reflect the multi-faceted care needs of the population, highlighting the complexity of care provision.

Of the 71 shortlisted QIs, most concerned physical (n = 29) or operational (n = 17) aspects of care, while only one QI concerned spiritual or cultural aspects of care. This distribution is similar to other QI reviews concerning end-of-life care of other terminal conditions .[179, 180] Overlooking spiritual concerns of people with dementia who may be approaching the end of life compared to those without dementia has also been observed in clinical practice.[140] The QIs concerning communication, advance care planning and legal aspects of care reflect receiving a diagnosis, treatment discussions with the patient and families, communication of final treatments to other professionals, receipt of treatment, and carers' well-being, which are crucial for dementia care. Although the shortlist included 15 QIs from this care domain, the availability of data in electronic data including electronic health records and routine administrative data sources concerning the care of older people and people with dementia is limited. However, the psychometric robustness of these QIs is encouraging for their implementation into clinical practice.

The focus on care processes, such as hospitalisations, could be because these are often easier to measure and target in interventions.[147] Most QIs were rated to have a positive score for their evidence base (based on integrating best research evidence with clinical expertise/expert opinion) for healthcare processes and outcomes, which may indicate poor or high care quality for people with dementia. QIs are often pointers for actions needed to improve or maintain the quality of care.

Some of these actions include identifying the sub-groups experiencing poorer quality of care, disproportionately among people with dementia.

When identifying people approaching the end of life, some QIs were designed to be applied prospectively before death whereas others were designed to be applied retrospectively, looking at the care provided to those who died, acknowledging the difficulties in prognostication among this population. Although the evidence base suggests that some QIs, such as the high incidence of critical care admissions among people with dementia nearing the end of life, are indicators of inappropriate care, significant variations in their occurrence are observed across and within countries. It is essential to be selective and focus on implementing a smaller number of robust QIs as the use of too many QIs could make the findings difficult to interpret. It is also important to build the evidence base (e.g., choice of the population of interest, selection of the time period for the end of life) to implement the QIs and inform clinical practice and policies.

In this systematic review, of 37 papers which were included only four were from the United Kingdom.[184-187] Furthermore, most of the robust QIs derived from the US. This was an unsurprising finding as US administrative health data, namely claims data from Medicaid, Medicare and Veterans Affairs have been used extensively for quantifying and investigating quality of care over many years. Additionally, the healthcare providers in the US are mandated to complete a Minimum Data Set (MDS), which is a comprehensive clinical assessment that includes information across care domains (including *psychosocial*, and *communication, advance care planning, ethical and legal* care domains) relevant to dementia and end-of-life care across care settings. Routinely collected electronic data such as information collected from all NHS hospital relevant to dementia and end-of-life care in the UK is standardised,[188] but does not provide sufficient information relevant to all domains of dementia care.

2.3.1 Healthcare processes and outcomes of interest for this thesis

While the breadth of the data available in the UK is high, the depth of the routine data available for research into the care of people with dementia, especially towards the end of life is limited.[158] Among the identified robust QIs which are usable with routinely collected electronic data, most of the available process and outcome QIs in the UK relevant to the care of people with dementia belong to the *physical* and *operational* care domains. Involvement of palliative care or identification of palliative care needs are available in a subset of routinely collected electronic health data,[189] but not available in national datasets. Although, the importance of care domains such as psychosocial, ethical or communication aspects of care for people with dementia is highlighted in national dementia guidelines,[69, 190] electronic recording of QIs related to these domains are scarce.

Furthermore, despite the interplay between health and social care services for optimal care of people with dementia, linkages between routinely datasets which capture both types of services in the UK are limited, [158, 181]and often focused on provision in care homes. Therefore, the choice of processes and outcomes as a focus in this thesis were driven by those which can be easily targeted in policies, and are thought to impact the wider health and social care system (e.g., hospital use). Services which have not been explored before, such as critical care admissions, and the availability of data were also considered when determining the focus for this thesis.

2.4 Summary

This chapter presented a systematic review which identified and assessed quality indicators usable with routine data for the care of older people and people with dementia who are nearing the end of life. In light of this evidence, healthcare processes and outcomes of interest for this thesis were presented. The next chapter will provide a summary of the rationale for this thesis and outline the aim and objectives of this thesis.

Chapter 3: Rationale, aim and objectives of this thesis

3.1 Rationale for thesis

Dementia has an immense impact on individuals and society. Despite some advances in prevention, diagnosis and treatments to improve care and slow down the progression of dementia, it remains one of the commonest causes of morbidity and mortality in the UK and worldwide, and is a substantial driver of national health and social care costs. The discrepancies between the increasing needs of people affected by dementia towards the end of life and available healthcare services can lead to burdensome and costly care experiences. The expected rise in the number of people who will live and die with dementia calls for further research to understand the patterns of healthcare use, the quality of care, and people with dementia from diagnosis until the end of life. This understanding is imperative for guiding policies, planning services, and improving the care of people affected by dementia.

At present there is limited evidence on subgroups of people with dementia who may be approaching the end of life, and when their use of healthcare services rise. Whilst previous studies have identified various biopsychosocial and environmental factors associated with the use of certain healthcare services, such as unplanned hospital admissions, important gaps in the literature have been highlighted regarding concurrent healthcare use. Understanding variation and reducing potentially burdensome healthcare use among people with dementia nearing the end of life should not be at the expense of promoting appropriate attendance for those in need; however, targeting patients whose who may benefit from alternative, more suitable care pathways is desirable. National and international policies seek to improve dementia care yet often fail to account for the diversity and complexity of manifestations, which may exacerbate differences in the quality of care received towards the end of life. Lack of clarity on illness trajectories and care pathways experienced by people with dementia, and the challenges of including people with dementia who may be approaching the end of life in research, magnify the difficulties encountered in building an evidence-base which captures universal experiences. Routinely collected electronic data in theory provide rich sources of information spanning many years on large number of people with dementia, further enriched by linkages between clinical and administrative datasets; these can be utilised to provide an evidence base for improving dementia care. However, although evidence on dementia from routine data studies is increasing, evidence regarding the care of people with dementia towards the end of life remains limited. A more detailed exploration of the population, their care use, and the quality of care provided could act as a springboard for developing policies and timely interventions to provide better care to people with dementia around the end of life.

3.2 Aim and Objectives

Aim

To identify and describe patterns in healthcare use; and investigate indicators of quality of care among people with dementia nearing the end of life using routine data.

Objectives

1. To describe patterns of healthcare use of people with dementia from the point of diagnosis to death
2. To identify subgroups of people with dementia who experience distinct patterns of healthcare use over the course of the illness until the end of life and to examine associated factors
3. To use these findings to describe quality of care received by people with dementia nearing the end of life and guide policy and practice for this population.

Chapter 4: Methods

This chapter provides details of the study design, theoretical and methodological considerations which underpin the thesis, background and an overview to the research methodology, the common elements of the thesis studies, ethical and governance procedures. Specific methods of each study are provided within the corresponding results chapters.

4.1 Thesis design, studies and links to objectives

This thesis is comprised of observational studies, employing the secondary analysis of routinely collected sociodemographic and clinical data from various linked datasets, informed by a systematic review. There are three studies contributing to the thesis; how each component of the thesis relates to each other (Figure 4-1) and to each thesis objective is demonstrated below. To meet the thesis aim, an observational quantitative research design was used.

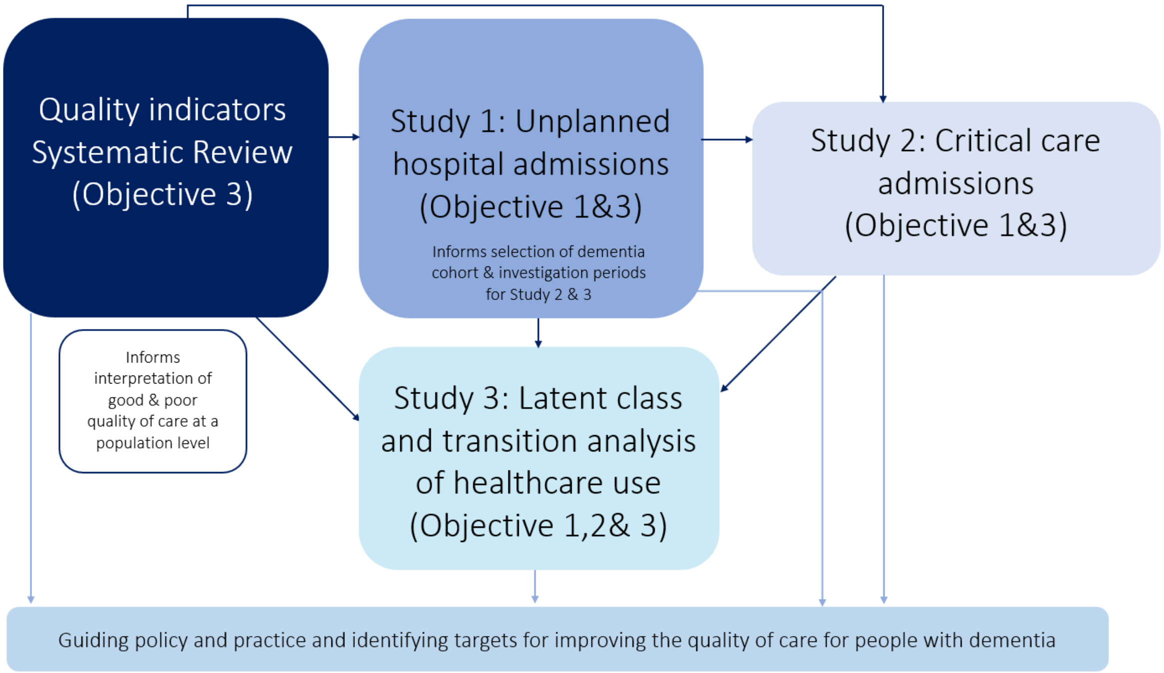

Figure 4-1. Overview of the thesis design and objectives

4.2 Evolution of the thesis protocol

At the beginning of this PhD, the initial plan for the thesis was to have two studies (Study 1 – investigating outcomes associated with a single healthcare service use and Study 2 – investigating concurrent use of multiple healthcare services). This thesis used data derived from the South London and Maudsley (SLaM) NHS Foundation Trust’s Clinical Record Interactive Search (CRIS), which was developed to enable researchers to search and retrieve anonymised electronic mental health records efficiently from a large and diverse south London catchment. The utility of CRIS data has been enhanced through external linkages as well as natural language processing. In this respect, during the first year of my PhD, a novel linkage was established between the CRIS data and adult critical care admissions data from national Hospital Episode Statistics (HES). Detailed information on CRIS and HES data are provided in Section 4.8.1. Patterns of critical care admissions have been explored in dementia populations outside of the UK,[164, 191] and can be used as a robust quality indicator to examine the quality of care provided to people with dementia nearing the end of life as shown in my systematic review.[11] As there was an evidence gap regarding the use of critical care among people with dementia in England, the decision was made to exploit this novel data linkage and incorporate critical care admissions into the thesis.

4.3 Population of interest

Analysed cohorts comprised people aged 50 years old or older at dementia diagnosis and the population of interest was therefore people with dementia. Different cut-off points for the identification of cohorts of people with dementia were used in the studies of this thesis. Procedures for identifying dementia diagnosis in electronic health records are detailed in Section 4.8.1.2.5. Thesis studies included 'dynamic cohorts' which is where the study participants can join or leave the cohort at different times (e.g., a person who was diagnosed with dementia in 2010 and died in 2013 and another person who was diagnosed in 2008 and died in 2015). Components of this thesis therefore also explored patterns of healthcare use among people with dementia within different time periods (Figure 4-2).

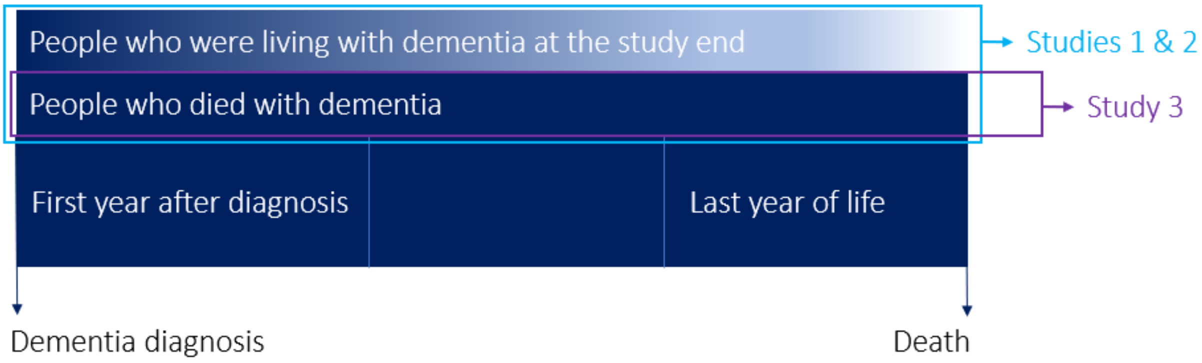

Figure 4-2. Population of interest for each study of this thesis

4.4 Ontological and epistemological considerations

The exploratory nature of this thesis' aim and the topic of interest – healthcare use of people with dementia who may be approaching the end of life – require a research approach which is flexible and applicable to the complexity of the real world.

I adopted a pragmatic approach to analysis for this thesis. While the digital positivism movement assumes that everything derived from big data research reflects reality,[192] pragmatism acknowledges that the research is shaped based on the researcher's and community's experience. Within the pragmatic approach, knowledge and reality are based on beliefs and habits that are socially constructed.[193] As a research paradigm, pragmatism orients itself toward solving practical problems in the real world.[194] Pragmatism allows understanding the research as a continual learning process, encouraging experimentation and prioritising understanding over theoretical or methodological purity.[60, 192] This is fitting where data are explored to understand patterns and possible differences.

Pragmatism provides epistemological foundations which support social complexity theory in healthcare.[60] Consequences measure research success within a pragmatic epistemology. This focus on the consequences aligns with the holistic system view of complexity theory, where outcomes are not pre-determined but emergent.[195] Additionally, this thesis is informed by Murtagh's model of factors affecting place of care and death in non-malignant conditions[1] and Donabedian's model for quality of care (See Section 1.2.2 & Section 1.3.1 for more information).[143]

4.5 Alternative methodological approaches

Healthcare use and quality of care can be investigated using many methodological approaches. Before introducing the methodological approach adopted in this thesis, other possible methodologies, specifically qualitative and prospective *de novo* data collection will be explored.

Qualitative methods can provide insight into personal experiences of the quality of care, adding context to their responses where necessary. Such research methods are useful when the aim is to understand 'why' a phenomenon is happening. Most qualitative studies derive data from a small sample of individuals, and the subjectivity of findings may limit their generalisability. In addition to difficulties in obtaining qualitative data directly from people with dementia whose language abilities may be impaired,[33] information about events that occurred a long time ago may be subject to recall bias even when obtained from others. As this thesis is more concerned with quantifying the patterns and subsets of care experienced by people with dementia (i.e., 'who') data from a large group of people with dementia drawn over a long period of time is needed ('when'), hence qualitative approaches were deemed to be less appropriate for this thesis.

Ideally, in longitudinal studies, people are recruited, and data are collected prospectively; this allows more opportunities to collect tailored information, as well as supplementary collection of further details for clarity when needed.[196] However, patient journeys within the health and social care system may be complex and span many years following a dementia diagnosis, and it is difficult to predict when someone approaches the end of life and even more difficult to retain them in a research study. Although there are ways to successfully involve people with varying of levels of mental capacity in research,[197] and examples of prospective studies of people with dementia exist,[31, 198-201] recruiting and retaining people with dementia in research studies remains challenging.[36] As this thesis is interested in what may happen ahead of the end of life, and additionally as it is not easy to predict the survival time of a person with dementia at a given point in their illness, it is difficult to budget for a study which can adequately follow up everyone until the end of their lives or expect a proxy to be engaged within the timeframe of a PhD.

4.6 Retrospective cohort studies

This thesis aimed to identify and describe patterns in healthcare use, and to investigate indicators of quality of care experienced among people with dementia nearing the end of life using routine data. the cohort design is particularly suited for understanding temporal patterns in healthcare (objective 1), describing populations of interest and outcome associations with putative risk factors (objective 2), and characterising quality of care over time (objective 2). Cohort studies derived from routine data further allow researchers to explore the temporal sequence of real life challenges, potentially over many years and in large samples , albeit with no control over the exposures or outcomes of interest.[202] Cohort studies can be prospective or retrospective; however, as discussed above, a prospective cohort study design would not have been feasible for this thesis, where people with dementia have a wide survival range from diagnosis,[16] and because of the challenge of differential attrition (loss to follow-up). Retrospective cohort studies allow for identification of a clear denominator and allows for the study of incidence of events which occur over many years without the necessity of follow-up over many years, making them quicker and cheaper than prospective cohort studies,[203] and providing more complete and naturalistic follow-up.

4.6.1 Identification of people with dementia in palliative and end-of-life care retrospective cohort studies

It has been argued that differences in subject and time period selection of retrospective cohort studies could lead to invalid conclusions about the quality and type of care provided to people approaching the end of life.[204] Generally, retrospective cohort studies in the palliative and end-of-life care research field have focused on the intensity of the healthcare received during a period before death.[205] This gives the advantage of knowing that everyone who is being studied has died. In real life, determining when someone is in the last months of life is not easy.[196, 206] Other studies base their sample selection on the place of care (e.g., living in residential care[207]) or point of contact with a healthcare service (e.g., having an unplanned hospital admission[201]). However, although associations exist, death may not be imminent or predictable for all participants recruited in these studies.

4.7 The use of routine data in dementia research

In the context of this PhD, where there are both challenges in following up people with dementia over the years in prospective cohort studies and in identifying people with dementia who may be approaching the end of life, routinely collected data are highly valuable. There are a few reasons why using routine data is appropriate for the objectives of this thesis. Routine datasets have been proven to be informative and cost-effective in assessing quality of care, although have been under-utilised in understanding the care of people with dementia, especially towards the end of life. [128, 208] Routine data linked between different data sources to can further access a wealth of complementary information without additional data collection burden,[164, 208-210] which would otherwise take extra time for people with dementia, families and healthcare professionals to provide via primary data collection.

Routinely collected data has the potential to capture the experiences of a large group of people receiving given services (unless people have chosen to opt out of secondary data use), making results more generalisable than most recruited cohort studies, as the sample is less likely to be subject to participation biases which are more common in studies where prospective and primary data collection approaches are adopted. More specifically, routine data from electronic health records can be used to overcome barriers faced in conventional longitudinal cohort studies where achieving adequate sample sizes may be challenging for investigating complex questions.[211] Furthermore, information collected about people with dementia in conventional recruited cohort studies often relies on proxies such as family members or healthcare professionals, and recall bias can compromise questionnaire-derived retrospective information on service use (e.g., Client Service Receipt Inventory[212]).

Assembly of a dementia cohort from routine datasets relies on the recording of a formal dementia diagnosis on people's records. An advantage of a recruited cohort study is that this allows researchers to capture people who may not have a formal dementia diagnosis and include them in their study if they screen positive. However, the advancement of technology, such as the use of natural language processing (NLP) to review the written notes in the electronic health records, may improve the inclusion of people with dementia in routine data studies who may not had a formal assessment.

Understanding the context and assembling of the datasets used in this thesis is essential for interpreting the findings. Beyond the volume and velocity of data, routine data linkages enable the collection of information from a variety of sources for generating new knowledge. While the processes and the purposes (e.g., financial, clinical, audits) for which data has been collected affect the validity of routine data, it reflects real-life use of healthcare services, and facilitates effective extraction of patterns of healthcare use. Detailed reporting of key design choices and codes used to characterise the study population are necessary for the reproducibility of healthcare studies using routine data.[213]

4.8 The research methodology

This thesis adopts a quantitative secondary research design, where retrospective cohort studies are assembled using data linkages across multiple routine datasets. Across three studies, both descriptive and inferential statistics were used to meet the aim and objectives of the thesis. Details of analysis related to each study are described in their respective chapters. This section focuses on the routine datasets used in this thesis and common variables extracted for all three studies.

4.8.1 Routine datasets used in this thesis

The CRIS data source was used to identify individuals with a dementia diagnosis for all studies of this thesis. Using established data linkages data from CRIS were used in combination with those from Hospital Episode Statistics (HES) and Office for National Statistics (ONS) datasets. As the research was carried out over three years (2020-2023), different cuts of data were used in the studies, to ensure the inclusion of most relevant and recent data available. However, no substantive changes in demographics or care are expected to occur between the different cuts of data across the thesis studies, particularly as none of these overlapped into COVID-19 pandemic lockdowns.

4.8.1.1 Dementia cohort dataset and setting: South London and Maudsley and CRIS data

Details of specific inclusion criteria for each study are described in respective Results chapters. However, the dementia cohorts in this thesis were all derived from cases routinely diagnosed at the South London and Maudsley NHS Foundation Trust (SLaM), one of the largest mental health care providers in Europe. SLaM provides comprehensive mental health services to a geographic catchment area of over 1.2 million residents in four south London boroughs – Croydon, Lambeth, Lewisham and Southwark – as well as some regional and national specialist services.[214] In routine NHS England settings, people who may have dementia are primarily ascertained in primary care, then referred to a specialist dementia diagnostic service, such as those provided by SLaM, for a formal dementia diagnosis assessment. In some cases, people may receive their dementia diagnosis, without a referral from primary care, in the context of care for another mental health condition, or via liaison services provided to local general hospitals.

The SLaM Biomedical Research Centre (SLaM BRC) Case Register and its Clinical Record Interactive Search (CRIS) application were developed in 2007-08 to render SLaM's electronic health records accessible for research use.[214, 215] CRIS was created with a patient-led oversight committee[216] and adheres to strict governance frameworks. The data are de-identified and provided in a data-secure format. Source clinical records have been fully electronic across all SLaM services since 2006 with imported legacy data prior to that date. The SLaM BRC Case Register aligns with WHO's description of a psychiatric case register – 'patient-centred longitudinal record of contacts with a defined set of psychiatric services originating from a defined population'. [217] Electronic health records include demographics, contact with services (e.g., community mental health visits, face-to-face appointments), detailed clinical assessments, care plans and medications. The CRIS platform allows researchers to extract information from both structured (e.g., date, numerical diagnosis codes) and unstructured (free-text information in written assessments, progress notes, correspondence) fields of the source electronic health records. Information stored in unstructured fields is extracted for large-scale analyses using individually developed and evaluated natural language processing algorithms, most using General Architecture for Text Engineering (GATE) software.[214, 218] This technique allows entities of interest derived from written information to be represented in structured tables. Researchers specify the information they require for their project in discussion with a dedicated data extraction team, and requirements are returned in spreadsheet format, exportable in CSV format for further analysis.

Information stored in SLAM BRC CRIS has been extensively linked over the last 15+ years with other external health and non-health sources. Data linkages are valuable, especially when they enable the capture of exposure data from one dataset and outcome data from another dataset,[214] and are particularly helpful for a condition like dementia where care provision is represented across multiple healthcare sectors (e.g., mental healthcare, primary care, acute general hospital care etc.). Secure linkages between datasets are coordinated by a dedicated Clinical Data Linkage Service (CDLS), with linked data stored on a CDLS server within the SLaM firewall representing a Secure Data Environment. The SLaM CDLS satisfies NHS requirements for the research governance model for linking data as described in the Department of Health Information Governance Review or ‘Caldicott 2’ report,[219] ensuring that information is linked to guarantee the legal and ethical rights of patients and caregivers. To establish linkage between datasets, personal identifiers (which are not available to the researchers) including names, date of birth, and postcode are used. Of relevance to this thesis, the CRIS dataset is linked to Hospital Episode Statistics (HES) datasets which provides information on the wider specialist healthcare use of people with dementia.

4.8.1.2 Illness and sociodemographic variables

Illness and sociodemographic variables which were used in all three studies of this thesis are introduced below. Additional variables which were extracted for each study are described in their respective chapters.

4.8.1.2.1 Age

Ages of people with dementia were derived from their year of birth. This variable was used to compute other variables of interest such as age at diagnosis, age at death, and age on admissions. Age was further classified into age-groups in some of the analyses.

4.8.1.2.2 Sex

Sex was classified as either male or female.

4.8.1.2.3 Ethnicity

Self-reported ethnicity was extracted and classified according to standard census codes as follows: White (British, Irish, any White background), Black (African, Caribbean, any Black background), Asian (Indian, Chinese, any Asian background), Mixed (White and Black Caribbean, White and Asian, White and Black African, or any other mixed background), Any other ethnicity (Any other ethnic background) and missing/not known.

4.8.1.2.4 Index of Multiple Deprivation

Neighbourhood-level socioeconomic status was estimated using the Index of Multiple Deprivation (IMD).[220] This is the official measure of relative deprivation in England which encompasses living conditions of individuals from 32,844 neighbourhoods termed Lower Layer Super Output Areas (LSOAs). Each LSOA, a standard national administrative unit, contains around 1500 residents. LSOAs were created based on the 2011 Census information. IMD 2015 was derived for the LSOA containing the patient's address (recorded closest to the diagnosis) and converted into quintiles of the national distribution (1 – most deprived, 5 – least deprived).

4.8.1.2.5 Dementia

The diagnosis of dementia in CRIS was determined from structured fields of ICD-10 diagnosis codes (F00x–03x) and supplemented by evidence of a dementia diagnosis recorded in text fields ascertained by a validated natural language processing (NLP) algorithm using General Architecture for Text Engineering (GATE) software.[214, 218, 221][b]

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[b] The identification of people with dementia was only supplemented by the NLP algorithm in the cohort identified for Study 1. This service was not available at the time of the data extraction for Study 2 and 3.

First known dementia diagnosis date anywhere mentioned in CRIS was extracted.

The dementia sub-type was determined based on the assigned clinical diagnosis on the clinical records (Alzheimer's disease, Vascular dementia, Mixed, Lewy body dementia, Dementia in other diseases or unspecified dementia (where aetiology was unrecorded)).

4.8.1.2.6 Dementia severity

Both Mini Mental State Examination (MMSE)[222] and Health of the Nation Outcome Scales (HoNOS) (or HoNOS-65 where appropriate)[223] cognitive problems scores were extracted to ascertain dementia severity (See Section 4.8.1.2.7). MMSE is a commonly used set of questions for screening cognitive function, which provides measures of orientation, registration, short-term memory as well as language functioning. MMSE[222] scores (from structured and unstructured fields) to estimate dementia severity were categorised into "mild" (MMSE≥20), "moderate" (MMSE=10-19) or "severe" (MMSE<10). The HoNOS cognitive problems score can be rated from 0 (no problem) to 4 (severe or very severe problem), has acceptable/good psychometric properties and strongly correlates with MMSE scores (correlation coefficient range -0.9 to -0.81).[224, 225]

4.8.1.2.7 Clinical presentation

For other aspects of clinical presentation, HoNOS or HoNOS-65 output was used where appropriate using scores at the nearest date to the first recorded dementia diagnosis. HoNOS is a 12-domain clinician-rated instrument commonly used in English mental health services and completed by clinical staff as a structured form in the source electronic health record. It comprises subscales rated 0 (no problem) to 4 (severe/very severe problem) and has acceptable/ good psychometric properties.[223] In addition to cognitive problems (see Section 4.8.1.2.6), it provides scores on agitated behaviour, self-Injury, drinking, physical illness, hallucinations, depressed mood, other mental problems, relationships, activities of daily living, living conditions, and occupational problems. Higher scores always indicate greater problems.

4.8.1.3 Datasets for the healthcare use: Hospital Episode Statistics

Hospital Episode Statistics (HES) is a database which contains details about all inpatient admissions, A&E attendances, and outpatient appointments at NHS hospitals in England, providing near-complete coverage for hospital use (secondary care including mental health admissions). Only 1% of UK hospital services are private and not included in HES, but they are likely to be less relevant for people with dementia.[226] Records could be excluded due to errors and removed if patients choose to opt-out of their data being used for research and planning purposes. A new national data opt-out was made available in 2018, requiring all health and social care organisations to be compliant by the end of March 2022, including SLaM.[227] The data's primary purpose is monitoring and finance, allowing hospitals to be paid for the care they deliver.[188] However, secondary use of data for research purposes are permitted. Since 1898, the use of HES datasets for research purposes, either for standalone analysis or linked with other datasets has increased.

HES data can be recorded in numerous ways. Information accessed in HES datasets is a snapshot of data taken on the Reconciliation and Post-Reconciliation dates for each month. The database is continually updated based on changes in patients' records. Initial information entered to the medical records by clinicians are often extracted and processed by clinical coders in each hospital for HES data.[228] Variability in data entry and the contemporaneous nature of the HES data may have implications on the accuracy of HES data used in research studies.[229] The large amounts of data held in HES datasets, and its national coverage, makes it a strong research tool for understanding the healthcare use of people with dementia who may be nearing the end of life. The information clinicians provide in medical notes and discharge summaries may be incomplete or unclear for sufficiently capturing the care provided in HES variables.[229]

The HES database is categorised into four domains: Admitted Patient Care (APC), Outpatients appointments (OP), Accident and Emergency (A&E) attendances, and Adult Critical Care (ACC). Admitted patient care refers to all hospital admissions where the episode of treatment required the use of a hospital bed. A hospital admission does not necessarily refer to overnight stays. OP refers to records of all outpatient appointments in English NHS hospitals. The record-level data are provided regardless of whether the patient attended the appointment or not. A&E attendances data gathers all attendances from A&E departments providing urgent care for illness and injury. The A&E dataset also includes attendances from speciality A&E departments, walk-in centres, and minor injury units. Adult critical care dataset contains records of all critical care periods which took place in intensive care and high-dependency units, where constant support and monitoring is required to maintain the functioning of at least one organ.

HES record-level data are provided in episode form. A single episode refers to the period of continuous care from a single consultant. Episodes can be grouped into spells. A spell commences when a patient is admitted for care to and ends when a patient is discharged, transferred, or dies. A continuous inpatient spell refers to the continuous period where patient's care was provided by different care providers (e.g., they moved between hospital wards or transferred to another hospital) before they were discharged or died.[188] The HES dataset are provided for each financial year which runs from 1st April to 31st March. This means some episodes may remain unfinished. For each study of the thesis, as recommended, data were checked for duplications and cleaned if unfinished episodes existed. For the linkage between CRIS and HES datasets, personal identifiers are compiled by CDLS, and transferred to the Health and Social Care Information Centre (HSCIC) using an NHS-approved secure file transfer. HSCIC adds a CRIS ID to all matched HES records and destroys patients' all personal identifiers. This information is stored in CDLS and provided to researchers in a fully anonymised format.[214] HES data quality has been criticised over the years. However, the change in the purpose of HES data, making it the main mechanism for reimbursement, has led to greater engagement with data quality and completeness.[230] The concerns over the accuracy of information recorded in HES were considered when selecting variables for the studies of thesis. As the HES data accuracy has likely improved over the years,[188] the information regarding the care of people with dementia from less recent years may be less accurate.

Data from CRIS was also extracted for specialist mental healthcare use for Study 3. Further details is provided in the Chapter 7.

4.8.1.4 Death registry

The Office for National Statistics (ONS) is responsible for collecting, analysing, and disseminating statistics about the UK’s population, society, and economy. Mortality information which is derived from the death certificates (including the underlying reason for death diagnoses) from the Office for National Statistics (ONS) is linked to the CRIS data in a similar way to the linkage process described for HES linkages.

4.9 Methodological challenges

The main advantage to using routine data is that this data are readily available. However, there can be some unforeseen challenges at different stages of obtaining data, data cleaning and data analysis. Flexibility is needed for timelines as the process of accessing the data and data extraction relies on other teams. Secondary research, using data which were collected for other purposes, relies on information, which is already collected, meaning that the researchers lack control over variables which were collected. Additionally, researchers ought to understand data veracity and provenance (i.e., what data points actually represent; motivations for recording data in particular ways). For instance, the systematic review conducted in the background of this thesis identified 71 robust QIs which are usable with routine data.[11] However, most of the QIs were not recorded in the datasets available for the use for this thesis. Similarly, potential factors identified to be associated with the healthcare use of people with dementia were limited or were not accurately recorded. While techniques to handle missing data can be used when appropriate, when there may be differences between those who had missing data and those who did not (missing not at random), decisions had to be made when choosing covariates. Initial protocols and selection of variables of interest had to be discussed with the data extraction team to assess feasibility.

The data cleaning stage requires an in-depth understanding of the coding of each variable, potential errors and necessary checks to ensure that the findings from the dataset is reliable. During this process I had to have many discussions with data extraction team and clinicians to understand the variables and their limitations. Using statistical techniques relies on making assumptions and manipulating data to conduct the analysis. Healthcare data are rarely neat, requiring adjustments to the analyses and sometimes categorising timelines to make sense of research findings. Finally, the preparation of variables, model building and interpretation stages of the structural equation modelling (SEM – see Chapter 7, Section 7.3.1) were lengthy and challenging. Acquiring the skills needed for statistical adjustments required training, practice and patience.

4.10 Patient and public involvement in thesis

Patient and public involvement (PPI) is a prerequisite for high-quality research. PPI is describes as 'research conducted in collaboration with members of the public, patients and families'.[231] This can include involving PPI members to identify research priorities, plan study designs, collect, analyse or interpret data, and the dissemination of research findings.[231] Although the importance of PPI in dementia and end-of-life care has been increasingly gaining recognition, most guidance focuses on involving PPI members in research with primary data collection.[232] Gold standards for conducting ethical dementia research were published in Spring 2023 (towards the end of this PhD) led by the Dementia Engagement and Empowerment Project network, which includes people with dementia all across the UK.[233] Standards established in this guidance by people with dementia around respect and acknowledgement, safety and wellbeing, and making information as simple, accessible and open as possible were followed during this PhD.[234, 235]

Working with PPI members was integral to this thesis for enhancing its relevance and impact while exploring the validity of the findings among key stakeholders. While experts including clinicians, researchers and commissioners were involved in the development of the QIs, PPI members, who are often referred to as "experts by experience" were not present.[11] In line with the target population and healthcare services examined in this PhD, I worked with a wide range of PPI members. The PPI members I worked with were:

(i) people with dementia,
(ii) friends and family who were often the primary and unpaid carer of the person with dementia,
(iii) bereaved unpaid carers who had care experiences of a person with dementia,
(iv) South London and Maudsley NHS Foundation Trust's service users and their friends and families,
(v) people with experiences relevant to care provided to people who may be approaching the end of life.

PPI members were able to provide diverse experiences and perspectives as they differed in terms of their sociodemographic (in terms of age, gender, ethnicity), illness-related (type of dementia, severity of dementia, comorbidities, physical abilities), and environmental characteristics (financial or additional support) and experiences of receiving varying levels of the quality of care (e.g., diagnosis process, care concordant with preferences of the person with dementia) and using different health and social care services (e.g., mental health, community care (staying at home or care home), primary care, secondary care, private and council funding).

From the conception of ideas, each stage of this thesis was discussed with the PPI members. Regular meetings were held with the EMBED-Care PPI group.[236] Having regular meetings with the same the EMBED-Care PPI members throughout the PhD gave us the opportunity to build rapport, and gave them a chance to have a better understanding of the overall aim of the PhD and how each study fits within the PhD.

Most of the PPI engagements throughout the PhD were held online (due to the COVID-19 pandemic and to enhance inclusivity and accessibility for those who may not be able to travel due to various reasons (e.g., caring responsibilities, travel costs, health reasons – burden associated with in-person meetings)). There were few opportunities to meet PPI members in person. PPI members were reimbursed for their time and contributions following the NIHR INVOLVE guidance.[237] The main way of engaging with PPI members was through presentations and facilitated discussions where either I was the only researcher present or had another researcher who helped with chairing and note-taking. All meetings were arranged 3-4 weeks in advance, where the PPI members had a chance to have their input into the meeting's agenda and read materials beforehand (when appropriate). Their contributions and reflections on each study are separately presented in the corresponding Results chapters.

I shared my initial ideas at one of Cicely Saunders Institute's PPI meetings. This meeting was focused on routine data studies and included PPI members who had experiences of palliative and end of life care, and a smaller number of public members who did not have any experiences of palliative and end of life care but were interested in this area. Ahead of presenting my research ideas, PPI members were given a brief introduction to routine data studies and terms which will be used throughout the day. This presentation was important in sense-checking and research priority setting before finalising my research aim and objectives. PPI members agreed that use of routine data for exploring healthcare patterns of people with dementia was innovative and inclusive. Although there were doubts around the potential of direct impact on clinical practice and people with dementia, PPI members agreed it could be useful in influencing policy and enhancing our understanding of what may be happening to people with dementia who may not be able to participate in primary data collection studies.

I also met with the EMBED-Care PPI members to initially build rapport, and then introduce my PhD and concepts relevant to routine data research in dementia to them. Most PPI members had a perception that researchers can extract any information needed from routinely collected electronic health datasets. It was important to highlight the gaps in the information available in routine data. Afterwards, they were able to advise on some additional information such as “carer availability” that I could potentially include my dataset and advised on some of the exploratory analyses such as looking at the effect of different dementia types in relation to the observed patterns.

When I had discussions about measuring the quality of care provided to people with dementia and presented my plan about the systematic review, a common complaint from the PPI members was things being missed out or not measured in different care settings. Several family caregivers of people with dementia shared their experiences of having to prompt the care professionals to ensure that all aspects of their relative’s care were being measured. This prompted prioritisation of QIs which are usable across care settings when making judgements about care quality. PPI members highlighted the importance of not only measuring the QIs for service planning purposes but making the care quality measures available to the public to inform their choices where possible. Although some of this information is available online (e.g., CQC), improving access to these resources was noted.

4.11 Reflexivity in quantitative research

Reflexivity is the act of self-reflection, examining one’s own beliefs, assumptions, and judgement systems, and thinking critically about how these could influence the research process.[238] While more common in qualitative research, it is also important to acknowledge researcher’s own interests and pre-conceptions when conducting quantitative research within a pragmatist approach. The explorative nature of my research necessitates reflexivity. In my case, this process involved reflecting carefully on my position as a potential outsider to the population of interest, reflecting on silent assumptions and biases which may exists in the existing datasets that I am using, thinking about how my biases may affect the way I frame the conclusions of the findings. Having the outsider perspective may have provided me with a more objective approach to analysis and the interpretation of findings. I am a non-English researcher, who does not have dementia care experiences in England. Although I have experiences of conducting research in English healthcare settings (including general acute care hospitals and SLaM) and with people with dementia, I had to have additional conversations with relevant stakeholders to contextualise my research. I had to balance views of people whose opinions and experiences I value, previous research literature, and my family’s experiences of dementia care in another country with a completely different health and care system, while making decisions about the analysis and the interpretation of the findings.

I also worked as a research assistant as part of a large research programme called "Empowering Better End of Life Dementia Care" (EMBED-Care).[57] Being part of the EMBED-Care programme was integral to my PhD and my PhD was nested in the programme. EMBED-Care brought together researchers, collaborators, clinicians, policymakers, patients and families to provide evidence in how care is provided for people of any age with any type of dementia can be improved to maximise their quality of life. This aim was met through different projects, using various methodologies. The programme included six inter-dependent workstreams, where my PhD contributed mainly through routine data analysis, to develop a complex intervention (EMBED-Care Framework) to improve palliative dementia care. The EMBED-Care framework was underpinned by programme theory, which was developed and refined informed by each of the workstream findings. The programme provided me with greater opportunities to engage with the wider clinical and policy stakeholders, increasing the potential impact of the PhD findings. My work as a research assistant enabled me to visit hospitals, engage with people with dementia and their families, learn more about how clinicians provide care input information to electronic health records, have public engagement opportunities, and learn about wider UK, European, and global health policies.

4.12 Ethical considerations and governance

At the conception stage of the PhD, a project proposal was submitted to the CRIS Oversight Committee which reviews the objectives and planned analyses planning to use CRIS data and linkages. This committee is chaired by a SLaM service user, includes SLaM Information Governance representation, and reports to the SLaM Caldicott Guardian.[239] Following review, the project proposal was approved by the committee (see Appendix 3 for CRIS data application form and the approval email). Access to CRIS data require an honorary contract with the SLaM. The process from acquiring an honorary contract to access data took five months. The CRIS Data team were key in advising on the data extraction and quality of variables, and in providing additional variables when requested. I completed a data request form to define the population and variables to be extracted from CRIS and linked datasets. Data were extracted as Microsoft Excel files by clinical informaticians and stored within the SLaM firewall. All data were de-identified. Data were accessed via a secure remote desktop.

The CRIS data resource including linkages has been successively approved for secondary analysis by the Oxfordshire Research Ethics Committee C since 2008 (current reference 23/SC/0257). Local Oversight Committee review and approval is a component of the approved security model.

Additional training was undertaken for data management, statistical data analysis, statistical analysis programmes including STATA and MPlus, structural equation modelling, and HES data analysis. My training and experiences were instrumental in planning, analysis, and interpretation of the PhD findings.

4.13 Summary

Chapter 5 reflected on the methodological and theoretical considerations, the literature pertinent to the study type, and source datasets which informed the thesis design. Additionally, key factors which influenced the conduct of the studies (i.e., ethical considerations, PPI, reflexivity, and methodological challenges) were outlined ahead of the detailed methods and results of each study. Chapters 6 (unplanned hospital admissions), 7 (critical care admissions) and 8 (subgroups of people with dementia based on multiple healthcare processes) present the three result studies of this thesis in the sequential order of conduct. The reporting of the studies are informed by the The REporting of studies Conducted using Observational Routinely-collected health Data (RECORD) statement.[240]

Chapter 5: Results Study 1 – Unplanned hospital admissions

This chapter presents the specific methods and the findings for Study 1. The analyses presented in this chapter have been published in the following peer-reviewed journal:

Yorganci E, Stewart R, Sampson EL, Sleeman KE. Patterns of unplanned hospital admissions among people with dementia: from diagnosis to the end of life. Age and Ageing. 2022 May;51(5):afac098.
DOI: https://doi.org/10.1093/ageing/afac098

Personal contributions to the publication: I was responsible for devising the study approach and analysis plan. I sought and gained approval from the CRIS oversight committee to conduct the research using the CRIS-HES linkage. I outlined the selection criteria to define the cohort and data extraction requirements. I cleaned the data, performed the analysis and drafted the manuscript. My PhD supervisors were consulted throughout and provided input on the analysis plan and review and editing of the manuscript. I would like to acknowledge Hitesh Shetty and Megan Pritchard for extracting the data.

5.1 Introduction

This study addressed the thesis objective 1: To describe the patterns of healthcare use of people with dementia from the point of diagnosis to death. This study also contributed to the thesis objective 3. (To use these findings to describe the quality of care received by people with dementia nearing the end of life and guide policy and practice for this population).

Several factors influenced the choice of unplanned hospital admissions for this study. Results from the systematic review show that the number of unplanned hospital admissions of people with dementia who may be approaching the end of life is a commonly used and robust process QI which can be used with routine data. A high percentage of people with dementia experiencing multiple unplanned hospital admissions may indicate poor care quality at a population level. Individual admissions may have been appropriate for providing the necessary care needed to a person with dementia. However, due to associations between the primary and community care provision and the occurrence of unplanned hospital admissions, a high percentage of people with dementia experiencing unplanned hospital admissions may point towards lack of care provision closer to home. Thus, examining the unplanned hospital admissions of people with dementia is important. The systematic review also revealed that the quality indicators relevant to people with dementia nearing the end of life can be applied prospectively to a living cohort or retrospectively to the decedents. An issue in the composition of the QIs related to unplanned hospital admissions is the lack of evidence for the time period (e.g., last year, three months, month, week, days) selected. Although the last year of life has been an established time period for investigating palliative and end-of-life care, the evidence for whether the rise in the rate of unplanned hospital admissions occur prior to this time period has not been explored.

There is also limited literature showing that people with dementia can experience a higher incidence of unplanned hospital admission within a year after their diagnosis compared to other time periods following their diagnosis .[98, 111] However, it is unclear whether the occurrence of the unplanned hospital admissions relates to people's proximity to the end of their life, or to the identification of unmet needs coinciding with the dementia diagnosis. Exploring this may help with informing the integration of a palliative care approach to post-diagnostic dementia services. Understanding the nature, the rate, and the patterns of unplanned hospital admissions from diagnosis until the end of life could contribute to our understanding of the quality of care, service planning, health and social care policy development, and provide new knowledge on how the care quality could be improved.

5.2 Methods

5.2.1 Design and data sources

This is a retrospective cohort study using data linkages between two clinical datasets (South London and Maudsley NHS Foundation Trust Biomedical Research Centre's (SLaM BRC) Clinical Record Interactive Search (CRIS) and Hospital Episode Statistics Admitted Patient Care (HES APC)), and a death registry (Office for National Statistics - ONS). Chapter 4, Section 4.8.1 of this thesis provides more detailed information on the datasets.

5.2.2 Setting and cohort

The cohort of this study comprises any person with dementia who was 50 or older at first recorded diagnosis of dementia in CRIS before 31st March 2017. ONS mortality records were used to retrieve information on the date of death of the decedents.

5.2.3 Sociodemographic and clinical variables

Data closest to the first dementia diagnosis on age, gender, and ethnic group were extracted from CRIS. Age at diagnosis was calculated using the date of birth and date of dementia diagnosis variables from CRIS. Additionally, the IMD scores, dementia subtype, the MMSE scores (closest record to diagnosis), the scores for the HoNOS subscales (closest record to diagnosis), year of diagnosis, and year of death were provided.

Numbers of unplanned hospital admissions were calculated for every six months from diagnosis to death or study end (31st March 2018). Six-monthly periods are commonly used for measuring care quality for people with dementia, and enable exploration of changes at a more granular level than yearly rates [11]. The secondary outcome was the percentage of time spent as an inpatient in hospital due to unplanned hospital admissions.

For people who experienced an unplanned hospital admission, HES ICD-10 diagnosis codes for the first and last unplanned hospital admission were used to calculate the Charlson Comorbidity Index of multimorbidity.[241] Suggested ICD-10 terms for calculating Charslon Comorbidity Index score from HES were based on codelists derived from Caliber.[242] Three-digit ICD-10 codes also include all codes below them (e.g. F00 includes F000, F001 and F002).

5.2.4 Unplanned hospital admissions

The number of unplanned hospital admissions which took place after the first recorded date of dementia diagnosis were derived from HES APC dataset.[243] HES data was available up to 31st March 2018 to allow at least one year of potential hospital admissions data follow-up for those who were diagnosed recently.[98] As the unplanned hospital admissions are not directly available in the HES APC dataset, following methods were used to identifying them for each person. First, using the admission method code, it was determined whether an admission was 'elective', 'non-elective' or 'transfer' (ADMIMETH coded as 21, 22, 23, 24, 25, 26, 27 or 28 are considered a non-elective admission). Elective admissions were removed. Unplanned hospital admissions were assembled using codes for spells' start dates and admission method. Hospitalisations were defined from HES episodes, combining contiguous episodes (i.e. where start and end dates were on the same day).[188] Duplicates based on the date of admission, date of discharge, the episode start and end dates, the admission and discharge methods were removed (Figure 5-1). Unplanned hospital admissions which happened for any reason were included in the analysis. Reasons for first and last unplanned hospital admissions did not differ, the most common medical reasons for unplanned hospital admissions included multiple ambulatory-care sensitive conditions (ACSCs) such as infections (Appendix 4).

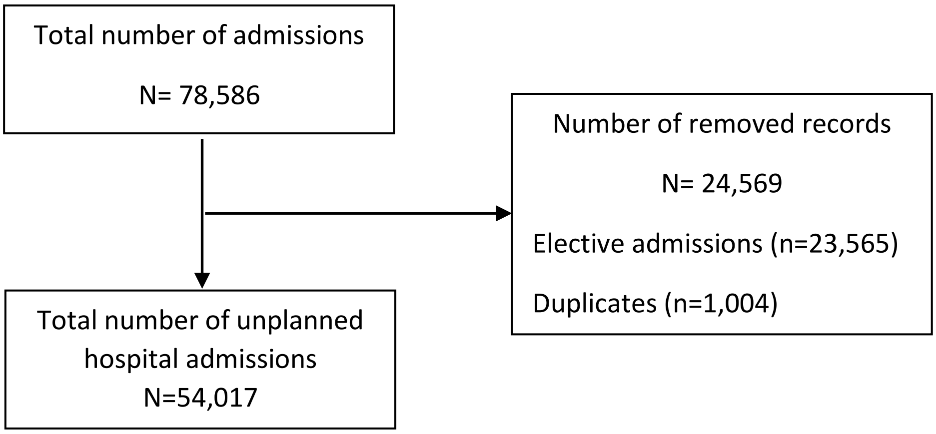

Figure 5-1. Flowchart of identifying the number of unplanned hospital admissions

5.2.5 Outcomes

The primary outcome was the number of unplanned hospital admissions from the first dementia diagnosis until death or study end (31st March 2018).

The secondary outcomes were: (i) the percentage of time spent as an inpatient in hospital due to unplanned hospital admissions calculated for every six months from diagnosis to death or study end (31st March 2018); (ii) the percentage of time spent as an inpatient in hospital due to unplanned hospital admissions within the last six and twelve months of life calculated for the decedents; and (iii) where people died using the discharge method variable from the HES APC dataset, where for individuals who died in hospital, place of discharged is coded as “patient died”.

5.2.6 Statistical analyses

Within this study, two approaches to the exploration of unplanned hospital admissions were adopted. Namely, these approaches are called “Looking forward” and “Looking back” methodologies.[244] Looking forward methodology allows conclusions to be drawn about survival in addition to service use. It allows exploration of any differences between those who survived and those who died after varying periods of time. In this study, this refers to looking at the patterns of unplanned hospital admissions from the point of diagnosis onwards. Looking back approach on the other hand, refers to the exploration of the healthcare patterns of people preceding an outcome, commonly death. It is a commonly used methodology in studies of end-of-life care where the researchers can focus on the time leading up the death among a cohort of decedents, and observe pre-terminal care.[196]

Sociodemographic and clinical characteristics of the cohort were described using mean (standard deviation (SD)), median (range (25th – 75th percentiles)), and percentages depending on the variable’s distribution. For describing the pattern of unplanned hospital admissions, the cumulative incidence of unplanned hospital admissions (= *number of people admitted at least once during the study period/total number in the cohort*), and the unplanned hospital admission rate (= *all admissions per person-months were calculated as time between CRIS dementia diagnosis and death or end of the follow-up period*)) with 95% confidence intervals (CIs) and standard errors (SEs) were calculated.[202] Incidence rate, also known as person-time rate incorporates time-at-risk all participants incorporated to a study directly into the denominator. Time spent in hospital as an inpatient was calculated as the percentage of days spent in hospital due to unplanned hospital admissions out of the total days contributed by each person. Numbers of unplanned hospital admissions were calculated for every six months from diagnosis to death or study end (31st March 2018), stratified by time to death (in years) for decedents, and time to study end date for people who remained alive. Six-monthly periods are commonly used for measuring care quality for people with dementia, and enable exploration of changes at a more granular level than yearly rates.[11]

5.3 Results

5.3.1 Cohort Description

19,221 people aged ≥ 50 years with a dementia diagnosis between 1995 and 2017 were identified (Table 5-1). Dementia incidence per 100,000 individuals (*number of new dementia diagnosis/population at risk (number of people aged 50 or older who lived in four boroughs which are within the catchment of SLaM based on ONS population estimates)*[261] *x 100,000*) between 1995 and 2016 are presented in Figure 5-2. Data is presented up to 2016, as only people diagnosed up to 31st March 2017 were included in the study. Before 1998, less than 10 people with a dementia diagnosis were identified in this study's cohort.

Mean age at diagnosis was 81.0 ((SD) 8.5) years. Most of the cohort were women (61.4%), white (73.1%) and nearly half of the first ever recorded dementia diagnoses were Alzheimer's disease (48.4%). In terms of the MMSE recorded closest to the diagnosis date, 40.6% of the cohort were categorised as mild (MMSE ≥20).

Table 5-1. Cohort characteristics (19,221)

Characteristic	All (n= 19,221)	Alive at the study end date (n=6,554)	Decedents (n=12,667)
	%	%	%
Age at diagnosis (mean, SD)	81.0 (8.5)	78.0 (8.9)	82.6 (7.8)
Age at the end of the follow-up period /death (mean, SD)	84.5(8.1)	82.6 (8.6)	85.6 (7.6)
Sex			
Female	61.4	63.0	61.0
Male	38.4	37.0	39.0
Ethnicity			
White British	62.4	51.0	68.2
African/Caribbean	14.6	22.5	10.6
White other	10.7	11.8	10.2
Asian	4.3	6.5	3.2
Any other ethnicity	2.7	4.5	1.7
Mixed	0.7	1.2	0.4
Missing	4.6	2.5	5.7
IMD quintile at diagnosis			
1 (most deprived)	29.6	30.3	29.4
2	34.8	34.3	35.0
3	18.1	19.1	17.6
4	9.1	8.5	9.3
5 (least deprived)	7.2	7.1	7.3
Missing	1.2	0.7	1.4
First recorded dementia diagnosis			
Alzheimer's disease	48.4	54.9	45.1
Vascular dementia	24.5	19.2	27.3
Unspecified dementia	23.4	22.0	24.2

Other dementia	2.7	2.8	2.6
Lewy body dementia	1.0	1.1	0.9
MMSE closest to diagnosis date			
Mild (≥20)	40.6	51.7	34.8
Moderate (10-19)	32.82	29.6	24.5
Severe (<10)	7.4	5.5	8.4
Missing	19.2	13.2	32.3

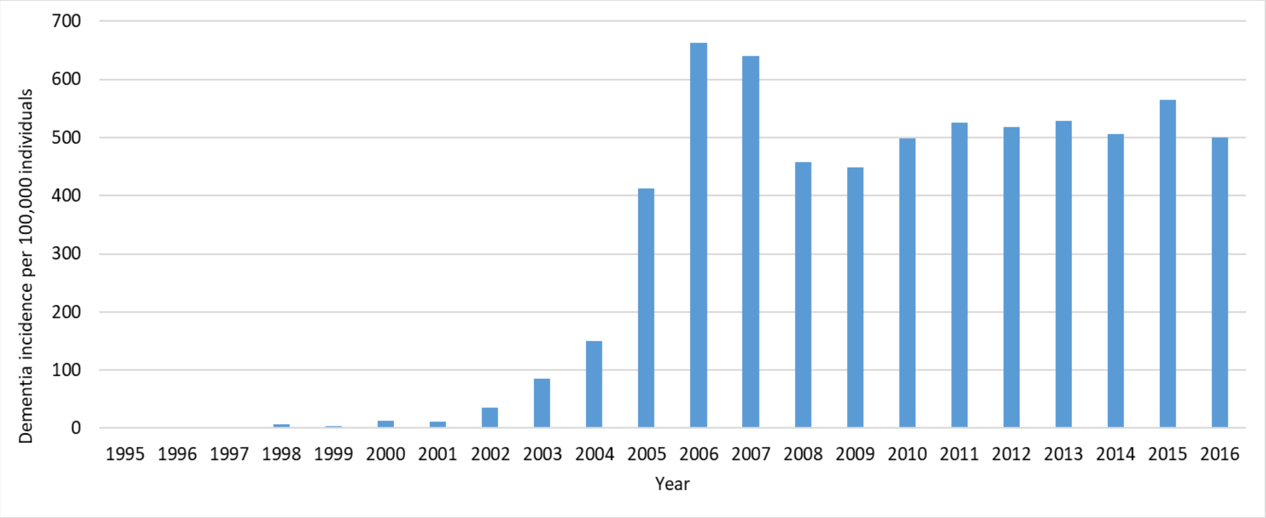

Figure 5-2. Dementia incidence per 100,000 individuals aged 50 or older (Between 1995 and 2016)

5.3.2. Main findings

For 19,221 people with dementia (61.4% female, mean age at diagnosis 81.0 years (SD 8.5)), the cumulative incidence of unplanned hospital admissions (n=14,759) was 76.8% (95% CI 76.3% - 77.3%). Individuals remained in the study for mean 3.0(SD 2.6) years, and 12,667(65.9%) died. Rates and lengths of unplanned hospital admissions remained relatively low and short in the months after the dementia diagnosis, increasing only as people approached the end of life. The percentage of time spent as an inpatient was <3% for people who were alive at the study end but was on average 19.6% and 13.3% for the decedents in the last six and twelve months of life, respectively. Variations in the rates of the unplanned hospital admissions among people with dementia were observed depending on survival after diagnosis. Higher rates of unplanned hospital admissions were observed following dementia for people with dementia who died within few years of receiving their diagnosis. Detailed findings are provided in the published paper.

5.3.3 Patient and public involvement

A summary of discussions I had with the PPI members is summarised below. These discussions shaped the research question of this study, design, choice of findings included in the publication, interpretation of the findings, and what may be explored in the subsequent two studies of the thesis.

PPI members highlighted the potential negative impacts of unplanned hospital admissions of people with dementia. Upon production of the initial findings of component I, I met with the PPI members, who could interpret the results from their perspectives and substantially input the discussion. Discussions with the PPI members highlighted the importance of steps taken closer to the time of dementia diagnosis (e.g., establishing care preferences and having time to plan for future) the events which took place later their dementia journey. However, the characteristics of people with dementia and their families which may influence the care became apparent. For instance, when the person with dementia was not admitted to the hospital, the family member was present either in person (when the person with dementia was living at home) or on the phone (when the person with dementia was living at a care home) and insisted on their relative to not be admitted and restated their care preferences repeatedly. This informed the inclusion of factors such as living alone and carer availability in Study 3. The level of staff training and competency to treat ACSCs such as infections in community was discussed as a potential reason for the unplanned hospital admissions from care homes. Factors such as financial ability, having district nurses and daily paid carers to help the person with dementia stay at home were mentioned as key elements in staying out of the hospital. These supported the selection of explanatory and indicator variables for Study 3.

PPI members noted the importance of providing training about dementia and especially the later stages of dementia, to all health and social care professionals who may be involved in dementia care. PPI members also noted that most of them were not told by a health or social care professional that dementia was a terminal condition. Conversations with PPI members revealed how little specialist input they or their relatives received after the dementia diagnosis. They noted that while it is important that people receive high-quality care in hospitals and in the community, healthcare professionals who may act as a link, such as paramedics, were also key actors. These discussions informed the interpretations and the discussion of the findings.

5.3.4 Publication 2: Patterns of unplanned hospital admissions among people with dementia: from diagnosis to the end of life

The findings from Study 1 were published in *Age and Ageing* and are presented below as the accepted manuscript for publication to ensure that figures and small text are readable.[245] The published version is open-access, and can be accessed using the link provided at the beginning of Chapter 5. This is followed by the supplementary materials (Appendix 4).

Patterns of unplanned hospital admissions among people with dementia: From diagnosis to the end of life

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Conflicts of interest

None.

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Abstract

Background: Hospitalisations are sentinel events for people with dementia. How patterns of unplanned hospital admissions change among people with dementia after diagnosis is relatively unknown.

Objective: To describe patterns of unplanned hospital admissions of people with dementia from diagnosis until death/study end.

Methods: Retrospective cohort study using mental healthcare provider data of people diagnosed with dementia in London, UK (1995-2017), linked to mortality and hospital data. The primary outcome was the rate of unplanned hospital admissions after diagnosis until death/study end. We calculated the cumulative incidence of unplanned hospital admissions. The rates of unplanned hospital admissions and the percentage of time spent as an inpatient were stratified by time from first dementia diagnosis.

Results: For 19,221 people with dementia (61.4% female, mean age at diagnosis 81.0 years (SD 8.5)), the cumulative incidence of unplanned hospital admissions (n=14,759) was 76.8% (95% CI 76.3% - 77.3%). Individuals remained in the study for mean 3.0(SD 2.6) years, and 12,667(65.9%) died. Rates and lengths of unplanned hospital admissions remained relatively low and short in the months after the dementia diagnosis, increasing only as people approached the end of life. Percentage of time spent as an inpatient was <3% for people who were alive at the study end but was on average 19.6% and 13.3% for the decedents in the last six and twelve months of life, respectively.

Conclusions: The steep rise in hospitalisations before death highlights the need for improved community care and services for people with dementia who are approaching the end of life.

Key words: hospitalization, dementia, incidence, death, retrospective studies

Key points:

- Rates of unplanned hospital admissions remain relatively low and stable after dementia diagnosis and only increase as people with dementia approach the end of life.
- People who died with dementia spent 19.6% and 13.3% of their time in hospital due to unplanned hospital admissions in the last six and twelve months of their lives, respectively.
- Investing in resources for dementia end-of-life care may help with reducing the negative impact of unplanned hospital admissions.

Introduction

The number of people living with dementia is increasing [1-3]. As dementia and comorbidities progress, provision of care can become challenging [4, 5]. Unplanned hospital admissions (those that occur unexpectedly and urgently [6]) for people with dementia can be associated with functional and cognitive decline, though the causal relationship remains unclear [7]. Understanding when unplanned hospital admissions are most likely to occur can guide investment in the resources needed for providing high-quality dementia care.

Most studies examining unplanned hospital admissions of people with dementia have focused on specific subgroups of people with dementia (e.g., people diagnosed with Alzheimer's disease or people who live in the community [8, 9]) or timeframes (e.g., year after diagnosis or last year of life) [10-12]. Prospective studies have been small [4, 13] or have obtained hospitalisation information from carers, and are therefore subject to recall bias. While some people live many years following a dementia diagnosis, for others the time between diagnosis and death is shorter. Patterns of unplanned hospital admissions, and how these change before death, are relatively unknown. In this study, we aimed to describe the patterns of unplanned hospital admissions of people with dementia from the point of diagnosis.

Methods

Setting & Data sources

This was a retrospective study using linkage between two clinical datasets (South London and Maudsley National Health Service (NHS) Foundation Trust Biomedical Research Centre's (SLaM BRC) Clinical Record Interactive Search (CRIS) and Hospital Episode Statistics (HES)), and a death registry (Office of National Statistics - ONS). HES is a database containing details of all admissions at NHS England hospitals [14]. Electronic health records were implemented across SLaM from 2006 [15]. The CRIS application provides research access to repository of anonymised structured and open-text data from electronic health records within SLaM.

SLaM provides mental healthcare services, including dementia assessment and management to 1.2 million residents in four London boroughs (Croydon, Lambeth, Lewisham, Southwark) in the UK. Potential cases of dementia are ascertained in primary care (which has high specificity [16]), followed by referral to a specialist dementia diagnostic service (such as SLaM) [17].

Cohort Description

The cohort was derived using the CRIS platform. All dementia diagnoses recorded in CRIS were determined from structured fields of ICD-10 diagnosis codes (F00x–03x) or supplemented by dementia diagnosis recorded in text fields by a validated natural language processing algorithm using General Architecture for Text Engineering (GATE) software [15, 18, 19]. We included any person with dementia who was 50 or older at first recorded diagnosis before 31st March 2017. HES data was available up to 31st March 2018 to allow at least one year of potential hospital admissions data follow-up for those who were diagnosed recently. ONS mortality records were used to retrieve information on the date of death of the decedents.

Demographics & Clinical Variables

We extracted data closest to the first dementia diagnosis from CRIS on age, gender, and ethnic group. Neighbourhood-level socioeconomic status was estimated using the Index of Multiple Deprivation (IMD)[20]. This is the official measure of relative deprivation in England which encompasses living conditions of individuals from 32,844 neighbourhoods termed Lower Layer Super Output Areas (LSOAs). Each LSOA contains around 1500 people. IMD was derived from the LSOA associated with the patient's address (recorded closest to the diagnosis) and converted into quintiles of the national distribution (1 – most deprived, 5 – least deprived). We extracted dementia sub-type (Alzheimer's disease, vascular dementia, Lewy body dementia, other or unspecified dementia (where aetiology was unrecorded)) and Mini Mental State Examination (MMSE)[21] scores (from structured and unstructured fields) to estimate dementia severity closest to dementia diagnosis, categorising into "mild" (MMSE≥20), "moderate" (MMSE=10-19) or "severe" (MMSE<10).

Outcomes

We retrieved information on non-elective hospitalisations (referred to as 'unplanned hospital admission') for each participant which started after the date of their first CRIS-recorded dementia diagnosis. The primary outcome was the number of unplanned hospital admissions from the first dementia diagnosis until death or study end (31st March 2018). Unplanned hospital admissions were identified through the HES inpatient codes for a spell's start date and admission method. Hospitalisations were defined from HES episodes, combining contiguous episodes (i.e., where start and end dates were on the same day). Numbers of unplanned hospital admissions were calculated for every six months from diagnosis to death or study end (31st March 2018). Six-monthly periods are commonly used for measuring care quality for people with dementia, and enable exploration of changes at a more granular level than yearly rates [22]. The secondary outcome was the percentage of time spent as an inpatient in hospital due to unplanned hospital admissions.

Statistical Analysis

We described the cohort's sociodemographic and clinical characteristics using mean (standard deviation (SD)), median (range (25th – 75th percentiles)), and percentages. We calculated the cumulative incidence of unplanned hospital admissions (= *number of people admitted at least once during the study period/total number in the cohort*), and the unplanned hospital admission rate (= *all admissions per person-months were calculated as time between CRIS dementia diagnosis and death or end of the follow-up period*)) with 95% confidence intervals (CIs) and standard errors (SEs) [23]. For time spent as an inpatient, we calculated the percentage of days spent in hospital due to unplanned hospital admissions out of the total days contributed by each person. We also calculated the percentage of days spent in hospital due to unplanned hospital admissions out of the total days contributed by each person for the last six and twelve months of life for the decedents. We analysed the admission rates and the time spent as an inpatient for six-monthly intervals from the point of diagnosis onwards, stratified by time to death (in years) for decedents, and time to study end date for people who remained alive.

Ethics Statement

The source database is approved for secondary analysis by the Oxfordshire Research Ethics Committee C (reference 18/SC/0372).

Public and patient involvement

This project is part of the EMBED-Care research programme which was developed and designed with people with dementia and their family carers from the funding application through to interpretation of these study findings [24].

Results

Cohort description

We obtained data on 19,221 people aged ≥ 50 years who had a dementia diagnosis between 1995 and 2017 (Table 1). Mean age at diagnosis was 81.0 (standard deviation (SD) 8.5) years. Most of the cohort were women (61.4%), white (73.1%) and nearly half of the first ever recorded dementia diagnoses were Alzheimer's disease (48.4%). In terms of the MMSE recorded closest to the diagnosis date, 40.6% of the cohort were categorised as mild (MMSE ≥20). The number of people in the cohort increased over the study period and 66.1% of people were diagnosed after 2009. Around two thirds (65.9% (n=12,667)) of the cohort died before the study end, while 34.1% (n=6,554) of the cohort were living with dementia at the study end. Sociodemographic and clinical characteristics of the cohort stratified by time to death/study end are presented in Appendix 1.

In total, there were 54,017 unplanned hospital admissions. Cumulative incidence rate was 76.8% (95% CI 76.3% - 77.3%); 14,759 people had at least one unplanned hospital admission. Of all unplanned hospital admissions, 20,140 (37.3%) took place in people who were in the last year of life. The median number of unplanned hospital admissions for the whole cohort was 3(1-5). The median time spent as an inpatient per admission was 5 (1-14) days per person. The mean total time spent in the hospital for the whole cohort was 32 (11-67) days. The median time spent as an inpatient in one unplanned hospital admission in the last year of life was 7 (2-18) days per person. The total time spent in the hospital in the last year of life was 30 (12-59) days per person.

The decedents

The mean age at diagnosis was 82.6 (SD 7.8); mean age at death 85.6 (SD 7.6). Decedents accounted for 72.7% (n=10,735/14,759) of all people who had an unplanned hospital admission. The cumulative incidence rate of unplanned hospital admissions for the decedents was 84.8% (95% CI 84.1% - 85.4%). Over a third of decedents (38.1%, n=4,697) died in hospital and 24.5% of these people (n=1,153) died during their first admission after diagnosis.

Admission rates for decedents ranged from 3 to 334 per 1000 person-months (Figure 1). In the first six months after diagnosis, higher admission rates were observed in the subgroup of people who lived less than a year after diagnosis. For subgroups of people who lived longer than two years after diagnosis, the following pattern was observed: admission rates in the first six months were low and remained relatively stable until the last 12 months of life when they increased steeply. Patterns of rates of unplanned hospital admissions for the whole cohort, and details of admission rates (95% CIs and SEs) are provided in Appendix 2.

Similarly, the percentage of days spent as an inpatient in hospital increased in the last year of life (Figure 2). Across the subgroups, percentage of days spent as an inpatient due to unplanned hospital admissions ranged between 0.6% - 12.6% in the first six months after diagnosis, and was highest for those with shortest survival. For people who lived with dementia for more than a year, percentage of days spent in hospital was low after diagnosis and increased towards the end of life. The decedents spent on average 19.6% (SD 3.1) and 13.3% (SD 2.5) of their time in hospital due to unplanned hospital admissions in the last six months and the last year of their lives, respectively.

People who were living at the study end

Mean age at diagnosis varied between 83.7 (SD7.7) and 72.5 (SD 9.9) across the subgroups (Appendix 2). People who were living with dementia at study end accounted for 27.3%(n=4,024) of 19,211 people. The cumulative incidence rate of unplanned hospital admissions for people who were living with dementia at the study end was 61.4% (95% CI 60.2% - 62.6%).

Admission rates for people who were living with dementia at the study end ranged from 4 to 77 per 1000 person-months (Figure 3). Across the subgroups, a drop in the admission rates in the first six-monthly interval after diagnosis was observed. The unplanned hospital admission rates remained relatively low and stable over the years after dementia diagnosis. Higher admission rates were observed for people who were diagnosed more recently compared to those who had been living with a dementia diagnosis for a longer time. Considering the total time after diagnosis, the percentage of time spent as inpatient in hospital due to unplanned hospital admissions for people were living with dementia at the study end ranged from 0.08% to 2.9% (Figure 4). Compared to the decedents, percentage time spent as inpatient in hospital due to unplanned hospital admissions remained low and stable across the subgroups.

Discussion

In this study, over three quarters (76.8%) of a large sample of people with dementia experienced at least one unplanned hospital admission after diagnosis. Rates of unplanned hospital admissions remained relatively low and stable after dementia diagnosis and did not increase for people who were living with dementia at the study end. Rates and lengths of unplanned hospital admissions increased steeply as people approached the end of their lives, regardless of survival duration. Higher rates of unplanned hospital admissions were observed for people who were diagnosed for less than a year. Admissions in the last year of life accounted for 37.3% of all unplanned hospital admissions for the whole cohort.

The cumulative incidence rate of unplanned hospital admissions reported in our study is similar to the one (75.9%) reported by a study of people with dementia from the same mental health trust for a shorter time interval (2008-2016) [12]. Previously reported cumulative incidence of hospitalisations of people with dementia with varying follow-up times ranged between 23.6% and 86.0% [8, 25, 26]. Lower hospitalisation rates have been reported in studies with people who were not approaching the end of their lives. This is also evident in our study, where the cumulative incidence rate was lower for people who were living at the end of follow-up (61.4%) compared to the decedents (84.8%). A similar cumulative incidence rate of 80.8% was observed in England for people older than 75 who had at least one unplanned hospital admission in the last year of life [27].

Comparisons of the hospitalisation rates of people with dementia and those other life-limiting conditions have shown mixed results [8, 28, 29]. Rates of unplanned hospital admissions of people with other life-limiting illnesses such as cancer and organ failure also increase towards death [30, 31]. An overlap between dementia and other factors (e.g., physical, psychological, financial, carer strain, service availability and dementia care expertise) is likely to drive hospitalisations towards the end of life [10]. For people with dementia, hospital environments may be distressing. If appropriate, dementia care in the community may be a better option towards the end of life [4]. Most people with dementia would prefer to live and die in a care home or at home [32]. However, in practice, it is difficult to determine when a person with dementia is approaching death [33]. In our sample, 38.1% died in the hospital, which is similar to national data [34] and 9.1% died on their first unplanned hospital admission after diagnosis. Most dementia deaths occur in care homes, therefore a smaller percentage of people with dementia die in hospitals compared to the general population [35, 36].

Access to palliative care, living in care homes and having continuity of care (e.g., consulting the same general practitioner (GP) consistently) are associated with reduced hospital admissions among people with dementia who may be approaching death [37-40]. Yet, people with dementia experience inequitable access to high quality palliative and end-of-life care [41]. In recent years, decline in the number of care home beds and in continuity in general practices have been observed in the UK [42, 43]. If primary and community care services are not equipped to address complex needs of people with dementia who are approaching the end of life, admission rates are likely to remain high. Lack of support for informal carers may also lead to waiting until a crisis point which may then require longer hospital stays [44]. Discussing and setting ceilings of care with people with dementia and carers regularly, and investing in community care and care homes may make meeting care preferences more likely [32]. However, interventions for avoiding hospitalisations for people with dementia have had disappointing results [45]. Future research should focus on reducing the length of time spent as inpatient, while improving dementia end-of-life care in hospitals. Unplanned hospital admissions and length of time spent in the hospital in the last year of life can be used as indicators of how well the health and social care systems are working for people with dementia and their families [46].

A strength of our study was the large sample which was not limited to decedents and included people living at home and in care homes, with any dementia diagnosis and severity, thus reducing biases which may be introduced by subject and time period selection [47]. Recruiting and retaining people with dementia in research studies is challenging [48]. Using routinely collected data permitted observation of trends for over 19,000 people of dementia of whom lived with a diagnosis for varying durations. While not best practice, people may be diagnosed with dementia during a hospital admission; in our analysis we included only unplanned hospital admissions which started after the dementia diagnosis date, as we were interested in hospital admission among people with an existing diagnosis of dementia. The identification of dementia diagnosis was limited to records of a single mental health trust which may under-record dementia diagnoses and limit generalisability [17, 49]. People may have been diagnosed at an earlier date than that recorded in CRIS [17]. The proportion of people with a dementia diagnosis is relatively high in this catchment area compared to national figures [12, 50]. However, the average age at diagnosis and death, and the duration between diagnosis and death from our findings are consistent with national averages [51]. Finally, this was a descriptive study using routine data; we did not test for differences or predictors of unplanned hospital admissions, which have been examined previously [26]. By leveraging the linkage between a mental health trust and national hospital data, we were able to have a near-complete picture of unplanned hospital admissions. Only 1% of UK hospital services are not provided by the NHS and these are likely to be less relevant for unplanned hospital admissions of people with dementia [52].

Although the number of people affected by dementia is increasing, understanding of the disease development and progression remains low amongst the public and healthcare professionals [53, 54]. Most hospitals provide training around caring for people with dementia but many do not include specific skills needed for care of those approaching the end of life [55]. Lack of confidence by staff and negative attitudes towards dementia in hospitals may lead to poor quality of care [56]. Opportunities to improve public perception of dementia as a neurodegenerative, terminal illness [54], and provision of dementia and end-of-life care training for healthcare professionals should be further developed where necessary and adopted by health policy.

Conclusion

A steep increase in the rates and lengths of unplanned hospital admissions occurs among people with dementia as they approach the end of life. This may indicate insufficient community resources for meeting care needs. Many people with dementia, and their loved ones, would prefer to spend less time in hospital towards the end of life [57]. Reducing the burden of unplanned hospital admissions will require well-resourced, high-quality, dementia and end-of-life care both in hospitals and community settings. Efforts to avoid unnecessary hospital admissions, long admission durations and readmissions must be prioritised.

Table 1. Characteristics of people diagnosed with dementia

Characteristic	All (n= 19,221)	Alive at the study end date (n=6,554)	Decedents (n=12,667)
	%	%	%
Age at diagnosis (mean, SD)	81.0 (8.5)	78.0 (8.9)	82.6 (7.8)
Age at diagnosis categories			
50-59	2.1	3.9	1.1
60 – 64	2.4	4.4	1.4
65 – 69	4.9	8.1	3.3
70 – 74	10.5	13.4	8.9
75 – 79	18.6	22.5	16.5
80 – 84	24.5	23.0	25.1
85 – 89	23.0	17.5	26.0
90 - 94	10.9	6.1	13.7
≥ 95	3.1	1.2	4.3
Age at the end of the follow-up period /death (mean, SD)	84.5(8.1)	82.6 (8.6)	85.6 (7.6)
Sex			
Female	61.4	63.0	61.0
Male	38.4	37.0	39.0
Ethnicity			
White British	62.4	51.0	68.2
African/Caribbean	14.6	22.5	10.6
White other	10.7	11.8	10.2
Asian	4.3	6.5	3.2
Any other ethnicity	2.7	4.5	1.7
Mixed	0.7	1.2	0.4
Missing	4.6	2.5	5.7
IMD quintile at diagnosis			
1 (most deprived)	29.6	30.3	29.4
2	34.8	34.3	35.0
3	18.1	19.1	17.6
4	9.1	8.5	9.3
5 (least deprived)	7.2	7.1	7.3
Missing	1.2	0.7	1.4
First recorded dementia diagnosis			
Alzheimer's disease	48.4	54.9	45.1
Vascular dementia	24.5	19.2	27.3
Unspecified dementia	23.4	22.0	24.2
Other dementia	2.7	2.8	2.6
Lewy body dementia	1.0	1.1	0.9
MMSE closest to diagnosis date			
Mild (≥20)	40.6	51.7	34.8
Moderate (10-19)	32.82	29.6	24.5
Severe (<10)	7.4	5.5	8.4
Missing	19.2	13.2	32.3

MMSE: mini-mental state examination; SD: standard deviation; IMD: index of multiple deprivation (1 = most deprived, 5 = most affluent).

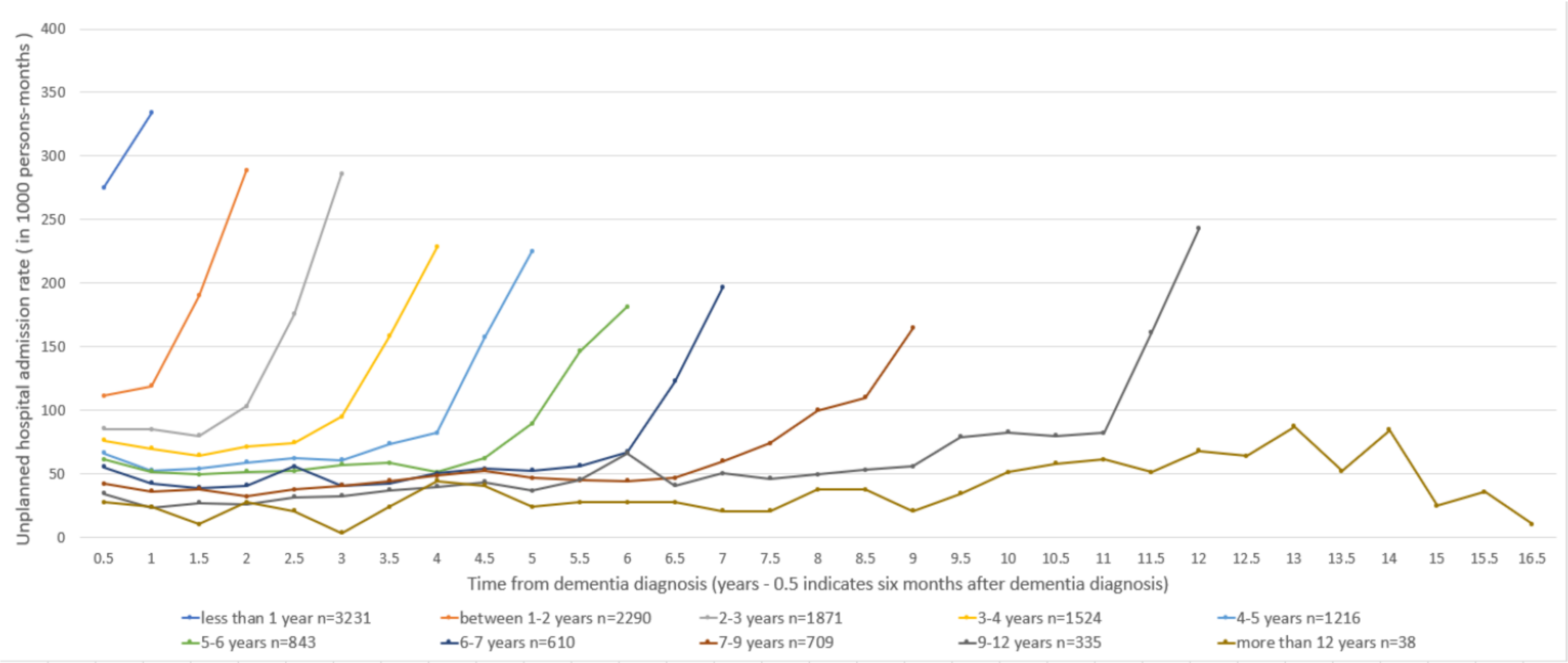

Figure 1. Unplanned hospital admission rates for people who died with dementia (n=12,667) by duration of survival after diagnosis.

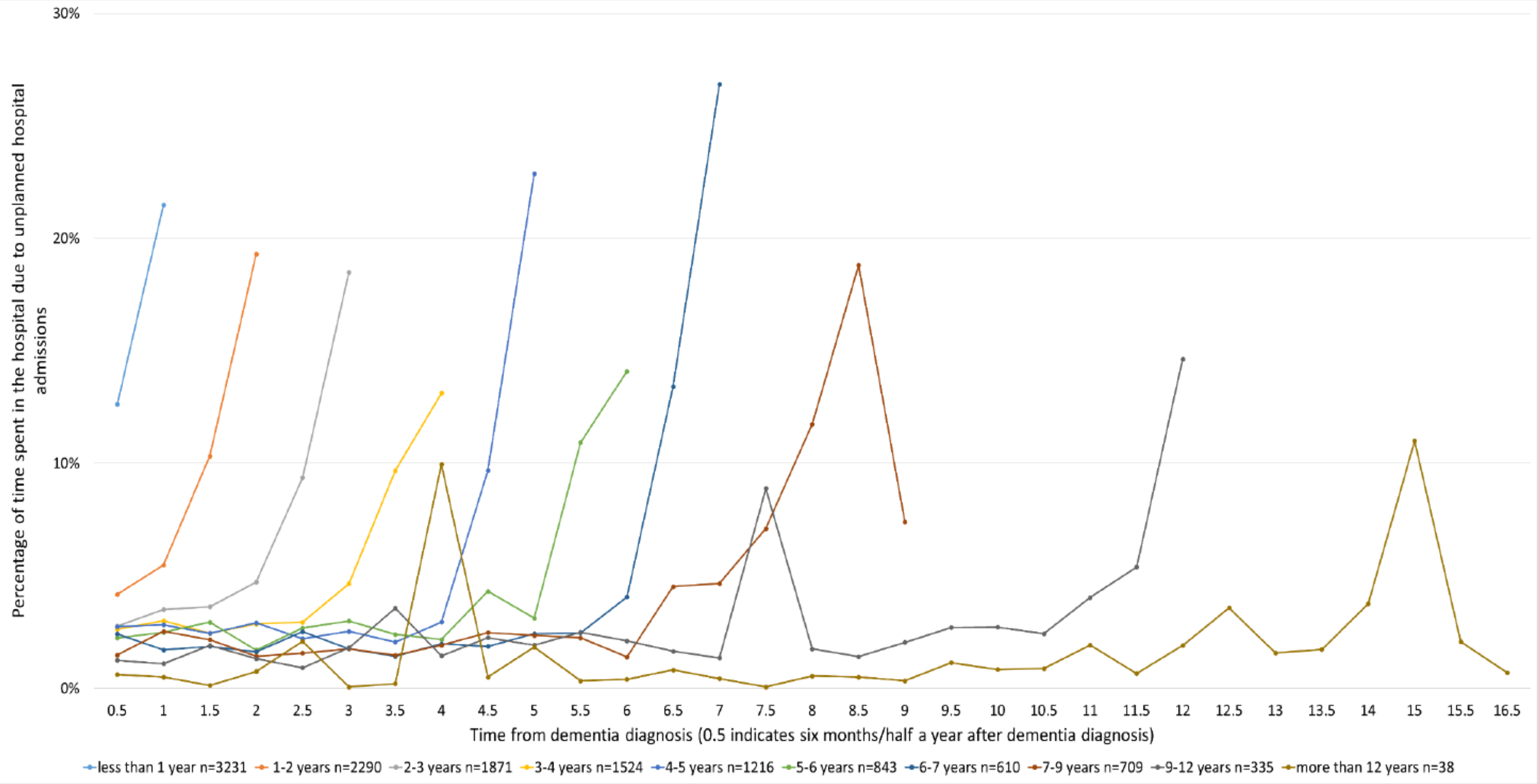

Figure 2. Percentage of time (six-month periods) spent in the hospital due to unplanned hospital admissions for people who died with dementia (n=12,667) by duration of survival after diagnosis.

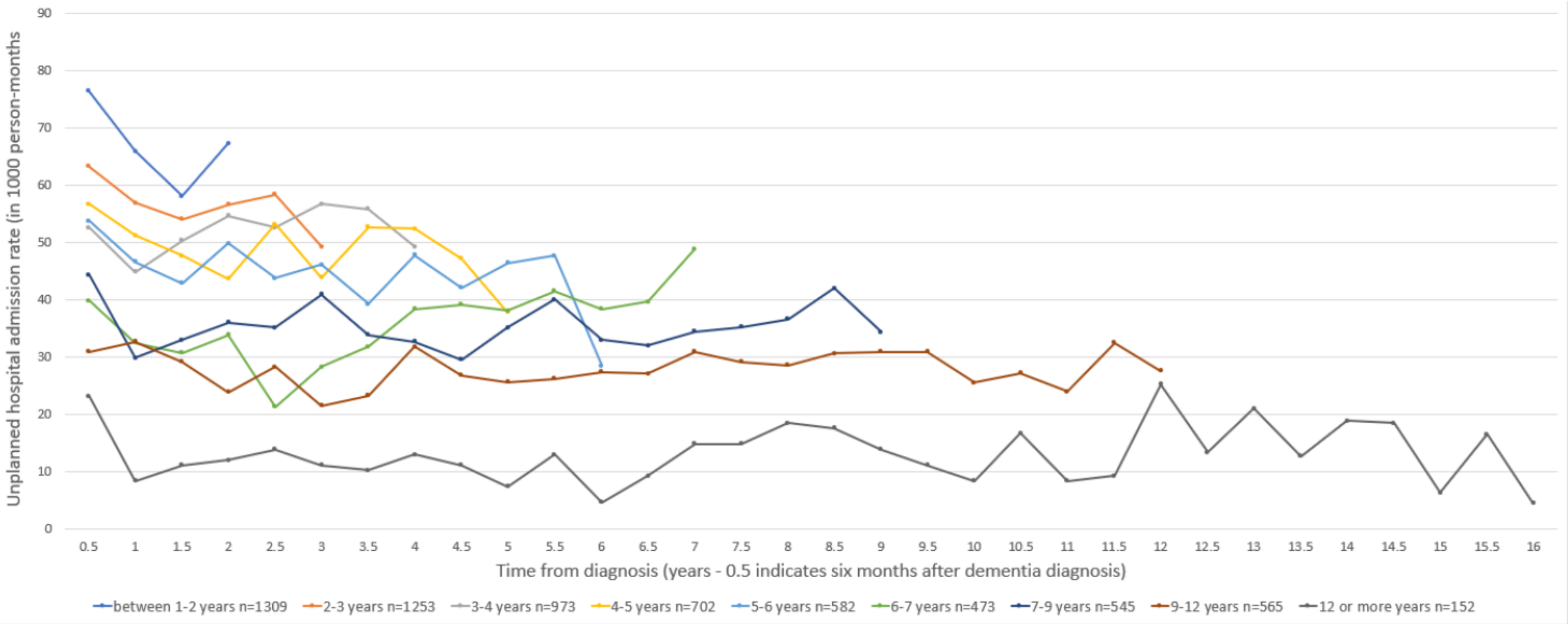

Figure 3. Unplanned hospital admission rates for surviving people with dementia (n=6,554) by duration of time after diagnosis.

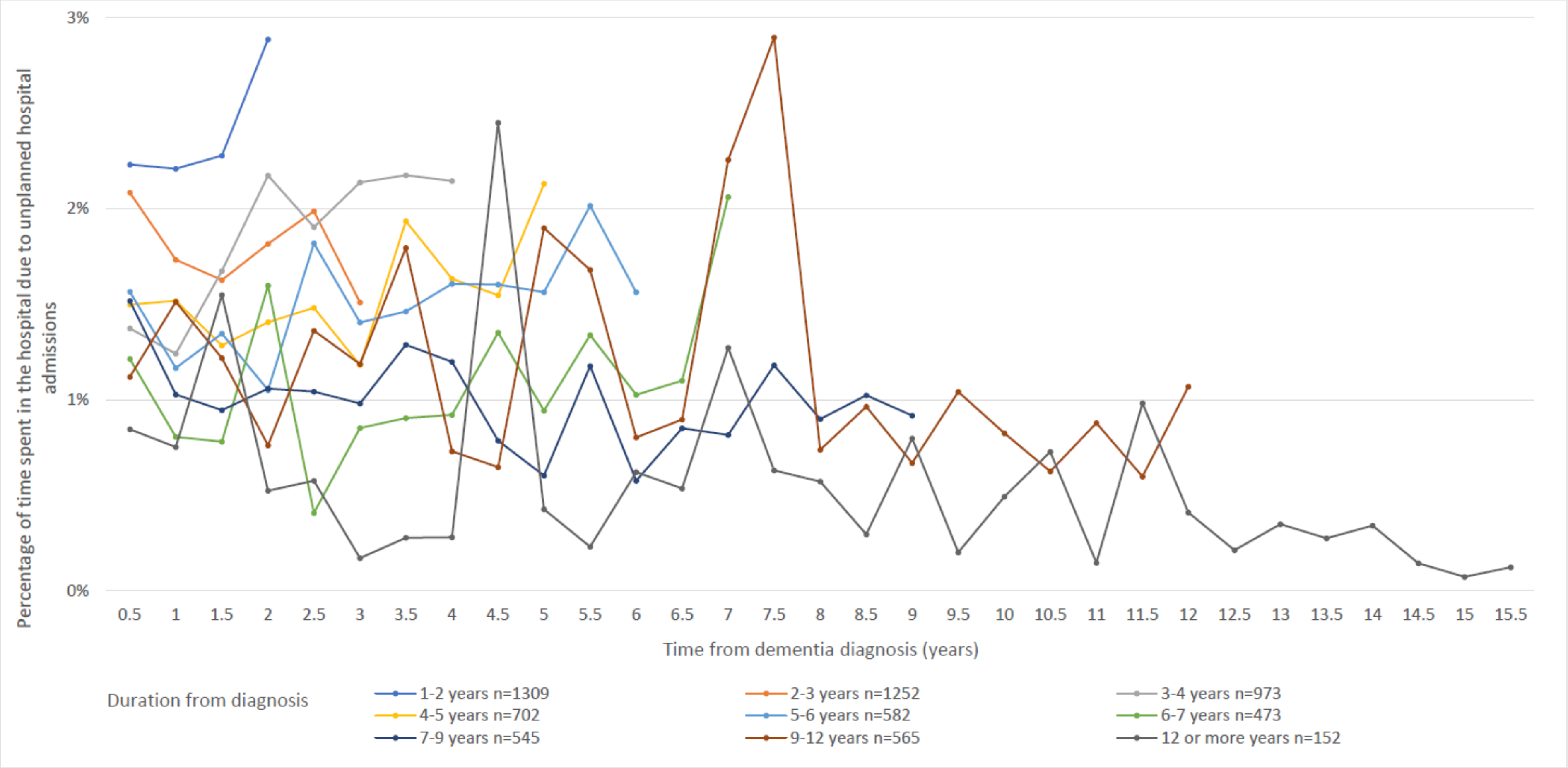

Figure 4. Percentage of time (six-month periods) spent in the hospital due to unplanned hospital admissions for surviving people with dementia (n=6,554) by duration of time after diagnosis.

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5.4 Summary

Results from Study 1, which included a dynamic cohort of people diagnosed with dementia, showed that high unplanned admission rates are common for people with dementia who may be approaching the end of life. Stratification of data as those who died and those who were alive by the study end highlighted the stark differences in unplanned admission rates. In this study, rates of unplanned hospital admissions remained relatively low and stable after dementia diagnosis and only increased as people with dementia approach the end of life. In this study for most groups of the people with dementia, the uptick trend in the rates of unplanned hospital admissions occurred towards the last year of life.

Stratification of data by survival after dementia diagnosis highlighted that people who were closer to death at the time of diagnosis tended to experience higher rates of unplanned hospital admissions compared to those who lived with dementia for many years. The differences in the percentage of time spent as an inpatient in hospital among people with dementia who had varying duration of survival after diagnosis were less prominent compared to the rates of unplanned hospital admissions. This may indicate that people who had a shorter survival duration after diagnosis may be having repeated number of short-stay unplanned hospital admissions. Heterogeneity in the admission rates based on stratification by survival was considered further in Study 2 and 3.

The cumulative incidence rate of unplanned hospital admissions reported in our study is similar to the one (75.9%) shown by a study of people with dementia from the same mental health trust for a shorter time interval (2008-2016).[98] Previously reported cumulative incidence of hospitalisations of people with dementia with varying follow-up times ranged between 23.6% and 86.0%.[97, 99, 246] Lower hospitalisation rates have been reported in studies with people not approaching the end of their lives or when limited to the hospitalisations of people with one type of dementia.[247, 248] This is also evident in our study, where the cumulative incidence rate was lower for people who were living at the end of follow-up (61.4%) compared to the decedents (84.8%). A similar cumulative incidence rate of 80.8% was observed in England for people older than 75 who had at least one unplanned hospital admission in the last year of life.[249] Among this sample, 38.1% died in the hospital, which is similar to national data.[86] Almost one in ten (9.1%) people with dementia died on their first unplanned hospital admission after diagnosis. Further information is required to understand to find out the proportion of unplanned hospital admissions that could have been avoided. Although the most common recorded reasons for admissions were ACSCs in this study, admission information of people with dementia is often accompanied by narratives explaining other events (social and medical) and circumstances leading up to the admission. In future research, the application of NLP algorithms to text entries available in electronic health records may enhance our understanding of the proportion of avoidable, and potentially inappropriate unplanned hospital admissions.

In previous studies, the year of receiving dementia diagnosis was also determined as a critical time period where an increase in healthcare use such as hospitalisations, was observed.[111, 112] These findings indicate that occurrence of healthcare use within the year of dementia diagnosis may be more prominent for people who may be closer to the end of life. This is also supported by the stark difference in the rates of unplanned hospital admissions among people with dementia who were alive at the study compared to the those of the decedents. The patterns of unplanned hospital admissions are explored in conjunction with SLaM services following the receipt of dementia diagnosis in Study 3.

One of the main strengths of this study was the large and inclusive sample which was not limited to decedents and included people living at home and in care homes with any dementia diagnosis and severity, thus reducing biases which may be introduced by subject and time period selection.[204] There may be some concerns about the generalisability of the findings, as the identification of people with dementia was limited to records of a single mental health trust which may limit generalisability.[82, 250] Additionally, the proportion of people with a dementia diagnosis is relatively high in this catchment area (Lambeth, Croydon, Southwark, Lewisham) compared to national figures.[98, 251] However, the average age at diagnosis and death, and the duration between diagnosis and death from our findings are consistent with national averages.[252] The other strength of the study is having a near-complete picture of unplanned hospital admissions of individuals over multiple years. Only 1% of UK hospital services are not provided by the NHS and would not be recorded in the HES ACP dataset, and healthcare provision is likely to be less relevant for unplanned hospital admissions of people with dementia.[226] By leveraging the data linkage between SLaM and HES ACP datasets, I was also able to provide a detailed description of our cohort (e.g., type of dementia diagnosis, severity, and functioning) in addition to the hospitalisation outcomes. In this study, a methodological understanding was gained in terms of the effect of using dynamic cohorts and focusing on the decedents separately. The patterns of unplanned hospital admissions were explored to gain an understanding of the timings on the disease trajectory, who may be more at risk of the hospitalisations, and which services may be involved in reducing avoidable hospitalisations.

This study did not explore differences among people with dementia based on other sociodemographic, environmental or illness-related characteristics. Detailed descriptives for the sample were provided. Within the analysis of large samples, it is possible to find statistically significant findings easily. However, the aim was to map out ‘when’ and ‘how much’ these unplanned hospital admissions occur. Factors associated with hospital admissions and their reasons have been studied previously. [111, 114] Biopsychosocial characteristics of people with dementia associated with healthcare use, including unplanned hospital admissions, are investigated in Study 3.

High rates of unplanned hospital admissions among decedents with dementia towards death raise important questions about different domains of the quality of care. Interpretation of the findings in relation to different aspects of the quality of care[147] are illustrated below (Table 5-2).

Table 5-2. Interpretation of the study findings in relation to the quality of care of people with dementia who may be approaching the end of life (Study 1)

Quality of care domain (See Appendix 1 for definitions)	**Interpretation of findings and implications**
Safety	Hospital environments may be harmful to people with dementia. As long as hospital remain a common place of care, improving safety and minimising harms while people spend time in hospitals should be prioritised. In contrast, people may be spending longer time in the hospital once they are admitted, if their previous place of care is no longer safe to return.
Effectiveness	Although the care delivered within the hospital may be effective in resolving the reason which led to the admission of the patient, the healthcare outside of the hospital may not be effective enough to resolve the issues, including ACSCs.[253]
Outcomes of care	Despite resolution of the acute medical crisis, the quality of life of people with dementia may be impaired.
Patient-centred care	Most people affected by dementia would prefer to not spend time in hospitals towards the end of life.[103] Achieving care concordant with people's preferences might be affected by the availability of responsive services in the community, people's comorbidities and whether advance care planning conversations and actions took place. For people with dementia who experience an unplanned hospital admission, care provision must prioritise understanding patient's preferences for the hospital stay and following discharge from hospital.
Timely access	Common occurrence of unplanned hospital admissions raises questions about whether people with dementia, their families and community health and social care staff were able to access the care and treatments they need without needing an unplanned hospital admission, when it was needed. Additionally, the study highlights differences based on the timing of the receipt of the dementia diagnosis.
Efficiency and value for	Extended hospital stays towards the end of life raise questions about the

money	efficiency of the care provided. Overall, the time spent in hospital by people with dementia is costly for the NHS, and often not beneficial for people with dementia. Both formal and informal care costs increase towards the end of life.[254]

The findings from this study demonstrated that there is value in exploring the quality of care experienced by people with dementia from diagnosis until the end of life to get a better understanding of the services which may support end-of-life care and those who may benefit from intervention. People who may be experiencing repeated unplanned hospital admissions shortly (e.g., within a year) after receiving their dementia diagnosis may be nearing the end of life and benefit from specialist services such as palliative care to manage complex reasons leading to their admissions. By using data linkages between routine datasets, this study was able to demonstrate high rates of unplanned hospital admissions, when they occur, and how they differ among people with dementia. In this study, the cohort was grouped by duration of survival since diagnosis to understand whether variations existed depending how long people lived with a diagnosis. The survival after occurrence of an event could also inform the quality of care of those nearing the end of life.

The next chapter of the thesis employs a different approach to the exploration of the patterns of healthcare use and the quality of care by looking at the incidence, and time trends of critical care admissions for people with dementia. It also seeks to understand whether dementia severity is associated with survival following a critical care admission to provide information about the appropriateness of the critical care admissions. Based on the findings from Study 1, the last year of life was chosen for the time period of exploration. Critical care admissions were also chosen to address the dearth of evidence about the incidence among people with dementia in England. Critical care admissions and interventions provided in the critical care units, such as mechanical ventilation are quality indicators commonly explored in other countries.

Chapter 6: Results Study 2 – Critical care admissions

This chapter presents the specific methods and the results of Study 2. The analyses presented in this chapter have been published in the following peer-reviewed journal:

Yorganci E, Sleeman KE, Sampson EL, Stewart R. Survival and critical care use among people with dementia in a large English cohort. Age and Ageing. 2023 Sep 1;52(9):afad157.

DOI: https://doi.org/10.1093%2Fageing%2Fafad157

Personal contributions to the publication: I was responsible for devising the study approach and analysis plan. I sought and gained approval from the CRIS oversight committee to conduct the research using the CRIS-HES linkage. I outlined the selection criteria to define the cohort and data extraction requirements. I cleaned the data, performed the analysis and drafted the manuscript. My PhD supervisors were consulted throughout and provided input on the analysis plan and review and editing of the manuscript. I would like to acknowledge Hitesh Shetty and Daisy Kornblum for extracting the data.

6.1 Introduction

This study addressed the thesis objective 1: To describe the patterns of healthcare use of people with dementia from the point of diagnosis to death. This study also contributed to the thesis objective 3: To use these findings to describe the quality of care received by people with dementia nearing the end of life and guide policy and practice for this population.

Results from the systematic review show that the number of critical care admissions of people with dementia who may be approaching the end of life is a commonly used process QI for measuring care quality. When a high percentage of people with dementia experience critical care admissions, there may be concerns about the quality of care. However, admissions of people with dementia to critical care units vary across countries.[122, 255] While some countries routinely examine admissions of people with dementia to critical care units, albeit not necessarily limited to those who died, in England, to our knowledge, critical care admissions of people with dementia are not routinely monitored and have not been examined in research.[256]

This study investigates critical care admissions of people with dementia, which occurred after a dynamic cohort of people from South London received their dementia diagnosis. The CRIS dataset was linked with the national hospital records (HES APC and HES ACC), and the death registry (ONS) to assemble a retrospective cohort study.

6.2 Methods

6.2.1 Design and data sources

This is a retrospective cohort study assembled through the linkage of two clinical datasets (South London and Maudsley NHS Foundation Trust Biomedical Research Centre's (SLaM BRC) Clinical Record Interactive Search (CRIS)[163, 215] and Hospital Episode Statistics Admitted Patient Care (HES APC) and Adult Critical Care (HES ACC)), and a death registry (Office for National Statistics - ONS). Mortality information was available until March 2021 to allow at least one year of follow-up. Chapter 4, Section 4.8.1 of this thesis provides more detailed information on the datasets.

6.2.2 Setting and cohort

Any person with dementia who was 50 or older diagnosed between 1st January 2006 and 31st March 2020 was included. All dementia diagnoses recorded in CRIS were determined from ICD-10 diagnosis codes (F00x–03x) recorded in structured fields. At the time of the data extraction for this study, the use of a validated natural language processing algorithm using GATE software for detecting supplemented by dementia diagnosis recorded in text fields which was available for Study 1 was not available for this study.

6.2.3 Clinical variables

The Mini Mental State Examination (MMSE [222]) scores that were recorded on the closest date to the critical care admission to estimate dementia severity were used, applying recommended cut-off points[257] (mild=MMSE≥20, moderate-severe=MMSE<20). The MMSE has good test-retest reliability and acceptable sensitivity and specificity to detect mild to moderate stages of dementia.[258, 259] For people with no recorded MMSE score at a date close to their critical care admission, the cognitive problems score from the Health of the Nation Outcome Scales (HoNOS)[260], a structured clinical outcome measure used routinely in English mental healthcare, was used to estimate dementia severity with standard recommended cut-off points (mild=0-2; moderate-severe=3-4 [260]). If there were no recorded measures (MMSE or HoNOS cognitive problems score) for estimating the dementia severity in the year preceding the critical care admission date, dementia severity was recorded as 'missing'. As the dementia severity was not recorded in HES, dementia severity of people with dementia at the time of their critical care admission was merely an estimate. Hence, the imputation of the missing values was not appropriate for estimating the dementia severity at the time of the critical care admission. For each participant, information on critical care admissions after the date of their first CRIS-recorded dementia diagnosis was linked to the information from HES APC to capture the length of the critical care unit and overall hospital stay. For each person, the dates for each hospital admission, critical care unit admission, critical care unit discharge, and hospital discharge were extracted.

6.2.4 Outcomes

Outcomes included one-year survival following a critical care admission grouped by dementia severity, and critical care use. One-year survival was determined by checking whether the individual who had a critical care admission was alive or not 365 days after their date of discharge from the critical care unit. The percentage of people with dementia who had a critical care admission, and the critical care admission rate (the number of critical care admissions divided by the person-years of follow-up of the overall cohort) were reported. Age-sex-standardised annual critical care use (number of critical care admissions of people with dementia per year /number of people living with dementia per year) were calculated using England's mid-year population estimates to adjust the number of critical care admissions observed in the sample for sex (male, female) and age groups (50-59, 60-69, 70-79, 80-89, >90).[261] Age-sex-standardised critical care use in the last year of life (number of critical care admissions of people with dementia in the last year of life per year / number of decedents with dementia per year were calculated using England's leading causes of death statistics to identify annual dementia deaths published by the ONS, to adjust the critical care use observed in the sample for sex and age groups.[262]

6.2.4.1 Critical care admissions

The number of critical care admissions which took place after the first recorded date of dementia diagnosis were derived from HES ACC dataset.[243] HES data was available up to 31st March 2020, allowing at least one year of potential hospital admissions data follow-up.[98] To understand where people died (i.e., during a critical care admission, on a general hospital ward, or elsewhere), hospital admissions data from Admitted Patient Care (APC) of people with dementia were also merged with the critical care data. Critical care admissions were assembled using codes for spells' start dates and admission method. Duplicates based on the date of admission, date of discharge, the episode start and end dates, the admission and discharge methods were removed (Figure 6-1).

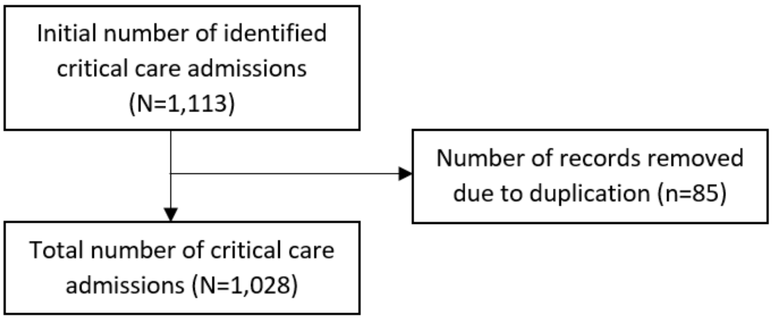

Figure 6-1. Flowchart of identifying the number of critical care admissions

6.2.4.2 Survival

One-year survival is a commonly used measure in end-of-life care research as it may inform the effect of a process on the individual's prognosis, and their proximity to the end-of-life period.[263, 264] Survival was used to obtain an estimation of the proximity of people with dementia to the end of their lives when they were admitted to a critical care unit. There is an increasing body of work suggesting that poor end of life care is often experienced by people with dementia. Prognostic uncertainty has been shown as one of the key reasons for this.[201] The information on survival could be useful for identifying the support and the services people may need in the upcoming months. Improved information on longer-term prognosis such as one-year survival, would allow hospital staff to feel more confident in adapting a palliative model of care for people with dementia where appropriate. Previous research outside of the UK investigated critical care admissions among people with advanced dementia. However, research shows that only a small percentage of people with dementia die at the advanced stages of dementia.[35] Hence inclusion of people with dementia at all stages of dementia severity and whether their survival was impacted by their dementia severity were questions of interest.

6.3 Statistical Analysis

Logistic regression and Kaplan-Meier survival plots to were used to investigate one-year survival following a critical care admission, and linear regressions for trend analyses. Survival time was calculated from the date of the critical care discharge to death or one-year (365.25 days) after the discharge date. All analyses were performed using STATA 15 software.[265] In medical research, Kaplan-Meier survival estimator is one of the most frequently used to measures to estimate the fraction of patients living for a certain amount of time after receiving a treatment or experiencing an admission.[266] Parallel survival curves indicate that hazards in groups of cases are proportional over time.[267]

6.4 Results

6.4.1 Cohort Description

Of 19,787 people diagnosed with dementia, 726 (3.7%) had ≥1 critical care admission at any point after receiving their dementia diagnosis, equating to 0.27 critical care admissions per person-years. Those with a CCA were median age 81 (IQR:75-86) on admission, nearly a quarter (n=175, 24.1%) died in hospital, including 11.1% (n=81) in the critical care unit; the remaining 551 (75.9%) were discharged after a median 10 (IQR:4-21) days total hospitalisation. Compared to people who did not have a CCA, people who had ≥1 CCA were younger when diagnosed with dementia (median age of 79 IQR(73-84) vs median age of 82 IQR(77-87)) and had a higher MMSE scores (21 IQR(17 – 24) vs 19 IQR(15.0– 23.0)), indicating milder cognitive impairment at the time of their diagnosis (Table 6-1).

Table 6-1. Cohort characteristics (N=19,787)

	Total	No critical care admission	Had ≥1 critical care admission
N	19,787	19,061	726
Sex			
woman	12071 (61.0%)	11696 (61.4%)	375 (51.7%)
man	7716 (39.0%)	7365 (38.6%)	351 (48.3%)
Ethnicity			
White	14,171 (71.6%)	13685 (71.8%)	486 (66.9%)
Mixed	142 (0.7%)	133 (0.7%)	9 (1.2%)
Asian	1,061 (5.4%)	1006 (5.3%)	55 (7.6%)
Black	3,149 (15.9%)	3010 (15.8%)	139 (19.2%)
Other	434 (2.2%)	414 (2.2%)	20 (2.8%)
Not known	831 (4.2%)	813 (4.3%)	18 (2.3%)
IMD Quintiles			
1	3,712 (18.8%)	3564 (18.7%)	148 (20.4%)
2	7,560 (3.8%)	7255 (38.1%)	305 (42.1%)
3	4,183 (21.1%)	4037 (21.2%)	146 (20.1%)
4	2,275 (11.5%)	2214 (11.6%)	61 (8.4%)

5	1,319 (6.7%)	1286 (6.7%)	33 (4.6%)
missing		705 (3.7%)	33 (4.4%)
Dementia diagnosis			
Alzheimer's disease	7,098 (35.9%)	6892 (36.2%)	206 (28.4%)
Mixed dementia	2,756 (13.9%)	2652 (13.9%)	104 (14.3%)
Unspecified dementia	4,745 (24.0%)	4569 (24.0%)	176 (24.3%)
Vascular dementia	3,671 (18.6%)	3476 (22.2%)	195 (26.9%)
Dementia in other diseases	1,496 (7.6%)	1,473 (4.0%)	23 (3.2%)
Age at diagnosis			
<60	309 (1.6%)	285 (1.5%)	24 (3.3%)
>=60 - <=64	430 (2.2%)	401 (2.1%)	29 (4.0%)
>=65 - <=69	916 (4.6%)	845 (4.4%)	71 (9.8%)
>=70 - <=74	1998 (10.1%)	1896 (9.9%)	102 (14.1%)
>=75 - <=79	3615 (18.3%)	3441 (18.1%)	174 (24.0%)
>=80 - <=84	4820 (24.4%)	4653 (24.4%)	167 (23.0%)
>=85 - <=89	4749 (24.0%)	4639 (24.3%)	110 (15.2%)
>=90 - <=94	2278 (11.5%)	2237 (11.7%)	41 (5.6%)
>=95	672 (3.4%)	664 (3.5%)	8 (1.1%)
Age at diagnosis, median (IQR)	82.0 (77.0, 87.0)	82.0 (77.0, 87.0)	79.0 (73.0, 84.0)
MMSE near diagnosis, median (IQR)	20.0 (15.0, 23.0)	19.0 (15.0, 23.0)	21.0 (17.0, 24.0)
MMSE categories			
mild	5313 (26.8%)	5046 (26.5%)	267 (36.8%)
moderate	4274 (21.6%)	4115 (21.6%)	159 (21.9%)
severe	1041 (5.3%)	1020 (5.4%)	21 (2.9%)
missing	9159 (46.3%)	8880 (46.6%)	279 (38.4%)
HoNOS cognitive problems	15807 (79.9%)	15244 (80.0%)	563 (77.5%)

MMSE: mini-mental state examination; HoNOS (health of the nation outcome scale) scores were dichotomised (scores 0 and 1—no or minor problems, scores 2 to 4—mild to severe problems) to facilitate interpretation.

6.4.2 Critical care admissions following dementia diagnosis

Age-sex-standardised annual critical care use of people with dementia ranged between 0.5% (512 per 100,000 people with dementia) and 9.8% (9,797 per 100,000 people with dementia). Over the 12-year period from 2008 to 2019, there was a decrease in overall critical care use (β=-0.05; 95% CI -0.01, -0.0003; p=0.04), while one-year survival remained steady (Figure 6-2) (OR 1.00, 95% CI 0.96 – 1.06, p=0.78).

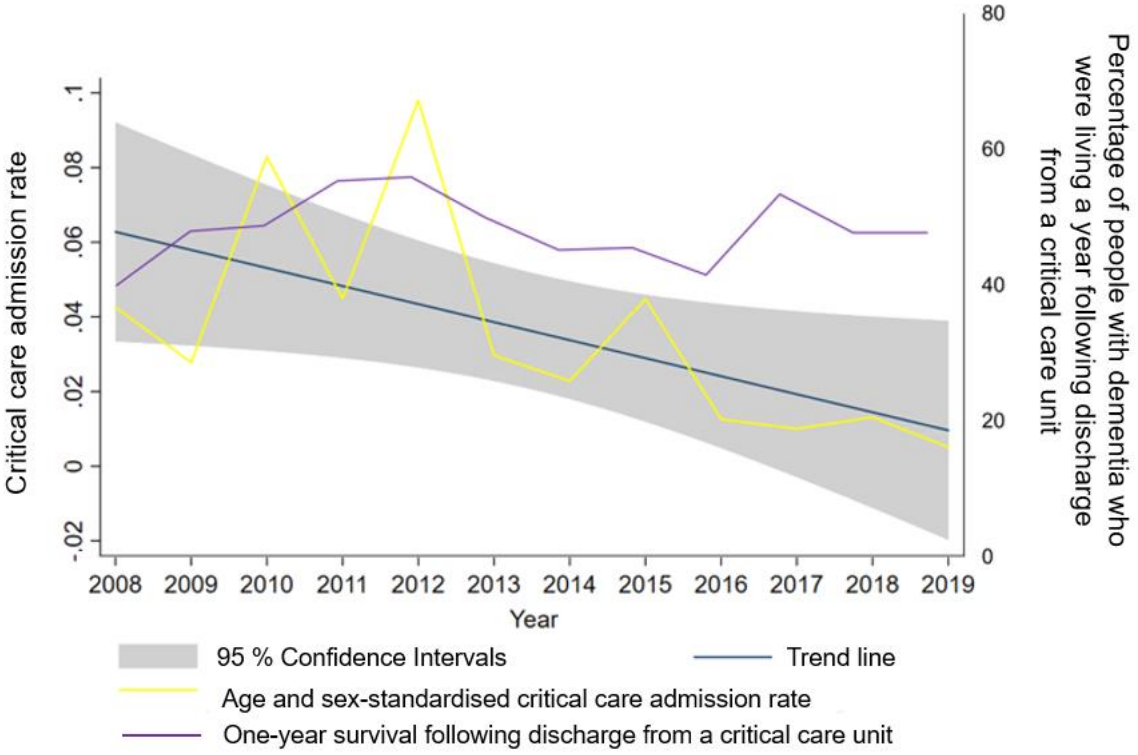

Figure 6-2. Annual age-sex-standardised critical care use among people with dementia between 2008 and 2019

6.4.3 Critical care admissions in the last year of life

Age-sex-standardised annual critical care use during the last year of life ranged between 0.9% (905 per 100,000 people with dementia) and 3.9% (3,859 per 100,000 people with dementia). Between 2008 and 2019, there was an increase in critical care admissions in the last year of life (β=0.11, 95% CI 0.01, 0.20, p=0.03) (Figure 6-3). Among the critical care admissions occurring in the last year of life, over half (51.6%) occurred in the last month of life (Figure 6-4), equating to 1.1% of people with dementia.

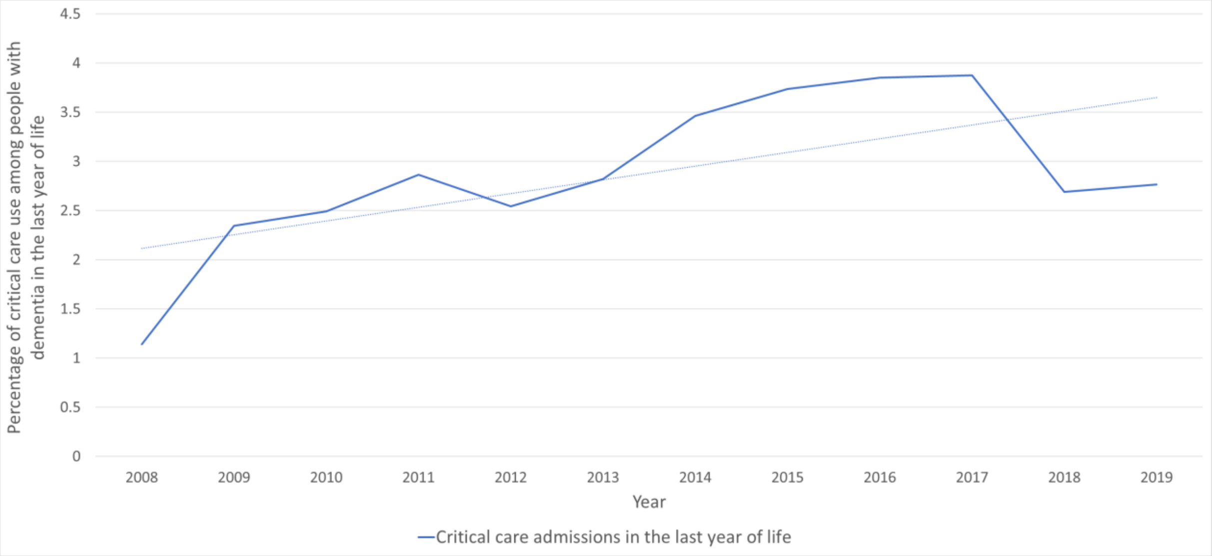

Figure 6-3. The trend in the percentages of critical care admissions among people with dementia that took place in the last year of life between 2008 and 2019

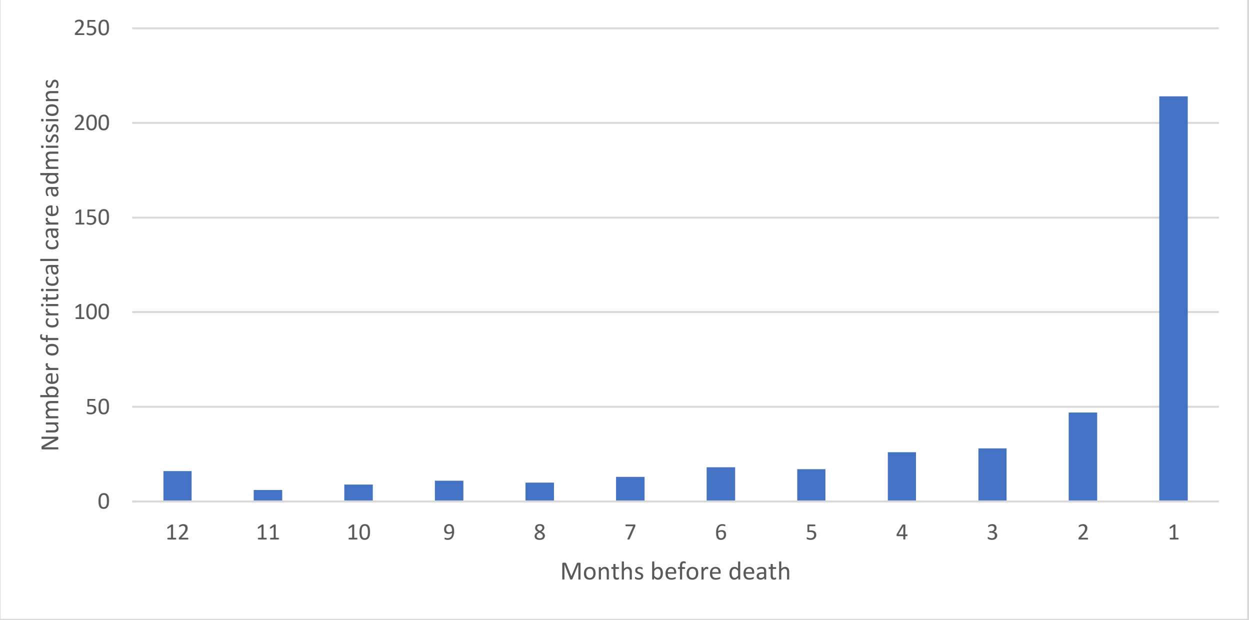

Figure 6-4. Number of critical care admissions among decedents with dementia in the last 12 months of life

6.4.4 Survival

The overall one-year survival of people with dementia who had a critical care admission was 47.5% (n=345). Dementia severity was not associated with one-year survival following a critical care admission (mild dementia vs moderate-severe dementia odds of one-year mortality, OR: 0.90, 95% CI [0.66-1.22]) (Figure 6-5).

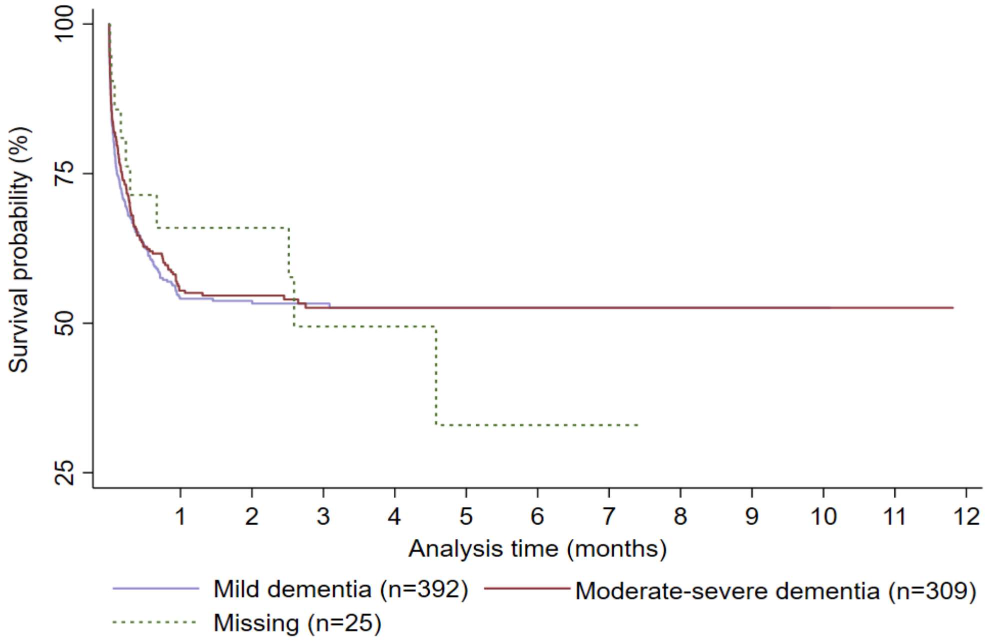

Figure 6-5. Kaplan-Meier survival plot showing the one-year survival following a critical care admission in people with a previous dementia diagnosis grouped by dementia severity

6.4.5 Sensitivity analysis for the survival analysis

The survival analysis exploring people's dementia severity included a composite variable. To ensure that there were no differences based on how the survival is grouped, a sensitivity analysis was conducted where the grouping of people based on their dementia severity were further broken down to seven different groups (mild MMSE score, mild HoNOS cognitive problems score, moderate MMSE score, moderate HoNOS cognitive problems score, severe MMSE score, severe HoNOS cognitive problems score, missing) and log-rank test for heterogeneity was run to check for differences in survival. No significant differences were identified (p=0.06).

6.4.6 Patient and public involvement

Findings from this study were discussed with the EMBED-Care PPI members and the EMBED-Care team which includes healthcare professionals and researchers. In comparison to other countries, low incidence of critical care admissions among people with dementia towards the end of life was not a surprise. However, the PPI members did not expect such a stark difference. The utility of measures of dementia severity were questioned. Although the critical care admissions which took place during the COVID-19 pandemic were not included in this study, the discussions took place following the outbreak of the COVID-19 pandemic. Concerns of denial of critical care to people with dementia during the COVID-19 pandemic based on their clinical frailty score were raised.[268] These concerns mainly related to the importance of monitoring the care received by people with dementia (i.e., those who received critical care, and those who did not) to ensure that their access to appropriate care is not restricted due their dementia diagnosis.

Findings were also discussed with healthcare professionals, including palliative care specialists working in hospitals. Healthcare professionals were not surprised with the increase in the rates of critical care admissions in the last year of life. Palliative care specialists highlighted the lack of recognition of dying and cumulative signs which may indicate that a person with dementia is approaching the end of life.

6.4.6 Publication 3: Survival and critical care use among people with dementia in a large English cohort

The findings from Study 2 were published in Age and Ageing and are presented below as the accepted manuscript for publication to ensure that figures and small text are readable.[269] The published version is open-access, and can be accessed using the link provided at the beginning of Chapter 6. .[269] This is followed by the supplementary materials (Appendix 5).

Survival and critical care use among people with dementia in a large English cohort

Emel Yorganci[1], Katherine E Sleeman[1], Elizabeth L Sampson[2,3], Robert Stewart[4,5] on behalf of the EMBED-Care Programme

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Conflicts of interest

RS declares research support received in the last 3 years from Janssen, GSK and Takeda.

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Abstract

Background: Admitting people with dementia to critical care units may not always lead to a clear survival benefit. Critical care admissions (CCAs) of people with dementia vary across countries. Little is known about the use and trends of CCAs of people with dementia in England.

Objective: To investigate critical care use and survival among people with dementia in a large London catchment area.

Methods: A retrospective cohort study using data from dementia assessment services in south London, UK (2007-2020) linked with national hospitalisation data to ascertain CCAs. Outcomes included age-sex-standardised critical care use and one-year post-CCA survival by dementia severity (binary: mild vs. moderate/severe). We used logistic regression and Kaplan-Meier survival plots for investigating one-year survival following CCA, and linear regressions for time-trends.

Results: Of 19,787 people diagnosed with dementia, 726 (3.7%) had ≥1 CCA at any time after receiving their dementia diagnosis. The overall one-year survival of people with dementia who had a CCA was 47.5% (n=345). Dementia severity was not associated with one-year survival following CCA (mild dementia vs moderate-severe dementia odds of one-year mortality OR: 0.90, 95% CI [0.66-1.22]). Over the 12-year period from 2008 to 2019, overall critical care use decreased (β=-0.05; 95%CI -0.01, -0.0003; p=0.03), while CCAs occurring during the last year of life increased (β=0.11, 95%CI 0.01, 0.20, p=0.03).

Conclusions: In this cohort, while critical care use among people with dementia declined overall, its use increased among those in their last year of life. Survival remains comparable to that observed in general older populations.

Key words: critical care, dementia, survival, routine data, intensive care

Key points

- In a large cohort with a dementia diagnosis, while overall critical care use decreased over the years, a slight increase was observed among critical care admissions which took place in the last year of the decedents' lives.
- One-year survival of people with dementia following a critical care admission was 48%, similar to that observed in general older populations.
- Data linkages and clinically relevant routinely collected data are essential for informing service planning and evaluating care quality of people with dementia

Introduction

The number of people living with dementia is increasing, [1] and providing high-quality and equitable care is a major challenge. Understanding different aspects of healthcare use is important for service planning, including critical care unit admissions [2]. While critical care admissions (CCAs) may be life-saving, those for people with dementia need careful consideration as to whether benefits outweigh burdens [3], and whether they are in accord with people's previous preferences especially at advanced stages of dementia [4]. CCAs in dementia may vary geographically and over time; those in the last year of life have increased in several countries [4, 5], but trends in England have not been described. We investigated CCAs among people with dementia from point of diagnosis, including survival and time trends, by leveraging a novel data linkage in a large south London catchment area.

Methods

Setting & data sources

A retrospective cohort was constructed using data linkages between (i) dementia assessment/management services (South London and Maudsley (SLaM) National Health Service Foundation Trust Clinical Record Interactive Search (CRIS)), (ii) hospital inpatient (2008- March 2020), (iii) hospital critical care (2008- March 2020), and (iv) the national death registry (Office of National Statistics (ONS). Mortality information was available up to March 2021 to allow at least one year of follow-up. The source database is approved for secondary analysis (Oxfordshire Research Ethics Committee C, reference 18/SC/0372). Hospital Episode Statistics (HES) Adult Inpatient Care contains details of all admissions in England, and HES Adult Critical Care contains details of CCAs to intensive care units and high dependency units [2]. SLaM provides mental health services to a catchment population of 1.2m south London residents; the CRIS platform provides research access to de-identified structured and open-text data from SLaM's electronic health records [6], including its comprehensive dementia assessment services.

We included any person with dementia who was ≥50 at diagnosis between 1st January 2006 and 31st March 2020. All dementia diagnoses recorded in CRIS were determined from ICD-10 diagnosis codes (F00x–03x) recorded in structured fields.

Clinical variables

We used Mini Mental State Examination (MMSE [7]) scores recorded on the closest date to the CCA to estimate dementia severity, applying recommended cut-off points [8] (mild=MMSE≥20, moderate-severe=MMSE<20). The MMSE has good test-retest reliability, and acceptable sensitivity and specificity to detect mild to moderate stages of dementia [9, 10]. For people with no recorded MMSE score, the cognitive problems score from the Health of the Nation Outcome Scales (HoNOS) [11], a structured clinical outcome measure used routinely in English mental healthcare, was used to estimate dementia severity with standard recommended cut-off points (mild=0-2; moderate-severe=3-4 [11]). For each participant, we retrieved information on CCAs after the date of their first CRIS-recorded dementia diagnosis and linked the information on CCAs to information from HES Admitted Patient Care to capture the length of critical care unit and overall hospital stay. For each person, we had dates of hospital admission, critical care unit admission, critical care unit discharge, and hospital discharge.

Outcomes

Outcomes included one-year survival following CCA by dementia severity, and CCA use. One-year survival was determined by checking whether the individual who had CCA was living or not 365 days after their discharge from the critical care unit. We reported the percentage of people with dementia who had a CCA, and the CCA rate (the number of CCAs divided by the person-years of follow-up of the overall cohort). We calculated age-sex-standardised annual critical care use (number of CCAs of people with dementia per year /number of people living with dementia per year). For standardisation, we used England's mid-year population estimates to adjust the number of CCAs observed in our sample for sex and age groups (50-59, 60-69, 70-79, 80-89, >90) [12]. We calculated age-sex-standardised critical care use in the last year of life (number of CCAs of people with dementia in the last year of life per year / number of decedents with dementia per year). For standardisation, we used England's leading causes of death statistics to identify annual dementia deaths published by ONS, to adjust the critical care use observed in our sample for sex and age groups (50-59, 60-69, 70-79, 80-89, >90) [13].

Statistical Analysis

We used logistic regression and Kaplan-Meier survival plots to investigate one-year survival following a CCA, and linear regressions for trend analyses. All analyses were performed using STATA 15 software [14].

Results

Of 19,787 people diagnosed with dementia, 726 (3.7%) had ≥1 CCA, equating to 0.27 CCAs per person-years. Those with a CCA were median age 81 (IQR:75-86) on admission, nearly a quarter (n=175, 24.1%) died in hospital, including 11.1% (n=81) in the critical care unit; the remaining 551 (75.9%) were discharged after a median 10 (IQR:4-21) days total hospitalisation. Compared to people who did not have a CCA, people who had ≥1 CCA were younger when diagnosed with dementia (median age of 79 IQR(73-84) vs median age of 82 IQR(77-87)) and had a higher MMSE scores (21 IQR(17 – 24) vs 19 IQR(15.0– 23.0)), indicating milder cognitive impairment at the time of their diagnosis (*See Supplementary Data)*. The overall one-year survival of people with dementia who had a CCA was 47.5% (n=345). Dementia severity was not associated with one-year survival following CCA (mild dementia vs moderate-severe dementia odds of one-year mortality, OR: 0.90, 95% CI [0.66-1.22]) (Figure 1). Age-sex-standardised annual critical care use of people with dementia ranged between 0.5% (512 per 100,000 people with dementia) and 9.8% (9,797 per 100,000 people with dementia). Over the 12-year period from 2008 to 2019, there was a decrease in overall critical care use (β=-0.05; 95%CI -0.01, -0.0003; p=0.04), while one-year survival remained steady (Figure 2). Age-sex-standardised annual critical care use during the last year of life ranged between 0.9% (905 per 100,000 people with dementia) and 3.9% (3,859 per 100,000 people with dementia). Between 2008 and 2019, there was an increase in CCAs in the last year of life (β=0.11, 95% CI 0.01, 0.20, p=0.03).

Discussion

In a large cohort of people with dementia, 3.7% experienced a CCA, potentially reflecting the careful selection process for admission to critical care units. Previous estimates of annual CCA rates for people older than 80 range between 3.0% to 16.5% [15]. The one-year survival following CCA of 47.5% is slightly lower than that reported among people with dementia in England admitted to hospital (58.5%)[16]. It is consistent with one-year survival following a CCA reported among older people generally (30-70%)[17] and people with cancer (40-55%)[18]. However, our observed proportion of CCAs that ended in death on a critical care unit (11.1%) was lower than general population reports (14-20%)[19].

In our study, CCAs among people with dementia decreased over the years observed, while CCAs in the last year of life increased. Evidence on temporal CCA trends is scarce. Previous US studies of CCA trends of older people (2001-2008[20]) and of people with dementia (1998-2015[21]) found no change. In contrast, US data showed increases in CCAs (2000 (6.1%) – 2007 (9.5%))[4] and life-sustaining treatments such as mechanical ventilation among people with advanced dementia [3]. Our findings agree with reported increases in other aspects of potentially burdensome care (e.g., Emergency Department attendance in the last months of life) [22]. Reasons for up-trending CCAs in the last year of life among people with dementia may be complex. The increasing emphasis on timely diagnosis of dementia in England [23], social care funding implications of having a formal dementia diagnosis [24], and provision of general hospital liaison psychiatry services [25], may have changed the composition of our cohort over time, contributing to observed trends. Following, the 2015 Prime Minister's Challenge on Dementia policy, which aimed that 66% of people with dementia in England should receive a diagnosis, an increase in this percentage was observed: from 47% to 59% between 2011 and 2015. Implementation of incentives by the National Dementia Commissioning for Quality and Innovation (CQUIN)[26] also led to increased recognition of dementia in acute hospitals [27]. While recognition of dementia by clinical teams has increased, skills and knowledge to deliver care for those who may be approaching the end of life are often lacking. Quality indicators such as the percentage of people with dementia who had a CCA in the last month and year of life, and the documentation of treatment and care preferences may drive improvements in care quality for people with dementia until the end of their lives [28].

This study has limitations. Our sample were diagnosed with dementia in a single mental health trust, and may not be representative [29]. Furthermore, we did not have sufficient information about reasons for the CCAs, treatments received, and frailty measures (e.g., the Clinical Frailty Scale [30]) which inform clinical decisions [31, 32], and have an increasingly large influence on CCA decisions than dementia severity. Finally, decisions to admit to critical care units may depend on critical care capacity. However, data on local/regional critical care bed occupancy or capacity were not available for further exploration [33]. Study strengths include the source data linkage which enabled us to determine CCA use among people with dementia diagnosed over a long time period. While most available information on critical care use among people with dementia is limited to those which occurred in the last year of life or only to people who had advanced dementia [3, 34], we were able to identify any CCA after the dementia diagnosis date.

Financial and individual burdens associated with dementia care are high and will increase in future. Critical care use among people with dementia, and relevant outcomes such as their survival and the concordance of care with their preferences should be monitored to minimise burden, and meet care needs appropriately. To make good judgements about the appropriateness of care and inform service provision at a population-level, access to high-quality and clinically relevant routinely collected data is essential.

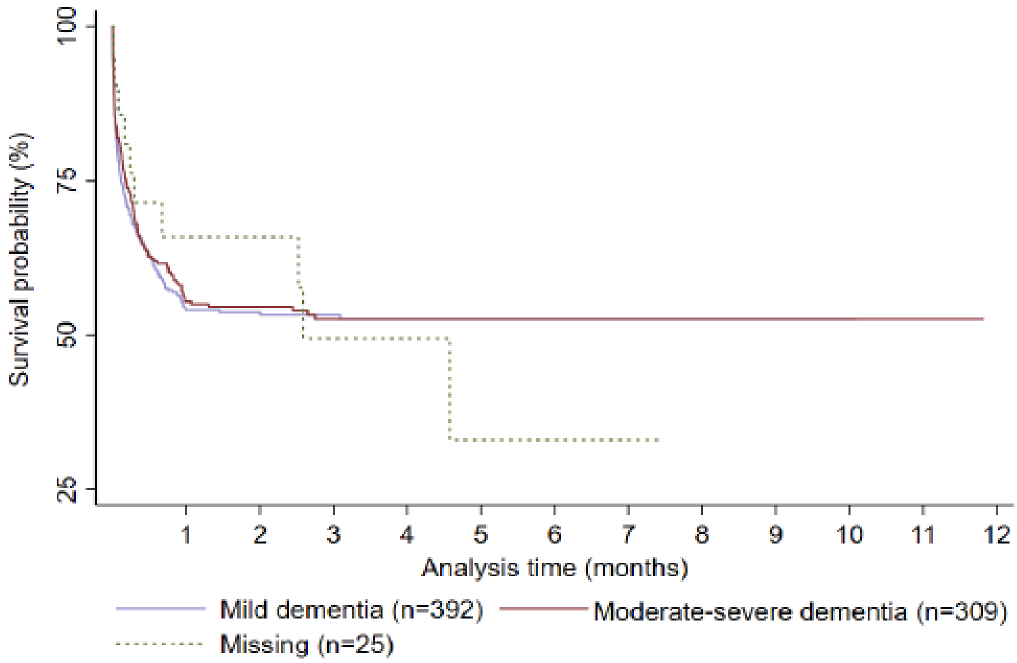

Figure 1. Kaplan-Meier survival plot showing the one-year survival following a critical care admission in people with a previous dementia diagnosis grouped by dementia severity

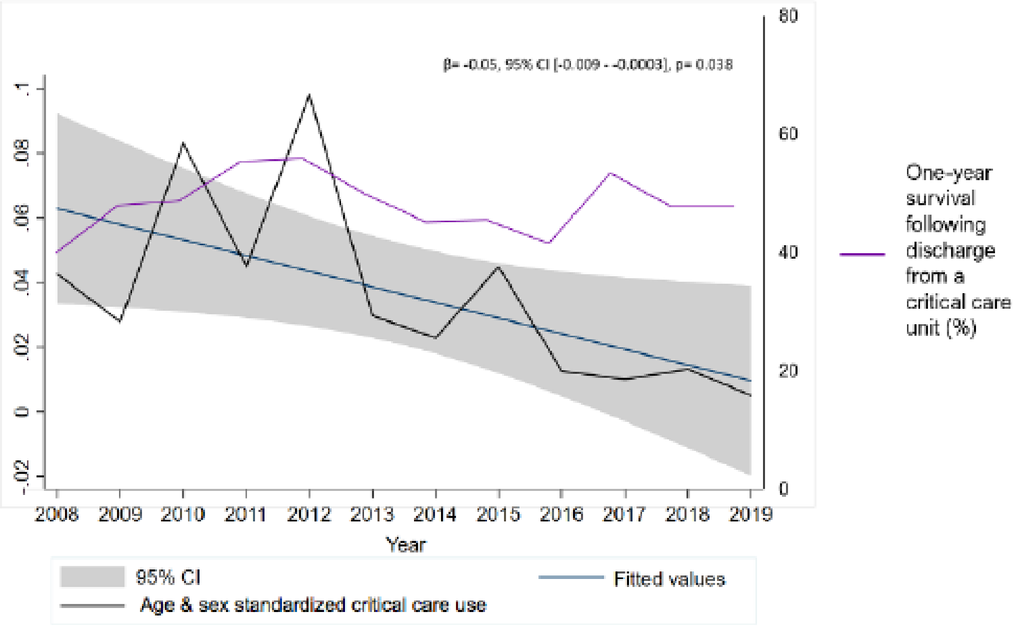

Figure 2. Annual age-sex-standardised critical care use among people with dementia between 2008 and 2019

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6.5 Summary

Study 2 exploited the novel data linkage between SLaM's CRIS dataset and HES's Adult Critical Care datasets to first determine the incidence of critical care admissions among people with dementia, then to explore trends in the critical care admissions over a 12-year period and explore the quality of care and appropriateness of the admissions by investigating the associations between dementia severity and survival. The choice of examining the one-year survival of people who were admitted to a critical care unit was based on the increased rates of unplanned hospital admissions in the last year of life determined in Study 1. The findings show that the one-year survival rate of people with dementia following a critical care admission was 47.5%, which remained consistent over the 12-year period (OR 1.00, 95% CI 0.96 – 1.06, p=0.78).

The results from this study which included a dynamic cohort of people diagnosed with dementia showed that 3.7% experienced one or more critical care admissions any time after their receiving their dementia diagnosis. Compared to the incidence of critical care admissions among older people, which ranged between 3.0% and 16.5%,[270] the cumulative incidence of critical care admissions among people with dementia in this study (3.7%) sits close to the lower end of this range. The wide range of incidences of critical care admissions among older people can be attributed to the variations in the study design, and differences in the study populations.[270] In England, while the case mix characteristics of people admitted to the critical care units and the total number of children and adults admitted are reported as part of the routine practice, admissions based on diagnoses and the cumulative incidences are not monitored.[256]

In this study a slight increase in the age and sex standardised rates of critical care admissions in the last year of life was identified. This trend is in line with the trends observed in Belgium (2010-2015)[128], and in the USA (2000-2009).[127] These trends agree with increases observed in other potentially burdensome care experienced among people with dementia, such as increase in unplanned hospital admissions of people with dementia,[98] and increase in the A&E visits in the last year of life.[110] Although the percentage of people admitted to critical care units is small in this sample, the trend of increasing critical care admissions mong people with dementia in the last year of life identified in our sample should be further explored, and monitored. In Belgium, which had similar percentages of people with Alzheimer's disease who had a critical care admission, living in a nursing home was associated with lower likelihood of a critical care admission.[164] This association between living in a nursing home and the A&E visits among people with dementia in the last year of life has also been observed in England.[41] In HES datasets, where people live prior to their hospital admission is recorded as their "usual place of care", which does not differentiate between homes or care homes. Future studies should explore the association between the place of care and critical care admissions among people with dementia in the last year of life.

The contrasting trends in the overall and the last year of life age and sex standardised rates of critical care admissions could be partly explained by the change in the composition of people diagnosed with dementia over the years. Increase recognition and diagnosis of dementia at earlier stages of the condition, coupled with prescriptions of antidementia medications might have resulted in more people with dementia living well for longer and less in need of critical care admissions.[73] People with dementia at moderate to severe stages of the condition experience more problems in their activities of daily living and functional abilities.[271] More people with dementia living with less impairments in activities of daily living near the end of their lives may also partly explain higher proportions of critical care admissions in the last year of life. A combination of an increased number of people with dementia who may be approaching the end of life over the years, and a lack of recognition of the progress of dementia among hospital staff and people affected by dementia, may explain these findings.

While an upwards trend in the proportion of people with dementia experiencing a critical care admission in the last year of life may require further investigation to ensure that people with dementia are not receiving invasive yet potentially futile treatments towards the end of their lives, caution must be taken to not apply findings relevant at a population level to individual admission decisions. A study conducted in Paris, which included people over 80 years old who were capable of expressing their opinions and had a potential indication for a critical care admission found that having a history of dementia reduced the probability of having their opinions asked about the admission.[272] Having a family member present whose opinions were asked, increased the probability of patient being asked for their opinions about the critical care admissions. A dementia diagnosis should be considered, and the decision to admit should be carried out in the light of clinical and preferential factors. These have important implications about the care of people with dementia, especially for those who may not have family members present when their eligibility for a critical care admission is being considered. Stigma towards people with dementia among other structural factors may explain the decrease in the overall critical care admissions among people with dementia over time.[273]

There are important limitations to be acknowledged about this study. As prognosis remains unclear, and with a 48% one-year survival rate, availability of data on clinical measures such as dementia severity and frailty for better understanding of care is needed. While these measures, in line with the recommended guidance,[274] may have been used in clinical practice, it is difficult to determine their uptake and use for research without available data. The use of Clinical Frailty Score (CFS) to guide the decision to admit, not as an absolute criterion, but in conjunction with the views of the families and patients where possible, is recommended by the National Institute for Health and Care Excellence on triage for critical care admission.[274] However, this information was not available in either of the datasets. Other studies have found positive correlations between dementia severity and the level of frailty.[275, 276] Dementia severity of people with dementia who experienced a critical care admission was not recorded in their hospital records. To estimate the dementia severity, MMSE scores and when not available HoNOS scores recorded to the closest date to their critical care admissions were extracted from the from the CRIS dataset.

Findings related to the association between dementia severity and the one-year following discharge from a critical care admission are limited by the logistic regression approach. Results show that most deaths following a critical care admission occur within the first six months of discharge among people with dementia or after twelve months. A time-to-event approach to survival analysis (e.g., a proportional hazards model) might be more informative in understanding the association between dementia severity factors and mortality following a critical care admission, while accounting for other factors such as age and sex.[277]

The interpretation of the findings in relation to the care of people with dementia and how quality of care may require further considerations for those who may be approaching the end of life are summarised in Table 6-2.

This was a novel data linkage study, providing evidence about the incidence of critical care admissions among people with dementia and their survival. Individuals with dementia should have access to appropriate care required, regardless of their diagnosis or severity of their dementia diagnosis. Increase in the proportion of people with dementia experiencing a critical care admission in the last year of life warrants monitoring. A key purpose of regularly monitoring care quality is to set benchmarks at national and regional levels, to detect changes and explore the underlying reasons for the changes further.[147] Investigating the concordance between quality indicators such as the percentage of people with dementia who had a critical care admission in the last month and year of life and the documentation of treatment and care preferences may drive improvements in care quality and person-centred care for people with dementia until the end of their lives.[11] Trends detected in this study warrant further exploration to understand the underlying reasons, and if needed interventions to ensure that the quality of care experience by people with dementia until the end of their lives is not compromised.

Findings from Studies 1 and Study 2 highlighted the patterns and differences in healthcare use among people with dementia. Previous studies of the thesis show an increase in healthcare use in proximity to death. Findings from Study 1 point towards a gradient pattern in the rates and lengths of unplanned hospital admissions in relation to the differences in duration between diagnosis and death. However, these studies predominantly describe the patterns and the impact of a single healthcare service use on the quality of care experienced among people with dementia. The next chapter of the thesis employs a different approach to the exploration of the patterns of healthcare use and the quality of care among people with dementia by exploring the use of multiple healthcare services concurrently at two critical points, diagnosis and the last year of life, during the dementia care trajectory.

Table 6-2. Interpretation of the study findings in relation to the quality of care of people with dementia who may be approaching the end of life (Study 2)

Quality of care domain (See Appendix 1 for definitions)	**Interpretation of findings and implications**
Access, person-centred experience, and equity	Based on increasing critical care admissions in the last year of life, whether people with dementia had opportunities to discuss and document their preferences about invasive treatments and critical care admissions near end of life must be explored. On the other hand, based on decreasing overall critical care admissions, whether people with dementia who may not be near end of their lives are having equitable access to critical care and being involved in decision-making despite their diagnosis should be explored.
Safety	The environment of the critical care units can be extremely distressing for people with dementia, with increased chances of infections, even when the use of invasive treatments is kept at minimum. On the other hand, as the number of people living longer with a dementia diagnosis is projected to increase,[15] a higher percentage of people with dementia are likely to benefit from their critical care admissions, when the harms associated with not receiving critical care is outweighed. Patient safety in intensive care units can be improved with regular training, use of bundles of care, and the promotion of a safety culture.[278]
Outcomes of care	A better understanding of outcomes such as the quality of life, and cognitive and physical functioning following the critical care admissions among people with dementia, besides their survival, place of death and repeated hospitalisations can inform the overall appropriateness of the quality of care.
Efficiency & cost-effectiveness	Whether the improvements in health and survival following critical care admissions among people with dementia at a population level are at an equipoise. While the low incidence of critical care admissions among people with dementia signals towards careful consideration regarding efficiency and the cost-effectiveness, slight increase observed in the admissions occurring in the last year of life may not be efficient or cost-effective for the overall quality of care experienced by people with dementia nearing the end of life.
Capacity	Critical care is a resource-intensive service and the overall capacity of the healthcare professionals, bed availability in critical care units and general hospital wards may have an impact on the quality of care.[121]

Chapter 7: Result Study 3 – Variations in healthcare use

This chapter presents the specific methods and the findings for Study 3.

Personal contributions: I was responsible for devising the study approach and analysis plan. I sought and gained approval from the CRIS oversight committee to conduct the research using the CRIS-HES linkage. I outlined the selection criteria to define the cohort and data extraction requirements. I cleaned the data, performed the analysis and drafted the manuscript. I sought advice from statisticians using the Biostatistics and Health Informatics Advisory Service and more detailed input in the conduct and presentation of the analysis from Ewan Carr. My PhD supervisors were consulted throughout and provided input on the analysis plan and review and editing of the manuscript. I would like to acknowledge Hitesh Shetty and Daisy Kornblum for extracting the data.

7.1 Introduction

This study addressed the thesis objective 2: To identify subgroups of people with dementia who experience distinct patterns of healthcare use over the course of the illness until the end of life and to examine associated factors. This study also contributed to the thesis objective 3. (To use these findings to describe the quality of care received by people with dementia nearing the end of life and guide policy and practice for this population).

Study 1 of the thesis showed that there may be a relationship between the time of dementia diagnosis and the increased healthcare use towards the end of life, as people with dementia who lived with a dementia diagnosis for a shorter duration had higher rates of unplanned hospital admissions. Adapting the healthcare system to be efficient and providing high-quality care to everyone with dementia, from diagnosis until the end of life, are public health priorities.[279] However, there is considerable variability in the healthcare needs and use among people with dementia influenced by biological, social and environmental factors,[1] such as dementia type,[41] comorbidities,[137] age, and gender,[114] and availability and accessibility of appropriate services.[41, 273, 280] To understand variations in healthcare use and care quality among people with dementia, prior studies, including Study 1 and 2 of the thesis, have considered quality indicators such as the frequency of dementia reviews, outpatient visits, the incidence of unplanned hospital admissions, and the location of death. [11, 79, 103, 245, 281] However, the number and type of services accessed concurrently and how healthcare use changes from diagnosis to the end of life remain unknown.

The period immediately following a dementia diagnosis and the last year of life have been identified as critical points that provide opportunities for improving care.[111, 282] The initial period offers opportunities for a holistic assessment of needs, educating people with dementia and their families about prognosis, future care planning, and preventative interventions.[273] Similarly, during the last year of life, many people with dementia experience frequent healthcare use, such as unplanned hospital admissions[245] and emergency department visits.[110] Some of these services may be of limited benefit, burdensome for individuals, and costly;[11, 207, 254] on the other hand, people with dementia also face barriers to receiving optimal care and access to specialist services.[36, 273, 283] The development of effective interventions for people with dementia to reduce hospital use and improve access to appropriate (yet not overly cumbersome) services depends on knowledge of who may be most at risk.[284] Understanding how patterns of healthcare use vary from diagnosis to death could help inform service planning.

Previous research exploring patterns and costs of care in people with dementia identified subgroups of low, moderate, and high healthcare use often among people who were newly diagnosed, or limited to a care setting.[285-287] While previous research has explored patterns of healthcare use among people with dementia, no study has examined healthcare use among people with dementia from diagnosis to death.

This study aimed to (1) identify subgroups within a large sample of people with dementia, characterised by healthcare use in the year after diagnosis and the last year of life (2) describe biopsychosocial factors associated with service use subgroups, and (3) explore moves between subgroups over time.

7.2 Methods

7.2.1 Study design and data sources

This was a retrospective study assembled using linkages between a clinical dataset (South London and Maudsley National Health Service (NHS) Foundation Trust Biomedical Research Centre's (SLaM BRC) Clinical Record Interactive Search (CRIS) and administrative datasets (Hospital Episode Statistics' Admitted Patient Care (APC), Adult Outpatient Care (OP), Accident & Emergency Care (A&E)), and the Office for National Statistics (ONS) death registry) (Figure 7-1). Detailed information on the individual datasets is detailed in Methods, Section 4.8.1.

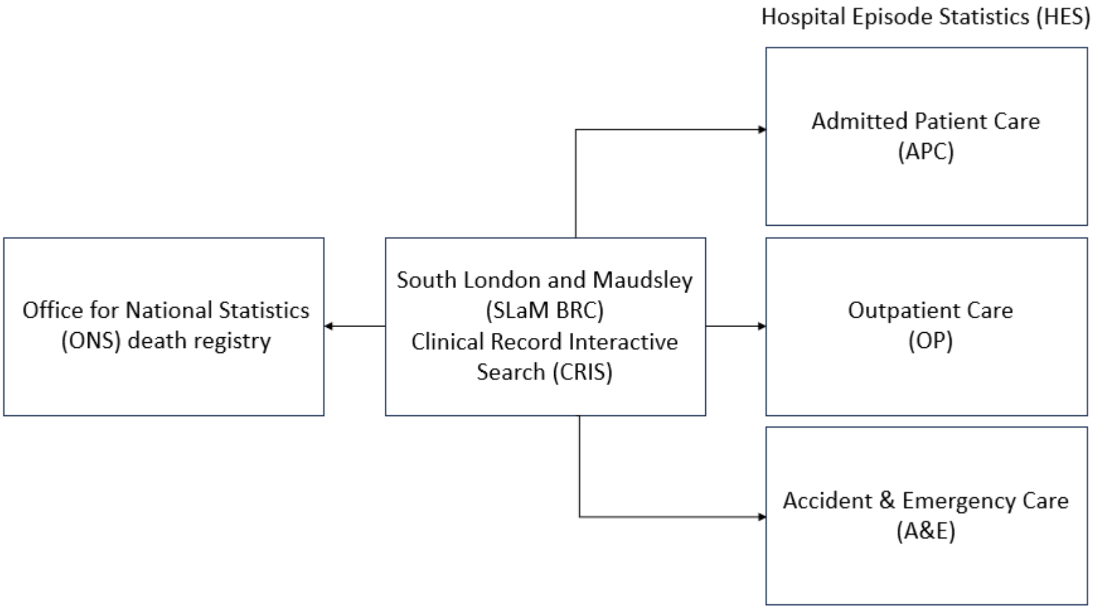

Figure 7-1. Datasets and linkages used in the study

7.2.2 Setting and cohort

The cohort was extracted from SLaM using the CRIS platform. All recorded dementia diagnoses from CRIS were determined from structured fields in the source record requiring International ICD-10 diagnosis codes (F00x–03x). The sample comprised decedents who were aged 50 or older at their first recorded dementia diagnosis between 2006 and 31st March 2020. The cohort was further restricted to those who lived for at least two years after receiving this dementia diagnosis to ensure at least one year of follow-up for each time period (Figure 7-2).

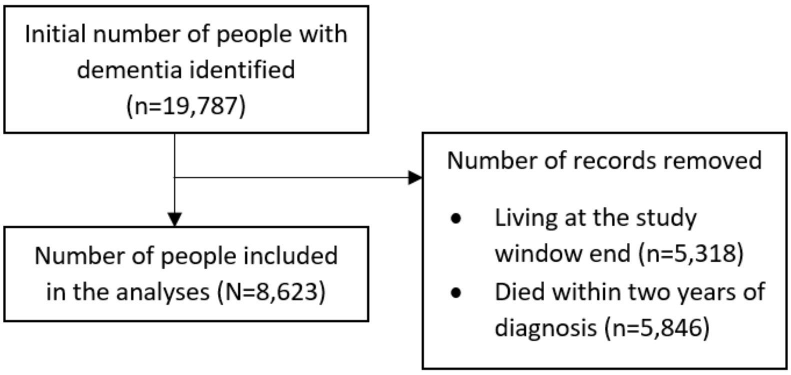

Figure 7-2. Cohort flowchart

7.2.3 Selecting the latent class indicators

The selection of healthcare measures which would be used to quantify healthcare use latent classes were based on:

- Number of unplanned hospital admissions (HES APC)
- Number of planned hospital admissions (HES APC)
- Combined duration of hospital inpatient episodes (HES APC)
- Number of A&E attendances (HES A&E)
- Number of outpatient appointments (HES OP)
- Number of community mental health nurse visits (SLaM)
- Number of community mental health allied health professionals (therapists) visits (SLaM)
- Number of other face-to-face mental healthcare events (SLaM)

Detailed descriptions of each indicator are presented in Table 7-1. These variables were used as the indicators of the latent classes.

Each indicator was measured over two time periods:

Time period 1: Within one year following the date of first recorded dementia diagnosis.
Time period 2: Within the one year prior to the date of death.

Initial models included critical care admissions as latent class indicators. However, critical care admissions were not discriminatory enough between groups and presented low quality of class indicator and separation between classes. Hence, they were not included in the final models.

Table 7-1. Descriptions for latent class indicators

Indicator	**Source database**	**Description**
Number of planned hospital admissions	HES APC	Elective hospital admissions were identified using the ADMIMETH variable. One admission was defined as a continuous inpatient stay (an unbroken period that a patient spends as an inpatient).
Number of unplanned hospital admissions	HES APC	Non-elective hospital admissions were identified using the ADMIMETH variable. One admission was defined as a continuous inpatient stay (an unbroken period that a patient spends as an inpatient)
Length of hospital stay	HES APC	Total number of days spent in hospital.
Number of A&E attendances	HES A&E	Total number of A&E attendances
Number of outpatient appointments	HES OP	Total number of outpatient appointments attended at a hospital.
Number of community mental health nurse visits	SLaM BRC CRIS	All home visits by a mental health nurse
Number of community mental health allied health professionals (therapists) visits	SLaM BRC CRIS	All home visits by allied health professionals (e.g., occupational therapists, physiotherapists, speech and language therapists)
Number of other face-to-face mental healthcare events	SLaM BRC CRIS	All other face-to-face events which occurred in the community not described as a nurse or an allied health professional visit (e.g., visit to a day care centre).

Note: All NHS hospital services are covered by HES datasets. Only 1% of UK hospital services are not provided by the NHS,[226] and these are unlikely to be relevant to the hospital use of people with dementia. Hence, the predictor variable was recorded as “0” when no record was detected.

7.2.4 Selecting the sociodemographic, illness-related and environmental variables

It is important to select indicators and covariates which would predict class membership informed by theory, and balancing theory-based information with what is available in the routine data resource. The model developed by Murtagh et al.[1] encompasses personal and demographic, disease-related and specific symptoms illness burden and trajectories, and environmental factors to explain what might influence place of care and death. This a comprehensive model including some factors which have been shown to affect healthcare utilisation by people with dementia towards the end of life. The inclusion of specific determinants for each category and the addition of ‘specific symptoms, illness burden, and trajectories’ makes this model appropriate for informing the study and analyses.

A range of sociodemographic, environmental and disease-related factors based on their reported associations with healthcare use in people with dementia were considered for the regression models.[1, 68] Some characteristics - including carer availability, social isolation, age of leaving formal education, and occupation - were extracted, but not included in the analysis due to large amount of missing and concerns about the quality of information.

Characteristics included in the study were: age, sex, ethnicity, neighbourhood-level socioeconomic status estimated using IMD,[220] dementia type, dementia severity (MMSE), HoNOS[260], comorbidities including depression, hypertension, receiving a care package, living alone and the total number of medications with strong anticholinergic effects (measured near the time of diagnosis) [169, 288] (see Appendix 6 for additional information) at both time points. Use of medications with strong anticholinergic effects (anticholinergic medication - the Anticholinergic Effect on Cognition scale)[288] is a quality indicator due to its association with increased risk of cognitive decline and of dementia and death.[169] The place of death (categorised as died in hospital/died elsewhere) was derived from HES as this was not available in the mortality dataset.

7.3 Statistical analysis and background for the statistical analysis methods

Sections 8.3.1 to 8.3.5 provide background information and rationale for the chosen statistical analysis methods of this study. The subsequent sections (Sections 8.3.6 to 8.3.7) outline the methods used to meet the study aims.

7.3.1 Structural equation modelling

Structural equation modelling (SEM) refers to a set of statistical techniques used to measure and analyse the relationships between observed and latent variables. SEM is a multivariate statistical analysis technique that is a combination of path models and measurement models. It employs statistical models to investigate the structural relationships between latent variables underlying the actual variables taken from observed data.[289] SEM requires the construction of a model to represent how observed or theoretical variables relate to each other. The structural aspect of the model implies theoretical assumptions between the variables. The equations in SEM refer to the mathematical and statistical properties of the implied model and its features, which are estimated with statistical algorithms run on observed data.

SEM is useful for social and healthcare scientists because it helps reveal phenomena which sit within the complexity of the social reality yet cannot be always directly observed or measured. Measuring relationships amongst all variables means the errors are more accurate than if each part of the model were calculated separately.[290]

While each technique under the SEM umbrella is different, the following are the logical steps that are followed in SEM: model specification, model identification, parameter estimation, model evaluation, and model explanation and communication of the findings. The model specification defines the hypothesized relationships among the variables (observed and latent) based on theory. In specifying pathways, relationships between variables can be left 'free' to vary or 'fixed' if the variables already have an estimated relationship, based on previous studies.[291] Model identification refers to checking if there is enough information in the data to estimate the model parameters. The maximum likelihood estimation method is used to identify the most probable parameters within observed data for a hypothesised model. The program makes an initial guess and searches incrementally from the starting values for values which can be a better fit.

In SEM, the information available from the data is contained in the observed variance-covariance matrix. Parameters are estimated by comparing the actual and the estimated covariance matrices of the best-fitting model. Once the model is estimated, it is important to check how well the estimated model explains the data. This is facilitated by formal statistical tests and fit indices that capture different elements regarding the fit of the model. In SEM, model evaluation generally includes comparing different models to each other. Depending on the model evaluation, modifications may be required to improve the overall goodness of model fit. In addition to potential improvements to the statistical fit, modifications must make sense theoretically. Explaining the model and how it improves existing understanding is the final step in constructing a SEM model, which must be understood to a way of understanding a more complex picture.

Although there is no consensus on determining adequate sample size for SEM, the number of observations per measured parameter and degree of freedom must be considered. Nylund-Gibson and Choi[292] recommends 300 or more cases. In case of complex data and large number of indicators, having a larger sample size is to the advantage of the researcher. Large sample sizes can provide sufficient statistical power and precise estimates for SEM. The reasons are that as the sample size increases, maximum likelihood estimator can converge on true value, while having smaller standard errors. Traditional regression models assume no residual measurement error, while SEM model accounts for measurement errors which may randomly occur. Indicator variables which will be used define unobserved classes should be selected based on theoretical knowledge. There is no consensus on the number of indicator variables to include, but generally more indicator variables lead to better results.[293] Having a strong theoretical rationale for using specific indicator variables makes identifying and interpreting the classes easier, and results in findings that have clearer application to practice.[294]

7.3.2 Latent class analysis

Some phenomena in social and health sciences, such as healthcare use of people with dementia, can be represented by a model in which there are distinct subgroups of individuals. Distinct subgroups (i.e., categories) comprise the latent variables, which have multinomial distributions. Categorical latent variables are defined as those in which "*qualitative differences exist between groups of people*". [295c]

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[c] A note on terminology: Available literature makes a distinction between LCA and latent profile analysis (LPA), LCA having categorical indicators, and LPA having continuous indicators. The indicators in my models, i.e., healthcare measures, are count variables. There is no consensus on whether such models should be called LCA or LPA. Given that LCA is a more common terminology, I will be referring to my analysis as LCA.

Latent class analysis (LCA) involves probing to find out how many classes can be identified in the data, estimating their proportional sizes and measures within each class in the population. Latent classes are not measured directly but instead indirectly via two or more observed variables. A mixture model is defined as a probabilistic model for representing the presence of subgroups within a population, without requiring that an observed data should identify the subgroup to which an individual observation belongs. Mixture models can be used in exploratory and confirmatory analyses. In the traditional basis of LCA, researchers start with the local independence model and consider parameter restrictions on the indicator variances. Some restrictions are imposed by the statistical analysis programme utilised. For instance, Mplus by default imposes local independence and homogeneity across classes.[296] The resulting profiles are summaries of persons with similar patterns.

Phenotyping defined as “identification of patients possessing characteristics of interest” is often performed based on clinical knowledge. A person-centred focus on analysis is useful, where data often include heterogenous groups of individuals. The latent class analysis estimates the probability of each individual belonging to multiple subgroups. Group allocation is determined based on their highest membership probability. The probability-based (soft) approach to clustering is a major advantage of mixture models compared to rule-based (hard) clustering techniques, as the analysis explicitly accounts for the mentioned classification uncertainty.

Similar to the selection of indicator variables including covariates in the LCA should have theoretical basis. External variables can be covariates affecting the classes, and distal outcomes affected by the classes or a combination. There are two approaches to including external variables and estimating more complex models, namely the one-step and the three-step (also known as a stepwise) approach to analysis.[297] The three-step approach includes first estimating the latent class measurements, model parameters, and all potential number of classes, then classification of cases to the classes based on the selected model, and finally examining the relationship between classes and external variables, while accounting for classification errors. The one-step approach involves simultaneous inclusion of all indicators and external variables in a single model. Researchers tend to prefer the three-step approach as it is more intuitive to build a model, and then relate the external variables to the model. There are some studies supporting the use of three-step model in comparison to one-step model, as it may reduce bias and yield better parameters for the models.[298]

Finally, guidance for conducting LCA recommends validating the selected class solutions.[294] This validation stage involves checking to ensure that the identified typology is relevant to practice, and class assignments are related to real-life experiences as expected. The classes are named and accompanied with a description. Of note, it is important to be cautious of the “naming fallacy,” wherein the name of the class may not accurately reflect the class membership.[294]

7.3.3 The application of latent class analysis to healthcare data

Over recent years, latent class analysis, a method which is often used in the Psychology field and applied to survey data to characterise developmental phenomena, has been applied to identifying complex patient profiles using electronic healthcare data. Applying LCA to healthcare data comes with its own challenges. The researcher must make decisions about the data format. Traditionally, LCA uses categorical indicator variables, while latent profile analysis (LPA) uses continuous indicator variables. However, most healthcare use data are represented as count variables and the healthcare data are often zero-inflated, meaning a large proportion of people may not be using the service of interest. This requires modelling the data in a different way. Advantages of using routinely collected healthcare data are the large samples and the good recording of events which would have been difficult to prospectively obtain from people with dementia and their families over a long span of time.

Criteria used to select the number of classes are evolving (Table 7-2). To select a final model, multiple fit indices should be used and reported; within these, Bayesian information criteria (BIC) should be included as it may be the most reliable fit statistic; finally, theoretical interpretability should be considered. A class solution with superior statistical fit is not useful if it does not make sense in practice and theory.

Table 7-2. Fit indices and criteria for model selection

Measure	**Selection criteria**	**Explanation**
Aikaike’s Information Criterion (AIC)	Parsimony	Model with the smallest AIC among a set of models is likely to be the best model. May select more complex models
Bayesian Information Criterion (BIC)	Parsimony and sample size	Model with the smallest BIC among a set of models is likely to be the best (and true) model. May select too parsimonious models.
Sample-size adjusted Bayesian information criterion (ssBIC)	Parsimony and sample size	Model with the smallest BIC among a set of models is likely to be the best (and true) model. Adjustment reduces sample size penalty.
Adjusted Lo-Mendell-Rubin	A small probability value (e.g., p <	An analytical correction to the

(LMR) likelihood ratio test	.05) indicates that the K0-class model provides significantly better fit to the observed data than the K −1-class model	likelihood ratio test statistic.
Vuong-Lo-Mendell-Rubin (VLMR) adjusted likelihood ratio test	A small probability value (e.g., p < .05) indicates that the K0-class model provides significantly better fit to the observed data than the K −1-class model	An analytical correction to the LMR likelihood ratio test statistic.
Bootstrapped likelihood ratio test (BLRT)	A small probability value (e.g., p < .05) indicates that the K0-class model provides significantly better fit to the observed data than the K −1-class model	Bootstrap resampling method approximates the p-value of the generalized likelihood ratio test comparing the K0-class mixture model with the K −1-class mixture model.
Entropy	Value close to 1 (not lower than 0.60, ideally 0.80 or higher)	Indicates how accurately the model defines classes. A measure of aggregated classification uncertainty.
Class size	Classes should not contain less than 5% of the sample	If a class size is too small, consider if model fit statistics support the selected model

7.3.4 Latent transition analysis

Latent transition analysis (LTA) also referred to as latent Markov modelling, is a longitudinal model, uniquely positioned to describe stability and change in latent classes across time.[299] LTA builds on LCA model as the measurement model, having the same set of latent class indicators at multiple time points, while providing additional transition probability parameters that describe movement among the latent classes. LTA is a special case of latent Markov models, where each latent variable is characterised by multiple indicators, and the latent class variable at a future time point is regressed onto the previous latent class variable.[299] Restrictions can be imposed on transition probability parameters if these are meaningful in terms of practice and theory. LTA is conducted in a similar manner to LCA and similarly has measurement and structural models. First, the researcher identifies LCA models for each time point, then explores covariates affecting the LCA models, then fit an LTA model informed by the LCA models, checking for measurement invariance, and finally once the LTA model is identified, auxiliary variables (i.e., covariates and distal outcomes) which may affect transition probabilities can be incorporated into the structural model. Sample size recommendations for LTAs are generally based on cross-sectional LCAs and LPAs, which range between 300 to 1,000 cases.[292] Researchers can have more confidence on the estimation of their LTA model parameters if their model have (a) homogenous classes, (b) between-class separation, (c) large transition probabilities, (d) large sample size, and (e) large class sizes at first time point.[299, 300]

7.3.5 Latent transition analysis compared to other longitudinal analysis methods

When exploring questions about change over time, LTA is one of many latent longitudinal models one can choose from. Each model provides a different way to describe changes over time to address specific research questions. One of the most used latent longitudinal models is the latent growth curve model which uses growth parameters (e.g., intercept and slope growth latent factors and their variances) to address research questions about the average rate of change over time. On the other hand, LTA models are more useful for describing discrete timepoint to timepoint changes, not requiring the duration between two time points to be same for everybody. Repeated measures LCA is another model person-centred model which measures latent classes repeated across time, mainly differing from LTA models as it does not have an autoregressive component or transition probabilities between repeated timepoints.[301]

A recent development to LTA models, was the introduction of the random intercept LTA (RI-LTA) model in 2020.[302] RI-LTA is an extension of LTA which provides a clearer interpretation of the data by allowing random intercept variation in the model, where between-subject variation is separated from within-subject latent class transitions over time. RI-LTA models use an additional latent variable, either continuous (factor) or categorical (groups), to capture variation at the individual level. RI-LTA may improve model fit compared to LTA; however, in situations where there are no stable between-subject differences, RI-LTA may not work. From recent comparisons of LTA and RI-LTA models, it was shown that RI-LTAs may provide little additional information in some contexts, such as for LTAs with two timepoints and those with indicator variables that are mainly representing a state (e.g., healthcare measures).[299] In such instances, LTA compared to RI-LTA may be sufficient if it provides a more parsimonious solution. Further research is needed to better understand the benefits and applicability of RI-LTA.

The choice of model depends on the research question and the available data. For the specific example of healthcare use patterns of people with dementia over time various considerations based on available literature and findings from the earlier study of patterns of unplanned hospital admissions were informative in choosing an LTA model. First, latent growth curve models tend to be used with data that are available for all participants over a distinct time period. Findings from study

1 showed that people with dementia are a heterogenous group in terms of their survival after receiving a dementia diagnosis. Second, the year after diagnosis and the year before death were determined to be key periods of where people with dementia particularly come in contact with healthcare services.[282] Third, the interest of this thesis is in the care of people with dementia who may be approaching the end of life, thus exploring opportune times for measuring and improving their care. Hence, limiting the sample to the decedents rather than predicting competing risk of death between multiple time points was both a pragmatic choice and partly based on previous findings which highlight higher rates of healthcare use in the last year of life.[110, 245, 269]

7.3.6 Statistical analysis methods used in the Study 3

The statistical analyses were in four parts. First, I described the cohort using appropriate summary statistics (frequencies for categorical variables; means and standard deviations (SDs) for continuous variables). Second, I used latent class analysis to identify subgroups based on the measures of healthcare use separately in the first year of diagnosis and in the last year of life. Latent class analysis allows identification of subgroups with shared commonality from multiple indicators of healthcare use. From our LCA models, each participant was assigned to given subgroups (separately for healthcare use in the first year of diagnosis and in the last year of life) based on their highest probability of class membership. Third, service use and socio-demographic characteristics of each group were described and the associations between characteristics of people with dementia and subgroups were analysed using multinomial logistic regression. The characteristics included in regression models were selected based on existing knowledge and theories.[1, 68, 114, 169]

Another approach to classifying individuals into healthcare groups is to also include covariates (i.e., biopsychosocial factors) as latent class indicators. The literature is conflicted on whether to include covariates when enumerating latent class models.[315] Previous studies applying this method have a small number of covariates and often use survey or stimulation data which are more suited for complex adjustment compared to real-life data.[315] The classification differences which may arise due to not including the covariates in our study was minimised by the large sample size.[316]

Fourth, latent transition analysis (LTA) was used to consider changes in healthcare use over time. LTA uses full information maximum likelihood estimation to incorporate LCA and autoregressive modelling. This allows for the exploration of unobserved subgroups within a given population and then change in class membership over time, and investigation of covariates to better understand the classes and transitions.[299] LCA estimates two main parameters, latent class membership probabilities and item-response probabilities, conditional on class membership. LTA provides estimated transition probabilities, which are the structural parameters related to the movement of individuals among the classes over time. We reported coefficients from the multinomial logistic regression as relative risk ratios (RRRs) accompanied with 95% confidence intervals (CI). The conversion of the estimated coefficients provides relative risk ratio, an exponentiated value of a coefficient (e^b, probability (outcome i)/probability(base outcome)), for one-unit change in the corresponding variable (i.e., risk of the possibility of belonging to a latent class relative to the base outcome). Standard errors and confidence and confidence intervals are similarly converted. This conversion affects how results are displayed but not how they are estimated.

7.3.6.1 Missing data

In line with recommendations,[303, 304] multiple imputation, with 20 sets, was used for the HoNOS cognitive problems, HoNOS physical problems, ethnicity and IMD variables, proportionate to missing ranging between 1.9% and 4.9%. Complete case analyses for the first year after diagnosis and the last year of life classes were conducted as sensitivity analysis (see Appendix 6).

7.3.6.2 Identifying the optimal number of classes

To identify the optimal number of classes, I estimated models with between 1 and 6 classes. The final model was chosen based on fit indices and based on clinical interpretability. I used model-fit indices including AIC, BIC, ssBI, where smaller numbers indicate better fit. Likelihood-ratio tests (LRTs including Vuong-Lo-Mendell-Rubin and adjusted Lo-Mendell-Rubin), entropy, the percentage and size of the smallest class, and an average latent class posterior probabilities to being >0.80 were also taken into account.[294] Model identification was determined by fitting the model using multiple sets of random starting values.[305]

Descriptors for each class were agreed upon through discussion with the research team, clinical teams, and patient and public representatives. Discussions I had with the PPI members will be presented in Section 7.4.7. Data preparation and descriptive analyses were undertaken in Stata 16.[265] Latent variable modelling was undertaken in Mplus 8.[296]

7.3.7 Sensitivity and exploratory analyses

A sensitivity analysis was conducted for the latent class analysis which included all decedents who lived for a year or longer after their dementia diagnosis. For LTA, I tested the fit and consistency of the classes over two time points, by comparing latent transition models in which parameters were freely estimated with models in which parameters were constrained to be equal across the time points (i.e., measurement invariance).[306] Additionally, latent transition analysis with different class structures and covariates effects (i.e., gender and duration between first year following dementia diagnosis and death) on the latent transition probabilities were also explored. During the model building and as part of the exploratory analyses, I tested the applicability of RI-LTA models and various other models exploring the effect of covariates on the transition probabilities. However, these models did not converge.

7.4 Results

7.4.1 Cohort description

I extracted data on 14,469 decedents who were diagnosed with dementia. 5,846 people for were diagnosed with dementia for less than two years (Figure 7-2). The excluded sample were diagnosed with dementia at an older age (p<0.001) and had a higher proportion of people with Vascular dementia (p<0.001) (see Appendix 6). Biopsychosocial characteristics and the use of healthcare services by the sample of 8,623 people with dementia are summarised in Table 7-3. 61.7% were female; 75.2% were of White ethnicity; 35.1% had Alzheimer's disease as their primary dementia diagnosis. The use of each healthcare service differed between the first year of diagnosis and the last year of life (Table 7-4). Compared to the last year of life, during the first year after diagnosis, participants had a higher use of specialist mental healthcare, higher planned hospital use, lower unplanned hospital use, and shorter combined hospital stays.

Table 7-3. Cohort characteristics (N=8,623)

Gender	
woman	5,323 (61.7%)
man	3,300 (38.3%)
Age at diagnosis – death	81.5 (7.7) - 86.3 (7.4)
Ethnicity groups	
White	6,487 (75.2%)
Mixed	55 (0.6%)
Asian	405 (4.7%)
Black	1,337 (15.5%)
Other	176 (2.0%)
Not known	163 (1.9%)
First dementia diagnosis	
Alzheimer's disease	3,030 (35.1%)
Mixed dementia	1,223 (14.2%)
Unspecified dementia	2,140 (24.8%)
Vascular dementia	1,624 (18.8%)
Dementia in other diseases	606 (7.0%)
IMD quintiles	
1 (Most deprived)	1,600 (18.6%)
2	3,280 (38.0%)
3	1,819 (21.1%)
4	1,000 (11.6%)
5 (Least deprived)	601 (7.0%)
Missing	323 (3.7%)
MMSE at diagnosis mean (SD)	18.2 (6.4)
mild	2,583 (30.0%)
moderate	2,259 (26.2%)

severe	574 (6.7%)
Missing	3,207 (37.2%)
Hypertension	2,053 (23.8%)
Depression	637 (7.4%)
HoNOS cognitive problems	
0	95 (1.1%)
1	999 (11.6%)
2	3,642 (42.2%)
3	2,799 (32.5%)
4	676 (7.8%)
Missing	412 (4.8%)
Physical illness or disability problems	4,259 (49.4%)
Missing	413 (4.8%)
Other mental and behavioural problems	2,060 (23.9%)
Missing	532 (6.2%)
Problems with relationships	1,316 (15.3%)
Missing	431 (5.0%)
Problems with activities of daily living	4,797 (57.7%)
Missing	439 (5.1%)
Problems with living conditions	984 (11.4%)
Missing	515 (6.0%)
Living alone at the time of diagnosis recorded in notes	
Yes	1,498 (17.4%)
No	7,125 (82.6%)
Recorded as a care package recipient at the time of diagnosis	
Yes	3,879 (45.0%)
No	4,744 (55.0%)
Number of medications with strong anticholinergic effects at diagnosis	
0	5,256 (61.0%)
1	1,832 (21.2%)
2	950 (11.0%)
3	414 (4.8%)
4	134 (1.6%)
5+	37 (0.4%)
Place of death	
Died in hospital	2,497 (29.0%)
Died elsewhere	6,126 (71.0%)

Note: MMSE: mini-mental state examination; SD: standard deviation; IMD: index of multiple deprivation (1 = most deprived, 5 = most affluent). HoNOS scores were dichotomised (scores 0 and 1—no or minor problems, scores 2 to 4—mild to severe problems) to facilitate interpretation.

Table 7-4. Age-standardised healthcare use of people with dementia in the first year after diagnosis & in the last year of life mean (SD) (N=8,623)

	First year after diagnosis	Last year of life
A&E visits	1.1 (2.1)	3.6 (8.6)
Unplanned hospital admissions	1.3 (2.9)	2.4 (1.7)
Length of hospital stay (days)	5.2 (9.8)	13.9 (21.6)
Planned hospital admissions	0.8 (6.0)	0.6 (4.3)
Hospital outpatient appointments	3.1 (5.5)	2.1 (4.5)
Other face-to-face appointments mental healthcare events	14.1 (27.9)	1.2 (4.6)
Community mental health nurse visits	3.8 (11.5)	0.7 (4.2)
Therapist visits	1.9 (6.6)	0.5 (3.2)

7.4.2 Model fit

The model fit statistics used to guide the selection of the number of classes are presented in Table 7-5. Based on the model fit statistics and the sizes of the classes, three (where the largest reduction in BIC is observed) and four-class solutions were further scrutinised and discussed with the wider team.

Table 7-5. Fit indices for latent class models with 1-6 classes (N=8,623)

	Fit indices				Likelihood ratio tests		
Classes	LL	BIC	ssBIC	AIC	VLMR p	Adjusted LMR p	Entropy
First year after diagnosis							
1	-113068.973	226185.945	226279.170	226185.945			
2	-110083.846	220466.745	220361.877	220233.693	<.0001	<.0001	0.785
3	-108337.055	217054.721	216921.253	216758.109	<.0001	<.0001	0.746
4	-107416.417	215295.006	215132.938	214934.835	<.0001	<.0001	0.787
5	-106819.589	214182.910	213992.240	213759.178	.0001	.0001	0.774
6	-106443.202	213511.695	213292.426	213024.404	.0578	.0590	0.762
Last year of life							
1	-84174.409	168857.308	168849.040	168184.816			
2	-83876.598	168052.249	167947.380	167819.196	<.0001	<.0001	0.907
3	-82491.985	165364.582	165231.114	165067.970	<.0001	<.0001	0.859
4	-81887.726	164237.623	164075.554	163877.451	<.0001	<.0001	0.804
5	-81396.287	163336.304	163145.635	162912.573	.3732	.3754	0.835
6	-81070.170	162765.631	162546.361	162278.340	<.0001	<.0001	0.834

Abbreviations: LL = log-likelihood; BIC = Bayesian Information Criterion; ssBIC = sample size adjusted BIC; AIC = Akaike information criterion; VLMR = Vuong-Lo-Mendell-Rubin; LMR = Lo-Mendell-Rubin.

7.4.3 Subgroups of healthcare use in the first year after dementia diagnosis

For the first year after diagnosis, a three-class model gave the optimal model fit (Table 7-5) and clinical interpretability following discussion within the research team. Posterior probabilities for class membership ranged between 81% to 95%. Table 7-6 provides descriptives for the sociodemographic, illness-related and environmental characteristics of the people with dementia for each class, while healthcare use among each class is demonstrated in Figure 7-3 and Table 7-7.

Table 7-6. Descriptives for the first year after dementia diagnosis classes

	Low healthcare use after diagnosis n=4,258 (49.4%)	Planned and unplanned hospital use after diagnosis n=2,939 (31.4%)	Mental healthcare use after diagnosis n=1,426 (16.5%)
	N=4,258	N=2,939	N=1,426
Gender			
woman	2,692 (63.2%)	1,757 (59.8%)	874 (61.3%)
man	1,565 (36.8%)	1,182 (40.2%)	552 (38.7%)
Age at diagnosis – death	81.3 (7.6) - 86.4 (7.2)	82.7 (7.5) - 87.0 (7.3)	79.7 (8.0) - 84.5 (7.9)
Ethnicity groups			
White	3,170 (74.4%)	2,231 (75.9%)	1,086 (76.2%)
Mixed	35 (0.8%)	11 (0.4%)	9 (0.6%)
Asian	222 (5.2%)	141 (4.8%)	42 (2.9%)
Black	641 (15.1%)	423 (14.4%)	273 (19.1%)
Other	98 (2.3%)	63 (2.1%)	15 (1.1%)
Not known	92 (2.2%)	70 (2.4%)	1 (0.1%)
First dementia diagnosis			
Alzheimer’s disease	1,742 (40.9%)	912 (31.0%)	376 (26.4%)
Mixed dementia	601 (14.1%)	470 (16.0%)	152 (10.7%)
Unspecified dementia	988 (23.2%)	746 (25.4%)	406 (28.5%)
Vascular dementia	711 (16.7%)	611 (20.8%)	302 (21.2%)
Dementia in other diseases	216 (5.1%)	200 (6.8%)	190 (13.3%)
IMD quintiles			
1	762 (17.9%)	578 (19.7%)	260 (18.2%)
2	1,527 (35.9%)	1,139 (38.8%)	614 (43.1%)
3	932 (21.9%)	594 (20.2%)	293 (20.5%)
4	546 (12.8%)	331 (11.3%)	123 (8.6%)
5	342 (8.0%)	179 (6.1%)	80 (5.6%)
Missing	149 (3.5%)	118 (4.0%)	56 (3.9%)
MMSE mean(SD)	18.3 (6.4)	18.3 (6.2)	17.8 (6.8)
mild	1,313 (30.8%)	794 (27.0%)	476 (33.4%)
moderate	1,097 (25.8%)	736 (25.0%)	426 (29.9%)
severe	280 (6.6%)	160 (5.4%)	134 (9.4%)
Missing	1,568 (36.8%)	1,249 (42.5%)	390 (27.3%)
Total HoNOS score	9.4 (5.1)	10.7 (5.1)	12.7 (5.6)
HoNOS cognitive problems			
0	39 (0.9%)	23 (0.8%)	33 (2.3%)
1	522 (12.3%)	311 (10.6%)	166 (11.6%)
2	1,850 (43.4%)	1,195 (40.7%)	597 (41.9%)
3	1,302 (30.6%)	1,015 (34.5%)	482 (33.8%)
4	308 (7.2%)	231 (7.9%)	137 (9.6%)
Missing	237 (5.5%)	164 (5.6%)	11(0.7%)
HoNOS physical problems	1,775 (41.7%)	1,699 (57.8%)	785 (55.0%)
Missing	237 (5.6%)	164 (5.6%)	12 (0.8%)
HoNOS other mental health issues	909 (21.3%)	666 (22.7%)	485 (34.0%)
Missing	299 (7.0%)	210 (7.1%)	23 (1.6%)
HoNOS relationship problems	514 (12.1%)	398 (13.5%)	404 (28.3%)
Missing	247 (5.8%)	171 (5.8%)	13 (0.9%)

HoNOS problems with daily living	2,204 (51.8%)	1,803 (61.3%)	972 (68.2%)
Missing	246 (5.8%)	176 (6.0%)	17 (1.2%)
HoNOS problems with living conditions	355 (8.3%)	382 (13.0%)	247 (17.3%)
Missing	278 (6.5%)	211 (7.2%)	26 (1.8%)
Living alone at the time of diagnosis	578 (13.6%)	574 (19.5%)	346 (24.3%)
Care package recipient	1,722 (40.4%)	1,280 (43.6%)	877 (61.5%)
Number of medications with strong anticholinergic effects at diagnosis			
0	2,924 (68.7%)	1,884 (64.1%)	448 (31.4%)
1	824 (19.4%)	641 (21.8%)	367 (25.7%)
2	359 (8.4%)	273 (9.3%)	318 (22.3%)
3	114 (2.7%)	104 (3.5%)	196 (13.7%)
4	31 (0.7%)	29 (1.0%)	74 (5.2%)
5	6 (0.1%)	7 (0.2%)	20 (1.4%)
6	0 (0.0%)	1 (0.0%)	3 (0.2%)

Note: MMSE: mini-mental state examination; SD: standard deviation; IMD: index of multiple deprivation (1 = most deprived, 5 = most affluent). HoNOS scores were dichotomised (scores 0 and 1—no or minor problems, scores 2 to 4—mild to severe problems) to facilitate interpretation.

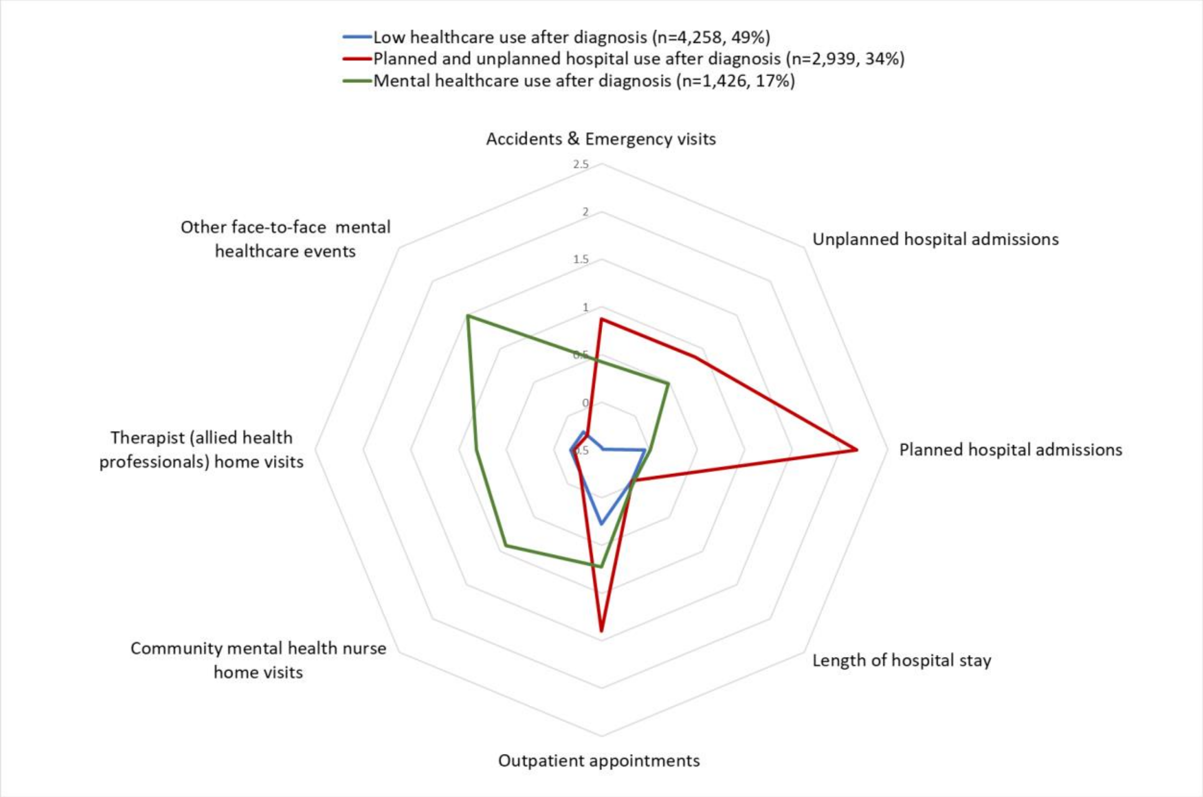

Figure 7-3. Radar plot showing healthcare use* classes of people with dementia in the first year after dementia diagnosis *For a clear interpretation of which indicators are above or below the sample means, I used the z-standardised mean scores in figures[307]

Table 7-7. Healthcare use of people with dementia in the first year after diagnosis (n=8,623)

	First year after diagnosis		
Mean (SD)	Low healthcare use after diagnosis n=4,258 (49.4%)	Planned and unplanned hospital use after diagnosis n=2,939 (31.4%)	Mental healthcare use after diagnosis n=1,426 (16.5%)
A&E visits	0.1 (0.3)	2.3 (2.7)	1.5 (2.0)
Planned hospital admissions	0.2 (0.7)	1.2 (9.4)	1.8 (3.0)
Unplanned hospital admissions	0.1 (0.1)	3.0 (3.5)	0.5 (1.1)
Length of hospital stay	0.0 (0.0)	2.1 (10.7)	0.1 (0.7)
Other face-to-face mental healthcare events	6.1 (5.5)	4.6 (3.9)	41.6 (45.7)
Community mental health nurse visits	1.6 (2.6)	1.4 (2.0)	13.1 (23.9)
Therapist visits	0.6 (1.8)	0.4 (1.1)	7.1 (13.2)
Outpatient appointments	2.2 (3.5)	4.6 (6.6)	2.8 (5.4)

The '*low healthcare use after diagnosis'* class was taken as the base for the regression analysis (Table 7-8). The classes were as follows:

Class 1 – Low healthcare use after diagnosis (n=4,258, 49%): Characterised by very low unplanned hospital (mean 0.1 SD (0.1) unplanned hospital admissions) and community mental healthcare use (community mental health nurse visits mean 1.6 SD(2.6)) ; interactions with healthcare mainly through face-to-face SLaM (mean 6.1 SD (5.5)), and outpatient appointments (mean 2.2 SD(3.5)).

Class 2 – Planned and unplanned hospital use after diagnosis (n=2,939, 34%): Characterised by high number of unplanned hospital visits including A&E visits and unplanned hospital admissions (mean 3.0 SD (3.5)). Compared to the 'low healthcare use' group, people in this group are more likely to have any other dementia diagnosis than Alzheimer's disease, less likely to be from a Mixed (RRR 0.46 (0.23-0.89)) ethnicity, more likely to be diagnosed at an older age (RRR 1.02 95%CI (1.02-1.04)) with more physical impairments (RRR 1.32 95%CI (1.27-1.38)). They are more likely to be male (RRR 1.26 95%CI (1.14-1.39)), living alone (RRR 1.52 95%CI (1.35-1.74)), and prescribed a higher number of medications with strong anticholinergic effects (RRR 1.15 95%CI (1.09-1.22)). A gradient effect was observed between the area-level deprivation (IMD) of where people lived and likelihood group membership, where people from most deprived areas were more likely to be in this subgroup compared to those who lived in the least deprived areas (IMD 5 vs IMD 1: RRR 1.50 95%CI (1.22-1.85)).

Class 3 – Mental healthcare use after diagnosis (n=1,426, 17%): Characterised by frequent contacts with the mental healthcare use services (e.g., community mental health nurse visits mean 13.1 SD (23.9)), and moderate hospital use (e.g., planned hospital admissions mean 1.8 SD (3.0)). Compared to the '*low healthcare use'* group, they are more likely to be diagnosed with vascular dementia (RRR 1.90 95% CI (1.62-2.23)), unspecified dementia (RRR 1.94 95% CI (1.62-2.31)), and dementia in other diseases (RRR 3.74 95%CI (2.97-4.73)). They are less likely to be from Asian (RRR 0.52 95% CI (0.37-0.73)), or other ethnicities (RRR 0.43 95% CI (0.25-0.75)). They are more likely be receiving a social care package (RRR 2.33 95%CI (2.06-2.63)), to be living alone (RRR 2.16 95%CI (1.86-2.52)), receiving a higher number of medications with strong anticholinergic effects (RRR 2.15 95%CI (2.03-2.28)), and experiencing physical problems (RRR 1.24 95%CI (1.17-1.30). People who lived in the most deprived three IMD Quintiles were more likely to be in this subgroup (IMD 5 vs IMD 1: RRR 1.40 95%CI (1.06-1.86)).

Table 7-8. Multinomial logistic regression with age and sex adjusted coefficients showing patient characteristics associated with the year after diagnosis classes: reference class: Class 1 Low healthcare use after diagnosis (N=8,623)

Characteristic	RRR (95% CI)	
	Planned and unplanned hospital use after diagnosis	Mental healthcare use after diagnosis
Male gender [Ref, woman]	**1.26 (1.14-1.39)**	0.99(0.88-1.13)
Age at diagnosis	**1.02 (1.02-1.04)**	**0.97 (0.97-0.98)**
Dementia diagnosis [Ref, Alzheimer's disease]		
Mixed dementia	**1.46 (1.26-1.68)**	1.20 (0.97-1.48)
Unspecified dementia	**1.44 (1.27-1.63)**	**1.90 (1.62-2.23)**
Vascular dementia	**1.67 (1.46-1.91)**	**1.94 (1.62-2.31)**
Dementia in other diseases	**1.96 (1.59-2.43)**	**3.74 (2.97-4.73)**
IMD Quintiles [Ref, 5 (least deprived)]		
1	**1.50 (1.22-1.85)**	**1.40 (1.06-1.86)**
2	**1.47 (1.21-1.79)**	**1.66 (1.28-2.16)**
3	**1.24 (1.01-1.53)**	**1.32 (1.02-1.74)**
4	1.17 (0.93-1.47)	0.95 (0.70-1.30)
Ethnicity groups [Ref, White]		
Mixed	**0.46 (0.23-0.89)**	0.71 (0.34-1.49)
Asian	0.95 (0.76-1.18)	**0.52 (0.37-0.73)**
Black	0.99 (0.86-1.13)	1.16 (0.99-1.36)
Other	0.93 (0.67-1.29)	**0.43 (0.25-0.75)**
Care package recipient [Ref, no]	**1.16 (1.05-1.28)**	**2.33 (2.06-2.63)**
Living alone [Ref, no]	**1.52 (1.35-1.74)**	**2.16 (1.86-2.52)**
Number of medications	**1.15 (1.09-1.22)**	**2.15 (2.03-2.28)**
HoNOS cognitive problems score	**1.11 (1.05-1.17)**	1.06 (0.98-1.14)
HoNOS physical problems score	**1.32 (1.27-1.38)**	**1.24 (1.17-1.30)**

Abbreviations: RRR (95% CI): Relative Risk Ratio (95% Confidence Intervals), Bold findings are statistically significant (p<.005). Ref: Reference Class, IMD: Index of Multiple Deprivation * 1= Most deprived, 5 = Least deprived, HoNOS: Health of the Nation Outcome Scales

7.4.4 Subgroups of healthcare use in the last year of life

For the classes based on healthcare use the last year of life, the model structure, response probabilities, and class prevalence were not similar to those identified for the first year after diagnosis.

The model fit criteria and discussion within the research team indicated that a 4-class model fit the data most appropriately for the last year of life healthcare use (Table 7-5). Posterior probabilities for class membership ranged between 79% to 94%. Table 7-9 provides descriptives for the sociodemographic, illness-related and environmental characteristics of the people with dementia for each class, while healthcare use among each class is demonstrated in Figure 7-4 and Table 7-10.

Table 7-9. Descriptives for the last year of life classes

	Low healthcare use in the last year of life n=2,756 (32.0%)	Moderate hospital use in the last year of life n=3,689 (42.8%)	High hospital use in the last year of life n=754 (8.7%)	Community mental healthcare use in the last year of life n=1,423 (16.5%)
	N=2,756	N=3,689	N=754	N=1,423
Gender				
woman	1,870 (67.9%)	2,342 (63.5%)	338 (44.8%)	773 (54.3%)
man	886 (32.1%)	1,347 (36.5%)	416 (55.2%)	650 (45.7%)
Age at diagnosis – death	81.9 - 87.3 (7.4) (7.8)	81.8 (7.6) - 86.5 (7.3)	80.5 (7.2) - 84.6 (7.1)	80.5 (7.6) - 84.6 (7.3)
Ethnicity groups				
White	2,078 (75.4%)	2,770 (75.1%)	533 (70.7%)	1,105 (77.7%)
Mixed	18 (0.7%)	25 (0.7%)	5 (0.7%)	7 (0.5%)
Asian	122 (4.4%)	173 (4.7%)	55 (7.3%)	55 (3.9%)
Black	400 (14.5%)	575 (15.6%)	129 (17.1%)	233 (16.4%)
Other	72 (2.6%)	64 (1.7%)	22 (2.9%)	18 (1.3%)
Not known	66 (2.4%)	82 (2.2%)	10 (1.3%)	5 (0.4%)
First dementia diagnosis				
Alzheimer's disease	1,053 (38.2%)	1,234 (33.5%)	253 (33.6%)	490 (34.4%)
Mixed dementia	363 (13.2%)	538 (14.6%)	119 (15.8%)	202 (14.2%)
Unspecified dementia	717 (26.0%)	900 (24.4%)	161 (21.4%)	362 (25.4%)
Vascular dementia	456 (16.5%)	765 (20.7%)	164 (21.8%)	239 (16.8%)
Dementia in other diseases	679 (24.7%)	959 (26.0%)	173 (23.0%)	395 (27.7%)
IMD quintiles				
1	1,018 (36.9%)	1,429 (38.7%)	293 (38.9%)	539 (37.9%)
2	576 (20.9%)	734 (19.9%)	173 (22.9%)	336 (23.6%)

3	338 (12.3%)	413 (11.2%)	99 (13.1%)	150 (10.5%)
4	200 (7.3%)	268 (7.3%)	53 (7.0%)	80 (5.6%)
5	112 (4.1%)	138 (3.7%)	20 (2.7%)	53 (3.7%)
Missing	18.3 (6.4)	18.1 (6.4)	19.4 (6.0)	17.8 (6.7)
MMSE mean(SD)				
mild	753 (27.3%)	1,029 (27.9%)	270 (35.8%)	531 (37.3%)
moderate	662 (24.0%)	925 (25.1%)	196 (26.0%)	476 (33.5%)
severe	160 (5.8%)	239 (6.5%)	32 (4.2%)	143 (10.0%)
Missing	1,181 (42.9%)	1,496 (40.6%)	256 (34.0%)	273 (19.2%)
Total HoNOS score	10.5 (5.4)	10.4 (5.2)	9.4 (5.0)	10.8 (5.6)
HoNOS cognitive problems				
0	28 (1.0%)	34 (0.9%)	10 (1.3%)	23 (1.6%)
1	282 (10.2%)	416 (11.3%)	115 (15.3%)	186 (13.1%)
2	1,141 (41.4%)	1,538 (41.7%)	340 (45.1%)	623 (43.8%)
3	907 (32.9%)	1,225 (33.2%)	211 (28.0%)	455 (32.0%)
4	234 (8.5%)	292 (7.9%)	30 (4.0%)	120 (8.4%)
Missing	164 (6.0%)	184 (5.0%)	48 (6.4%)	16 (1.1%)
HoNOS physical problems	1,320 (47.9%)	1,899 (51.5%)	369 (48.9%)	671 (47.2%)
Missing	163 (5.9%)	186 (5.0%)	48 (6.4%)	16 (1.1%)
HoNOS other mental health issues	694 (25.2%)	815 (22.1%)	144 (19.1%)	406 (28.5%)
Missing	200 (7.3%)	244 (6.6%)	57 (7.6%)	31 (2.2%)
HoNOS relationship problems	388 (14.1%)	546 (14.8%)	95 (12.6%)	287 (20.2%)
Missing	173 (6.3%)	190 (5.2%)	51 (6.8%)	17 (1.2%)
HoNOS problems with daily living	1,609 (58.4%)	2,152 (58.3%)	369 (48.9%)	848 (59.6%)
Missing	176 (6.4%)	192 (5.2%)	50 (6.6%)	21 (1.5%)
HoNOS problems with living conditions	324 (11.8%)	441 (12.0%)	59 (7.8%)	160 (11.2%)
Missing	213 (7.7%)	224 (6.1%)	49 (6.5%)	29 (2.0%)
Living alone at the time of diagnosis	504 (18.3%)	625 (16.9%)	113 (15.0%)	255 (17.9%)
Care package recipient	1,149 (41.7%)	1,529 (41.4%)	300 (39.8%)	900 (63.2%)
Time in SLaM	317.0 (16.0-973.0)	290.0 (14.0-868.0)	628.0 (106.0-1177.0)	1204.0 (879.0-1674.0)
Number of medications with strong anticholinergic effects				
0	1,733 (62.9%)	2,341 (63.5%)	491 (65.1%)	690 (48.5%)
1	566 (20.5%)	768 (20.8%)	169 (22.4%)	329 (23.1%)
2	312 (11.3%)	364 (9.9%)	70 (9.3%)	204 (14.3%)
3	96 (3.5%)	156 (4.2%)	16 (2.1%)	146 (10.3%)
4	40 (1.5%)	42 (1.1%)	7 (0.9%)	45 (3.2%)
5	8 (0.3%)	16 (0.4%)	1 (0.1%)	8 (0.6%)
6	1 (0.0%)	2 (0.1%)	0 (0.0%)	1 (0.1%)

Note: MMSE: mini-mental state examination; SD: standard deviation; IMD: index of multiple deprivation (1 = most deprived, 5 = most affluent). HoNOS scores were dichotomised (scores 0 and 1—no or minor problems, scores 2 to 4—mild to severe problems) to facilitate interpretation.

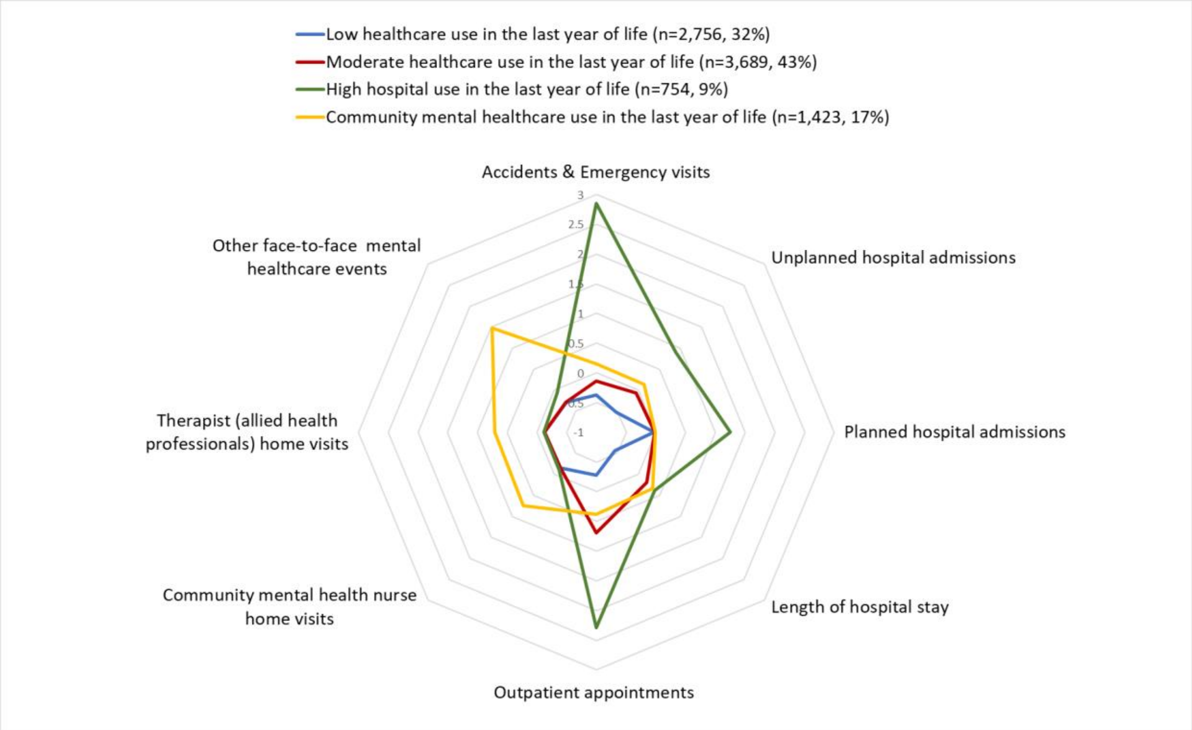

Figure 7-4. Radar plot showing healthcare use* classes of people with dementia in the last year of life *For a clear interpretation of which indicators are above or below the sample means, I used the z-standardised mean scores in figures[307]

Table 7-10. Healthcare use of people with dementia in the last year of life (n=8,623)

	Last year of life			
Mean (SD)	Low healthcare use in the last year of life n=2,756 (32.0%)	Moderate hospital use in the last year of life n=3,689 (42.8%)	High hospital use in the last year of life n=754 (8.7%)	Community mental healthcare use in the last year of life n=1,423 (16.5%)
A&E visits	0.1 (0.3)	2.6 (2.7)	23.1 (24.2)	3.9 (6.2)
Planned hospital admissions	0.0 (0.1)	0.0 (0.2)	0.9 (5.5)	0.1 (0.3)
Unplanned hospital admissions	1.3 (0.6)	2.0 (1.3)	3.3 (2.5)	2.7 (2.2)
Length of hospital stay	0.0 (0.0)	13.6 (17.9)	16.5 (19.1)	16.4 (24.8)
Other face-to-face mental healthcare events	0.0 (0.3)	0.0 (0.2)	0.9 (1.9)	7.1 (8.8)
Community mental health nurse visits	0.0 (0.1)	0.0 (0.0)	0.1 (0.4)	3.9 (10.5)
Therapist visits	0.0 (0.1)	0.0 (0.0)	0.0 (0.2)	2.0 (6.1)
Outpatient appointments	0.5 (1.2)	2.3 (4.2)	7.5 (9.7)	2.1 (3.4)

The '*low healthcare use in the last year of life'* class was taken as the base for the regression analysis (Table 7-11). The last year of life classes were as follows:

Class 1 – Low healthcare use in the last year of life (n=2756, 32%): Low healthcare use (n=2756, 32%): This group is characterised by low contact with hospital (e.g., A&E visits mean 0.1 SD (0.3)) and mental healthcare services (face-to-face Slam appointments mean 0.0 SD (0.3)). Almost everyone (99%) in this group died outside of a hospital.

Class 2 – Moderate hospital use in the last year of life (n=3,689, 43%): This group is characterised by low mental healthcare use (e.g., other face-to-face mental healthcare events 0.0 SD (0.2)), but moderate unplanned hospital use (e.g., unplanned hospital admissions mean 2.0 SD (1.3)), in addition to moderate outpatient appointments. Compared to those in the low healthcare use group, membership of this group was associated with male gender (RRR 1.22 95% CI (1.09-1.35)), mixed dementia (RRR 1.25 95% CI (1.07-1.46)), vascular dementia (RRR 1.41 95% CI (1.22 -1.62)), and dementia in other diseases (RRR 1.26 95% CI (1.03-1.55)). 41% of people in this group died in a hospital.

Class 3 – High hospital use in the last year of life (n=754, 9%): This group is characterised by high hospital use, a very high number of A&E visits, and higher unplanned and planned hospital admissions compared to the other three groups. People in this class are more likely to be men (RRR 2.51 95% CI (2.12-2.96)) and diagnosed at a younger age (RRR 0.98 95% CI (0.97-0.99)). They are significantly more likely to have a mixed (RRR 1.31 95% CI (1.02-1.66)) or a vascular dementia diagnosis (RRR 1.33 95% CI (1.06-1.67)). They are more likely to be of Asian ethnicity (RRR 1.58 95% CI (1.13-2.22)). They are less likely to receive medications with strong anticholinergic effects (RRR 0.88 0 95% CI (0.81-0.97)) and less severe cognitive problems at diagnosis (RRR 0.77 95% CI (0.69-0.84)). Half (51%) of people in this group died in a hospital.

Class 4 – Community mental healthcare use in the last year of life (n=1,423, 17%): This group is characterised by higher numbers of use of mental healthcare services while having moderate number of uses of hospital services. People in this class are more likely to be men (RRR 1.69 95% CI (1.48-1.92)) and diagnosed at a younger age (RRR 0.98 95% CI (0.97-0.99)). They are more likely to have dementia in another disease (RRR 1.40 95% CI (1.08-1.81)). They are likely to be receiving a care package (RRR 2.43 95% CI (2.12-2.77)), more likely to be receiving higher number of medications with strong anticholinergic effects (RRR 1.35 95% CI (1.28-1.44)) but have less severe cognitive problems (RRR 0.92 95% CI (0.85-0.99)) and less severe physical problems (RRR 0.92 95%CI (0.96-0.98)). Two in five (40%) of people in this group died in a hospital.

Table 7-11. Multinomial logistic regression with age and sex adjusted coefficients showing patient characteristics associated with the last year of life class: reference class: Class 1: Low healthcare use in the last year of life (N=8,623)

Characteristic	RRR (95% CI)		
	Moderate hospital use in the last year of life	High hospital use in the last year of life	Community mental healthcare use in the last year of life
Male gender [Ref, woman]	**1.22 (1.09-1.35)**	**2.51 (2.12 -2.96)**	**1.69 (1.48-1.92)**
Age at diagnosis	1.01 (0.99-1.02)	**0.98 (0.97-0.99)**	**0.98 (0.97-0.99)**
Dementia diagnosis [Ref, Alzheimer's disease]			
Mixed dementia	**1.25 (1.07-1.46)**	**1.31 (1.02 -1.66)**	1.18 (0.96-1.44)
Unspecified dementia	1.06 (0.94-1.21)	0.89 (0.71-1.11)	1.05 (0.89-1.24)
Vascular dementia	**1.41 (1.22 -1.62)**	**1.33 (1.06-1.67)**	1.04 (0.86-1.26)
Dementia in other diseases	**1.26 (1.03-1.55)**	1.12 (0.80-1.56)	**1.40 (1.08-1.81)**
IMD Quintiles [Ref, 5 (least deprived)]			
1	1.03 (0.83-1.28)	0.84 (0.58-1.21)	1.25 (0.93 -1.70)
2	1.05 (0.86-1.28)	1.09 (0.79-1.53)	1.31 (0.99 -1.73)
3	0.95 (0.77-1.18)	1.11 (0.78-1.57)	**1.42 (1.06-1.91)**
4	0.93 (0.74-1.17)	1.14 (0.78-1.67)	1.12 (0.19-1.16)
Ethnicity groups [Ref, White]			
Mixed	1.02 (0.55-1.87)	0.91 (0.33-2.51)	0.64 (0.26-1.59)
Asian	1.05 (0.83-1.34)	**1.58 (1.13-2.22)**	0.78 (0.56-1.08)
Black	1.06 (0.32-1.22)	1.10 (0.88-1.38)	0.98 (0.82 -1.18)
Other	**0.66 (0.47-0.92)**	1.14 (0.64-2.02)	**0.44 (0.26-0.74)**
Care package recipient [Ref, no]	0.99 (0.90-1.10)	0.94 (0.80-1.11)	**2.43 (2.12-2.77)**
Living alone [Ref, no]	0.93 (0.82-1.06)	0.89 (0.71-1.12)	1.06 (0.89-1.26)
Number of medications	0.99 (0.94-1.05)	**0.88 (0.81-0.97)**	**1.35 (1.28-1.44)**
HoNOS cognitive problems score	0.97 (0.91-1.04)	**0.77 (0.69-0.84)**	**0.92 (0.85 -0.99)**
HoNOS physical problems score	1.05 (0.99-1.10)	1.00 (0.93-1.08)	0.95 (0.90-1.01)

Abbreviations: RRR (95% CI): Relative Risk Ratio (95% Confidence Intervals), Bold findings are statistically significant (p<.005). Ref: Reference Class, IMD: Index of Multiple Deprivation * 1= Most deprived, 5 = Least deprived, HoNOS: Health of the Nation Outcome Scales

7.4.5 Transitions between classes over time

Transitions between the subgroups between two timepoints are visualised in Figure 7-5. The class membership between two time points was not stable (i.e., three-class solution in the first time period and a four-class in the second time period). There were no clear patterns to the moves between classes between two time periods (e.g., of those in the '*low healthcare use after diagnosis'* class, in the last year of life time period 33% transitioned to the '*low healthcare use in the last year of life*' class, 40% to the '*moderate hospital use in the last year of life'* class, 11% to the '*high hospital use in the last year of life'* class, and 16% to the '*community mental healthcare use in the last year of* *life'* class). Notable transitions between two time periods relevant to clinical practice and policy, and the characteristics of the people with dementia who are described below (See Appendix 6 for relevant tables).

Transition from '*low healthcare use after diagnosis'* class to '*high hospital use in the last year of life*' class: 11% of people with dementia who were in the '*low healthcare use'* class in the first year following their diagnosis transitioned to the '*high hospital use in the last year of life*' class. Compared to the other people who were in the '*low healthcare use after diagnosis'* class, the group of people who experienced this transition included a larger proportion of males, a smaller proportion of people with an Alzheimer's disease diagnosis, and a larger proportion of people diagnosed with mixed and vascular dementia diagnoses, who were diagnosed younger and died younger compared to those who transitioned to '*low healthcare use in the last year of life'* and '*moderate healthcare use in the last year of life'* classes, where a smaller proportion had a care package in place in the first year after their diagnosis.

Transition from '*planned and unplanned hospital use after diagnosis'* class to '*low healthcare use in the last year of life*' class: 31% of the people with dementia who were in the '*planned and unplanned hospital use after diagnosis*' class in the first year following their diagnosis transitioned to the 'low healthcare use in the last year of life' class. Compared to the other people who were in the '*planned and unplanned hospital use after diagnosis*' class, the group of people who experienced this transition included a larger proportion of females, a larger proportion of people with an Alzheimer's disease diagnosis, a larger proportion of people who were from a White ethnic group, and were diagnosed older, yet lived with a dementia diagnosis for a longer time and died at an older age.

Transition from '*mental healthcare use after diagnosis'* class to *'community mental healthcare use in the last year of life*' class: 31% of the people with dementia who were in the '*mental healthcare use after diagnosis*' class in the first year following their diagnosis transitioned to the *'community mental healthcare use in the last year of life'* class. Compared to the other people who were in the *'mental healthcare use after diagnosis'* class in the first year after diagnosis, the group of people who experienced this transition, included a larger proportion of males, a larger proportion of people with dementia diagnoses in other diseases, larger proportion of depression as reported in HoNOS at diagnosis, a higher number of medications with strong anticholinergic effects receipts, and a larger proportion of care package recipients.

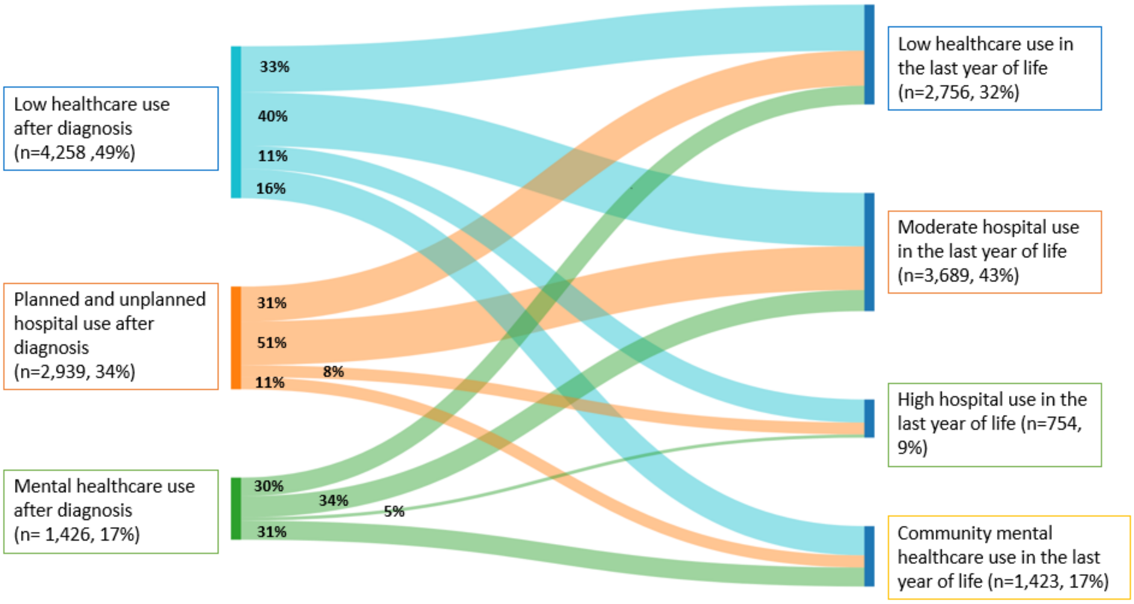

Figure 7-5. Sankey diagram for transitions between first year after diagnosis classes and classes in the last year of life based on healthcare use

7.4.6 Sensitivity and exploratory analyses

Class structures observed in the last year of life analysis with all decedents who lived for a year or longer after their dementia diagnosis were similar to those observed in the main analyses (Appendix 6). The likelihood ratio difference test demonstrated that the model with invariance constrained and the one without the invariance constrained differed significantly ($G^2\Delta = 52$, $df\Delta = 44$, $p < 0.05$), confirming that the class structures were not consistent over time.

LTA with three-class models at both timepoints and models exploring the effects of gender and proximity to death were conducted as a sensitivity analysis. The sensitivity analyses reveal similar transition patterns to those presented in Figure 8-5 and potential differences in transition probabilities depending on person’s sex (being male) and proximity to death (those who have less time between the date of their dementia diagnosis and death) increasing the likelihood of transitioning to high hospital use group in the last year of life (Appendix 6).

7.4.7 Patient and public involvement

Initial findings from study 3 were discussed with three separate PPI groups and with a group of old age psychiatrists from SLaM. These discussions were essential for the validation of the subgroups and the interpretation of the findings.

The explanations for diagnosis at later age being associated with the group with higher hospital use and frequent A&E visits resonated with the PPI members. Ethnicity (being Asian and other ethnicity) which was one of the risk factors associated with being in the group with higher hospital use and frequent A&E visits resonated with the PPI members. They mentioned cultural expectations from family members having to take care of the relative with dementia and the option of a care home not being possible. Going to A&E meant that the responsibility of the person with dementia is no longer on the family members, but with the hospital staff. The lack of resources available in non-English languages and accessing services for dementia too late due to cultural beliefs of dementia being part of aging were also discussed.

Dementia type was another factor which came up in discussions multiple times. The consensus among the PPI group was that when someone had a lesser-known type of dementia (compared to Alzheimer's or Vascular Dementia), all aspects of care were influenced. Discussions with healthcare professionals also underscored the acute care needs of people who have vascular and mixed dementias. The diagnosis was delayed, and symptoms were confusing to health and social care professionals. Many members of the local community were not aware of different types and symptoms of dementia.

7.5 Discussion

In this study of healthcare use in people with dementia followed from diagnosis to death, using data linkages across five datasets, I observed distinct classes of healthcare use within the cohort in the first year following a dementia diagnosis and the last year of life. I identified three subgroups based on their healthcare use in the first year after diagnosis and four subgroups based on their healthcare use in the last year of life. Of relevance to this thesis, the latter included a small group (*'high hospital use in the last year of life'* (9%)) of people with dementia who experienced frequent unplanned hospital use. While subgroups in the first year after diagnosis were distinct from those observed in the last year of life, I identified biopsychosocial characteristics associated with these, highlighting and unpicking the unpredictability in the care journey of people with dementia.[117]

In line with the literature, the findings show that male gender was associated with more frequent service use such as high unplanned hospital use at both time periods.[114, 308] Associations with different ethnic groups (e.g., Asian ethnicity was associated with lower likelihood of belonging to the *'mental healthcare use after diagnosis'* class, while positively associated with a likelihood of belonging to the '*high hospital use in the last year of life'* class) and age (e.g., diagnosis at older age was associated with the *'planned and unplanned hospital use after diagnosis'* class in the first year after diagnosis, whereas younger age was associated with '*high hospital use in the last year of life'*) varied depending on the classes and the time period. In terms of illness-related factors, I identified higher likelihood of healthcare use among people diagnosed with a non-Alzheimer's disease dementia, particularly for those with mixed and vascular dementia. These associations may be due to higher prevalence of co-existing physical conditions associated with these diagnoses, and/or availability of better management and support for Alzheimer's disease in community.[138, 309]

Findings highlighted the reversal of the association between cognitive impairment and healthcare use in the first year following diagnosis and in the last year of life. While more severe cognitive problems were associated with '*planned and unplanned hospital use after diagnosis*', less severe cognitive issues were associated with later hospital and community care use in the last year of life. The latter finding is counter-intuitive, although might possibly reflect dementia diagnoses at earlier stages in people with comorbid conditions who will require higher levels of later end-of-life care. Similar findings have been observed in previous studies for hospital use towards the end of life among people with dementia.[110, 114]

Social factors such as living alone and receiving a care package were associated with higher likelihood of receiving specialist mental healthcare use. Higher proportion of care package receipt in this subgroup may be due to identification of complex needs by the specialist mental healthcare teams.[310] Living alone and living in the most deprived areas were associated with hospital use and community mental healthcare use in the first year after diagnosis. These may be explained by the differential access to services (i.e., unplanned access to hospitals in response to an emergency vs. referral and assessment-based access to specialist mental healthcare) and difficulties observed in access to dementia diagnosis and subsequent treatments among more deprived groups due to availability of the services disproportionate to the needs of the communities in those areas.[311] Studies focusing on healthcare use towards the end of life among people with dementia at a larger geographical scale (e.g., national) and those using other measures of socioeconomic status found an association between deprivation or lower socioeconomic status and higher burdensome healthcare use, which was not evident in our study.[41, 311, 312] Further research from an intersectional lens is needed to understand the combined effects of the identified characteristics.[313]

In this study, people with dementia moved to different groups characterised by use of healthcare services in the last year of life were not always consistent or similar to their healthcare use in the first year after diagnosis. Risk factors associated with high healthcare use were also observed in groups who transitioned to 'less favourable' classes in the last year of life. As highlighted in the sensitivity analyses, people who lived longer with a diagnosis had a higher chance of transitioning to a low healthcare use in the last year of life. Dynamic moves over the course of dementia care trajectory and similar class structures have been observed previously where people who were in the last year of their lives were excluded, with stable class structures over time when primary care use was included as a class predictor, and a small group of people who were labelled as 'multiple healthcare users'.[285]

7.5.1 Strengths and limitations

This study is novel in its use of a linkage between specialist mental health services and hospital care, which allowed access to a rich repository of information about biopsychosocial characteristics of people with dementia, and exploration of how different services fit together. The study also adds to a growing body of work which has applied latent class and longitudinal modelling to the electronic health records of people with dementia, and includes the last year of life time period, which is associated with high hospital use.[165, 314] Clustering techniques using electronic healthcare data have been used in other patient populations in guiding care and service planning. The use of routine data provided a large sample size, and minimised biases such as recall bias which are often associated with survey data.

In terms of limitations, there may be a risk of bias in the approach to classification of individuals to groups [315]. Although there are methods which can be used to reduce bias, most studies applying such methods have a small number of covariates and often use survey or stimulation data which are more suited for complex adjustment compared to real life data;[316] classification bias in this study was also minimised by the large sample size.[315] I had access to limited information about social care receipt, and were not able to track the timing of care home residence, which has been shown to reduce unplanned hospital use in the last year of life.[41, 114] Also, information was primarily collected at the time of diagnosis, and was limited on covariates between the two time points studied, which is also likely to impact the results.[23]

The cohort included in the study was limited to people who had a dementia diagnosis for at least two years. Although most people with dementia live for longer than two years after receiving their dementia diagnosis,[168] people who had less than two years between their diagnosis to death might represent a group with higher healthcare needs and use. The sensitivity analysis looking at the impact of time between diagnosis and death on transitioning between classes in two timepoints from Study 3 and the trends in unplanned hospital admissions observed in Study 1 suggests that people who had a shorter survival after diagnosis may be more suspectable to burdensome care experiences. As there will be less time from diagnosis to the end of life, people included in dementia care (i.e., people with dementia, families, and health and care professionals) might have less opportunity to change the trajectory of care towards the end of life. Hence, the size and composition of the latent classes identified in this study may differ due to this selection criteria. Individual-level indicators of socioeconomic position such as educational level and the most recent occupation of the individuals may have been more informative; in this respect, measures such as the education level or people's last recorded occupation were extracted from CRIS but were found to be inadequately recorded (>70% missing) and were not included in the analyses. Even though the regression models in this study were adjusted for several confounder factors, there is still a risk of residual confounding. Studies which include more biopsychosocial characteristics of people with dementia and health and social care service measures are needed to further our understanding of distinct healthcare use groupings. Finally, external validation of the identified groups is needed to improve their generalisability, although there are similarities in terms of sizes of classes and significant covariates with other published findings, and confirmatory views of people with experiences of healthcare use (people with dementia, family members, healthcare professionals) about the identified groups provide some support for the external validity of our findings. While the names given to the latent classes observed at both time periods may appear to be similar, it is important to highlight that these groups do not represent same groups of people and are merely labels to summarise common characteristics of the group.

7.5.2 Implications for clinical practice, policy and research

First, a third of people were in the '*hospital use'* group in the year following their diagnosis, had transitioned to the low healthcare use group by the last year of their life. This may signal the detection of needs and having plans for care in place earlier on the dementia trajectory, which may reduce the need for hospital care in the last year of life.[317] Data linkages with other key health and social care services may guide our understanding of how services work together to meet the needs of people with dementia,[117] and services which may be key in reducing burdensome care experiences in the last year of life.

Second, a small proportion (9%) of people with dementia was characterised by high emergency hospital use in the last year of life. The findings show that people in this group were more likely to be men, have mixed and vascular dementia, be from an Asian ethnicity, and receive lower number of medications. Although some of the observed high hospital use may be in line with the increased and complex needs observed towards the end of life,[287] the reasons for high numbers of repeated A&E visits and whether these indicate inadequate care provision (including difficulties with access or limited number of services) outside of hospitals should be explored. Identification of this subgroup should be prioritised in clinical practice to target better care. The large proportion of people with dementia (including the moderate and community mental health care classes) visiting hospitals in the last year of life also underscores calls for improving hospital environments and care for people with dementia, and investing in social care services such as nursing homes which may reduce A&E attendances.[41] Although the relatively small 9% proportion suggests that many people with dementia are not high care consumers at the end of life, this class is likely to be generating very high proportions of the total cost of dementia, hence there are economic imperatives to see what can be learned about those who remain low healthcare users until the end of life, and those who transition to this class.

Finally, approximately one in five (17%) people with dementia receive specialist mental health care as measured by attending appointments, and community care provided by multidisciplinary teams during both time periods (including outpatient and community settings), and not many people receive specialist mental healthcare input to their care.[318] While high healthcare use is expected for people who may have mental and physical multiple long-term conditions,[319] this group did not have high unplanned hospital use, highlighting the potential role of specialist care provision in dementia care. Better integration of specialist and hospital services for people with dementia must be supported by adequate funding.

This study generated multiple implications for future research.

First, our findings describe the differences in the experiences among people with dementia who are often grouped and treated as a homogenous group in healthcare and policy. There is a need for further qualitative studies to unpick the underlying reasons for the patterns observed and the associated risk factors.

Second, the role of the specialist mental healthcare services is seldom explored in relation to the end-of-life care among people with dementia. End-of-life care needs of people with dementia in the '*community mental healthcare use in the last year of life*' class and the support needed by the teams from palliative and end-of-life care specialists must be better understood.

Third, these findings and methods can be replicated in other regions, that face similar challenges in providing high quality to people with dementia until the end of life. Describing and understanding their population's healthcare patterns at a more detailed level can assist decision-makers in prioritising support for services or subgroups of people with dementia who may be otherwise overlooked.

Fourth, the need for data linkages with other key health (e.g., primary care) and social care services (e.g., social care funding receipt and care home residency) to guide our understanding of how services work together to meet the needs of people with dementia, and services which may be key in reducing burdensome care experiences in the last year of life is highlighted.

Fifth, the application of methodological techniques such as joint modelling to gain a better understanding of proximity to death and healthcare use subgroups, and services and characteristics which may influence transition probabilities, should be explored.[292]

Finally, this study relies on when and if people affected by dementia interact with certain healthcare services. Transitions from '*planned and unplanned hospital use after diagnosis'* in the first year following diagnosis class to '*low healthcare use in the last year of life*' class may indicate that the health and care needs of these people were picked up by the professionals and resolved earlier in their disease trajectory which may have led to low healthcare use, with the substitution of other care services (e.g., care homes). Future studies should explore with people affected with dementia, ways in which their needs can be identified proactively, and managed efficiently without the need of unnecessary access to healthcare services.

This study identified the extent to which multiple healthcare services are used concurrently during two critical periods of the overall time spent living with dementia, as well as sociodemographic and clinical characteristics associated with such use. Findings explore the relationship between these two time periods in attempt to understand whether the type of healthcare use observed in the last year of life can be anticipated and planned better. Identification of subgroups of people with dementia who may experience burdensome care towards the end of their lives should be prioritised in primary, post-diagnostic dementia and emergency services to ensure adequate support is provided across the disease trajectory.

The interpretation of the findings in relation to the care of people with dementia and how quality of care may require further considerations for from or even prior to dementia diagnosis and for those who may be approaching the end of life are summarised in Table 7-12.

Table 7-12. Interpretation of the study findings in relation to the quality of care of people with dementia who may be approaching the end of life (Study 3)

Quality of care domain (See Appendix 1 for definitions)	**Interpretation of findings and implications**
Access	The findings highlight potential issues with access to several services, namely to community and specialist mental healthcare services at both timepoints. Access and signposting to appropriate community care, information about dementia for people affected by dementia, could be facilitated though formal personalised post-diagnostic support. In England, the NHS Long Term Plan provides a clear vision for a consistent standard of care for people with dementia to live in their own homes for longer and avoid unnecessary hospital admissions.[107] More people with dementia with complex care needs may benefit from the multidisciplinary specialist community mental healthcare input, but these services, including community services for family caregivers such as day care centres may not be equally visible or accessible to everyone.
Safety	Three main implications for the safety of people with dementia. First, disproportionate number of repeated A&E visits experienced by a small number of people with dementia raises concern about their safety in emergency departments, which is not be the best environment for caring for people with dementia.[208] Second, although people with dementia who are admitted to the hospital are likely to be at a ward dedicated to the care of older people for most of their stay, they are likely to experience transfers between different parts of the hospital and sometimes transfers to other hospitals. Third, people with dementia who do not access services in the first year after diagnosis, but subsequently transition to a higher healthcare use subgroup, and those who experience repeated A&E visits may not be safe at their usual place of care (home/care home). Prioritising and ensuring patients' safety are linked to better access to information on previous health and social care input,[320] capacity to deliver care closer to home, and development dementia-friendly care environments.[81]
Timely	The findings raise important questions about the timely access to health and social care services. Unplanned and potentially avoidable hospital use and prolonged hospital stays have been postulated to be linked with lack of timely access to primary and community services.[273] Namely, the findings raises questions about whether most people with dementia had timely access to post-diagnostic and other services prior to the last year of

	life and during the last year of life (e.g., securing funds to move to a care home or seek additional home care services) which could have limited the unplanned hospital use.
Efficiency and value for money	The findings from this study suggest that specialist mental healthcare input may reduce some of the unplanned hospital use among people with dementia. Efficiency or inefficient of delivery of dementia care in emergency departments have been widely discussed.[208, 321, 322] These findings contribute to the need to gain a better understanding of what people with dementia value in their care and whether the delivery of the services are efficient in meeting care needs in line with their values. Given the limited access to specialist mental health care, efficiency of care delivery (e.g., frequency and format of visits and communication across teams) to meet the growing needs of people with dementia until the end of life should be assessed. Care delivered during prolonged hospital stays may not be good value for money, due to potential harms. However, hospital visits may provide an opportunity to seek input from multiple disciplines and put preventative measures in place.[317] Whether investing in comprehensive needs assessment, signposting to community services, discharge and personalised care planning during hospital admissions shortly after their diagnosis is efficient for reducing future end-of-life admissions for people with dementia should be explored.
Capacity	The findings highlight multiple issues regarding capacity of the services which may lead to poor care quality. Unplanned hospital use may reflect the focus on treating acute medical issues during hospital visits, rather than understanding the dementia trajectory and the role of acute events, and not taking overall health and care journey of people with dementia into account due to lack of resources. There are implications for larger workforce and specialist capacity community, and in hospitals for people with dementia who may have more complex care needs but also increased capacity to deliver equitable care through better resources (i.e., dementia and end-of-life care training and specialist input, linked care records).
Equity	People with dementia are characterised with increasing care needs and subgroup of people with dementia, as highlighted in this study, are characterised by increased healthcare use in the last year of life. The findings raise questions about whether the resources needed to provide appropriate and person-centred care to everyone with dementia until the end of their lives are fairly and equitably distributed. Furthermore, the

	findings also suggest that the quality of care provided to people with a non-Alzheimer's diagnosis, people from minority ethnic groups, and those who live in more deprived areas may not be equitable. In line with the inverse care law principles,[323] more investment should be directed to people with dementia who may face additional barriers to care.

7.6 Summary

This study identified the extent to which multiple healthcare services are used concurrently during two critical periods of the dementia trajectory, the year after diagnosis and the year of death, and the associated sociodemographic characteristics. In this chapter, the rationale and how previous studies and evidence led to this study and the implications of the findings for future research, policy and in relation to the quality of care have been illustrated. The next chapter will provide a broad discussion of the whole thesis.

Chapter 8: Discussion

This chapter presents a summary of key findings. It discusses how the thesis fits into the wider context of healthcare use of people with dementia nearing the end of life, as well as broader strengths and limitations, and implications for policy, clinical practice and research. Discussions and conclusions of the studies are presented in their corresponding results chapters.

8.1 Overview

This thesis identified patterns in healthcare use and investigated indicators of quality of care to quantify the experiences of people with dementia who may be nearing the end of life using routine data. As background work, I assessed the psychometric properties of all available and relevant quality indicators. I then provided a shortlist of 71 robust quality indicators usable with routinely collected electronic data to quantify the care provided to older people and those with dementia who may be approaching the end of life (see Chapter 2).[11] This thesis demonstrates several examples of how routinely collected electronic data can be analysed to inform and enable the improvement of care received by people with dementia nearing the end of life. In Studies 1 and 2 (see Chapter 5 & Chapter 6), patterns of healthcare use, namely unplanned hospital admissions and critical care admissions, were identified and analysed to investigate quality of care and opportunities for understanding the population of “people with dementia nearing the end of life” better and improving the care experiences. In Study 3 (Chapter 7), I investigated patterns of multiple healthcare service use among people with dementia and identified variations in these and associated biopsychosocial factors. Each analysis addressed an aspect of the evidence gaps discussed in the background chapter of the thesis.

In this thesis, Study 1 (see Chapter 5) showed that higher rates of unplanned hospital admissions were experienced by people who live with a dementia diagnosis for a shorter period, and both the rates and combined durations of hospital stay increased consistently towards the end of life, becoming noticeably higher in the last year of life. The importance the end-of-life period was highlighted by the marked differences in the rates and lengths of unplanned hospital admissions observed between those who were living by the study end and the decedents. Potential targets across the disease trajectory, and across care settings, were identified to improve the quality of care across care domains and will be discussed in this chapter.

Due to the lack of evidence on critical care admissions among people with dementia in England, Study 2 (see Chapter 6) of this thesis used a novel data linkage between an electronic mental health records depository and a national hospitalisation dataset to explore the incidence of critical care admissions, trends over time, and the survival of people with dementia who experienced these admissions. Critical care admission among people with dementia nearing the end of life is an established quality indicator. In this study, less than 4% of people with dementia experienced a critical care admission. However, the increase in the incidence of critical care admissions in the last year of life over the 12-year period highlights the importance of routine monitoring of specialist healthcare use among people with dementia.

In Study 3, an approach to analysis was employed where patterns of use of multiple healthcare services extracted from a data linkage were examined in the first year after diagnosis and the last year of life, to explore if there are opportunities to improve the quality of care and understand the level of service provision required to meet the needs of people with dementia from diagnosis until the end of life. Healthcare use in the first year after diagnosis was not a predictor of patterns of healthcare use in the last year of life. Distinct subgroups of people with dementia with similar patterns of healthcare were identified. Risk factors associated with high healthcare use included being male, having a non-Alzheimer's disease diagnosis, Asian ethnicity, living alone, and having physical problems.

The overall, unique contribution of this thesis is the new understanding of heterogeneity which exists in the healthcare use among people with dementia, outlining their differential needs, and the highlighted targets for improving the care quality of people with dementia nearing the end of life. It adds to the evidence base that a significant proportion of people with dementia towards the end-of-life experience care which may not be in line with their care preferences. This thesis also highlights a need for more in-depth research and policy focus on dementia end-of-life care. It also provides a case for embedding dementia, palliative and end-of-life care competencies across the care trajectory. To improve the quality of care for people with dementia, efforts should be focused on addressing areas that need the most attention and raising awareness of end-of-life care needs, services, and management of people with different diagnoses of dementia across care settings and teams.

8.2 Discussion of key findings

This section highlights the main contributions of this thesis to the existing literature.

8.2.1 Patterns of healthcare use

8.2.1.1 Hospital use

This thesis provides evidence for the sizeable increase in unplanned hospitalisation among people with dementia which occurs in the last year of life by examining the occurrence from the point of diagnosis (see Chapter 5). Previous research has highlighted that many A&E visits take place in the last year of life,[41, 110] and high levels of hospital use in the years after dementia diagnosis,[97, 98, 111] but has not captured changes over the full course of dementia. In this thesis, an increase in service use in the first year after diagnosis, specifically hospitalisations, was not observed. Higher rates of unplanned hospital admissions in people with dementia who had a shorter survival following dementia diagnosis may explain these differences between findings in this thesis and previous literature.[98, 111]

Unplanned hospital use, critical care use and longer lengths of hospital stays among people with dementia towards the end of life may also be explained by risk aversion and concerns around safety on the part of clinical teams.[324] If healthcare professionals lack confidence and knowledge about the community-based care options available for people with dementia, they may refer them to hospitals even if care closer to their homes is more appropriate and possible. It is therefore crucial for professionals working outside of hospitals to have the resources to support and reassure these teams and families.[325]

Fundamental to this thesis was the selection of hospital use and specialist services use as markers for quality of care, and the examination of service use together. In Study 3 (see Chapter 7), I identified groups of people with dementia with different characteristics who experience planned or unplanned hospital admissions in the first year after diagnosis. The '*planned and unplanned hospital use after diagnosis*' subgroup, who experience frequent unplanned hospital care in the year following their diagnosis, may indicate unmet needs by community and other post-diagnostic services.[273] Similar to these findings, a previous prospective study showed higher mortality rate following an unplanned hospital admission among people with dementia, with nearly half of people dying within a year.[201] An Australian study similarly showed poorer health to be associated with unplanned hospital admissions.[326] In the same study, people who were seen by a specialist service were more likely to have a planned admission, while a negative association was observed between having a planned hospital admission and speaking a first language other than English, highlighting potentially inequitable access to planned care for people in similar circumstances.[326]

In the final study of this thesis, the concurrent use of outpatient care provided in hospitals with other healthcare services was also explored. Outpatient visits to the acute hospital are likely to occur following hospital admissions for further investigations and medication reviews.[281] The role of outpatient care towards the end of life, especially for people with dementia at the later stages of the condition, is not well-understood. While outpatient care may be less frequently required at the very end of life (i.e., last month or days before death), there may be a role for outpatient care for improving the care towards the end of life. Individuals with dementia and their loved ones may perceive hospitals as a place of "safety". Community-based care and timely access to outpatient appointments, as well as comprehensive comorbidity management, may be safer alternatives to A&Es.[327]

8.2.1.2 Specialist mental healthcare use

The evidence on the care of people with dementia who receive specialist dementia care until the end of their lives from mental healthcare services is scarce, and has mainly focused on the role of liaison psychiatry in the acute hospital setting.[36, 328] Although whether individuals with dementia were seen by the same teams or professionals was not explored,[118] continuity in receipt of services for a small number of people with dementia from diagnosis until the last year of life was observed. By analysing the use of multiple healthcare services, minor evidence of the potential to substitute some hospital care with specialist community mental healthcare among a subgroup of people with dementia was highlighted. Evidence is required from longitudinal studies, potentially utilising routine data and using techniques such as propensity score matching, to understand if the impact of specialist community mental healthcare on unplanned hospital use is observed among people with dementia. It is also important to highlight that people who received specialist mental healthcare still had a higher number of hospital admissions and outpatient visits compared to '*low healthcare use*' subgroups at both time periods. This may be due to the identification of needs by the specialist mental healthcare teams. While evidence exists that the continuity of care from GP services has an impact on unplanned hospital use in the last three months and last year of life,[118, 329] evidence on the involvement of community services such as community mental health care nurses and therapists is lacking.

There may be several explanations for the observed hospital and specialist mental healthcare patterns towards the end of life:

(i) Supply-induced demand theory refers to the increase in the use of healthcare services due to availability (supply) of the services.[330] This hypothesis is supported by the observation of higher A&E visits among people with dementia in urban areas, where A&E departments are available nearby compared to rural areas in England.[41, 308] Proximity and availability of transport to the available A&E departments, and reliance on community and informal care networks in addition to formal care services, may also impact the use of A&E departments towards the end of life.[331]

(ii) Most people with dementia have increasingly complex care needs towards the end of life, which may partly explain the increase in hospital use towards the end of life.[137, 332] The hypothesis that more complex needs lead to more healthcare use is also supported by the observation that people with dementia who receive a social care package have more interactions with the specialist mental health teams (See Chapter 7, Section 7.4).

(iii) Finally, high unplanned healthcare use observed across the studies of this thesis can be seen as an indicator of unmet needs and uncoordinated care.[287, 310] Coordination of care does not necessarily mean communication between groups but may also indicate a lack of communication between people with dementia (or their carers) and healthcare professionals. Lack of planned admissions or care receipt from primary or specialist services may have a knock-on effect on the experiences of medical emergencies.

8.2.1.3 Interpreting appropriateness of care

Equating the occurrence of a healthcare process or outcomes to high or poor quality of care has been a criticism of quality indicators (e.g., people with dementia dying in hospital).[333] Caution must be taken not to interpret all unplanned hospital use as a representation of poor care quality. Similarly, although the proportion of hospital deaths is reported throughout the studies of this thesis, the findings present the journey which leads to death and how people with dementia can start from different points, experience various combinations of healthcare service use, and still die in hospital.[1]

Another common criticism has been around the examination of isolated quality indicators.[333, 334] By combining the use of multiple healthcare services, the aim was to identify subgroups whose experiences may be the focus for improving care quality. There may be a need to stratify who may require and benefit the most from hospital care. In understanding the appropriateness of hospital care, it will be important to re-explore the applicability of valid QIs for people with dementia nearing the end of life and the ‘benchmark’ proportions of people expected to use healthcare, such as A&Es, with the increased acute care needs among people with dementia due to multimorbidities.[24]

8.2.2 Quality of care

This thesis sheds light on multiple domains of quality of care,[50,335, 336] highlighting the complexities in care provision, resources needed to explore quality of care in more detail and provide high-quality and equitable care to people affected by dementia until the end of life.

Previous studies have examined multiple healthcare use among people with dementia but often excluded the end-of-life period or focused on a non-dementia cohort of people who may be approaching the end of life.[135, 165, 285, 337, 338] The findings from this thesis make novel contributions to our understanding of heterogeneity in the quality of care experienced by people with dementia who may be nearing the end of life. The patterns of healthcare use observed in the thesis highlight the connections between the different domains of the quality of care. For instance, if people with dementia do not have equitable access to the services they need in a timely manner, the likelihood of achieving a person-centred care experience towards the end of life is lower. While a subgroup of people with dementia were receiving community-based specialist mental health care (See Chapter 7, Section 7.4), most patterns of studied healthcare use point toward a risk of potentially avoidable and burdensome experiences, which increases in the last year of life. Hence, the distribution and benefits of care among people with dementia and across dementia care trajectory may be not be fair.[339]

A major concern regarding the quality of care of people with dementia is related to the safety of individuals. For people with dementia who may be approaching the end of life, the benefit of being in specific parts of hospitals such as A&E departments and critical care units as demonstrated in this thesis, may be outweighed by risks and long-term consequences. Yet, when the other domains of quality of care such as the capacity of services, and equitable and timely access to effective community care are not fulfilled, some of the observed patterns of potentially burdensome hospital care (e.g., long lengths of hospital stay (See Chapter 5 & Chapter 7)) may be for the safety of the individuals.[109] This is supported by evidence showing that people with dementia may visit A&E departments as a place of safety, and a place where they face the least resistance to receiving the care they need.[273]

Patterns of healthcare use examined in this thesis may indicate poor quality of care towards the end of life because of a lack of concordance about the goals of care among all stakeholders (namely healthcare professionals, individuals with dementia and their families).[340, 341] As dementia progresses, goals of care may evolve. Without ongoing communication regarding the illness trajectory, and a clear understanding about care expectations and preferences, it is difficult to plan and provide high quality care. The lack of recognition of the life-limiting nature of dementia might be making it harder to achieve person-centred care, which is a domain of care quality, and contributing to burdensome incidences of healthcare use (e.g., repeat unplanned hospital admissions) towards the end of life. However, information about people's goals of care are not available in the datasets used in this thesis.

When analysed in terms of subgroups among people with dementia, the thesis provides a better understanding of who may be more at risk of poorer quality of care towards the end of life. The stratification is important, as previous research underscores the importance of having a specific target population in success of interventions (See Chapter 7, Section 7.5). Targeting efforts to improve the experiences of the people who may be sitting at the margins, sometimes referred as "designing for the extremes", has been shown to be a successful strategy for improving the quality of care in other healthcare areas such as HIV.[342]

An important domain of quality of care relevant to this thesis, which examines the use of costly healthcare services, is whether the patterns examined indicate value for money.[343] The concept of value for money focuses on the ratio between the associated costs of the healthcare service and the value gained from its use and delivery.[343] Individual instances of hospitalisation may be needed to improve outcomes for people with dementia. Yet, findings reported in this thesis, such as high incidences of repeat unplanned hospital use, and limited access to specialist mental health community services at a population level may be poor value for money. Healthcare providers are accountable to taxpayers for investing in high quality care and not contribute to waste of resources which may benefit others. There is evidence showing that the general population value improvements in dementia care.[344] Investments in health and social care services which can provide high-quality dementia end-of-life care to more people with dementia are likely to be good value for money for the whole population. However, these investments should be supported by further research investigating the person-centeredness, effectiveness and cost-effectiveness of models of care and healthcare services.[344]

8.2.3 People with dementia approaching the end of life

To acknowledge the variability in access to a formal diagnosis, different rates of decline towards death and difficulties around prognostication of dementia in clinical practice in this thesis,[177, 345, 346] an inclusive approach was taken to define and identify people with dementia approaching the end of life. Some people will be closer than others to the end of their lives at the time of a dementia diagnosis (See Chapter 5). This thesis provided evidence that this patient group are more likely to experience potentially burdensome unplanned hospital use. However, this needs to be confirmed in future studies. One explanation is that people with quickly declining cognitive and physical functioning may have higher healthcare use.[347]

This thesis also provides evidence to challenge the view that all people with dementia receive high levels of hospital care until the end of life. A third of people with dementia did not frequent hospitals, while a smaller group were characterised by high hospital use (See Chapter 7). There is, however, a possibility that some people with dementia who did not receive a large amount of specialist mental health or hospital care had unmet healthcare needs.[109] People who may be approaching the end of life have differing needs and health care use patterns to those who may be living well with dementia.

At a population level, understanding who may be approaching the end of life among people with dementia, and planning and implementing pre-emptive and preventative approaches to improve care quality as early as possible, should be prioritised. Currently in England, people with dementia tend to receive care towards the end of their lives from mostly generalist/non-specialists health and care professionals.[36] When care from specialist palliative care is provided to people with dementia, it is often at the very end of life or to those only with advanced dementia.[348] Understanding dementia severity is helpful for positioning care, and clinical interactions.[111] However, current evidence, including findings from this thesis (See Chapter 6 and Chapter 7), is mixed on the associations between dementia severity and service use.[35, 97, 111, 253, 349] Lack of an association between dementia severity and healthcare use towards the end of life might be due to a positive association between residing in a care home and dementia severity.[349]

Without improving prognostic accuracy, having a strict definition for people with dementia approaching the end of life may not be helpful, and lead to inequities in access to end-of-life related specialist services such as palliative care.[35, 44] It is important to highlight the clinical importance and the potential to predict whether a person with dementia is in their last year of life in relation to thesis findings and in dementia and end-of-life care research. The thesis findings show a consistent increase in unplanned healthcare use in the last year of life, which may be an indicator of a person with dementia approaching the end of their lives. While prognostication of who may be in the last year of life was not in the scope of this thesis, large datasets such as those included in this thesis which are rich sources of information about people with dementia and their survival can be exploited to answer this question. Ultimately, at a population level, having a better understanding of proximity to death may lead to more equitable and timely access to health and care services needed by people with dementia. However, implementation of such prognostication tools in clinical practice at an individual level must take into account the views of the clinicians and people affected by dementia.

8.2.4 Biopsychosocial characteristics of people with dementia at risk of poor-quality care

Differences in healthcare use and varying quality of care among people with dementia according to biopsychosocial factors are reported in the literature.[68, 117, 350] In this thesis (Study 3), the direction of the associations between the biopsychosocial characteristics of people with dementia and the type of healthcare use differed depending on the timepoint. This section highlights biopsychosocial characteristics of people with dementia who may be at risk of poor-quality care.

This thesis finds an association between male gender and higher service use at the time of diagnosis and in the last year of life. This finding is consistent with the literature.[41, 114, 308] Men are more at risk of other illnesses associated with dementia including hypertension, obesity, coronary artery disease, and brain injury,[350] they tend to have a shorter lifespan, they receive more medical attention,[78] and more likely to have family carers around them who can detect the need for healthcare.[351] On the other hand, almost two thirds of residents living in care homes are women,[352] and care homes have been shown to be associated with reduced acute care use.[41]

In this thesis, the potentially negative and differential impact of having a dementia diagnosis other than Alzheimer's disease on the healthcare patterns was shown. These findings are in line previous evidence regarding the association between vascular and mixed dementias and frequent hospital use.[68, 138, 309] More awareness among the public, and knowledge among healthcare professionals, is needed about different types of dementia. People who had more physical problems were also more likely to be in the '*high hospital use in the last year of life*' group. This is in line with the literature which highlights the impact of multimorbidities on healthcare use.[8, 24, 137]

In this thesis, several social factors were associated with healthcare use. The thesis findings show that people with dementia who were living alone were more likely to receive hospital care in their first year after diagnosis (See Chapter 7, Section 7.4). Societal changes such as declines in family size, increases in geographical mobility, and increasing female labour market participation are leading to reductions in the supply of informal care for people with dementia.[353] Reduction in informal care may have a knock-on effect on the increase in unplanned healthcare use towards the end of life.[254, 354, 355]

Differences in healthcare use was observed among people from White and other ethnic groups. These findings enhance our limited understanding of complex associations between ethnicity and healthcare access and use.[41, 308] Sociodemographic factors associated with higher hospital use in the year after diagnosis shown in Study 3 have also been shown to be associated with higher risk of dementia.[20, 356, 357] Health inequalities experienced by people from ethnic minority groups have been widely documented.[41, 117, 308, 358] The findings of this thesis should be used to explore further the intersectionality of different characteristics and identities.

8.3 Strengths and limitations

The strengths and limitations of the methodology was discussed in the methods section and specific strengths and limitations of each study were discussed in their respective results sections. The following section will discuss the strengths and limitations of the thesis as a whole.

8.3.1 Identification of people with dementia and longitudinal retrospective study design

A relatively large, real-world sample of people with a dementia diagnosis in the South London and Maudsley (SLaM) NHS Trust was included in the thesis. Having access to health records spanning over a long period via CRIS, which is a strength of this thesis, meant that I was able to assemble sufficiently large cohorts of people with dementia and decedents (with near-complete ascertainment of mortality) and capture the full history of dementia from diagnosis to end of life.

A key advantage of using CRIS was having access to clinical measures of dementia severity, impact on physical abilities and activities of daily living which are not typically recorded in other clinical datasets such as primary care data or administrative datasets. Comprehensive measures such as HoNOS were accessed, compensating for lack of information such as comorbidities which were not available for everyone in cohorts of thesis studies.

The estimated proportion of people with dementia in the SLaM catchment that receive a specialist diagnosis is considered relatively high at 75.2%.[82] Heterogeneity of the cohorts mirrors the complexity among people with dementia encountered in clinical practice, which may make the findings more generalisable. The sample evaluated reflects a diverse, multi-ethnic urban population. People from ethnically minoritised groups are often under-represented in primary research studies.[359] Disproportionate sampling of people from ethnically minoritised groups and rarer dementia types can result in more efficient parameter estimates.[360] Although the sample studied is not representative of the English population, the findings may be generalisable to the broader population, given that standardised care frameworks exist within England. Additionally, the characteristics of cohorts included in the studies (see Chapter 5, Section 5.4) were similar to those reported at a national level, in terms of the mean age at diagnosis, survival, incidence of dementia types, sex, and comorbidities.[361]

Accuracy of diagnosis and its timing are important elements of the studies. There may be a considerable time period between seeking a dementia diagnosis and the recording of formal dementia diagnosis. The date of dementia diagnosis obtained from CRIS may not be the earliest recorded recognition of dementia. Linkages with primary care records and care homes data could enable researchers to capture more accurate and inclusive cohorts of dementia.[82] Additionally, for people who had more frequent contacts with SLaM, recording of risk factors might have been more accurate (e.g., dementia severity, type and number of medications, whether they were living alone, receipt of social care package), which may have influenced the findings.

Finally, an important limitation of using electronic healthcare records for identifying people living with dementia is the ascertainment bias caused by the reliance on a recorded diagnosis. The dementia diagnosis rate in the UK is around 65%, where significant variations exist based on the level of deprivation and rurality across regions, and where people who may have milder cognitive symptoms are more likely to live with dementia undiagnosed.[362, 363] Additionally, many people living in care homes with dementia, may not have a formal dementia diagnosis.[364] The thesis findings might have differed if people living with dementia without a recorded diagnosis were included in the studies. Some of the undiagnosed people living with dementia may be at a milder stage of the condition, which might have reduced the cumulative incidence of hospital use observed in thesis studies. Conversely, recording of a formal dementia diagnosis may have triggered further investigations and adjustment to the treatments of existing conditions leading to an increase in healthcare use across the included healthcare services. For instance, people with sleep problems and depression with dementia are more likely to be undiagnosed.[362] If included in the thesis, the proportion of people observed to be receiving specialist mental healthcare services might have been larger.

Retrospective cohort study designs to explore the quality of end-of-life care have received criticism, as analysing healthcare use during the time before death assumes all people during that period would have been considered prospectively as being in their last months of life.[204] To minimise this bias the thesis also explored healthcare use at a “known” timepoint, diagnosis, in addition to the time before death. A dynamic cohort including people who did not die within the study window was included in the first and second studies of this thesis. Studies 1 and 2 provided supporting evidence that increases in healthcare use are observed in the last year of life and at consistently higher rates among decedents compared to those who remained alive. Therefore, the final study was limited only to the decedents.

8.3.2 Use of routinely collected data and novel data linkages

This thesis utilised novel data linkages to unveil patterns of healthcare use which would not be otherwise possible. To our knowledge, this is one of the first studies to link a critical care database to a cohort of people with dementia in England. This is also one of the first studies to use latent class analysis to identify subgroups of people with dementia based on their healthcare use near diagnosis and in the last year of life, made only possible by data linkages with relatively complete follow-up.[365]

However, the use of routine data collected for clinical and administrative purposes for research comes with its own limitations. Although different datasets from HES can be linked together, information recorded in each dataset and the quality of variables are not consistent. Several variables which were extracted from HES datasets were deemed unusable due to high levels of missing or poor quality of information. For instance, relevant to this thesis, the medical reason for hospital visits is provided in different diagnostic formats in inpatient, outpatient and A&E datasets, but with significant proportions of missing or limited information (e.g., for the A&E dataset, 9.9% of diagnoses were “diagnosis not classifiable” and 44.1% were missing), making it difficult to understand why people were visiting the hospital.

The outcomes of interest were narrowly focused on operational and physical aspects of care, which limit the interpretations about the overall quality of care. The quality of care related to the psychosocial, communication, advance care planning, ethical, legal, spiritual, and cultural care domains are seldom captured or available to researchers from electronic routine datasets.[366] With the advancement of free-text analytics, richer information recorded in written formats in the electronic health records can be utilised to capture reasons for seeking care and other important aspects of quality of care among people with dementia.[367]

Finally, linked data can provide potentially important opportunities for generating economic outputs, which is an important component for evaluating and improving the quality of care provided to people with dementia.[332, 368-370] Although, making cost calculations was outside of the scope of the PhD timeframe, the findings of this thesis could inform future economic analyses. Establishing linkages with primary care, specialist palliative care, and social care datasets will enable a more comprehensive understanding of care costs. Social care costs account for the majority of the dementia care costs.[13] Obtaining a true cost estimate for dementia care from diagnosis until the end of life just from the use of hospital services, without accounting for the social care costs (including formal and informal care costs) is not possible.[254, 369]

8.3.3 Models of healthcare, healthcare use and the quality of care

Another strength of this thesis was its use of multiple models of healthcare, healthcare use and quality of care including: complexity theory,[60, 61] factors associated with healthcare use and the place of death for non-malignant conditions,[1, 64] domains of quality of care, and aspects of care relevant to end-of-life period.[143, 180, 339] These models highlighted important concepts worthy of investigation and consideration for the design and the interpretation of the studies.

The use of theories aided in understanding different aspects of the thesis, yet they also had limitations. None of the aforementioned models were designed specifically for people with dementia. However, these models are regularly adapted and used in healthcare, and dementia and end-of-life care research.[66, 371] The use of complexity theory and consideration of findings across different domains of the quality of care are in line with a pragmatist approach, where the findings are considered within real-life paradigms, which exist beyond the limitations of dementia-specific scenarios.[61] Not all of the factors or domains highlighted in these theories were considered in this thesis. Structural and wider social factors associated with healthcare use among people with dementia were outside of the scope of the thesis, [313, 372, 373,374] though existing evidence was brought into the interpretations of the thesis findings.

8.3.4 Validity and consistency of findings

While the findings have not been replicated in a different dataset, steps such as using national statistics to age and sex standardise critical care admissions (Study 2), checking the existence and the validity of the latent subgroups with relevant stakeholders (i.e., clinicians, PPI members, commissioners) (Study 3), and comparing the consistency of the findings with the existing literature were taken. Although the thesis findings were based on a sample derived from a specific South London catchment and health service, the profile of people with dementia included in the studies resembles statistics derived from national cohorts.[361] Findings from this thesis should act as a springboard to investigate patterns of healthcare use at a national level and in other local areas for validation and a better understanding of consistency of the findings.

8.3.5 Engagement with public, people affected by dementia, clinicians and policymakers

It has been argued that engaging with the public should be a crucial part of healthcare research.[375] People with dementia, their family carers, bereaved carers and clinicians have been an integral part of the development of the research questions, and the interpretation of the findings as discussed throughout this thesis.[232] These discussions have been crucial in understanding the implications of the findings in relation to lived experience.

A pragmatist approach calls attention to the ways in which change can be directed for individual and societal benefits.[60, 194] Efforts were made to engage with researchers and policymakers at local and national levels to increase the impact of thesis findings on the care of people with dementia. For instance, I presented my thesis findings to the local commissioners for old age community services in London and discussed implications for their local population. In another instance, dementia, palliative and end-of-life care related evidence summarised in a policy brief[376] and my thesis findings were disseminated in a policy brief at a reception at the House of Lords to politicians and other third-party stakeholders (e.g., charities and thinktanks). Presenting evidence to policymakers is essential for influencing policy, but without influencing wider opinion, such efforts might not be enough to achieve change.[377] Therefore, whenever possible, I engaged with the members of the public to discuss and disseminate thesis aims and findings, often in combination with wider research throughout the PhD.

8.4 The COVID-19 pandemic, people with dementia, and its implications for the thesis findings

The impact of the COVID-19 pandemic and lockdowns on care of people with dementia must be considered, when discussing the implications for thesis findings. The COVID-19 pandemic highlighted the existing health inequalities and inequities in England and in other countries.[358] People with dementia were disproportionately affected by COVID-19 and the associated restrictions.[378] Although the COVID-19 restrictions have been mostly removed at the time of writing, the pandemic is likely to have had a knock-on effect on the current and future care of people with dementia.[379]

The thesis provides evidence regarding the relationship between the timing of dementia diagnosis on the healthcare use towards the end of life, where people who lived with a diagnosis for a shorter duration had higher incidences of unplanned hospital use. Delayed access to receiving an official dementia diagnosis due to lockdowns, and avoidance due to fear of contamination and restrictions to attend healthcare facilities, may have led to higher unplanned healthcare use, longer lengths of hospital stays, and delayed access to social and specialist care services among people with dementia.[380] Conversely, the proportion of people with dementia who were receiving care from community specialist mental healthcare teams until the end of their lives may have increased.

During the pandemic, some new services and adaptations to the existing services were introduced (e.g., virtual wards) to reduce pressures on hospitals.[381] The effect of these services, which may be particularly relevant to people with dementia approaching the end of life, on the existing quality indicators and the healthcare services explored in the thesis is unclear.

In England, rapid improvements to allow access to routinely collected data for research have occurred since the beginning of the COVID-19 pandemic.[181] Researchers are able to gain access to national datasets quickly and remotely through trusted research environments.[382] Utility of the quality indicators identified in the background work of this thesis can be maximised with infrastructures allowing access to up-to-date and linked datasets.

Finally, the COVID-19 pandemic prompted unprecedented discussions about healthcare, ageism, care homes, death, dying and grief at a societal level. Whether these discussions will have long-lasting impact on the patterns of healthcare use among people with dementia and their families, healthcare providers and the quality of care towards the end of life should be explored in future studies.

8.5 Implications for research

One of the purposes of routine data analyses and descriptive studies is to generate hypotheses for exploration and guide the direction of future research.[383] This section will, therefore, present implications of the thesis for research which have not been covered in previous sections of this thesis.

(i) This thesis includes an example of applying SEM techniques longitudinally to a large cohort of people with dementia using routine data. Applying proven methodologies from other fields can speed up knowledge generation about people with dementia nearing end of life and increase the utility of routine data.[384, 385] For instance, SEM models can be used to gain a better understanding of underlying reasons to certain healthcare outcomes observed towards the end of life among people with dementia.

(ii) Despite an emphasis on personalised and complex care needs of people with dementia, clustering (also known as phenotyping)[285, 314, 386, 387] methods are underutilised and have been limited to people with dementia who are not likely to be approaching the end of life.[273] Understanding clusters of healthcare use and the associated patient profiles aids with going a step further and tailoring the care needed for subgroups within the population. Future analytic work in this area could involve creating algorithms to identify people based on needs and identify preventative interventions that could aim to minimise high and potentially burdensome healthcare use towards the end of life.[388]

(iii) Most people with dementia have family or friends who may be helping with their care and healthcare interactions, especially towards the end of life.[28] Models accounting for the dyadic effects of carers' healthcare use, healthcare seeking behaviours and well-being on the healthcare use of people with dementia across their disease trajectory should be explored in future research studies.

(iv) An analysis of concurrent use of hospital, specialist mental care, specialist palliative care, and primary care services is needed to understand people who may be most at risk of poor care quality and the role of each service in improving the quality of care provided to people with dementia. To the best of my knowledge, the number of people with dementia receiving community or hospital specialist palliative care in England is not clear. This will be an important step in understanding the scale of specialist palliative care need and the type and amount of involvement required to achieve improvements to the quality of care experienced among people with dementia.

(v) In this thesis, trends in critical care use were explored and the impact of relevant policies were discussed (See Chapter 6, Section 6.5). With an increased emphasis on integration of care through integrated care boards, applying methods such as interrupted time series analysis or network analysis may be useful to gain better understanding of their effect and the impact of other relevant health and social care policies on the patterns of healthcare use at a health system level.[389-391]

(vi) Interventions such as discharge planning, which has been shown to be effective in reducing hospital readmissions in other populations should be further explored.[392] A high proportion of people with a completed discharge summary is a quality indicator for older people and people with dementia who may be approaching the end of life, yet the evidence is limited.[11] Similarly, a growing body of literature advocates for advance care planning for people with dementia in the face of an uncertain illness trajectory to ensure high quality end-of-life and reduce unplanned hospital admissions.[393, 394] Effectiveness of such interventions must be explored among people with dementia.

(vii) In future studies, for a more comprehensive understanding of overall quality of care, patient-reported outcome and experience measures should be combined with the interpretation of quality indicators.[180]

(viii) Qualitative research can further our understanding of underlying reasons for the observed patterns of healthcare use in this thesis.[9] With purposive sampling strategies to participant recruitment, efforts can be directed to the inclusion of subgroups among people with dementia (e.g., people with non-Alzheimer's disease dementia diagnoses, people of non-White ethnicities, people with dementia who experience unplanned hospital use shortly after their dementia diagnosis, people with dementia who receive specialist mental health care) who have been highlighted in this thesis to qualitative research studies.[395]

8.6 Implications for policy and clinical practice

Throughout the course of this PhD, I have made efforts to approach clinicians, commissioners and policymakers. The thesis findings were included in evidence calls by the UK government and presented to representatives from the Department of Health and Social Care in England. Findings from Study 1 were also presented to the representatives at the Australian Government Department of Health and Aged Care by another clinical researcher. At a local level, I presented all the findings from the thesis to a local London integrated care board. In terms of clinical engagement, the findings have been presented and discussed at a national dementia end-of-life and palliative care training course aimed predominantly at nurses and long-term care professionals.

Reflecting on the findings from this thesis, I focus here on the practical implications for policy and clinical practice to improve the quality of care provided to people with dementia from diagnosis to the end of life.

8.6.1 Improved recognition of dementia trajectories and its life-limiting nature

This thesis contributes to the literature advocating for better recognition of heterogeneity and unpredictability in dementia care. It argues for more support for people with dementia who may be approaching the end of life, by highlighting the frequency of potentially avoidable and burdensome healthcare use near death and the heterogeneity in patterns of multiple healthcare service use.

Training in dementia care is not mandatory across the NHS, despite being widely recommended, including by Health Education England.[396] This is problematic considering the number of potential healthcare professionals people affected by dementia may encounter. Furthermore, while hospitals provide training about caring for people with dementia and have access to specialist support (including but not limited to geriatricians, old age liaison psychiatrists, and less often to palliative care specialists), many training courses do not include specific skills needed for care of those approaching the end of life.[396] An example is the potential impact of lack of recognition of dementia's progression on the rates of critical care admissions among people with dementia in the last year of life (Study 2, Chapter 6). Improving recognition of dementia trajectories can ensure that standard treatments and care are tailored and when needed specialist care input is sought. To improve continuity of care and empower healthcare professionals who build relationships with people with dementia and their families following diagnosis, dementia end-of-life care skills and competency should be strengthened within teams such as primary care and mental healthcare specialists.

8.6.2 Variations in healthcare use

As the number of people with dementia has increased, their needs and their healthcare use have not only increased but also diversified.[397] Arranging the healthcare system in the interests of the majority, inevitably leads to disparities and lower care quality experienced by others.[342] This conflict arising from a utilitarian approach to healthcare delivery is pertinent in provision of dementia care where addressing personal needs is often considered to be a central pillar of optimal dementia care.[341, 398, 399]

In the healthcare literature, variations are often classified as warranted and unwarranted.[63, 400] If observed variability is due to higher and more complex healthcare needs (i.e., warranted),[319] then hospitals should be adapted to appropriately address these needs. If some of the observed variations are unwarranted, underlying reasons (e.g., lack of knowledge about dementia, implicit biases about individuals from certain ethnic groups or areas) should be explored and these variations should be minimised (e.g., where better alternatives are available, access to these services should be improved). More efforts can be made to inform the people with dementia and their families about the potential harms associated with unplanned hospital use. There may also be a need to change the public's perception and knowledge of where healthcare can be delivered. However, as long as hospitals, especially emergency departments, are perceived as a path of least resistance,[273] and in absence of accessible and sufficient community and home care, these efforts are likely to be unsafe and futile.

8.6.3 Hospital care provision

The number of people, including people with dementia, attending A&E and staying in hospital longer than necessary is increasing in England.[401] Findings from all three studies highlight the need for support and training for hospital staff in dementia and end-of-life care (See Chapter 7, Section 7.4). Findings from Studies 1 and 2 indicate that a large proportion of hospitalised people with dementia can benefit from a palliative care approach as they are highly likely to be nearing the end of life. Previous evidence from older people who may be approaching the end of life shows that hospital encounters may provide a good opportunity to discuss care needs and advance care planning.[317, 402] People with dementia who are in the hospital may not have the capacity to have advance care planning conversations.[402] Healthcare professionals providing care to people with dementia in hospitals should explore care preferences by collaborating with the informal carers and healthcare professionals who may be more familiar with the person.

The NHS Long Term Plan advocates for personalised and proactive planning for everyone identified as being in the last year of life, with a view to reduce hospital admissions towards the end of life.[154] Developing a personalised health care plan for people seen in medical outpatients and frequently admitted can reduce re-admissions.[392] However, the evidence specific to people with dementia who may be at different stages of the condition is limited, hence further evidence is required to understand the acceptability of these interventions for people with different dementia severity. My thesis findings highlight the variability in when people receive their dementia diagnosis, and from whom, in proximity to their death. Increased investments in the community must be accompanied by support in hospitals, such as appointing more discharge coordinators, to improve the care of people with dementia until the end of life.[403]

8.6.4 Community care provision

Findings from my thesis show that specialist multidisciplinary mental health care teams play an important role in the care of people with dementia from diagnosis until the end of life. Specifically, 17% of people had specialist mental healthcare teams visiting them at their home in the first year after diagnosis and in the last year of life. However, who is in the best position to deliver which aspects of care is relatively unknown. Realistically, it may not be possible nor appropriate to provide specialist mental healthcare to everyone, as this group may differ and require specific input due to their behavioural psychological symptoms and a targeted approach may be more efficient.[404] However, people with biopsychosocial factors associated with being at risk of moderate hospital use in the year after diagnosis, and high hospital use in the last year of life can be screened and prioritised for eligibility (Study 3).

Visibility and understanding of what care can be provided in the community must be improved. In England, care provided in the community often remains behind closed doors.[54] While attending hospital is a routine most people are familiar with, awareness and understanding of the services available in the community are often only gained after the need for them has arisen. This occurrence will likely be affected by people's education level, prior knowledge and the health and care professionals they interact with.

As demonstrated by the groups identified who accessed specialist mental health community services in Study 3, people with more complex health and social needs may need care from several different community services. Recently, limited access to specialist services has been recently criticised.[318] Involvement from specialist services in dementia care is likely to improve care and reduce burdensome care experiences. Having dedicated dementia coordinators for people with dementia who need care from multiple providers may be helpful.[405] Emerging evidence from care of older people who may be nearing the end of life show that having a consistent key point of contact may be helpful in reducing unplanned hospital use towards the end of life.[406] For some people with dementia, this person may be their GP (primary care).

8.6.5 Integration of dementia and end-of-life care provision

Dementia care is multidisciplinary, as demonstrated in this thesis. The thesis findings shed light on how the quality of care provided to people with dementia can be monitored and assessed; and provides potential strategies for improving care quality until the end of life (See Chapter 2). Integrating and boosting collaboration across services which care for people with dementia should be a priority given that the dementia care journey remains highly variable and unpredictable (Study 3).

Within the Health and Care Act 2022, wide reaching reforms were made to include the legal foundations for the integrated care boards.[6] An amendment was introduced mandating that the integrated care boards have a legal responsibility to commission health services, including palliative care services, that meet their population needs. A palliative care approach for dementia refers *"to all treatment and care in dementia, including adequate treatment of behavioural and psychological symptoms of dementia, comorbid diseases, and (inter- or concurrent) health problem"*.[407] Another duty of the integrated care boards is reducing inequalities in care and improving care quality.[6] The thesis highlights potential inequalities and inequities experienced among people with dementia along the care trajectory. Potential of palliative care involvement in improving the quality of life of people affected by dementia and reducing inequalities must be investigated and implemented.

When a palliative care approach is adopted earlier on the care trajectory, it is more likely to have an impact on end of life outcomes.[94, 139, 408, 409] When to integrate palliative care during the dementia care trajectory is widely debated.[407] With the efforts to improve access to dementia diagnosis, new technologies to improve diagnostic accuracy, and care, people may live with a dementia diagnosis longer.[15] The EMBED-Care programme is building evidence to understand current and future dementia palliative care need and integration of palliative care to routine dementia care.[57]

One of the priorities of the national plan is that *"People are identified as likely to be in the last 12 months of life and are offered personalised care and support planning"*.[408] Policies which are reliant on prognostication may hinder access of people with dementia to specialist services. The thesis findings indicate that it is hard to predict healthcare service use among people with dementia in the last year of life based on their healthcare use in the year following their dementia (Study 1 and 3). Rather than relying on prognosis, building a close working relationship with the specialists and adopting a palliative care approach may be more appropriate in dementia care. When people affected by dementia get in touch with services, approaches which promote integration of palliative care proactively rather than in reaction to a crisis should be considered.[407]

8.6.6 Monitoring the quality of care provided to people with dementia across care domains using routine data

Within the scope of this thesis, healthcare processes, outcomes and the potentially associated biopsychosocial characteristics were explored to investigate the quality of care provided to people with dementia and how it changes towards the end of life.

In England, similar to other countries without a centralised dementia registry, the quality of care provided to people with dementia is monitored in various ways by separate organisations. For example, Dementia Profile[361] includes 14 QIs from prevention to dying well with dementia, Palliative and End of Life Care Profiles reports dementia specific QIs,[410] CQC regards the quality of care provided in care homes,[93] and the National Audit of Dementia[411] provides an overview the care of people with dementia in general hospitals. Various health and care data are routinely collected across care settings. In addition to difficulty in collating reports regarding the overall quality of care received by everyone with dementia from organisations, it is not possible to collate information from all sources for quality improvement or research purposes. Development and implementation of a minimum data set for people living in care homes is currently underway.[412] Similarly, a dementia registry, enriched by linkage of multiple national data sources, would be a timely advance.

Learning health systems, where routinely collected data can be reused to improve healthcare delivery and investigate quality, trends, and inequalities, may help future understanding of dementia care. For instance, important QIs which have been shown to be distinctive between groups of people with dementia (Study 3) such as the length of stay and the number of A&E visits, are not routinely reported.[413] Within a learning health system, such trends could be detected and incorporated to quality improvement and monitoring of the quality of care easily. Population health management, which is proposed by the NHS, aims to improve population health through data-driven planning and the delivery of proactive care to optimise health outcomes.[414] Considering people with dementia must be a part of this approach.

Finally, monitoring the quality of care provided to people with dementia should be planned with contributions of people affected by dementia. Involvement of people affected by dementia will not only ensure aspects of quality of care which may be otherwise overlooked are prioritised, but can build trust and shift the power balance from healthcare providers to patients.

8.6.7 Interoperability of information systems

Sharing information between different health and social care teams and empowering the teams to work collaboratively could improve the care of people with dementia. Currently, different organisations across the health and social care systems hold their own set of records, which may lead to lack or limited communication regarding crucial information about care recipients. Although, caring for people with dementia often demands a holistic, system-level approach, there is no whole-system approach to interoperability standards for health and social care data.[7] Using technology to ensure access to information can help identify patterns and gaps in care and improve care proactively. Initiatives such as shared care records hold potential to improve communication across health and care providers. In England, the NHS has recently agreed to launch a new system which aims to reduce fragmentation. Information on the involvement of liaison psychiatry and palliative and end-of-life care specialists in the care of people with dementia would enable better understanding of care for this population.

Chapter 9: Conclusion

This thesis provides new findings on the patterns of healthcare use among people with dementia, and highlights the differences experienced by people with dementia who were approaching the end of life by taking novel approaches to the analysis of routinely collected linked datasets. Among a large English cohort of people with dementia, there was heterogeneity in the frequency and type of services used over time. This thesis discovered that individuals with dementia in the final stages of their lives frequently use multiple healthcare services and experience outcomes linked to poor care quality. The research provides guidance on how to alleviate adverse healthcare experiences and enhance the quality of care for all.

The results demonstrate that hospitals are a common place of care for people with dementia and can be an indication that people are approaching the end of their lives. Results regarding critical care admissions of people with dementia are first of their kind in a large English dementia cohort, providing novel findings including a decrease in the rates of overall critical care admissions but an increase in critical care admissions in the last year of life. Increases in rates of unplanned hospital admissions, length of stay, and critical care admissions urgently call for end-of-life care specific dementia training in hospitals and highlight the essential place integration of palliative and end-of-life care in hospitals. Finally, different profiles of healthcare use in the first year after dementia diagnosis, and in the last year of life were identified. In line with recent recommendations, this analysis goes beyond the place of death, the emphasis on single indicators of quality, and explores how services fit together. Almost one in six people with dementia access specialist mental health services in the first year following their dementia diagnosis, and in the last year of life. High levels of hospital use which could be avoidable was experienced by approximately one in ten people with dementia in the last year of life. Further research is needed to understand why these variations exist, and how experiences can be improved.

To make good judgements about the appropriateness of care and inform service provision at a population-level, access to high-quality and clinically relevant routinely collected data at a national level is essential. This will require investment in skills, workforce and infrastructure in healthcare and research. Linkages between clinical and administrative datasets, and data mining of free-text can provide rich sources of information for exploration of the quality of care and healthcare patterns of people with dementia until the end of their lives. The work contributes to a growing body of evidence from routinely collected data demonstrating patterns of healthcare use that demand policy developments and changes to clinical practice to ensure that healthcare resources are allocated fairly, and all people affected by dementia can receive high quality care until the end of their lives.

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Appendices

Appendix 1. Definitions of different domains of quality of care

Table. Definitions of different domains of quality of care

Access	'the ability to obtain care when needed, and to obtain it easily and conveniently'
Safety	'the avoidance of harm from care, as well as from the environment in which care is carried out'[415]
Effectiveness	'improvement in health that is achieved, or can be expected to be achieved, under the ordinary circumstances of everyday practice'[339] 'the extent to which care delivers its intended outcome or results'[51]
Outcomes of care	'changes in health status or quality of life'[179]
Person-centred / experience	'Putting the person who uses services at the centre of their care, treatment and support, ensuring that everything that is done is based on what is important to that person from their own perspective'[93]
Timely	'reduction in waits and sometimes harmful delays for both those who receive and those who give care'[416]
Efficiency	'maximizing output for a given input'[417] 'a measure of the cost at which any given improvement in health is achieved'[339]
Value for money	'the ratio of some measure of valued health system outputs to the associated expenditure'[343]
Capacity	'sufficiently well-resourced and with adequate distribution to enable delivery of appropriate services'[415]
Equity	'what is just or fair in the distribution of care and its benefits among the members of a population'[339]
Healthy, independent living	'care that supports independence of individuals' [93]
Health improvement	'care that aims to improve health status of individuals or population'[418]

Appendix 2. Supplementary material for the systematic review

Supplementary Table S1: Search terms

	Dementia	Terms relating to older people	End of life	Quality Indictors
Medical subject headings	exp Dementia/	Exp elder care/ Exp geriatric patients/ Exp geriatrics/ Exp gerontology/	exp Palliative Care/ exp Terminally Ill Patients/	Outcome and Process Assessment (Health Care) Exp Quality Assurance, Health Care Exp Quality Improvement
Keywords	dement*.mp alzheimer*.mp chronic* adj3 cerebrovascular.mp memory adj3 (impair* or insufficien* or complain*).mp cognit* adj2 (impair* or declin*).mp	Ag?ing.tw Old* person.tw Old* people.tw Elder*.tw Old* adult*.tw Geriatric*.tw Gerontol*.tw Senior*.tw Nursing home*.tw Long term care.tw	palliat*.mp end of life.mp EOL.mp life limit*.mp terminal*.mp dying.mp end stage.mp late stage.mp advanced.mp ceiling adj3 care.mp goal* adj3 care.mp last adj4 life.mp	Quality of Health Care.sh Qualit*.mp Utilisation Performance Assurance Benchmark Measur* Criter* Assess* Indicat* Validat* Evaluat*

				Scale
	Limit to human			

Electronic Search Strategy for PsycINFO (above)

Electronic Search Strategy for EMBASE

	Dementia	**Terms relating to older people**	**End of life**	**Quality Indictors**
Medical subject headings	exp Dementia/	Exp Aged/ Exp Aged hospital patient/ Exp Elderly care/ *Veteran/	exp Terminal care/ exp Terminally Ill Patient/ exp Dying/	Outcome and Process Assessment (Health Care) ("Outcome and Process Assessment (Health care)" or "Quality Assurance, Health care" or "Quality Improvement" or "Quality indicators, health care" or "quality of health care").sh.
Keywords	dement*.mp alzheimer*.mp chronic* adj3 cerebrovascular.mp memory adj3 (impair* or insufficien* or complain*).mp	Ag?ing.tw Old* person.tw Old* people.tw Elder*.tw Old*	palliat*.mp end of life.mp EOL.mp life limit*.mp terminal*.mp dying.mp	((quality or qualities or utili?ation or performance or assurance or benchmark*) adj2 (measur* or criter* or assess* or indicator* or validat* or evaluat*)).tw.

	cognit* adj2 (impair* or decline).mp	adult*.tw Geriatric*.tw Gerontol*.tw Senior*.tw Nursing home*.tw Long term care.tw	end stage.mp late stage.mp advanced.mp ceiling adj3 care.mp goal* adj3 care.mp last adj4 life.mp	
	Limit to humans			

Electronic Search Strategy for CINAHL

	Dementia	**Terms relating to older people**	**End of life**	**Quality Indictors**
Medical subject headings	(MH “Dementia+”)	(MH “Aged”) (MH “Health Services for the Aged”)	(MH "Terminally Ill Patients+") OR (MH "Palliative Care")	MW Outcome and process assessment (MH "Quality Assurance") (MH "Quality Improvement")
Keywords	TX dement* TX alzheimer* TX (chronic N3 cerebrovascular) TX memory N3 (impair* or insufficien* or	TI Ag?ing OR AB Ag?ing TI Old* person OR AB Old* person TI Old* people OR AB Old* people	TX palliat* TX end of life TX EOL TX life limit* TX terminal* TX dying	TX ((quality or qualities or utili?ation or performance or assurance or benchmark*) N2 (measur* or criter* or assess* or indicator*

	complain*) TX cognit* N2 (impair* or declin*)	TI Elder* OR AB Elder* TI Old* adult* OR Old* adult* TI Geriatric* OR AB Geriatric* TI Gerontol* OR AB Gerontol* TI Senior* OR AB Senior* TI Veteran* OR AB Veteran* TI Nursing home* OR AB Nursing home* TI Long term care OR AB Long term care	TX end stage TX late stage TX advanced TX ceiling N3 care TX goal* N3 care TX last N4 life	or validat* or evaluat*)) TX Assess* TX Indicat* Validat* Evaluat* Scale
	Limit to human			

Electronic Search Strategy for Web of Science

	Dementia	**Terms relating to older people**	**End of life**	**Quality Indictors**

Keywords	TS=(Dement*) TS=(Alzheimer*) TS=(chronic AND cerebrovascular) TS=(Memory near/2 impair*) TS=(Memory near/2 insufficien*) TS=(Memory near/2 complain*) TS=(Cognit* near/2 impair*) TS=(Cognit* near/2 declin*)	TS=(Elder*) TS=("Old* person") TS=("Old* people") TS=("Old* adult*") TS=(Geriatric*)	TS=(Palliat*) TS=("end of life") TS=(EOL) TS=(life limit*) TS=(terminal*) TS=(dying) TS=(end stage) TS=(late stage) TS=(advanced) TS=(ceiling near/3 care) TS=(goal* near/3 care) TS=(last near/4 life)	TS=("Quality of Health Care") TS=(Qualit*) TS=(Utilisation OR Performance OR Assurance OR Benchmark) TS=(Measur*) TS=(Criter*) TS=(Assess*) TS=(Indicat*) TS=(Validat*) TS=(Evaluat*) TS=(Scale)

Supplementary Table S2 has been presented in the Chapter 2, Section 2.2.1

Supplementary Table S3: PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	4
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	5
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	6

Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	6 (Supplementary Table S2)
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	6
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	6 & Supplementary Table S1
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	6-7
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	7
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	7 & Supplementary Link S4
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	N/A
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	N/A

Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	7

Page 1 of 2

Section/topic	**#**	**Checklist item**	**Reported on page #**
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	N/A
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	N/A
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	8
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	Supplementary Link S4
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	N/A
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each	N/A

		intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	N/A
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	N/A
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	N/A
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	11-13
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	14
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	15-16
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	18

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097 For more information, visit: **www.prisma-statement.org**.

Supplementary Link S4: Data Extraction Sheet

Excel sheet which includes all data is stored in Figshare Repository can be downloaded from this link: https://figshare.com/s/2595153c63b923eaa0e8

Supplementary Table S5 has been presented in Chapter 2, Section 2.2.2

Supplementary Table S6: Summary of papers included in the systematic review

Author, country	Year	Study design and aim	Target population	Setting	Data source	Number of quality indicators*	Example quality indicator
Bail et al. [419] Australia	2016	a narrative analysis of acute care literature to develop a conceptual proposition	Complex older adults (including patients with dementia)	Hospital	Not specified	4 – O	Pressure injuries **Numerator:** Number of patients with pressure injuries who were untreated **Denominator:** The number of patients admitted to hospital **Benchmark: -** **Type:** Outcome **Domain:** Physical aspects **Usability:** Weak
Choi et al. [420] Republic of Korea	2018	a comparative design approach to evaluate the outcomes of a community-based	Palliative care patients	Community palliative care	Administrative data**	5 – O	Changes in patients' symptoms **Numerator:** Number of people who received palliative care **Denominator:** Number of registered people

		palliative care project conducted in Busan city, Korea, from 2013 to 2015.					**Benchmark: -** **Type:** Outcome **Domain:** Physical aspects **Usability:** Moderate
Claessen et al. [421] The Netherlands	2011	Phased approach: Inventory (Existing QIs, Systematic Review) & Development and testing of draft sets (Expert Panel Consultation) to describe the development and initial testing of a set of quality indicators for palliative care, applicable for all settings in which palliative care is	End of life care	Applicable across care settings	Survey	49 – O	Dying peacefully **Numerator:** The number of relatives who indicate that their relative died peacefully **Denominator:** The total number of relatives among whom this quality indicator was measured **Benchmark: -** **Type:** Outcome **Domain:** Spiritual and cultural aspects **Usability:** Moderate

		being provided for adult patients in The Netherlands					
Cook et al. [422] UK	2016	a survey of Commissioning for Quality and Innovation (CQUIN) indicators for community nursing in focusing on indicators for end of life care	Palliative care patients	Community nursing	Survey	13 – P	Use of a diary issued to all patients in the last few days of life to improve the communication with relatives, on their satisfaction with the End of Life care of their loved one; in order to identify areas for change and improvements in care in the last few days of life. **Numerator:** Number of patients who use the diary within last few days of life to improve communication and satisfaction with end of life care **Denominator:** Number of people on the end of life register **Benchmark: -** **Type:** Process **Domain:** Communication, advance care

							planning, and ethical and legal aspects **Usability:** Weak
De Schreye et al. [423] Belgium	2017	modified RAND/UCLA appropriateness method to develop indicators of appropriate and Weak end-of-life care for people with cancer, chronic obstructive pulmonary disease or Alzheimer's disease, measurable with population-level administrative data	People with Alzheimer's disease	Applicable across care settings	Population-level administrative data	28 17 – P 11 - O	Gastric protectors **Numerator:** those who received two or more prescriptions of gastric protectors in the last 6 months prior to death (i.e. prescription until death) **Denominator:** number of people who died with Alzheimer's disease **Benchmark:** <22.4% **Type:** Process **Domain:** Physical aspects **Usability:** Robust
Gozalo et al. [424]	2011	Secondary data analysis to describe rates of burdensome	Nursing home residents	Applicable across care settings	Population-level administrative	3 – P	Any transfer in the last 3 days of life **Numerator**: the number of residents who

USA		transition in this population, identify factors that were associated with an increased rate of burdensome transition, and examine the association between regional rates of burdensome transition and outcomes that are markers of Weak quality in end-of-life care.			data		transfer within the last 3 days of life **Denominator:** the number of nursing home residents who died **Benchmark:** - **Type:** Process **Domain:** Multiple care domains **Usability:** Weak
Guthrie et al. [425] Canada	2019	Secondary data analysis to propose and then examine a preliminary set of QIs for seriously ill	Seriously ill home care residents	Home care	Standardized assessment tool	11 – O	Prevalence of social isolation **Numerator:** Client is alone for long periods of time or all of the time - AND - Client indicates feeling lonely - OR Decline in social

		home care clients in six Canadian provinces.					activities, client is distressed **Denominator:** All clients who were reassessed **Benchmark:** - **Type:** Outcome **Domain:** Psychosocial aspects **Usability:** Robust
Heckman et al. [426] Canada	2019	Qualitative interviews of quality assurance framework to understand physicians' and specialists' perspectives on such a system and identify barriers to its implementation	Dementia end of life	Applicable across care settings	Administrative Data	14 – P	Patients referred to a specialist if one or more of the following is documented: 1. Course of the dementia is rapidly progressive 2. Characteristics suggest rare types of dementia, such as focal or frontal features or visual hallucinations in early stages of the dementia 3. Persistent patient or caregiver complaints of problematic symptoms, or unexplained

							investigation results 4. Uncertainty about the diagnosis 5. Patient is younger than 65 years **Numerator:** The number of patients referred for one of the five criteria **Denominator:** All patients seen with documentation of one or more of these five criteria **Benchmark:** - **Type:** Process **Domain:** Multiple domains **Usability:** Moderate
Kendell et al. [427] Canada	2020	Literature review and stakeholder interviews/Delphi to describe the current state of care for	Older people with frailty	Long-term care	Administrative Data	8 7– P 1 – O	Readmission within 30 days of previous discharge **Numerator:** The number of patients who were re-admitted within the last 30 days of

		older persons with frailty					last discharge **Denominator:** Number of people who had an admission **Benchmark:** - **Type:** Outcome **Domain:** Multiple domains **Usability:** Moderate
Kergoat et al. [428] Canada	2009	Reliability and feasibility study to create a quality assessment tool for acute care	End of life care	Hospital	Administrative Data	5 – P	Patient-centred care - Level of care as expressed by the patient) - item 165; Inform the patient and brief the family on the patient's clinical situation, Ordinal variable with 3 levels : - neither item present - at least one item present - both items present **Numerator:** - **Denominator: -** **Benchmark: -**

							Type: Process **Domain:** Other/multiple domains **Usability:** Moderate
Kröger et al.[429] Canada	2007	Literature review and RAND/UCLA evaluating face and content validity, feasibility and reliability of process quality indicators developed previously in the United States or other countries for Canada	Dementia	Applicable across care settings	Medical files or by interview	63 – P	**IF** a vulnerable elder presents with symptoms of dementia that correspond in time with the initiation of new medications (prescriptions, over the counter or supplements) **THEN** the physician should discontinue or justify the necessity of continuing these medications **Numerator:** Number of people where the physician discontinued or justified the necessity of continuing newly initiated medications **Denominator:** Vulnerable elders who present with symptoms of dementia **Benchmark:** - **Type:** Process

							Domain: Structure and process **Usability:** Robust
Leemans et al. [430] Belgium	2017	Two round RAND/UCLA expert consultation to develop a minimal indicator set for efficient quality assessment in palliative care	End of life care	Applicable across care settings	Survey	31 15 – P 16 - O	Pain assessment **Numerator:** number of patients who were subjected to a general symptom assessment on a validated scale **Denominator:** total number of patients for whom this indicator was measured **Benchmark: -** **Type:** Process **Domain:** Physical aspects **Usability:** Moderate
Leff et al. [431] USA	2015	RAND Modified Delphi for the network's quality-of-care framework, which includes ten quality-of-care	Homebound older people with complex conditions	Home care	Administrative data	19 7 – P 12 - O	Pain **Numerator:** Unclear **Denominator:** Unclear **Benchmark:** -

		domains, thirty-two standards, and quality indicators that are being tested in the field.					**Type:** Outcome **Domain:** Physical domain **Usability:** Weak
Lind et al. [432] Sweden	2013	Review of existing QIs in national Swedish policy documents relevant to palliative care and end of life care.	End of life care	Applicable across settings	Not specified	2 -P	Pain **Numerator:** Fraction of people aged 65 years and older who have died, for whom pain was estimated with the aid of a scientifically evaluated instrument such as an NRS or a VAS, during the final week of life **Denominator:** People aged 65 years and older who have died **Benchmark:** - **Type:** Process **Domain:** Physical aspects **Usability:** Weak

Lindenauer et al. [433] USA	2011	Secondary data analysis to describe the development, validation, and results of a risk-standardized measure of hospital readmission rates among elderly patients with pneumonia employed in federal quality measurement and efficiency initiatives.	End of life care	Hospital	Administrative Data	1-O	Rehospitalization within 30 days of treatment for pneumonia **Numerator:** People who were admitted within 30 days of treatment for pneumonia **Denominator:** All patients with a principal discharge diagnosis of pneumonia **Benchmark: -** **Type:** Outcome **Domain:** Multiple domains **Usability:** Robust
Lorenz et al. [434] USA	2007	Literature review and expert panel to develop a set of quality indicators (QIs) broadly addressing palliative	End of life care	Applicable across care settings	Administrative data	16 – P	**ALL** vulnerable elders (VEs) should have in the outpatient chart patient's surrogate decision maker, or documentation of a discussion to identify or search for a surrogate decision maker. **Numerator:** ALL VEs should have in the

		and end-of-life care as it applies to vulnerable elders (VEs).					outpatient chart patient's surrogate decision maker, or documentation of a discussion to identify or search for a surrogate decision maker **Denominator:** Unclear (All VEs who died) **Benchmark:** - **Type:** Process **Domain:** communication, advance care planning, and ethical and legal aspects **Usability:** Weak
Masaki et al. [435] Japan	2017	Literature review, expert panel, Delphi process to develop and build a consensus of quality indicators for end-of-life care for elders in Japan from the perspective of	Older people	Applicable across care settings	Not specified	29 – P	**IF** the elderly is undergoing treatment or care **THEN** The medical team should reach a consensus about the prognosis and treatment goals —based on the state of functional decline due to age and stage of illness. **Numerator:** Number of people who had a decision-making/discussion around where their treatment and care are heading

		nursing science					discussion jointly with family *or if they don't have a family, appointment of someone else in case a decision is needed to be made in future) **Denominator:** Number of elderly undergoing treatment or care **Benchmark: -** **Type:** Process **Domain:** communication, advance care planning, and ethical and legal aspects **Usability:** Moderate
Mays et al. [436] USA	2018	Expert consultation to identify QIs that could be used to assess the quality of care of primary care providers (PCPs) participating in NH practices.	Nursing home residents	Community – PCPs participating in NH practices	Not specified	77 – P	**IF** a NHR has suspected or definite diagnosis of delirium, acute confusional state, or reduced level of consciousness, **THEN** there should be a documented attempt to identify a potential aetiology. **Numerator:** Number of NHRs with suspected or definite diagnosis of delirium, acute confusional state, or reduced level of

							consciousness with attempted identification of aetiology **Denominator:** Number of NHRs with suspected or definite diagnosis of delirium, acute confusional state, or reduced level of consciousness **Benchmark: -** **Type:** Process **Domain:** Structure and processes **Usability:** Moderate
Miranda et al. [437] Belgium, Italy, Spain	2018	Literature review and expert panel to answer the research question: 'What is the quality of primary palliative care in Belgium, Italy and Spain for older people who died	Dementia	Community – Primary palliative care	Survey	9 7 – P 2 – O	Multidisciplinary consultation **Numerator:** Number of patients for whom a multidisciplinary consultation took place approximately once a week or approximately everyday **Denominator:** All patients for whom the question was answered **Benchmark:** "At least once a week"

		non-suddenly with mild or severe dementia?' using quality indicators (QIs)					**Type:** Process **Domain:** communication, advance care planning, and ethical and legal aspects **Usability:** Weak
Morris et al. [438] Europe, Canada, USA	2013	Expert opinion for the development of interRAI's second-generation home care quality indicators (HC-QIs)	Frail older living in the community	Community – home	Standardized assessment tool	23 – O	Falls **Numerator:** Number of home care clients who had a fall. **Denominator:** Number of home care clients **Benchmark:** 22.3% **Type:** Outcome **Domain:** Physical aspects **Usability:** Robust
Mukamel et al. [439] USA	2012	To develop prototype EOL QMs that can be calculated from data sources available for all nursing homes	End of life care	Community – nursing homes	Administrative Data	2 1 – P 1 – O	Place of death **Numerator:** Percentage of people who died in the hospital **Denominator:** All who died

		nationally					**Benchmark: -** **Type:** Outcome **Domain:** communication, advance care planning, and ethical and legal aspects **Usability:** Weak
Mularski et al. [440] USA	2006	Literature review and expert consensus group to use a consensus process to develop a preliminary set of quality measures to assess palliative care in the critically ill	Critically ill	Hospital care (Critical care)	Administrative data	14 – P	Goals of care and resuscitation status **Numerator**: Total number of patients transferred out of the ICU with documentation that the goals of care and resuscitation status were communicated to the receiving team. **Denominator:** Total number of patients transferred out of the ICU alive to another service in the hospital or other care facility. (Exclusions: Patients who die in the ICU and patients discharged to home from the ICU without home care services.) **Benchmark: -**

							Type: Process **Domain:** communication, advance care planning, and ethical and legal aspects **Usability:** Moderate
Nelson et al.[441] USA	2006	Literature review and expert panel to develop a practical set of measures for routine monitoring, performance feedback, and improvement in the quality of palliative care in the intensive care unit (ICU).	Critically ill	Intensive care units	Standardized assessment tool	8 4 – P 4 – O	Social work support **Numerator:** Number of patients with documentation that social work support was offered to the patient/ family **Denominator:** Total number of patients with ICU length of stay >3 days **Benchmark: -** **Type:** Process **Domain:** communication, advance care planning, and ethical and legal aspects **Usability:** Moderate
Oborne et al.[185]	2002	Cross-sectional survey to develop an indicator of	Nursing home residents	Community – nursing	Administrative data	2 – P	Appropriate neuroleptic prescription (a) psychotic disorders; b) organic mental syndromes with behaviour presenting

UK		appropriate neuroleptic prescribing based on US OBRA guidelines		home			danger to patient, others or interfering with provision of care; c) hiccough, nausea, vomiting (short-term only) **Numerator:** Percentage of NH residents who were prescribed neuroleptic medications appropriately. **Denominator:** Number of NHs residents **Benchmark: -** **Type:** Process **Domain:** Physical aspects **Usability:** Robust
Odenheimer et al. [442] USA	2013	A new measurement set for dementia management developed by an interdisciplinary Dementia Measures Work Group (DWG) representing	People with dementia	Applicable across care settings	Not-specified	10 - P	Palliative care counselling and advance care planning **Numerator**: Percentage of patients, regardless of age, with a diagnosis of dementia, or their caregiver(s), who 1) received comprehensive counselling regarding ongoing palliation and symptom management and end-of-life decisions and

		the major national organizations and advocacy organizations concerned with the care of individuals with dementia					2) have an advance care plan or surrogate decision-maker in the medical record or documentation in the medical record that the patient did not wish or was not able to name a surrogate decision-maker or provide an advance care plan within 2 years of initial diagnosis or assumption of care **Denominator:** All patients with dementia diagnosis **Benchmark: -** **Type:** Process **Domain:** communication, advance care planning, and ethical and legal aspects **Usability:** Weak
Roberts et al. [443] UK	1994	Two round Delphi study to obtain a consensus view from consultant geriatricians about	Old people end of life	Hospital – geriatric care	Not specified	11 3 – P 8 – O	Reduce carer burden **Numerator:** Number of carers with reduced carer burden **Denominator: All those who use geriatric**

		appropriate performance measures for geriatric medical services					**services** **Benchmark: -** **Type:** Outcome **Domain:** Psychosocial aspects of care **Usability:** Weak
Saliba et al. [444] USA	2005	Delphi study to develop a set of specific care processes associated with better outcomes for general medical conditions identified as quality improvement targets for institutionalized vulnerable elders.	Nursing home residents	Community – nursing homes	Medical records or interview	110 – P	Flu vaccination **Numerator:** Number of home clients who did not have a flu vaccination **Denominator:** Number of home care clients **Benchmark:** 0.34 **Type:** Process **Domain:** Physical aspects of care **Usability:** Robust
Schenck et	2010	To develop a set of	End of life care	Hospice and	Standardized	47	**Numerator:** Percent of patients who have

al. [445] USA		quality measures, with complete specifications, and data collection tools for use by hospice and palliative care providers in quality improvement.		palliative care	assessment tool	31 – P 16 – O	documented discussion to identify spiritual or religious concerns as they affect care **Denominator:** Palliative care and hospice patients for whom the process/outcome was expected **Benchmark:** - **Type:** Outcome **Domain:** Spiritual and cultural aspects of care **Usability:** Moderate
Schnitker et al. [446] Australia	2015	Literature review and expert panel to develop process quality indicators (PQIs) to support the improvement of care services for older people with cognitive	Dementia end of life care	Hospital – Emergency departments	Administrative data	11 – P	Delirium Screening **Numerator:** The number of older ED patients who have a suspected or definite diagnosis of delirium where the ED provider documented an attempt to attribute the altered mental state to a potential etiology **Denominator:** The number of older ED patients who have a suspected or definite diagnosis of delirium (identified by using

		impairment in emergency departments					medical record review) **Benchmark:** 70% **Type:** Process **Domain:** Structure and processes **Usability:** Robust
Sinuff et al. [447] Canada	2015	Delphi study to develop quality indicators related to EOL communication and decision making	End of life care	Applicable across settings	Not specified	26 24 – P 2 – O	Before hospitalization, the patient and/or a family member discussed their preferences for using or not using medically appropriate life-sustaining treatments with their family doctor or other doctor **Numerator:** The number of patients and/or family members that discussed their preferences for using or not using medically appropriate life-sustaining treatments with their family doctor or other doctor before hospitalization **Denominator:** All patients admitted to acute care setting

							Benchmark: - **Type:** Process **Domain:** communication, advance care planning, and ethical and legal aspects **Usability:** Weak
Terrell et al. [448] USA	2009	Literature review and expert panel to develop ED-specific quality indicators for older patients to help practitioners identify quality gaps and focus quality improvement efforts	Older vulnerable people attending emergency departments	Hospital – Emergency departments	Administrative data	23 21 – P 2 – O	Detecting Whether Cognitive Abnormalities Were Previously Recognized 5. **IF** an older adult presenting to an ED is 1) found to have an abnormal mental status, 2) has no change in mental status from baseline, and 3) is discharged home, **THEN** the ED provider should document whether there has been previous recognition or diagnosis of an abnormal mental status by another health care provider (or document an unsuccessful attempt to determine this) **Numerator**: Number of older adults presenting to an ED where the ED provider documented a previous recognition or diagnosis of an abnormal mental status by

							another health care provider (or document an unsuccessful attempt to determine this) **Denominator:** Number of older adults presenting to an ED who were found to have an abnormal mental status, 2) had no change in mental status from baseline, and 3) was discharged home **Benchmark: -** **Type:** Process **Domain:** communication, advance care planning, and ethical and legal aspects **Usability:** Weak
Towers et al. [449] UK	2015	To create a draft toolkit and explore its feasibility as a care home quality indicator	End of life care	Community – Care home	Standardized assessment tool	8 – O	Personal safety - Feeling safe and free from fear Residents feel safe and free from fear of physical and psychological harm and are supported to manage risks **Numerator**: The number of residents who feel safe and free from fear of physical and psychological harm and are supported to

							manage risks **Denominator:** All care home residents **Benchmark: -** **Type:** Outcome **Domain:** Psychosocial aspects of care **Usability:** Robust
Twaddle et al.[450] USA	2007	Secondary data analysis to provide practice standards, guidelines and performance measures for delivering effective palliative care and to assess current levels of performance for these measures.	Patients with advanced chronic conditions	Hospital	Administrative Data	10 7 – P 3 - O	Documentation of discharge plan **Numerator:** The percentage of all cases with documentation that such a meeting between patient/family and members of the healthcare team to discuss the patient’s treatment preferences or the plans for discharge disposition occurred during the first week of the hospital stay **Denominator:** All admitted patients **Benchmark:** 90%

							Type: Process **Domain:** communication, advance care planning, and ethical and legal aspects **Usability:** Moderate
Van der Ploeg et al. [451] The Netherlands	2008	A modified version of the RAND/UCLA appropriateness method to describe the adaptation of a set of systematically developed US quality indicators for healthcare for vulnerable elders in The Netherlands	Old people end of life care	Applicable across care settings	Not specified	7- P	Depression - **IF** a vulnerable elder has comorbid dementia or a somatic disease, **THEN** an existing depression should still be treated. **Numerator:** Number of people where depression is treated **Denominator:** Number of vulnerable elders with depression and comorbid dementia or a somatic disease **Benchmark:** - **Type:** Process **Domain:** Psychosocial aspect

							Usability: Robust
Van Riet Paap et al. [452] The Netherlands	2014	a modified RAND Delphi procedure to compose a set of palliative care QIs based on existing sets of QIs on the organisation of palliative care	Dementia end of life care	Applicable across care settings	Not specified	10 – P	Use of opioids - Opioids are accessible and available for persons in need of palliative care 24/7. **Numerator:** - **Denominator: -** **Benchmark: -** **Type:** Process **Domain:** Physical aspects **Usability:** Weak
Wenger et al. [453] USA	2007	Literature review and expert panel to use a formal decision-making strategy to reach clinically appropriate, internally consistent decisions on the	Vulnerable elders (VEs) with advanced dementia (AD) or Weak prognosis (PP).	Applicable across care settings	Medical records or interviews	248 – P	**IF** an outpatient VE was referred to a consultant and revisited the referring physician, **THEN** the referring physician's medical record should acknowledge the consultant's recommendations, include the consultant's report, or indicate why the consultation did not occur. **Numerator:** Outpatient VEs of whom the

		application of quality indicators (QIs) to vulnerable elders (VEs) with advanced dementia (AD) or Weak prognosis (PP).					referring physician's medical record acknowledges the consultant's recommendations, includes the consultant's report, or indicates why the consultation did not occur **Denominator**: Outpatient VEs who were referred to a consultant and revisited the referring physician **Benchmark: -** **Type:** Process **Domain:** Structure and processes **Usability:** Robust
Zimmerman et al. [454] USA	1995	Development and testing of a set of indicators of quality of care in nursing homes, using resident-level	Nursing home residents	Community - nursing homes	Administrative data	23 7- P 16-O	Prevalence of little or no activity **Numerator:** Number of people with little or no activity **Denominator**: Total number of nursing home residents **Benchmark: -**

assessment data	**Type:** Outcome **Domain:** Physical aspects of care **Usability:** Robust

*P: Process, O: Outcome, QI: Quality indicator, NH: Nursing home, ED: Emergency department, PCP: primary care providers

** Administrative data includes routinely collected data that were not predominantly collected for research/purpose-specific (e.g. electronic medical records, and data collected for insurance purposes)

Supplementary Table S7. Shortlist of Recommended Quality Indicators Grouped by Domain of Care

QI Description	Quality indicator Characteristics		Psychometric properties						Population	Setting	Data Source
	Standard	**Indicator type**	**Acceptability**	**Evidence base**	**Definition**	**Feasibility**	**Reliability**	**Validity**	*Dementia* *Older people* *Both*	*Place of care & Place of residence where applicable*	
Operational aspects of care											
No. of people who received official palliative care status, enabling financial government support for palliative care at any point prior to death/ No. of people who died	>6.2%	Outcome	Positive	Positive	Positive	Positive	Unknown	Unknown	Dementia	Not specified	Population-level health insurance registry linked with healthcare databases

with Alzheimer's disease											
No. of people who received specialized palliative care (*hospital palliative unit OR palliative day care centre OR multidisciplinary home care*) in the last two years prior to death/No. of people who died with Alzheimer's disease	>9.5%	Process	Positive	Positive	Intermediate	Positive	Unknown	Unknown	Dementia	Not specified	Population-level health insurance registry linked with healthcare databases
No. of people who had a first referral to specialized	<2.6%	Process	Positive	Positive	Intermediate	Positive	Unknown	Unknown	Dementia	Not specified	Population-level health insurance

palliative care OR received the official palliative statute in the last week before death/ No. of people who died with Alzheimer's disease											registry linked with healthcare databases
No. of people who had one or more hospital admissions in the last [6, 3, 1] month/s prior to death/ No. of people who died with Alzheimer's disease	NA	Outcome	Positive	Positive	Positive	Positive	Unknown	Unknown	Dementia	Hospital – Place of residence not specified	Population-level health insurance registry linked with healthcare databases

No. of people with at least one ICU admission during last 30 days of life/ The number of patients who were admitted to ICU in the last 30 days	NA	Outcome	Positive	Positive	Positive	Positive	Unknown	Unknown	Both	Intensive care unit – Place of residence not specified	Population-level health insurance registry linked with healthcare databases
No. of people who visited ED within the last month and year of life/ No of people who had ED visits for any diagnosis	NA	Outcome	Positive	Positive	Intermediate	Positive	Unknown	Unknown	Both	Emergency department	Population-level health insurance registry linked with healthcare databases
No. of people who had one or more ICU admissions in the last month of life/No. of	NA	Outcome	Positive	Positive	Positive	Positive	Unknown	Unknown	Both	Intensive care unit – Place of residence	Population-level health insurance registry linked with

patients who were admitted to ICU in the last 30 days										not specified	healthcare databases
Overall 30-day readmission rate for people who had a principal discharge diagnosis of pneumonia	NA	Outcome	Positive	Positive	Positive	Positive	Positive	Positive	Both	Hospital – Place of residence not specified	Population-level health insurance registry linked with healthcare databases
No. of inpatient days in the last 30 days of life OR last year life OR most recent year/No. of patients admitted in the last 30 days of life OR last year life OR most recent year	NA	Outcome	Positive	Positive	Intermediate	Positive	Unknown	Unknown	Both	Hospital	Population-level health insurance registry linked with healthcare databases

Proportion of patients who received continuity of care (defined as seen by the same family physician) within the last year of life/most recent year	NA	Outcome	Positive	Positive	Intermediate	Positive	Unknown	Unknown	Both	Not specified	Population-level health insurance registry linked with healthcare databases
An increase in average number of contacts with a family physician in the last month prior to death compared to the previous 23 months/ No. of people who died with Alzheimer's	>82.6	Outcome	Positive	Positive	Intermediate	Positive	Unknown	Unknown	Dementia	Primary care – Place of residence not specified	Population-level health insurance registry linked with healthcare databases

disease											
No. of inpatient days in the last 30 days of life OR last year life OR most recent year/No. of patients admitted in the last 30 days of life OR last year life OR most recent year	NA	Outcome	Positive	Positive	Intermediate	Positive	Unknown	Unknown	Both	Hospital	Population-level health insurance registry linked with healthcare databases
No. of people who died in hospital/ No. of people who died with Alzheimer's disease	NA	Outcome	Positive	Positive	Positive	Positive	Unknown	Unknown	Dementia	Hospital – Place of residence not specified	Population-level health insurance registry linked with healthcare databases
No. of people who died at home or nursing home/	>58.9	Outcome	Positive	Positive	Positive	Positive	Unknown	Unknown	Dementia	Nursing home – Place of residence	Population-level health insurance

No. of people who died with Alzheimer’s disease										not specified	registry linked with healthcare databases
Communication, advance care planning and ethical and legal aspects of care											
No. of people who had their follow-up appointment after being discharged (or documented that it was postponed or not needed) from a hospital/No of people who had a scheduled follow-up appointment after being discharged from	NA	Process	Positive	Positive	Positive	Positive	Unknown	Positive	Both	Hospital - – Place of residence not specified	Medical records

the hospital											
No. of people with a discharge summary/No of people who were discharged from a hospital to home or to a nursing home	NA	Process	Positive	Positive	Intermediate	Positive	Unknown	Positive	Both	Hospital - – Place of residence not specified	Medical records
No. of people who received education about the purpose of the drug, how to take it, and the expected side effects or important adverse reactions/No of people who were prescribed a new	NA	Process	Positive	Positive	Intermediate	Unknown	Unknown	Positive	Both	Not specified	Population-level health insurance registry

medication											
No. of people who discussed treatment with a cholinesterase inhibitor/No of people with mild to moderate Alzheimer’s disease	NA	Process	Positive	Positive	Positive	Positive	Unknown	Positive	Dementia	Not specified	Medical records
No. of people (and caregivers) who discussed patient safety, information on education on how to deal with conflicts at home, and community resources for dementia/No of	NA	Process	Positive	Positive	Positive	Positive	Unknown	Positive	Dementia	Not specified	Medical records

people with dementia											
No. of people with dementia (and/or caregivers) the target behavioural disturbance/safety issue justifying the use of restraints was documented in the medical record and communicated to the patient and/or caregiver/guardian. / No. of people with dementia who were physically restrained in	NA	Process	Positive	Positive	Positive	Unknown	Unknown	Positive	Dementia	Hospital - Place of residence not specified	Medical records

hospital											
No. of people whose specific treatment preferences were followed/No. of people with specific treatment preferences (for example, a do-not-resuscitate order, no tube feeding, or no hospital transfer) documented in a medical record	NA	Process	Positive	Positive	Positive	Positive	Unknown	Positive	Both	Not specified	Medical records
No. of people who are able to identify a physician or a clinic to call for	NA	Process	Positive	Positive	Positive	Unknown	Unknown	Positive	Older people	Not specified – People who live at home	Population-level health insurance registry

medical care or know the telephone number or other mechanism to reach this source of care/No of people who live at home											
No. of people who had a documentation (during the emergency department visit or within the first 2 days after admission) of communication with a continuity physician, of an	NA	Process	Positive	Positive	Positive	Unknown	Unknown	Positive	Both	Hospital - Place of residence not specified	Population-level health insurance registry

attempt to reach a continuity physician, or that there is no continuity physician/No. of people who were treated at an emergency department or admitted to a hospital											
No. of outpatients who had one of the following at the follow-up visit: Result of the test initiated or acknowledged, note that the test was not needed or	NA	Process	Positive	Positive	Intermediate	Unknown	Unknown	Positive	Both	Hospital - Place of residence not specified	Population-level health insurance registry

reason why it will not be performed, Note that the test is pending/No. of outpatients who were given an order for a diagnostic test											
No. of people with dementia who had a discussion around antipsychotic risk-benefit/No of people with dementia and behavioural symptoms newly treated with an antipsychotic	NA	Process	Positive	Positive	Intermediate	Unknown	Unknown	Positive	Dementia	Not specified	Population-level health insurance registry
No. of people who	NA	Process	Positive	Positive	Positive	Positive	Unknown	Positive	Both	People who	Population-

had the name and contact information for the patient's surrogate decision maker or a discussion to identity or search for a surrogate decision maker within 48 hours of nursing home admission/No. of nursing home residents										live at a nursing home	level health insurance registry
No. of people where the treatment preferences were considered or attempt was	NA	Process	Positive	Positive	Positive	Unknown	Unknown	Positive	Both	Intensive care unit Place of residence not specified	Population-level health insurance registry

made to identify them within 48 hours of ICU admission/No. of people who were admitted to the ICU and survived 48 hours											
No. of people where life-sustaining treatment withdrawal orders were followed/No. of people with treatment preferences s to withhold or withdraw life-sustaining	NA	Process	Positive	Positive	Positive	Positive	Unknown	Positive	Both	Hospital – Place of residence not specified	Population-level health insurance registry

treatment											
Sum of number of contacts with a family physician or other primary care professional in the last three months prior to death/ No. of people who died with Alzheimer's disease	NA	Outcome	Positive	Positive	Intermediate	Positive	Unknown	Unknown	Dementia	Primary care – Place of residence not specified	
Psychosocial aspects of care											
No. of people received serotonin reuptake inhibitors in the last three months prior to death/ No. of people who died with	<7.2%	Process	Positive	Intermediate	Positive	Positive	Unknown	Unknown	Dementia	Not specified	Population-level health insurance registry linked with healthcare databases

Alzheimer's disease											
No. of people who had their performance in communicating and personal care was evaluated/Number of people with a diagnosis of dementia in an intermediate stage	NA	Process	Positive	Unknown	Intermediate	Positive	Unknown	Positive	Dementia	Not specified	Medical records
No. of people whose depression was treated/ No. of vulnerable elders with depression and comorbid	NA	Process	Positive	Positive	Positive	Unknown	Unknown	Positive	Dementia	Not specified	Population-level health insurance registry

dementia or a somatic disease											
No of vulnerable elders with depression who were offered psychotherapy, or antidepressant treatment within 2 weeks after diagnosis unless there is documentation (e.g., “watchful waiting”) within that period that the patient has improved, or unless the patient has substance abuse or	NA	Process	Positive	Positive	Positive	Unknown	Unknown	Positive	Older people	Not specified	Medical records

dependence, in which case treatment may wait until six weeks after the patient is in a drug or alcohol-free state/ No. of vulnerable elders with depression											
No of people who were screened for depression/No of people who were newly diagnosed with dementia	NA	Process	Positive	Positive	Positive	Unknown	Unknown	Positive	Dementia	Not specified	Population-level health insurance registry
No. of people with the presence or absence of suicidal ideation and psychosis	NA	Process	Positive	Positive	Positive	Unknown	Unknown	Positive	Older people	Not specified	Population-level health insurance registry

(consisting of, at minimum, auditory hallucinations or delusions) documented in medical records/No. of people diagnosed with depression											
Carers											
No. of people whose caregivers were asked about their needs for support services/No of people with a diagnosis of cognitive impairment/deme	NA	Process	Positive	Unknown	Intermediate	Positive	Unknown	Positive	Dementia	Not specified	Medical records

ntia											
No. of caregivers who were assessed for depression or thoughts of suicidality within 6 months of losing their spouse/No. of vulnerable elders who lost their spouse	NA	Process	Positive	Positive	Intermediate	Unknown	Unknown	Positive	Both	Not specified	Medical records
No. of people whose caregivers were asked about their needs for support services/No. of community-dwelling people aged 75+ with a	NA	Process	Positive	Unknown	Intermediate	Positive	Unknown	Positive	Both	People who live at home	Medical records

diagnosis of cognitive impairment/dementia receiving home care services											
Physical aspects of care											
Screening											
No. of people who were checked for tobacco use/No. of community-dwelling people aged 75+ with a diagnosis of cognitive impairment/dementia	NA	Process	Positive	Positive	Positive	Positive	Unknown	Positive	Dementia	People who live at home	Medical records
All community-dwelling should	NA	Process	Positive	Positive	Positive	Positive	Unknown	Positive	Dementia	People who live at	Medical records

be weighed at least every 6 months and these weights should be documented in the medical record - No. of people who were weighed every 6 months/No. of community-dwelling patients aged 75+ with a diagnosis of cognitive impairment/dementia										home/in community	
No of people for which it was documented that the provider	NA	Process	Positive	Unknown	Intermediate	Positive	Unknown	Positive	Older people	People who live at home	Medical records

inquired again about symptoms of cognitive impairment within 12 months of the first presentation/No of community-dwelling people aged 75+ with symptoms of cognitive impairment but without a diagnosis of dementia											
No. of people with a documented mediation change within 6 weeks of discharge/No. of	NA	Process	Positive	Positive	Positive	Positive	Unknown	Positive	Both	Hospital – Place of residence not specified	Medical records

vulnerable adults who were discharged from a hospital to home and he or she received a new prescription medication or change in medication (medication termination or change in dosage) before discharge											
No. of people who received blood transfusion in the last month prior to death /No. of people who died with Alzheimer’s	<0.3%	Process	Positive	Intermediate	Positive	Positive	Unknown	Unknown	Dementia	Hospital – Place of residence not specified	Population-level health insurance registry linked with healthcare databases

disease											
No. of people who had diagnostic testing (spirometry OR radiography OR blood drawn OR electrocardiogram) in the last month prior to death/No. of people who died with Alzheimer's disease	Below 25.5, Diagnostic testing e Medical imaging < 24.9, Diagnostic testing e ECG or pulmonary function testing <15.5	Process	Positive	Intermediate	Positive	Positive	Unknown	Unknown	Dementia	Hospital – Place of residence not specified	Population-level health insurance registry linked with healthcare databases & Medical records and administrative datasets
No. of people who received surgery in the last [6, 3, 1]	<0.5	Process	Positive	Intermediate	Positive	Positive	Unknown	Unknown	Dementia	Hospital – Place of residence	Population-level health insurance

month(s) prior to death/ No. of people who died with Alzheimer's disease										not specified	registry linked with healthcare databases & Medical records
No. of people who received statins and did not have declining statin use in the last [12, 6, 1] months prior to death/ No. of people who died with Alzheimer's disease and received statins	<4.7	Process	Positive	Intermediate	Positive	Positive	Unknown	Unknown	Dementia	Not specified	Population-level health insurance registry linked with healthcare databases & Medical records & administrative data
No. of people who received two or more prescriptions of	<22.4	Process	Positive	Intermediate	Positive	Positive	Unknown	Unknown	Dementia	Not specified	Population-level health insurance registry linked

gastric protectors in the last 6 months prior to death (i.e. prescription until death)/ No. of people who died with Alzheimer's disease											with healthcare databases
No. of people who received calcium or vitamin D in the last [6, 3, 1] months prior to death/ No. of people who died with Alzheimer's disease	<5.5	Process	Positive	Intermediate	Positive	Positive	Unknown	Unknown	Dementia	Not specified	Population-level health insurance registry linked with healthcare databases & Medical records & administrative data
No. of people who	<41.1	Process	Positive	Intermedia	Positive	Positive	Unknown	Unknown	Dementia	Not specified	Population-

received antihypertensives in the last [6, 3, 1] months prior to death/ No. of people who died with Alzheimer's disease				te							level health insurance registry linked with healthcare databases
No of people who had serum levels of vitamin B12 and thyroid-stimulating hormone measured/No of vulnerable elders who were newly diagnosed with dementia	NA	Process	Positive	Positive	Positive	Positive	Unknown	Positive	Dementia	Not specified	Medical records & administrative data
No. of people who received a	<31.1	Process	Positive	Intermediate	Positive	Positive	Unknown	Unknown	Dementia	Not specified	Population-level health

prescription for prophylactic gout medication in the last 3 months prior to death/ No. of people who died with Alzheimer's disease											insurance registry linked with healthcare databases & Medical records & administrative data
No. of people who had a cancer diagnosis and received chemotherapy in the [12, 6] months prior to death/ No. of people who died with Alzheimer's disease and had a cancer diagnosis	0.0	Process	Positive	Intermediate	Positive	Positive	Unknown	Unknown	Dementia	Not specified	Population-level health insurance registry linked with healthcare databases

No. of people who received neuropathic medication when receiving morphine in the last 2 years prior to death/ No. of people who died with Alzheimer's disease	>2.7	Process	Positive	Positive	Positive	Positive	Unknown	Unknown	Dementia	Not specified	Population-level health insurance registry linked with healthcare databases
No. of people patients admitted in the last 30 days of life who use mechanical ventilation at least once/No of people who were admitted to a hospital within	NA	Process	Positive	Positive	Intermediate	Positive	Unknown	Unknown	Both	Hospital – Place of residence not specified	Population-level health insurance registry linked with healthcare databases

the last 30 days of life											
No. of people who received the following medications as first- or second-line therapy: Tertiary amine tricyclics (amitriptyline, imipramine, doxepin, clomipramine, trimipramine) Monoamine oxidase inhibitors (unless atypical depression is present), Benzodiazepines	NA	Process	Positive	Positive	Positive	Positive	Unknown	Positive	Both	Not specified	Population-level health insurance registry linked with healthcare databases & Medical records & administrative data

Stimulants (except methylphenidate) /No of vulnerable elders who received antidepressant medication											
No. of people with a baseline ECG before initiation if one was not performed in the prior 3 months/No of people with a history of cardiac disease who are started on a tricyclic medication	NA	Process	Positive	Positive	Positive	Positive	Unknown	Positive	Both	Not specified	Medical records & administrative data
No. of people who were prescribed	NA	Process	Positive	Positive	Positive	Positive	Unknown	Positive	Both	Not specified	Medical records &

monoamine oxidase inhibitors (MAOI) is not used for at least 2 weeks after termination of the selective serotonin reuptake inhibitor (SSRI) and for at least 5 weeks after termination of fluoxetine)/No. of people taking a selective serotonin reuptake inhibitor (SSRI)											administrative data
No. of people who did not receive medications that	NA	Process	Positive	Positive	Positive	Positive	Unknown	Positive	Both	Not specified	Medical records & administrative

have the potential for serious interactions with MAOIs or for at least 2 weeks after termination of the MAOI/No. of people who were taking an MAOI											data
No. of people who had electrolytes checked at least yearly/No. of people who were prescribed a thiazide or loop diuretic	NA	Process	Positive	Positive	Positive	Positive	Unknown	Positive	Both	Not specified	Medical records & administrative data
No. of people who were prescribed a medication with	NA	Process	Positive	Positive	Positive	Positive	Unknown	Positive	Both	Not specified	Medical records & administrative

strong anticholinergic effects when alternatives were available/No of vulnerable elders											data
No. of people who were treated concomitantly with misoprostol or a proton pump inhibitor/No. of people with a risk factor for gastrointestinal bleeding (aged ≥ 75, peptic ulcer disease, history of GI bleeding, warfarin use, chronic	NA	Process	Positive	Positive	Positive	Positive	Unknown	Positive	Both	Not specified	Medical records & administrative data

glucocorticoid use) who are treated with a nonselective NSAID											
No. of people with documentation that the goal for the INR is 2.0 to 3.0 or reason for other goal/ No. of vulnerable elders who were prescribed anticoagulants for atrial fibrillation	NA	Process	Positive	Positive	Positive	Unknown	Unknown	Positive	Both	Not specified	Medical records & administrative data
No. of people who had a documented screening of occurrence of	NA	Process	Positive	Positive	Positive	Unknown	Unknown	Positive	Both	Not specified	Population-level health insurance registry linked with

recent falls annually/No. of vulnerable elders											healthcare databases & Medical records & administrative data
Prevalence of falls – No. of people who had a fall/No. of nursing home residents not completely dependent on bed mobility (Risk adjusted for Parkinson's disease, ADL impairment, vision impairment)	NA	Outcome	Unknown	Positive	Positive	Positive	Positive	Intermediate	Both	Nursing home	Medical records
Prevalence of delirium – No. of	NA	Outcome	Positive	Positive	Positive	Positive	Unknown	Unknown	Both	Not specified	Medical records &

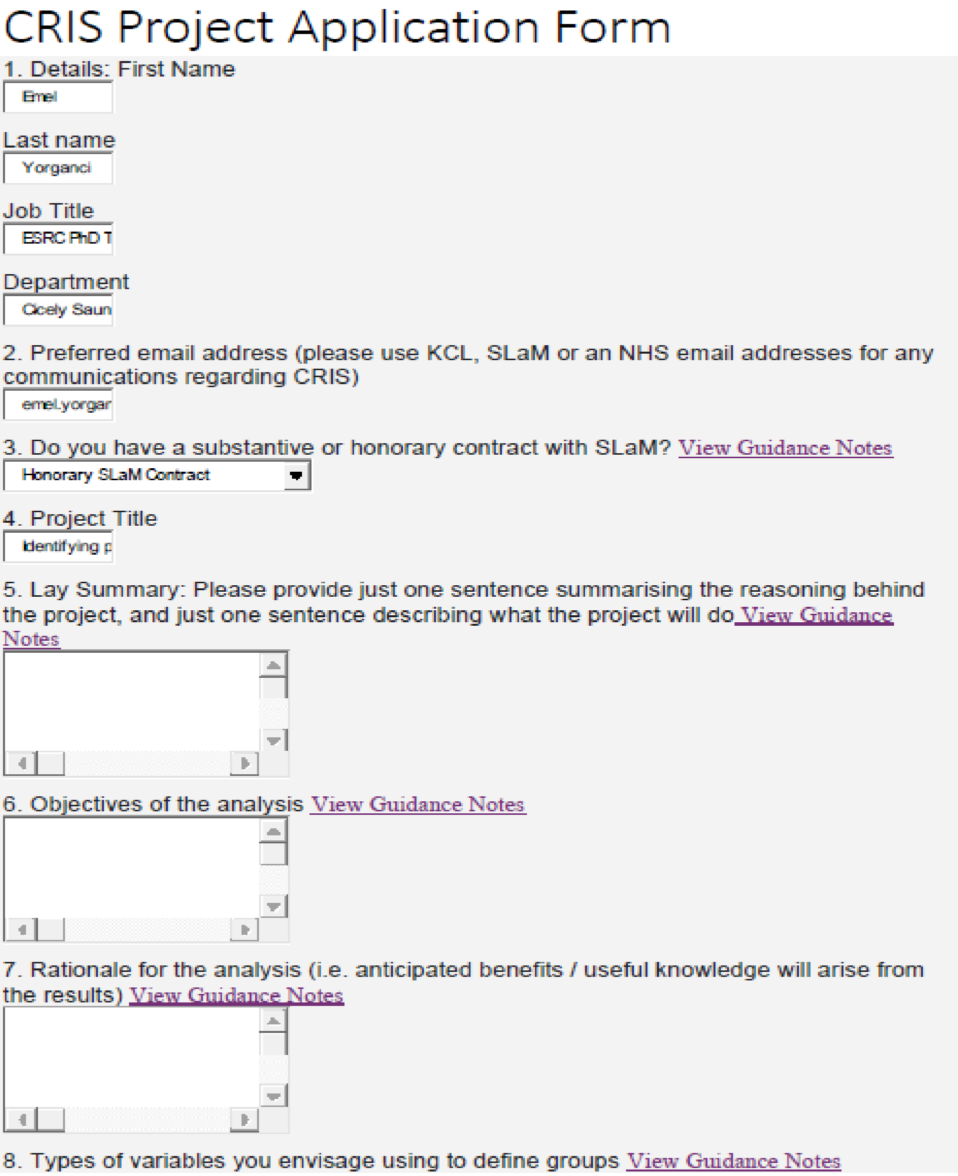
people who had a sudden new onset/change in mental function OR had become agitated or disoriented/No of people who are on reassessment											administrative data
Prevalence of statis/ulcers - No. of people who had any lesion caused by pressure, shear force, resulting in damage of underlying tissues -OR had an open lesion caused by poor circulation in	NA	Outcome	Positive	Positive	Positive	Positive	Unknown	Unknown	Both	Not specified	Medical records & administrative data

the lower extremities/ No of people who are on reassessment											
No. of people who were screened for chronic pain targeted history and physical examination initiated within 1 month and treatment offered/No. of vulnerable elders	NA	Process	Positive	Positive	Intermediate	Positive	Unknown	Positive	Both	Not specified	Medical records & administrative data
No. of people with a medical record that contains documentation about presence or absence of pain	NA	Process	Positive	Positive	Positive	Unknown	Unknown	Positive	Both	Not specified	Medical records

during the last 7 days of life/No. of people who were conscious during the last 7 days of life and who died an expected death											
Prevalence of constipation – No. of people who had no bowel movement in 3 days/ No of people who are on reassessment	NA	Outcome	Positive	Positive	Positive	Positive	Unknown	Unknown	Both	Not specified	Medical records & administrative data
Spiritual and cultural aspects of care											
No of people who had an interpreter or translated materials which were used to	NA	Process	Positive	Positive	Positive	Unknown	Unknown	Positive	Older people	Not specified	Medical records

facilitate communication/No. of vulnerable elders who were deaf or did not speak English *(excluding people with advanced dementia)*

Appendix 3. CRIS data application form, the approval email, honorary SLaM contract



CRIS Project Application Form

1. Details: First Name
Emel

Last name
Yorganci

Job Title
ESRC PhD T

Department
Cicely Saun

2. Preferred email address (please use KCL, SLaM or an NHS email addresses for any communications regarding CRIS)
emel.yorgar

3. Do you have a substantive or honorary contract with SLaM? View Guidance Notes
Honorary SLaM Contract

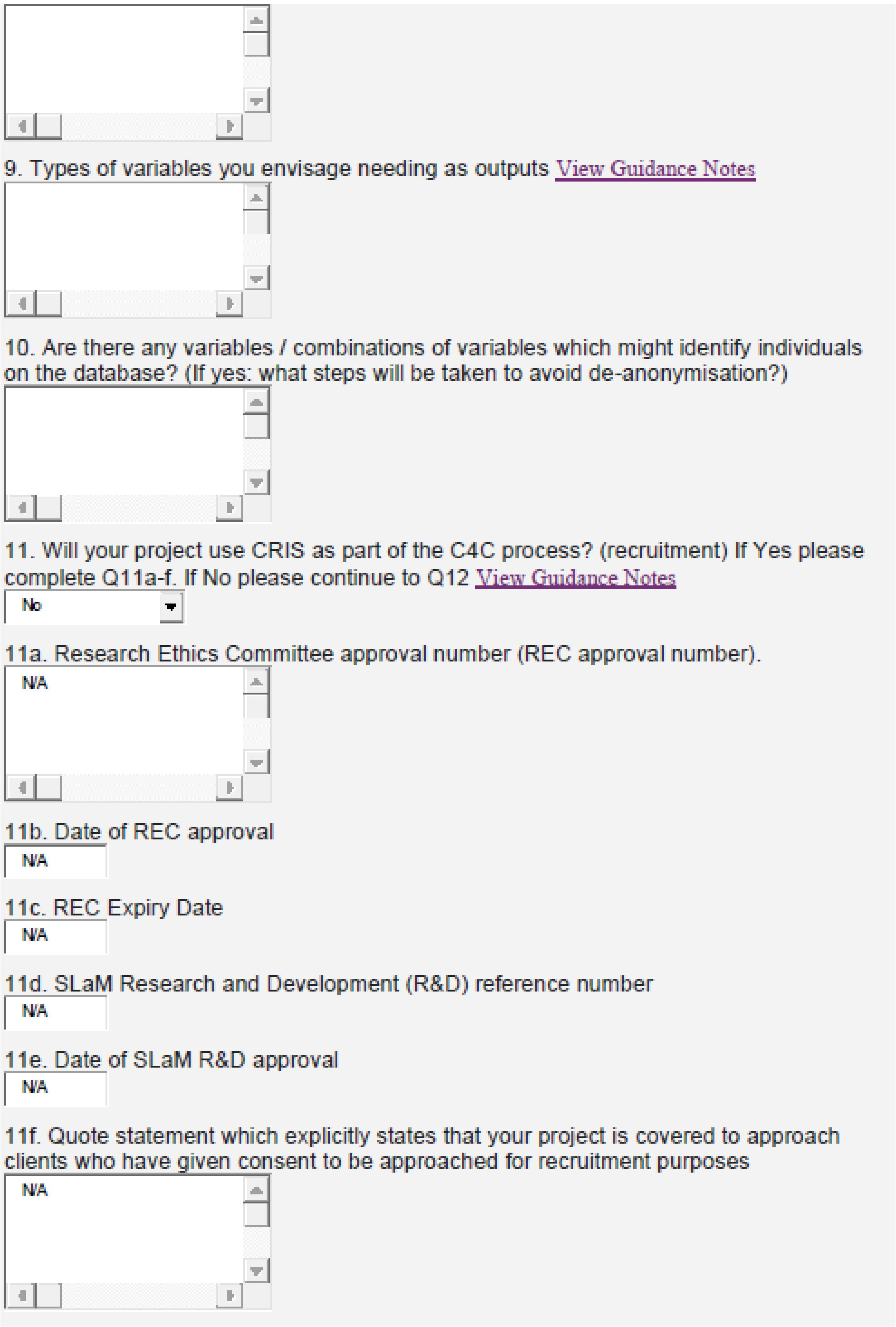
4. Project Title
Identifying p

5. Lay Summary: Please provide just one sentence summarising the reasoning behind the project, and just one sentence describing what the project will do View Guidance Notes

6. Objectives of the analysis View Guidance Notes

7. Rationale for the analysis (i.e. anticipated benefits / useful knowledge will arise from the results) View Guidance Notes

8. Types of variables you envisage using to define groups View Guidance Notes



9. Types of variables you envisage needing as outputs View Guidance Notes

10. Are there any variables / combinations of variables which might identify individuals on the database? (If yes: what steps will be taken to avoid de-anonymisation?)

11. Will your project use CRIS as part of the C4C process? (recruitment) If Yes please complete Q11a-f. If No please continue to Q12 View Guidance Notes

No

11a. Research Ethics Committee approval number (REC approval number).

N/A

11b. Date of REC approval

N/A

11c. REC Expiry Date

N/A

11d. SLaM Research and Development (R&D) reference number

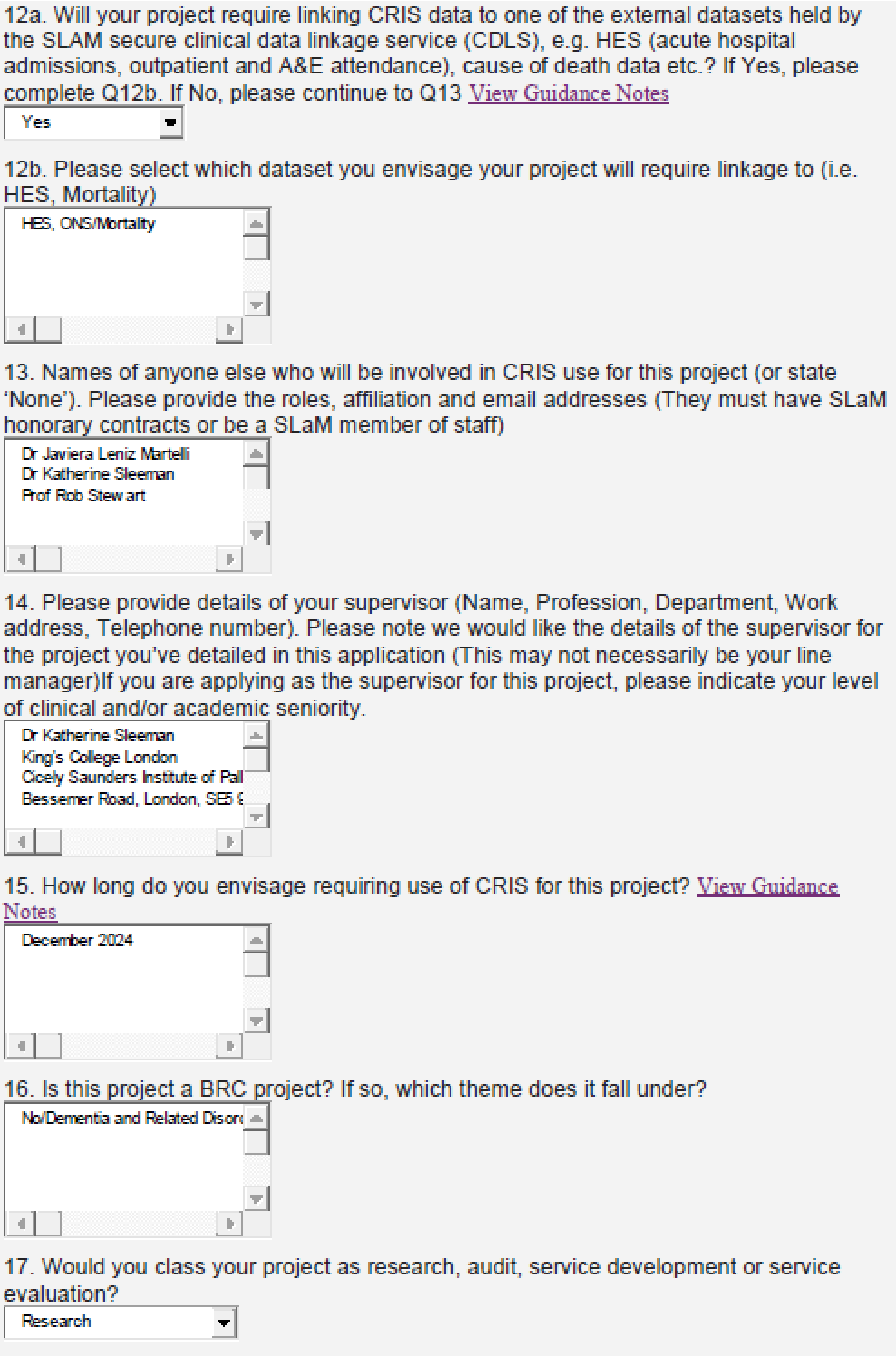
N/A

11e. Date of SLaM R&D approval

N/A

11f. Quote statement which explicitly states that your project is covered to approach clients who have given consent to be approached for recruitment purposes

N/A



12a. Will your project require linking CRIS data to one of the external datasets held by the SLAM secure clinical data linkage service (CDLS), e.g. HES (acute hospital admissions, outpatient and A&E attendance), cause of death data etc.? If Yes, please complete Q12b. If No, please continue to Q13 View Guidance Notes

Yes

12b. Please select which dataset you envisage your project will require linkage to (i.e. HES, Mortality)

HES, ONS/Mortality

13. Names of anyone else who will be involved in CRIS use for this project (or state 'None'). Please provide the roles, affiliation and email addresses (They must have SLaM honorary contracts or be a SLaM member of staff)

Dr Javiera Leniz Martelli
Dr Katherine Sleeman
Prof Rob Stewart

14. Please provide details of your supervisor (Name, Profession, Department, Work address, Telephone number). Please note we would like the details of the supervisor for the project you've detailed in this application (This may not necessarily be your line manager)If you are applying as the supervisor for this project, please indicate your level of clinical and/or academic seniority.

Dr Katherine Sleeman
King's College London
Cicely Saunders Institute of Pal
Bessemer Road, London, SE5

15. How long do you envisage requiring use of CRIS for this project? View Guidance Notes

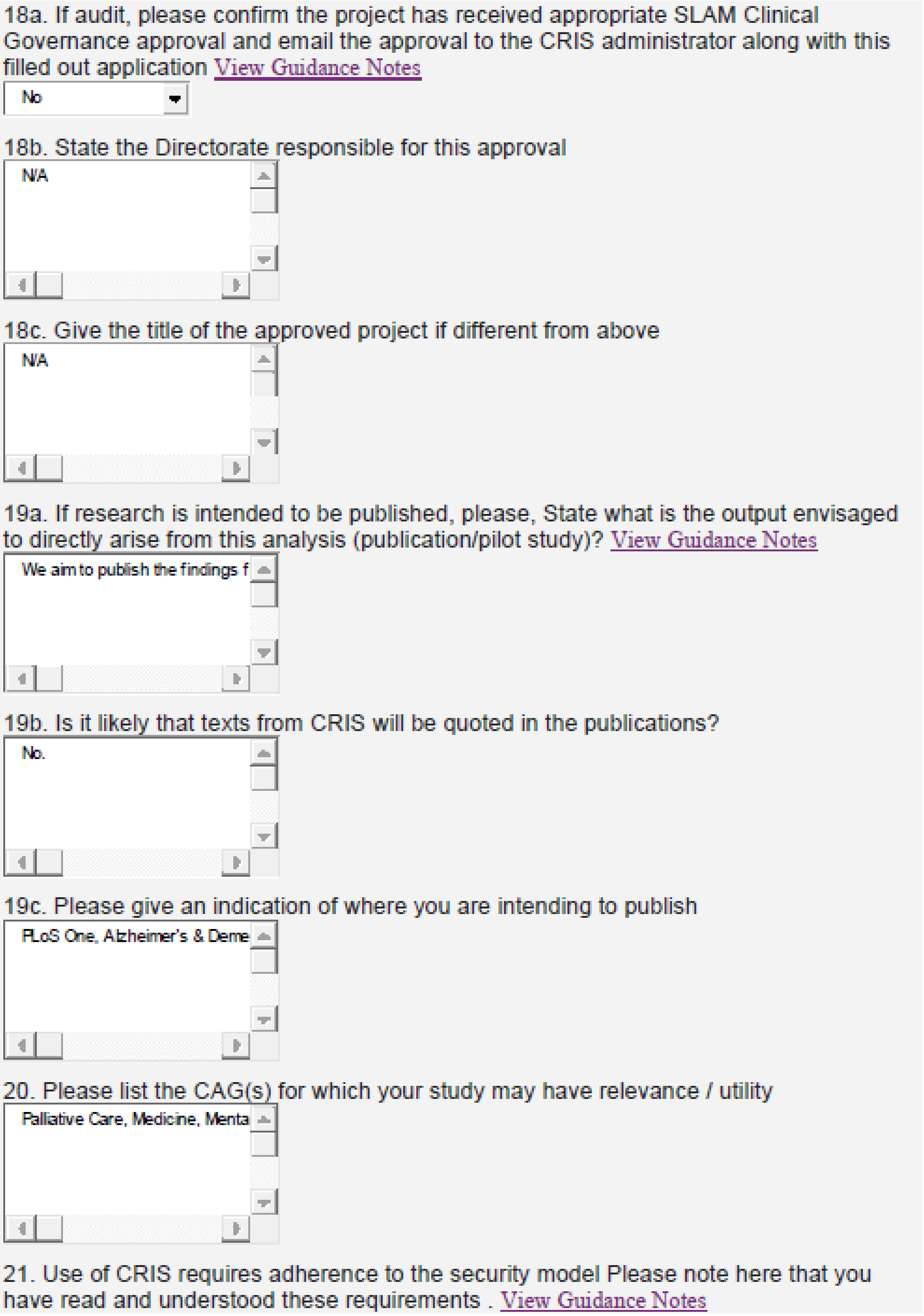
December 2024

16. Is this project a BRC project? If so, which theme does it fall under?

No/Dementia and Related Disor

17. Would you class your project as research, audit, service development or service evaluation?

Research



18a. If audit, please confirm the project has received appropriate SLAM Clinical Governance approval and email the approval to the CRIS administrator along with this filled out application View Guidance Notes

No

18b. State the Directorate responsible for this approval

N/A

18c. Give the title of the approved project if different from above

N/A

19a. If research is intended to be published, please, State what is the output envisaged to directly arise from this analysis (publication/pilot study)? View Guidance Notes

We aim to publish the findings f

19b. Is it likely that texts from CRIS will be quoted in the publications?

No.

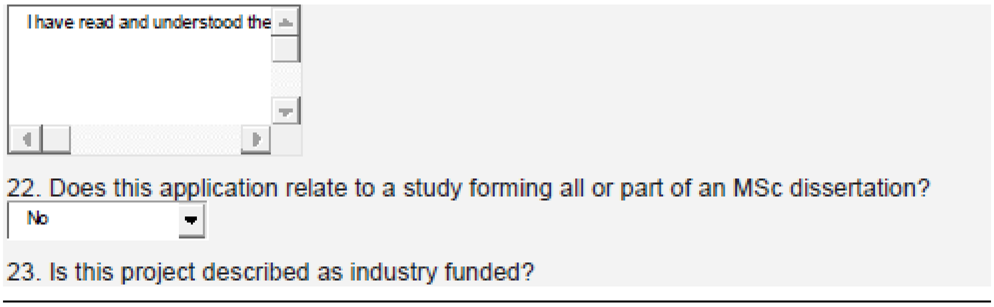
19c. Please give an indication of where you are intending to publish

PLoS One, Alzheimer's & Deme

20. Please list the CAG(s) for which your study may have relevance / utility

Palliative Care, Medicine, Menta

21. Use of CRIS requires adherence to the security model Please note here that you have read and understood these requirements . View Guidance Notes



I have read and understood the

22. Does this application relate to a study forming all or part of an MSc dissertation?

No

23. Is this project described as industry funded?

5. Lay Summary: Please provide just one sentence summarising the reasoning behind the project, and just one sentence describing what the project will do

One third of people aged over 65 will die with dementia, where England has one of the highest rates of hospital death in dementia (40%), with few people dying at home. This project aims to describe groups of patients with dementia who experience distinct end of life care outcomes related to healthcare utilisation.

6. Objectives of the analysis

1. To describe the trajectories of healthcare utilisations of patients with dementia from the point of diagnosis to death
2. To identify sociodemographic and illness-related factors associated with healthcare utilisation of individuals with dementia approaching the end of life
3. To identify groups of people with dementia who experience different patterns of healthcare utilisation over the course of the illness trajectory and how individuals change group membership overtime
4. To project the future population burden of healthcare utilisation by patients with dementia approaching the end of life

7. Rationale for the analysis (i.e. anticipated benefits / useful knowledge will arise from the results)

About one third of people with dementia live until advanced stages, but many will die in the early or moderate stages from diseases other than dementia. Hence it is important to explore the healthcare utilisation across different stages of dementia. There is evidence that hospital admissions in individuals with dementia increases around the point of diagnosis and during the year of death. There is also evidence that multiple hospital admissions in the last 90 days of life of people with dementia are associated with sociodemographic factors such as being male, from a deprived area, depressed mood and presence of physical illness. However, we know very little about how the healthcare utilisation changes over the course of the illness trajectory and who are the groups who experience these outcomes. Understanding how the healthcare utilisation differs for distinct groups of individuals with dementia at different points of the illness trajectory and how it changes over time is important in order to inform preventative interventions, and for setting policy and funding priorities. This study will shed light on variability in groups and healthcare utilisation trajectories of individuals with dementia towards the end of life. Better characterisation of these groups, how and when they might change towards the end of life could have significant implications for understanding modifiable risk factors, which could be targeted by interventions. We will also gain a better understanding about people who experience indicators of poor quality of care, such as unplanned hospital admissions.

8. Types of variables you envisage using to define groups

MMSE scores

Diagnosis – Coded ICD, NLP

First point of contact with the services

Time period/year

Age

Sex

Deprivation of area

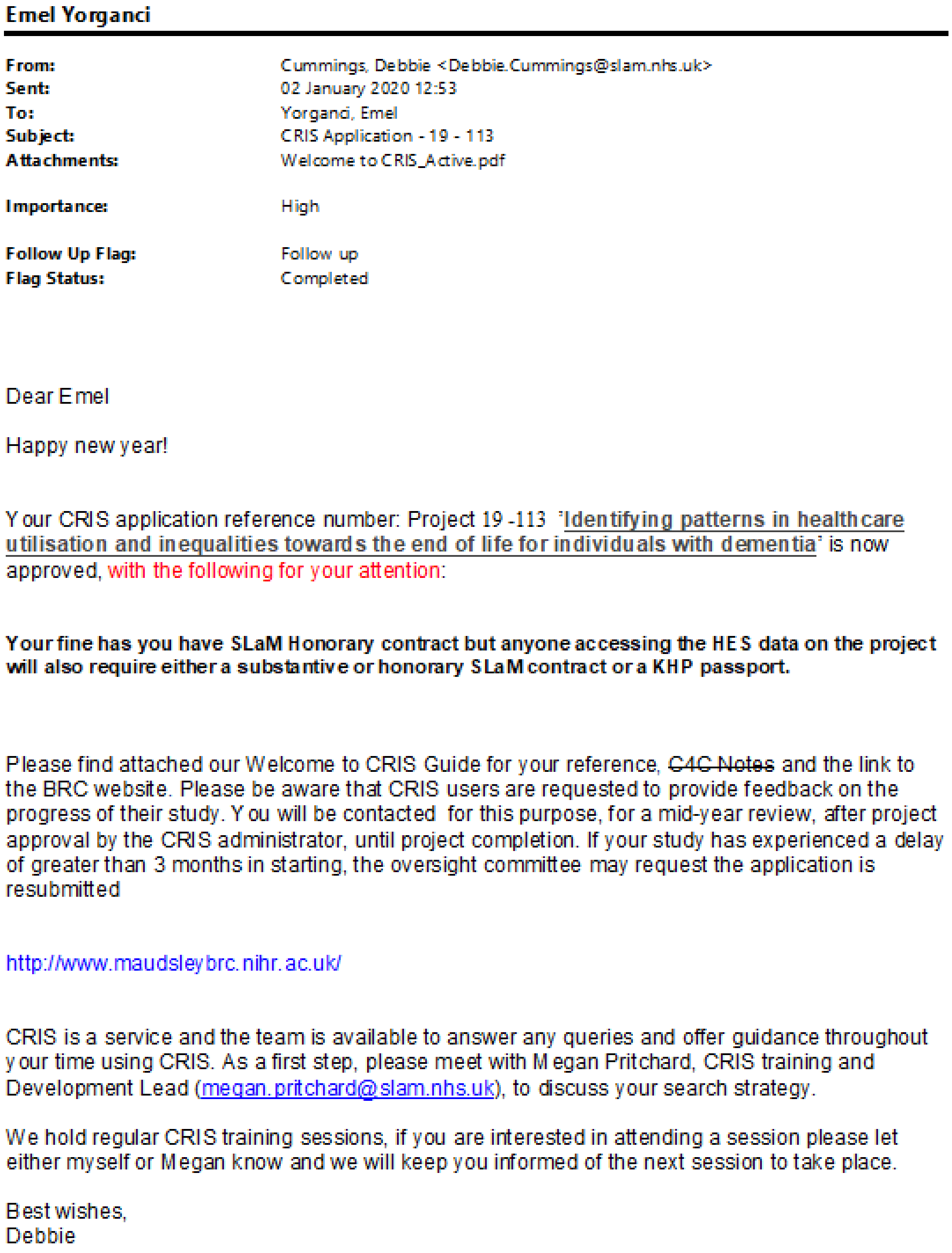
9. Types of variables you envisage needing as outputs

Services used within SLaM

HES – hospital contacts – A&E, critical care, admissions, length of stay (date of admission and date of discharge)

10. Are there any variables / combinations of variables which might identify individuals on the database? (If yes: what steps will be taken to avoid de-anonymisation?)

The only thing I can think of is potentially looking at information around whether they have an informal carer or not, whether they live alone or not. But Megan warned me that the reliability of this information depends on the timepoint the information is extracted from. E.g. if a carer assessment was completed at the time of diagnosis, we can assume that the person had a close carer at that point, but not necessarily later.



Emel Yorganci

From: Cummings, Debbie <Debbie.Cummings@slam.nhs.uk>
Sent: 02 January 2020 12:53
To: Yorganci, Emel
Subject: CRIS Application - 19 - 113
Attachments: Welcome to CRIS_Active.pdf

Importance: High

Follow Up Flag: Follow up
Flag Status: Completed

Dear Emel

Happy new year!

Your CRIS application reference number: Project 19 -113 'Identifying patterns in healthcare utilisation and inequalities towards the end of life for individuals with dementia' is now approved, with the following for your attention:

Your fine has you have SLaM Honorary contract but anyone accessing the HES data on the project will also require either a substantive or honorary SLaM contract or a KHP passport.

Please find attached our Welcome to CRIS Guide for your reference, ~~C4C Notes~~ and the link to the BRC website. Please be aware that CRIS users are requested to provide feedback on the progress of their study. You will be contacted for this purpose, for a mid-year review, after project approval by the CRIS administrator, until project completion. If your study has experienced a delay of greater than 3 months in starting, the oversight committee may request the application is resubmitted

http://www.maudsleybrc.nihr.ac.uk/

CRIS is a service and the team is available to answer any queries and offer guidance throughout your time using CRIS. As a first step, please meet with Megan Pritchard, CRIS training and Development Lead (megan.pritchard@slam.nhs.uk), to discuss your search strategy.

We hold regular CRIS training sessions, if you are interested in attending a session please let either myself or Megan know and we will keep you informed of the next session to take place.

Best wishes,
Debbie

Debbie Cummings
BRC Nucleus Administrator

South London and Maudsley NHS Foundation Trust
SLaM Biomedical Research Centre Nucleus | Maudsley Site | Ground Floor | Mapother House |
De Crespigny Park | Denmark Hill | London | SE5 8AF
Telephone: 020 3228 8553

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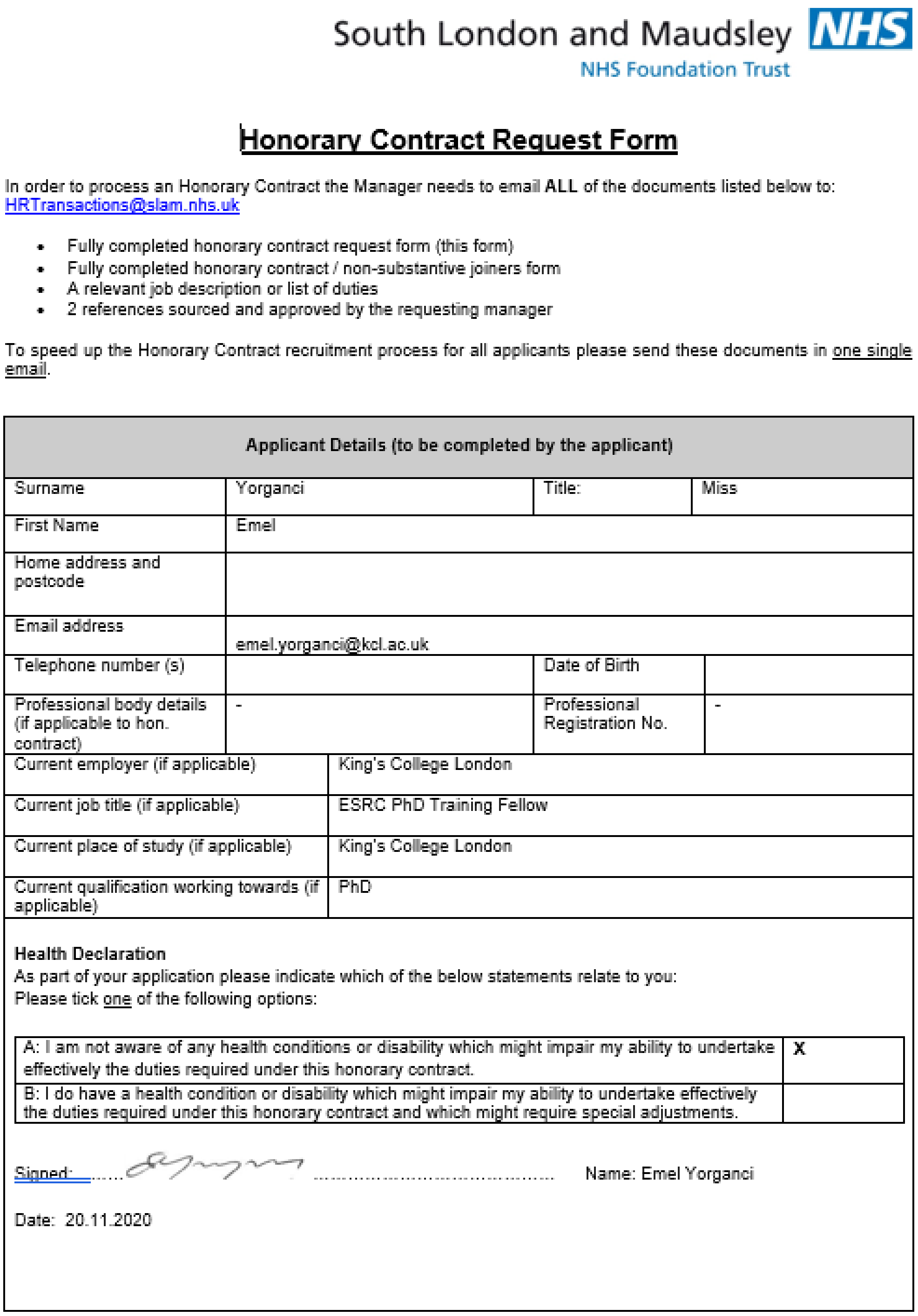
020 3228 6000 The switchboard number for SLaM

For more information about CRIS, see our website: http://www.maudsleybrc.nihr.ac.uk/about-us/core-facilities/clinical-record-interactive-search-cris/

South London and Maudsley NHS Foundation Trust
Overall rating of 'good' - Care Quality Commission



South London and Maudsley NHS
NHS Foundation Trust

Honorary Contract Request Form

In order to process an Honorary Contract the Manager needs to email **ALL** of the documents listed below to: HRTransactions@slam.nhs.uk

- Fully completed honorary contract request form (this form)
- Fully completed honorary contract / non-substantive joiners form
- A relevant job description or list of duties
- 2 references sourced and approved by the requesting manager

To speed up the Honorary Contract recruitment process for all applicants please send these documents in one single email.

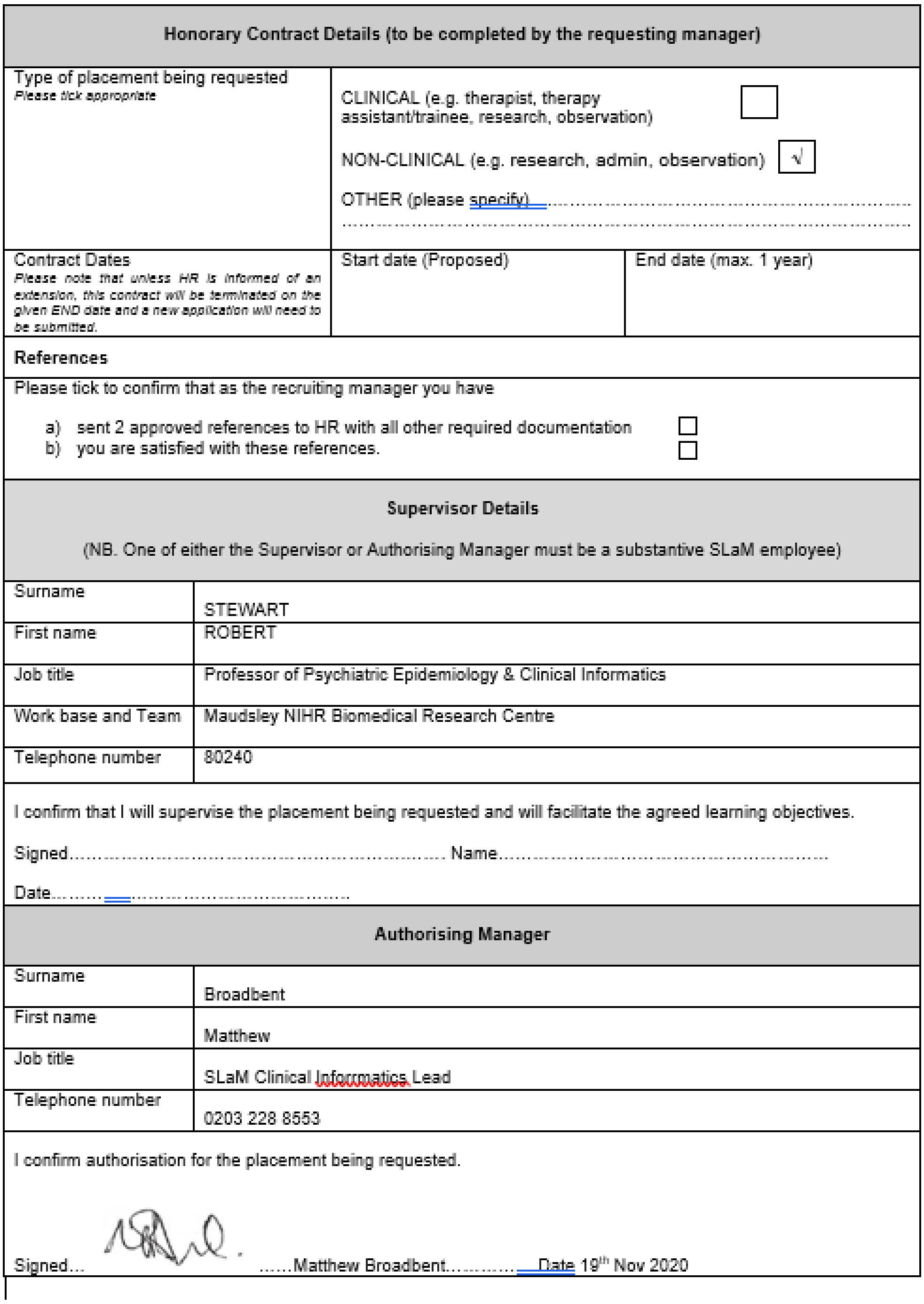
Applicant Details (to be completed by the applicant)			
Surname	Yorganci	Title:	Miss
First Name	Emel		
Home address and postcode			
Email address	emel.yorganci@kcl.ac.uk		
Telephone number (s)		Date of Birth	
Professional body details (if applicable to hon. contract)	-	Professional Registration No.	-
Current employer (if applicable)	King's College London		
Current job title (if applicable)	ESRC PhD Training Fellow		
Current place of study (if applicable)	King's College London		
Current qualification working towards (if applicable)	PhD		

Health Declaration
As part of your application please indicate which of the below statements relate to you:
Please tick one of the following options:

A: I am not aware of any health conditions or disability which might impair my ability to undertake effectively the duties required under this honorary contract.	X
B: I do have a health condition or disability which might impair my ability to undertake effectively the duties required under this honorary contract and which might require special adjustments.	

Signed: ……………………………………………… Name: Emel Yorganci

Date: 20.11.2020



Honorary Contract Details (to be completed by the requesting manager)		
Type of placement being requested *Please tick appropriate*	CLINICAL (e.g. therapist, therapy assistant/trainee, research, observation) ☐ NON-CLINICAL (e.g. research, admin, observation) ☑ OTHER (please specify)………………………………………………………… ……………………………………………………………………………………	
Contract Dates *Please note that unless HR is informed of an extension, this contract will be terminated on the given END date and a new application will need to be submitted.*	Start date (Proposed)	End date (max. 1 year)

References

Please tick to confirm that as the recruiting manager you have

a) sent 2 approved references to HR with all other required documentation ☐
b) you are satisfied with these references. ☐

Supervisor Details

(NB. One of either the Supervisor or Authorising Manager must be a substantive SLaM employee)

Surname	STEWART
First name	ROBERT
Job title	Professor of Psychiatric Epidemiology & Clinical Informatics
Work base and Team	Maudsley NIHR Biomedical Research Centre
Telephone number	80240

I confirm that I will supervise the placement being requested and will facilitate the agreed learning objectives.

Signed……………………………………………………………. Name………………………………………………………

Date………………………………………………

Authorising Manager

Surname	Broadbent
First name	Matthew
Job title	SLaM Clinical Informatics Lead
Telephone number	0203 228 8553

I confirm authorisation for the placement being requested.

Signed… ……Matthew Broadbent………… Date 19th Nov 2020

Appendix 4. Supplementary material for Study 1

In order to identify diagnosis of dementia, Structured Query Language (SQL) (codes) as well as GATE (text) were used from the following source tables in the electronic health records: Attachment, Diagnosis, Event Correspondence, Presenting circumstances, Mental state formulation, Ward progress notes

Table. Identification of dementia diagnosis from CRIS dataset

Example terms (*Used in NLP to search text)*	ICD-10 Codes
Vascular dementia	F01*
Alzheimer's and vascular	
Alzheimer’s Dementia	F00*, F05.1
atypical dementia	
atypical dementia, both vascular and Alzheimer’s disease	F00.2
Dementia - Unspecified	F03, F03.0, FO3.0, F00.3
Dementia Mixed	F00.1, F00.2, F02, F009
Lewy Body Dementia	F02.3
Parkinson’s Dementia	F023

Supplementary material available online with Publication 2[245]

Table 1. Characteristics of people with dementia stratified by time to death/ end of the follow-up period (n=19,221)

	Decedents (n=12,667)										**People who were alive at the study end (n=6,554)**								
Follow-up since dementia diagnosis (years)	<1 (n=3,231)	1 – 2 (n=2,290)	2 – 3 (n=1,871)	3 – 4 (n=1,524)	4 – 5 (n=1,216)	5 – 6 (n=843)	6 – 7 (n=610)	7 – 9 (n=709)	9 – 12 (n=335)	>12 (n=38)	1 – 2 (n=1,309)	2 – 3 (n=1,252)	3 – 4 (n=973)	4 – 5 (n=703)	5 – 6 (n=582)	6 – 7 (n=473)	7 – 9 (n=545)	9 – 12 (n=565)	>12 (n=152)
Had at least one unplanned hospital admission after dementia diagnosis (%) (n=14,759)	66.8	87.0	89.9	92.3	92.4	93.1	93.1	94.2	94.3	97.4	46.6	56.9	85.1	69.1	71.0	69.8	69.5	68.5	65.8
Gender (%)																			
Female	57.1	57.3	61.6	60.8	64.9	63.6	66.7	70.1	69	60.5	64.9	65.5	65.7	61.8	35.1	34.5	34.3	34.3	38.2
Ethnicity (%)																			
Black	8	9.4	11.4	9.9	11.9	12.5	14.3	13.7	17.3	18.4	23.5	21.8	23.1	20.9	21.0	23.0	23.9	23.7	17.8
Asian	2.9	3.6	2.8	2.5	3.2	4.4	4.4	3.8	3.6	2.6	6.0	6.8	6.8	4.8	6.7	7.2	7.3	5.8	10.5
Other ethnic group	2.4	2.8	2.4	1.3	1.6	1.6	1.6	1.8	1.5	2.6	3.4	9.0	9.0	3.1	3.1	3.8	4.4	4.8	5.9
White	76.8	78.4	79.3	82.7	79.7	75.4	75.4	76.7	73.1	73.7	62.6	59.7	59.7	68.9	67.7	64.7	63.5	63.9	58.6
Missing	9.9	5.9	5.9	3.6	3.5	4.3	4.3	4.0	4.5	2.6	4.4	2.7	2.7	2.3	1.6	1.3	0.9	1.8	7.2
Age at diagnosis Mean (SD)	84.7 (7.3)	83.7 (7.7)	83.1(7.4)	82 (7.7)	81.4(7.5)	80.4 (7.6)	79.5 (7.9)	78.6 (7.6)	76.8 (7.9)	74.1 (9.2)	80.3 (8.6)	79.7 (8.0)	78.9 (8.6)	77.8 (9.1)	77.8 (8.2)	76 (8.8)	74.5 (9.1)	73.7 (8.8)	72.5 (9.9)
Age at death/window end Mean (SD)	85.1 (7.1)	85.2 (7.7)	85.6 (7.4)	85.5 (7.7)	85.9 (7.5)	85.8 (7.6)	85.9 (8.0)	86.5 (7.6)	86.9 (7.9)	87.4 (9.1)	81.8 (8.6)	82.2 (8.0)	82.4 (8.6)	82.3 (9.0)	83.3 (8.2)	82.5 (8.8)	82.3 (9.1)	84.1 (8.8)	85.9 (9.9)
First recorded dementia diagnosis (%)																			
Alzheimer's disease	36.5	42.4	47.4	49.1	47.0	52.0	53.8	52.8	57.3	63.2	52.9	59.4	60.6	55.3	55.3	52.9	53.2	45.1	44.7
Vascular dementia	30.5	30.2	25.3	24.0	28.5	23.8	22.5	24.1	23.3	23.7	17.3	16.9	17.7	19.2	19.1	18.0	22.8	25.3	31.6
Unspecified dementia	29.6	24.1	24.0	22.5	21.3	20.6	20.8	20.0	16.7	7.9	26.0	20.9	17.6	20.8	22.9	26.0	19.8	23.2	17.8
Lewy body dementia	1	1.1	1.2	1.1	0.3	0.8	0.5	0.6	0	0	1.8	0.9	1.3	1.0	1.2	0.2	1.1	0.5	0.7
Other dementia	2.5	2.3	2.1	3.4	2.9	2.7	2.5	2.5	2.7	5.3	2.1	2.0	2.8	3.7	1.6	3.0	3.1	5.8	5.3
MMSE[a] nearest to the diagnosis (%) (n=12, 236)	17.1(6.4)	17.6 (6.4)	17.6 (6.4)	18.2 (6.4)	18.6 (6.2)	18.7 (6.2)	18.8 (6.2)	19.1 (6.3)	18.4 (6.7)	20.6 (6.9)	20.2 (6.2)	20.0 (6.1)	19.4 (6.1)	20.1 (6.0)	20.6 (5.8)	20.2 (6.3)	20.4 (6.1)	20.0 (6.2)	20.8 (6.8)

MMSE categories (%)																			
Mild (≥20)	24.7	31.8	34.4	40.7	40.6	42.6	43.6	46.7	43.0	57.9	49.6	50.6	50.8	53.1	57.7	55.2	55.8	49.0	40.1
Moderate (10-19)	32.7	35.6	37.2	33.7	37.1	36.9	33.0	30.8	30.5	18.4	30.6	29.7	33.4	29.0	27.8	29.2	27.7	28.0	17.8
Severe (<10)	8.4	9.2	9.8	8.7	7.0	6.8	8.0	6.2	9.6	7.9	4.8	7.0	7.0	5.6	4.6	6.6	5.3	5.3	4.6
Missing	34.2	23.4	18.6	15.3	15.3	13.8	15.4	16.4	17.0	15.8	15.0	8.8	8.8	12.4	9.8	9.1	11.2	17.7	37.5
IMD Quintiles (%)																			
1 (most deprived)	29.9	30.1	28.8	29.3	29.5	27.5	27.9	29.3	26.6	18.4	30.9	29.4	32.0	26.3	26.5	31.5	31.6	34.0	31.6
2	35.8	33.7	35.0	34.1	34.1	34.2	37.4	35.4	40.0	42.1	35.8	35.9	31.8	37.4	32.5	34.5	33.0	30.3	37.5
3	16.6	18.2	17.4	18.2	18.8	19.3	14.9	18.2	16.7	15.8	18.2	18.8	19.1	19.5	21.8	19.5	18.2	20.0	14.5
4	9.1	10.1	9.6	9.3	9.4	8.5	9.7	9.3	6.0	10.5	8.1	8.1	9.0	9.0	9.3	7.4	10.3	8.0	7.9
5 (least deprived)	6.9	6.9	7.6	7.6	6.8	8.8	8.4	6.5	9.3	13.2	6.3	7.2	7.4	7.5	9.5	7.0	6.6	6.4	4.6
Missing	1.7	1.1	1.7	1.6	1.4	1.7	1.8	1.3	1.5	0	0.8	0.7	0.7	0.3	0.5	0.2	0.4	1.4	4.0

[a]MMSE scores range between

Table 1. Incidence rates and 95% confidence intervals (CIs) for unplanned hospital admissions of people with dementia (n=19,221) – Corresponding to Figure 1, Appendix 2

Six- monthly time intervals from time of diagnosis (0) to death	*0.5*	*1*	*1.5*	*2*	*2.5*	*3*	*3.5*	*4*	*4.5*	*5*	*5.5*	*6*	*6.5*	*7*
Duration between diagnosis and death (number of people) (number of admissions)	*Rate* *95% CIs - Lower limit* *95% CIs - Upper Limit* *Standard Error*													
less than one-year n=3,231	275.2	333.7												
n-4,226	265.5	315.4												
	285.2	352.7												
	5	9.5												
between 1-2 years n=3,599	98.8	99.9	141.6	205.3										
n=7,538	94.6	95.7	135.8	193.4										

	103	104.2	147.5	217.8								
	2.1	2.2	3	6.2								
2-3 years n=3,123	76.5	73.6	69.6	84.4	128.6	191						
n=8,367	72.6	69.8	65.9	80.3	122.7	178.6						
	80.5	77.5	73.4	88.6	134.6	204.1						
	2	2	1.9	2.1	3	6.5						
3-4 years n=2,479	66.8	59.9	58.7	64.6	65.9	80	118.9	166.3				
n=7,865	62.8	56.1	55	60.6	61.9	75.6	112.6	153.7				
	71	64	62.7	68.8	70.2	84.7	125.5	179.7				
	2.1	2	2	2.1	2.1	2.3	3.3	6.6				
4-5 years n=1,919	62.7	52	51.7	53.3	58.7	54.6	65.9	71.3	115.3	149.5		
n=6,821	58.3	47.9	47.7	49.2	54.4	50.4	61.3	66.5	108.3	135.8		
	67.4	56.3	56	57.6	63.3	59	70.7	76.3	122.7	164.3		
	2.3	2.1	2.1	2.2	2.3	2.2	2.4	2.5	3.7	7.3		
5-6 years n=1,425	58.2	49.5	46.7	50.8	48.7	52.5	50.5	49.8	53.9	71.8	106.5	118.8
n=5,470	53.3	44.9	42.3	46.2	44.1	47.8	45.9	45.3	49.2	66.3	98.7	104.6

	63.5	54.4	51.4	55.7	53.5	57.5	55.5	54.7	59	77.7	114.8	134.4		
	2.6	2.4	2.3	2.4	2.4	2.5	2.4	2.4	2.5	2.9	4.1	7.6		
6-7 years n=1,083	48.5	38	35.3	37.6	40.5	35.1	37.7	44.9	47.4	46.2	49.8	54.4	86.9	128.3
n=3,971	43.3	33.5	30.9	33.1	35.8	30.8	33.2	40	42.3	41.2	44.6	49	78.8	111.4
	54	43	40	42.5	45.6	39.9	42.7	50.3	52.9	51.6	55.5	60.3	95.6	147.1
	2.7	2.4	2.3	2.4	2.5	2.3	2.4	2.6	2.7	2.7	2.8	2.9	4.3	9.1
7-9 years n=1,254	42.9	33.5	35.9	33.7	36.5	40.7	39.9	41.5	42.7	41.5	42.7	39.3	40.3	48.9
n=5,138														
	38.4	29.5	31.8	29.8	32.4	36.3	35.5	37	38.2	37	38.2	35	35.9	44.1
	47.8	37.8	40.3	38.1	41.1	45.4	44.6	46.3	47.5	46.3	47.5	44	45	54.1
	2.4	2.1	2.2	2.1	2.2	2.3	2.3	2.4	2.4	2.4	2.4	2.3	2.3	2.6
9-12 years n=900	32.2	29.2	28.3	24.6	29.4	25.5	28.3	34.8	32.9	29.6	33.3	41.8	32.2	38.1
n=3,866	27.7	24.9	24.1	20.7	25.1	21.5	24.1	30.1	28.4	25.3	28.7	36.6	27.7	33.2
	37.2	34.1	33.1	29.1	34.3	30.1	33.1	40	38	34.5	38.4	47.5	37.2	43.6
	2.4	2.3	2.3	2.1	2.3	2.2	2.3	2.5	2.5	2.3	2.5	2.8	2.4	2.7
more than 12 years n=190	24	11.6	10.9	15.3	15.3	9.5	13.1	19.7	17.5	10.9	16	9.5	13.1	16

n=665	16.8	6.9	6.4	9.7	9.7	5.3	8	13.2	11.5	6.4	10.3	5.3	8	10.3
	33.3	18.5	17.6	22.9	22.9	15.7	20.3	28.2	25.6	17.6	23.8	15.7	20.3	23.8
	4.2	2.9	2.8	3.3	3.3	2.6	3.1	3.8	3.6	2.8	3.4	2.6	3.1	3.4
Six- monthly time intervals from time of diagnosis (0) to death	*7.5*	*8*	*8.5*	*9*	*9.5*	*10*	*10.5*	*11*	*11.5*	*12*	*12.5*	*13*	*13.5*	*14*
7-9 years n=1,254	58.7	73.9	80.3	114.5										
n=5,138		0												
	53.3	66	69.3	91.1										
	64.5	82.5	92.7	142										
	2.9	4.2	6	13										
9-12 years n=900	35.5	36.3	38.8	40.1	48.1	44.5	43	37.9	63.9	67.4				
n=3,866	30.8	31.4	33.9	35.1	42.2	38.2	35.8	30.1	49.7	39.4				
	40.8	41.6	44.4	45.8	54.6	51.7	51.3	47.3	80.8	108.4				
	2.6	2.6	2.7	2.7	3.2	3.4	4	4.4	7.9	17.4				
more than 12 years n=190	16	22.6	21.8	15.3	16	17.5	25.5	19.7	18.2	39.4	24.2	33.8	20.4	33.1

n=665	10.3	15.6	15	9.7	10.3	11.5	18	13.2	12.1	27.9	16.7	23.6	11.7	20.3
	23.8	31.6	30.7	22.9	23.8	25.6	35	28.2	26.4	54.2	34.1	47.1	33.4	51.2
	3.4	4.1	4	3.3	3.4	3.6	4.3	3.8	3.6	6.7	4.4	6	5.5	7.8

Table 2. Incidence rates and 95% confidence intervals (CIs) for unplanned hospital admissions of people who died with dementia (n=12,677) – Corresponding to Figure 1, Manuscript

Six- monthly time intervals from time of diagnosis (0) to death	*0.5*	*1*	*1.5*	*2*	*2.5*	*3*	*3.5*	*4*	*4.5*	*5*	*5.5*	*6*	*6.5*	*7*
Duration between diagnosis and death (number of people) (number of admissions	*Rate* *95% CIs - Lower limit* *95% CIs - Upper Limit* *Standard Error*													
less than one-year n=3,231	275.2	333.7												
n-4,226	265.5	315.4												
	285.2	352.7												
	5	9.5												

between 1-2 years n=2,990	111.2	118.9	190	288.5						
n=6,018	105.7	113.2	181.6	270.6						
	116.9	124.7	198.7	307.3						
	2.8	2.9	4.4	9.4						
2-3 years n=1,871	85.3	84.7	79.9	103	175.3	285.8				
n=6,211	80.1	79.5	74.8	97.2	166.6	266.1				
	90.9	90.2	85.3	109	184.4	306.5				
	2.8	2.7	2.7	3	4.6	10.3				
3-4 years n=1,524	75.9	69.6	64.1	71	74.5	94.9	157.9	228		
n=5,747	60.5	47.3	48.9	53.4	69	88.8	148.6	209.7		
	72.3	57.8	59.5	64.6	80.2	101.4	167.5	247.4		
	2.9	2.8	2.6	2.8	2.9	3.2	4.8	9.6		
4-5 years n=1,216	66.2	52.4	54	58.8	62	60.7	73.5	82.1	157.1	224.9
n=4,932	60.5	47.3	48.9	53.4	56.4	55.3	67.4	75.7	146.7	203.1
	72.3	57.8	59.5	64.6	67.9	66.6	79.9	88.9	168.1	248.4

	3	2.7	2.7	2.8	2.9	2.9	3.2	3.4	5.4	11.6				
5-6 years	61.3	51.4	49.2	51.4	52	56.9	58.3	51.2	62.1	89.4	146.4	181.3		
n=843														
n=3,722	54.7	45.4	43.4	45.4	46	50.6	52	45.3	55.5	81.4	134.6	158.5		
	68.4	57.9	55.6	57.9	58.6	63.8	65.3	57.7	69.2	97.9	159	206.4		
	3.5	3.2	3.1	3.2	3.2	3.4	3.4	3.2	3.5	4.2	6.2	12.2		
6-7 years	55.2	42.3	38.8	40.4	55.5	40.4	42.3	50	53.8	52.5	56.3	66.9	122.7	196.3
n=610														
n=2,670	36	30.8	32.6	26.9	48.2	34.3	36.1	43.1	46.7	45.4	49	58.9	110	168
	48.3	42.3	44.3	37.7	63.5	47.4	49.4	57.6	61.7	60.3	64.4	75.7	136.5	228.2
	3.9	3.4	3.3	3.3	3.9	3.3	3.4	3.7	3.8	3.8	3.9	4.3	6.8	15.3
7-9 years	41.8	36.2	38.1	32	37.6	40.4	44.4	48.2	52.7	46.3	44.7	44.2	46.5	59.9
n=709														
n=3,382	36	30.8	32.6	26.9	32.1	34.7	38.4	41.9	46.1	40.2	38.6	38.2	40.4	52.9
	48.3	42.3	44.3	37.7	43.8	46.8	51.1	55.1	59.9	53.1	51.4	50.9	53.4	67.6
	3.1	2.9	3	2.7	3	3.1	3.2	3.4	3.5	3.3	3.2	3.2	3.3	3.8
9-12 years	34.3	23.4	26.9	25.9	31.3	32.3	36.8	39.8	43.3	36.3	45.3	66.2	40.8	50.2
n=335														
n=1,875														
	43.2	30.8	34.8	33.6	39.8	40.9	45.9	49.3	53.1	45.4	55.3	78.1	50.4	60.8

	4.1	3.4	3.7	3.6	3.9	4	4.3	4.4	4.6	4.3	4.7	5.7	4.5	5
more than 12 years n=49	27.2	23.8	10.2	27.2	20.4	3.4	23.8	44.2	40.8	23.8	27.2	27.2	27.2	20.4
n=287	12.8 51.3	10.6 46.8	2.8 27.2	12.8 51.3	8.5 42.1	0.3 15.9	10.6 46.8	24.8 73.5	22.3 69.1	10.6 46.8	12.8 51.4	12.8 51.4	12.8 51.3	8.5 42.1
	9.6	9	5.9	9.6	8.3	3.4	9	12.3	11.8	9	9.6	9.6	9.6	8.3
Six- monthly time intervals from time of diagnosis (0) to death	*7.5*	*8*	*8.5*	*9*	*9.5*	*10*	*10.5*	*11*	*11.5*	*12*	*12.5*	*13*	*13.5*	*14*
7-9 years n=709 n=3,382	73.7 65.9	99.6 87.7	109.7 92.6	164.3 128.9										
	82.1	112.7	129	206.7										
	4.1	6.4	9.3	19.8										
9-12 years n=335 n=1,875	46.3 37.6	49.3 40.3	52.7 43.4	55.7 46.1	78.7 66.3	82.7 67.8	79.7 62.1	82 59.2	161.3 116.9	243.3 124.9				

	56.4	59.7	63.5	66.8	92.8	99.8	100.7	110.9	217.3	431.6				
	4.8	5	5.1	5.3	6.8	8.1	9.8	13.1	25.5	76.9				
more than 12 years n=49	20.4	37.4	37.4	20.4	34	51	57.8	61.2	51	68	64	86.9	51.9	84.2
n=287	8.5 42.1	19.9 64.8	19.9 64.8	8.5 42.1	17.5 60.3	29.8 82	35 90.5	37.6 94.7	29.8 82	42.9 103	38.7 100.1	51.7 137.7	23.1 101.8	43.2 149.3
	8.3	11.3	11.3	8.3	10.8	13.2	14	14.4	13.2	15.2	15.5	21.7	19.6	26.6
Six- monthly time intervals from time of diagnosis (0) to death	*14.5*	*15*	*15.5*											
more than 12 years n=49	24.7	35.7	10.1											
n=287	4.9	9.9	0.9											
	79.1	95.3	47.1											

Table 3. Incidence rates and 95% CIs for unplanned hospital admissions of people with dementia who were alive by the study end (n=6,544) – Corresponding to Manuscript, Figure 3

Six- monthly time intervals from time of diagnosis (0) to death	0.5	1	1.5	2	2.5	3	3.5	4	4.5	5	5.5	6	6.5	7
Duration between diagnosis and death (number of people) (number of admissions)	Rate 95% CIs Lower limit 95% CIs Upper Limit Standard Error													
between 1-2 years n=1,279	76.5	65.9	58.1	67.4										
n=1,565	70.5	60.4	52.2	56.7										
	82.9	71.9	64.6	79.5										
	3.2	2.9	3.2	5.8										
2-3 years	63.3	56.9	54.1	56.7	58.4	49.3								

n=712														
n=2,156	57.8	51.7	49.1	51.5	52.3	39.9								
	69.2	62.5	59.6	62.2	65	60.4								
	2.9	2.8	2.7	2.7	3.2	5.2								
3-4 years n=607	52.6	44.9	50.4	54.6	52.6	56.7	55.8	49.3						
n=2,118	46.9	39.7	44.8	48.9	46.9	50.8	49	38.3						
	58.7	50.6	56.4	60.9	58.7	63.1	63.3	62.5						
	3	2.8	2.9	3.1	3	3.1	3.6	6.2						
4-5 years n=486	56.7	51.3	47.7	43.7	53.2	43.9	52.7	52.5	47.2	37.8				
n=1,889	49.9	44.8	41.5	37.7	46.6	37.9	46.1	45.9	40.2	27.7				
	64.3	58.5	54.7	50.3	60.5	50.6	60	59.7	55.1	50.4				
	3.7	3.5	3.4	3.2	3.6	3.2	3.5	3.5	3.8	5.8				
5-6 years n=413	53.8	46.7	43	49.8	43.8	46.1	39.2	47.8	42.1	46.4	47.7	28.5		
n=1,748	46.5	39.9	36.5	42.8	37.3	39.4	33.1	41	35.7	39.7	39.8	18.7		
	62	54.3	50.3	57.7	51.2	53.6	46.2	55.5	49.3	54	56.7	41.6		
	3.9	3.7	3.5	3.8	3.5	3.6	3.4	3.7	3.5	3.6	4.3	5.8		
6-7 years	39.8	32.5	30.7	33.9	21.3	28.3	31.8	38.4	39.1	38.1	41.6	38.4	39.7	48.9

n=330														
n=1,301	33	26.4	24.8	27.6	16.5	22.6	25.8	31.7	32.4	31.4	34.6	31.7	31.7	34.6
	47.7	39.6	37.7	41.2	27.2	35	38.8	46.1	46.9	45.8	49.6	46.1	49	67.2
	3.7	3.4	3.3	3.4	2.7	3.1	3.3	3.7	3.7	3.6	3.8	3.7	4.4	8.3
7-9 years n=379	44.4	29.9	33	36	35.1	41	33.9	32.7	29.6	35.1	40	33	32	34.5
n=1,801														
	37.6	24.4	27.2	29.9	29.1	34.4	28	26.9	24.1	29.1	33.6	27.2	26.3	28.5
	52.1	36.3	39.7	43	42	48.4	40.7	39.3	35.9	42	47.4	39.7	38.7	41.3
	3.7	3	3.2	3.3	3.3	3.6	3.2	3.2	3	3.3	3.5	3.2	3.1	3.3
9-12 years n=387	30.9	32.7	29.2	23.9	28.3	21.5	23.3	31.8	26.8	25.6	26.2	27.4	27.1	30.9
n=1,991	25.4	27	23.8	19.1	23	17	18.5	26.2	21.7	20.7	21.2	22.2	22	25.4
	37.3	39.2	35.3	29.5	34.4	26.9	28.8	38.2	32.7	31.4	32.1	33.4	33.1	37.3
	3	3.1	2.9	2.7	2.9	2.5	2.6	3.1	2.8	2.7	2.8	2.8	2.8	3
more than 12 years n=99	23.1	8.3	11.1	12	13.9	11.1	10.2	13	11.1	7.4	13	4.6	9.3	14.8
n=378	15.3	4.1	6.1	6.7	8.1	6.1	5.4	7.4	6.1	3.5	7.4	1.8	4.8	8.8
	33.6	15.2	18.8	20	22.3	18.8	17.6	21.2	18.8	14	21.2	10.1	16.4	23.5
	4.6	2.8	3.2	3.3	3.6	3.2	3.1	3.5	3.2	2.6	3.5	2.1	2.9	3.7

Six- monthly time intervals from time of diagnosis (0) to death	*7.5*	*8*	*8.5*	*9*	*9.5*	*10*	*10.15*	*11*	*11.5*	*12*	*12.5*	*13*	*13.5*	*14*
7-9 years n=379	35.2	36.7	42	34.4										
n=1,801	0	0	0	0										
	28.8	28.4	30.6	17										
	42.7 3.6	46.7 4.7	56.4 6.6	62.8 11.5										
	0	0	0	0										
9-12 years n=387	29.2	28.6	30.6	30.9	30.9	25.6	27.2	24	32.5	27.6				
n=1,991	23.8	23.3	25.2	25.4	25.2	19.9	20.5	17.1	21.5	10.5				
	35.3 2.9	34.7 2.9	36.9 3	37.3 3	37.6 3.2	32.4 3.2	35.3 3.8	32.8 4	47.2 6.5	60.4 12.3				
more than 12 years n=99	14.8	18.5	17.6	13.9	11.1	8.3	16.7	8.3	9.3	25.3	13.4	21	12.7	18.8
n=378	8.8	11.7	10.9	8.1	6.1	4.1	10.2	4.1	4.8	14.8	7.5	12.5	5.7	8.9
	23.5	28	26.9	22.3	18.8	15.2	25.8	15.2	16.4	40.6	22.2	33.3	25	35.5
	3.7	4.1	4	3.6	3.2	2.8	3.9	2.8	2.9	6.5	3.7	5.2	4.8	6.7

Six- monthly time intervals from time of diagnosis (0) to death	*14.5*	*15*	*15.5*
more than 12 years n=99 n=378	18.4 1.3 20.3 4.5	6.3 5.5 39.3 8.3	16.5 0.4 20.5 4.4

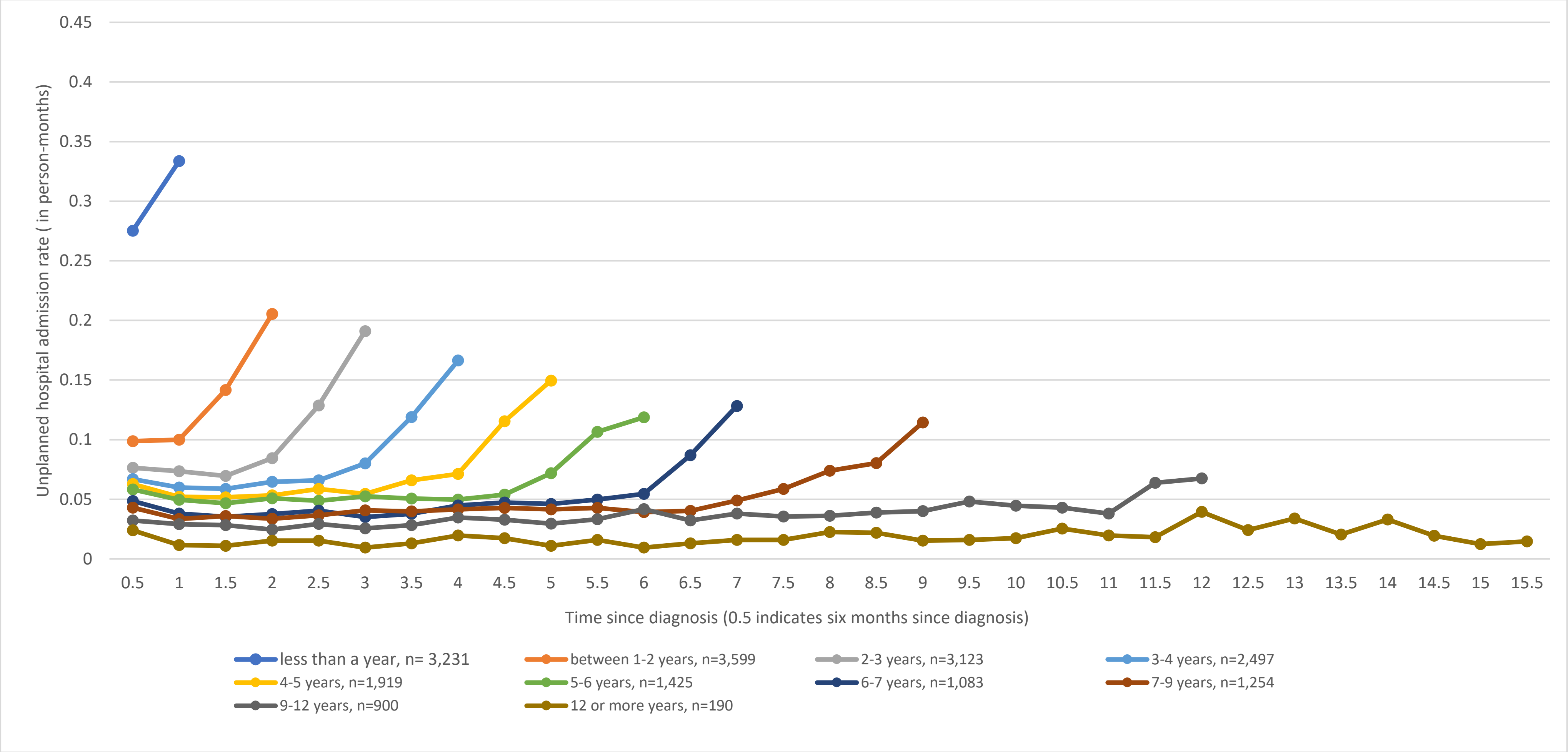


Figure 1. Unplanned hospital admission rates per person-month for six-monthly intervals of 19,221 of people with dementia. Each point indicates the rate of unplanned hospital admissions for the six-month long time interval in person-months (rates range from 0.010 – 0.334)

Table. Sociodemographic and illness-related characteristics of the cohort grouped by mortality at the study end (N=19,221)

Characteristic	All (n= 19,211)		Alive at the study end date (n=6,554)		Decedents (n=12,667)	
	No	%	No	%	No	%
Age at diagnosis (mean, SD)	81.0 (8.5)		78.0 (8.9)		82.6 (7.8)	
Age categories						
50-59	397	2.1	258	3.9	134	1.1
60 – 64	462	2.4	290	4.4	173	1.4
65 – 69	949	4.9	528	8.1	412	3.3
70 – 74	2,012	10.5	876	13.4	1,122	8.9
75 – 79	3,571	18.6	1,476	22.5	2,085	16.5
80 – 84	4,711	24.5	1,506	23.0	3,177	25.1
85 – 89	4,421	23.0	1,144	17.5	3,292	26.0
90 - 94	2,098	10.9	399	6.1	1,731	13.7
≥ 95	600	3.1	77	1.2	541	4.3
Age at window end/death (mean, SD)	84.5(8.1)		82.6 (8.6)		85.6 (7.6)	
Age at window end						
Age categories						
50-59	152	0.8	95	1.5	52	0.4
60 – 64	260	1.4	165	2.5	99	0.8
65 – 69	527	2.7	274	4.2	248	2.0
70 – 74	1,193	6.2	544	8.3	632	5.0
75 – 79	2,436	12.7	994	15.2	1,425	11.3
80 – 84	4,108	21.4	1,516	23.1	2,576	20.3
85 – 89	5,120	26.6	1,571	24.0	3,542	28.0
90 - 94	3,841	20.0	1,028	15.7	2,843	22.4
≥ 95	1,584	8.2	367	5.6	1,250	9.9
Sex						
Female	11,847	61.4	4,129	63.0	7,718	61.0

Male	7,374	38.4	2,425	37.0	4,949	39.0
Ethnicity						
British	11,987	62.4	3,345	51.0	8,642	68.2
African Caribbean	2,811	14.6	1,475	22.5	1,336	10.6
White other	2,065	10.7	774	11.8	1,291	10.2
Asian	831	4.3	426	6.5	405	3.2
Any other ethnicity	510	2.7	293	4.5	217	1.7
Mixed	131	0.7	79	1.2	52	0.4
Missing	886	4.6	162	2.5	724	5.7
IMD quintiles closer to diagnosis						
1	5,687	29.6	1,983	30.3	3,704	29.4
2	6,685	34.8	2,250	34.3	4,435	35.0
3	3,476	18.1	1,249	19.1	2,227	17.6
4	1,743	9.1	560	8.5	1,183	9.3
5	1,392	7.2	464	7.1	928	7.3
Missing	238	1.2	48	0.7	190	1.4
First recorded dementia diagnosis						
Alzheimer's disease	9,310	48.4	3,600	54.9	5,710	45.1
Vascular dementia	4,714	24.5	1,256	19.2	3,458	27.3
Unspecified dementia	4,500	23.4	1,440	22.0	3,060	24.2
Other dementia	510	2.7	186	2.8	324	2.6
Lewy body dementia	187	1.0	72	1.1	115	0.9
Whether they were ever diagnosed with						
Alzheimer's disease	10,107	52.6	4,106	62.7	6,001	47.4
Vascular dementia	5,819	30.3	1,633	24.9	4,186	33.1
Lewy Body	411	2.1	418	2.3	263	2.1
Parkinson's dementia	1,142	5.9	417	6.4	725	5.7
Mixed dementia	3,819	19.9	1,447	22.1	2,372	18.7
Other	4,546	23.7	1,339	20.4	3,207	25.3
MMSE closest to diagnosis						

≥20 (mild)	7,795	40.6	3,388	51.7	4,407	34.8
≥10 - <20 (moderate)	6.308	32.8	1.938	29.6	4.370	24.5
<10 (severe)	1,427	7.4	361	5.5	1,066	8.4
Missing	3,691	19.2	867	13.2	2,824	22.3
MMSE closest to death/window end						
≥20 (mild)	6,555	34.1	3,039	46.4	3,516	27.8
≥10 - <20 (moderate)	6,720	35.0	2,047	31.3	4,673	36.9
<10 (severe)	2,555	11.7	601	9.2	1,654	13.1
Missing	3,691	19.2	867	13.2	2,824	22.3
HoNOS Categories[a]						
Aggressive, disruptive or agitated behaviour (total n = 17,114)	3,638	21.3	901	14.9	2,737	24.7
Problems with occupation and activities (total n = 16,856)	5,674	33.7	1,701	28.3	3,973	36.6
Problems with living conditions (total n = 16,940)	2,187	12.9	672	11.1	1,515	13.9
Problems with activities of daily living (total n = 17,067)	10,606	62.1	3,010	49.9	7,596	68.8
Problems with relationships (total n = 17,055)	3,082	18.1	879	14.6	2,203	20.0
Other mental and behavioural problems (total n = 16,839)	4,663	27.7	1,604	27.0	3,059	28.1
Problems associated with hallucinations (total n = 7,795)	2,346	13.8	723	12.0	1,623	14.7
Physical illness or disability problems (total n = 17,111)	9,455	55.3	2,761	45.6	6,694	60.5
Cognitive problems (total n = 17,109)	14,558	85.1	4,866	80.4	9,692	87.7
Problems drinking or drug-taking (total n = 7,830)	554	3.2	234	3.9	320	2.9
Non-accidental self-injury (total n = 17,108)	284	1.7	91	1.5	193	1.8
Problems with depressed mood (total n = 17,078)	2,578	15.1	962	15.9	1,616	14.7

Year of diagnosis						
<= 2000	67	0.4	61	0.9[b]	62	05
2001 – 2004	732	3.8			676	4.3
2005 – 2008	5,727	29.8	598	9.1	5,129	40.5
2009 – 2012	5,641	29.4	1,492	22.8	4,149	32.8
2013 – 2016	6,632	34.5	4,046	61.7	2,586	20.4
2017	422	2.2	357	5.5	65	0.5
Year of death						
<=2000	-	-	-	-	13	0.1
2001-2003	-	-	-	-	58	0.5
2004-2006	-	-	-	-	761	6.0
2007-2009	-	-	-	-	2,323	18.3
2010-2012	-	-	-	-	3,118	24.6
2013-2015	-	-	-	-	3,506	27.7
2016-2018	-	-	-	-	2,888	22.8

People who had at least one unplanned hospital admission	Total (14,759)		Alive at the study end date (n=6,554)		Decedents (n=12,667)	
Charlson comorbidity index for the first unplanned hospital admission after diagnosis						
0	6,703	45.4	4,352	66.4	6,813	53.8
1	1,309	8.9	479	7.3	830	6.6
2-4	2,002	13.6	560	8.5	1,442	11.4
5-7	3,048	20.7	785	12.0	2,263	17.9
>8	1,697	11.5	378	5.8	1,319	10.4
Charlson comorbidity index for the last unplanned hospital admission before death/window end						
0	6,477	43.9	4,363	66.6	6,558	51.8
1	1,319	8.9	483	7.4	836	6.6

2-4	1,968	13.3	556	8.5	1,430	11.3
5-7	3,391	23.0	802	12.2	2,589	20.4
>8	1,604	10.9	350	5.3	1,254	9.9

MMSE: mini-mental state examination; SD: standard deviation; IMD: index of multiple deprivation (1 = most deprived, 5 = most affluent). [a] HoNOS contains 12 sub-scales covering behaviour, impairment, symptoms, and social functioning/context, with each scored on a five- point scale ranging from 0 (no problem) to 4 (severe/very severe problem) [16]. HoNOS scores were dichotomised (scores 0 and 1— no or minor problems, scores 2 to 4—mild to severe problems) to facilitate interpretation. Reported only people who mild to severe problems. [b] One of the cells was smaller than 10, hence merged.

Table. 20 most common primary diagnoses (ICD-10 three-digit code) for the first and last hospitalisations following their first ever recorded dementia diagnosis (n=14,759)

Three-digit ICD-10 primary discharge diagnosis	n(%)		n (%)	
Urinary tract infection, site not specified	1,390	(9.42)	1,416	(9.59)
Lobar pneumonia, unspecified	658	(4.46)	635	(4.3)
Pneumonia, unspecified	502	(3.4)	479	(3.25)
Fracture of neck of femur	441	(2.99)	448	(3.04)
Unspecified acute lower respiratory infection	410	(2.78)	388	(2.63)
Pneumonitis due to food and vomit	330	(2.24)	296	(2.01)
Tendency to fall, not elsewhere classified	327	(2.22)	329	(2.23)
Syncope and collapse	312	(2.11)	319	(2.16)
Sepsis, unspecified	264	(1.79)	243	(1.65)
Acute renal failure, unspecified	244	(1.65)	271	(1.84)
Unspecified dementia	213	(1.44)	201	(1.36)

Senility	196	(1.33)	201	(1.36)
Disorientation, unspecified	187	(1.27)	186	(1.26)
Alzheimer disease, unspecified	181	(1.23)	176	(1.19)
Cerebral infarction, unspecified	178	(1.21)	162	(1.1)
Unknown and unspecified causes morbidity and mortality	170	(1.15)	179	(1.21)
Constipation	167	(1.13)	145	(0.98)
Chest pain, unspecified	154	(1.04)	147	(1.0)
Congestive heart failure	145	(0.98)	148	(1.0)
Pertrochanteric fracture	140	(0.95)	146	(0.99)

Appendix 5. Supplementary material for Study 2

Supplementary data for the manuscript titled "*Survival and critical care use among people with dementia in a large English cohort*"

Table 1. Population characteristics

	Total	No critical care admission	Had ≥1 critical care admission
N	19,787	19,061	726
Sex			
female	12071 (61.0%)	11696 (61.4%)	375 (51.7%)
male	7716 (39.0%)	7365 (38.6%)	351 (48.3%)
Age at diagnosis			
<60	309 (1.6%)	285 (1.5%)	24 (3.3%)
>=60 - <=64	430 (2.2%)	401 (2.1%)	29 (4.0%)
>=65 - <=69	916 (4.6%)	845 (4.4%)	71 (9.8%)
>=70 - <=74	1998 (10.1%)	1896 (9.9%)	102 (14.1%)
>=75 - <=79	3615 (18.3%)	3441 (18.1%)	174 (24.0%)
>=80 - <=84	4820 (24.4%)	4653 (24.4%)	167 (23.0%)
>=85 - <=89	4749 (24.0%)	4639 (24.3%)	110 (15.2%)
>=90 - <=94	2278 (11.5%)	2237 (11.7%)	41 (5.6%)
>=95	672 (3.4%)	664 (3.5%)	8 (1.1%)
Age at diagnosis, median (IQR)	82.0 (77.0, 87.0)	82.0 (77.0, 87.0)	79.0 (73.0, 84.0)
MMSE near diagnosis, median (IQR)	20.0 (15.0, 23.0)	19.0 (15.0, 23.0)	21.0 (17.0, 24.0)
MMSE categories			
mild	5313 (26.8%)	5046 (26.5%)	267 (36.8%)
moderate	4274 (21.6%)	4115 (21.6%)	159 (21.9%)
severe	1041 (5.3%)	1020 (5.4%)	21 (2.9%)
missing	9159 (46.3%)	8880 (46.6%)	279 (38.4%)
HoNOS cognitive problems	15807 (79.9%)	15244 (80.0%)	563 (77.5%)

MMSE: mini-mental state examination; HoNOS (health of the nation outcome scale) scores were dichotomised (scores 0 and 1—no or minor problems, scores 2 to 4—mild to severe problems) to facilitate interpretation.

Appendix 6. Supplementary material for Study 3

Sections:

1. *Sample characteristics*
2. *Further information about the methods*
3. *Comparison of included vs excluded people with dementia*
4. *Decedents, three-class model for the last year of life & latent transition analysis*
5. *Modelling specifications*
6. *Sensitivity analysis (complete case analysis – multinomial logistic regression)*
7. *Transitions between classes over time (descriptive tables)*

1. Sample characteristics

Neighbourhood-level socioeconomic status was estimated using the Index of Multiple Deprivation (IMD).[11] This is the official measure of relative deprivation in England which encompasses living conditions of individuals from 32,844 neighbourhoods termed Lower Layer Super Output Areas (LSOAs). Each LSOA contains around 1500 people. IMD was derived from the LSOA associated with the patient's address (recorded closest to the diagnosis) and converted into quintiles of the national distribution (1 – most deprived, 5 – least deprived).

The Health of the Nation Outcome Scale (HoNOS) is used to rate adult mental health service users. Together, the scales rate various aspects of mental and social health. Each question can be rated from 0-4:

0	No problems within the period stated
1	Minor problem requiring no action
2	Mild problem but definitely present
3	Moderately severe problem
4	Severe to very severe problem

Number of medications include anticholinergics, anticoagulants, hypertensives, antidepressants, and antipsychotics.[13]

A social care package means that people may be entitled to free healthcare, personal care (such as help with getting washed and dressed), or care home fees, including accommodation costs.[28, 29]

2. Further information about the methods

Latent class analysis (LCA) can identify subpopulations who differ from one another in term of their patterns of selected indicators. Within the LCA, count variables were used for each healthcare measure and we reported means (SDs) instead of item response probabilities. For a clear interpretation of which indicators are above or below the sample means, we used the z-standardised mean scores in figures.[307] I also reported the predicted probabilities of each healthcare use for each class. I took a three-step approach to account for covariates in LCA models.[301] After defining the latent classes according to measures of healthcare use, the next step was to determine how the set of indicator variables (measures of healthcare use) and biopsychosocial characteristics varied according to latent class group.

3. Comparison of included vs excluded people with dementia

	People with dementia who were included in the main analysis (lived for two or more years with a dementia diagnosis)	People with dementia who were excluded from the main analysis (lived for two or less years with a dementia diagnosis)
N	8,623	5,874
Gender		
woman	5,323 (61.7%)	3,286 (56.2%)
man	3,300 (38.3%)	2,561 (43.8%)
Age at diagnosis – death	81.5 (7.7) - 86.3 (7.4)	84.4 (7.5)- 85.3 (7.5)
Ethnicity groups		
White	6,487 (75.2%)	4,503 (77.0%)
Mixed	55 (0.6%)	25 (0.4%)
Asian	405 (4.7%)	249 (4.3%)
Black	1,337 (15.5%)	613 (10.5%)
Other	176 (2.0%)	111 (1.9%)
Not known	163 (1.9%)	346 (5.9%)
First dementia diagnosis		
Alzheimer's disease	3,030 (35.1%)	1,601 (27.4%)
Mixed dementia	1,223 (14.2%)	812 (13.9%)
Unspecified dementia	2,140 (24.8%)	1,543 (26.4%)
Vascular dementia	1,624 (18.8%)	1,367 (23.4%)
Dementia in other diseases	606 (7.0%)	524 (8.9%)
IMD quintiles		
1 (Most deprived)	1,600 (18.6%)	1,067 (18.2%)
2	3,280 (38.0%)	2,326 (39.8%)
3	1,819 (21.1%)	1,177 (20.1%)
4	1,000 (11.6%)	668 (11.4%)
5 (Least deprived)	601 (7.0%)	399 (6.8%)
Missing	323 (3.7%)	210 (3.6%)
MMSE at diagnosis mean (SD)	18.2 (6.4)	17.0 (6.5)
mild	2,583 (30.0%)	870 (14.8%)
moderate	2,259 (26.2%)	1,077 (18.3%)
severe	574 (6.7%)	300 (5.1%)
Missing	3,207 (37.2%)	3,627 (62.0%)
Hypertension	3,803 (44.1%)	2,272 (38.7%)
Depression	371 (4.3%)	279 (4.8%)
HoNOS cognitive problems		
0	95 (1.1%)	44 (0.8%)
1	999 (11.6%)	469 (8.0%)
2	3,642 (42.2%)	1,885 (32.2%)
3	2,799 (32.5%)	2,207 (37.7%)
4	676 (7.8%)	719 (12.3%)
Missing	412 (4.8%)	523 (9.0%)
Physical illness or disability problems	4,259 (49.4%)	3,818 (54.1%)
Other mental and behavioural problems	2,060 (23.9%)	1,721 (29.3%)

Problems with relationships	1,316 (15.3%)	1,084 (18.5%)
Problems with activities of daily living	4,797 (57.7%)	4,056 (69.1%)
Problems with living conditions	984 (11.4%)	792 (13.5%)
Living alone at the time of diagnosis recorded in notes		
Yes	1,498 (17.4%)	868 (14.8%)
No	7,125 (82.6%)	5,006 (85.2%)
Recorded as a care package recipient at the time of diagnosis		
Yes	3,879 (45.0%)	1,840 (31.3%)
No	4,744 (55.0%)	4,034 (68.7%)

4. Decedents, three and four-class model for the last year of life & latent transition analysis

Decedents

11,209 decedents (Mean age 82 (SD 8), 61% women, 34% Alzheimer's disease, 75% White ethnicity) with dementia were grouped into four groups based on their healthcare use in the last year of their lives (Figure). Almost a third of people (29%) with dementia had no or very low numbers of interactions with hospital or specialist mental health services and all died outside of a hospital (100%). People with intermediate healthcare use (43%) were characterised by not attending EDs, having community mental health nurse visits, and having fewer hospital admissions. Despite fewer admissions and short stays, 40% of people in this group died in a hospital. Of people who had high community mental healthcare use and occasional acute (secondary care) hospital admissions (29%), 43% died in a hospital. People in the high ED attendance group (8%) had the highest percentage (54%) of dying in a hospital. People of Asian ethnicity, those with vascular dementia and mixed dementia, people who were diagnosed at an older age, and those with significant physical illnesses were more likely to be in this group.

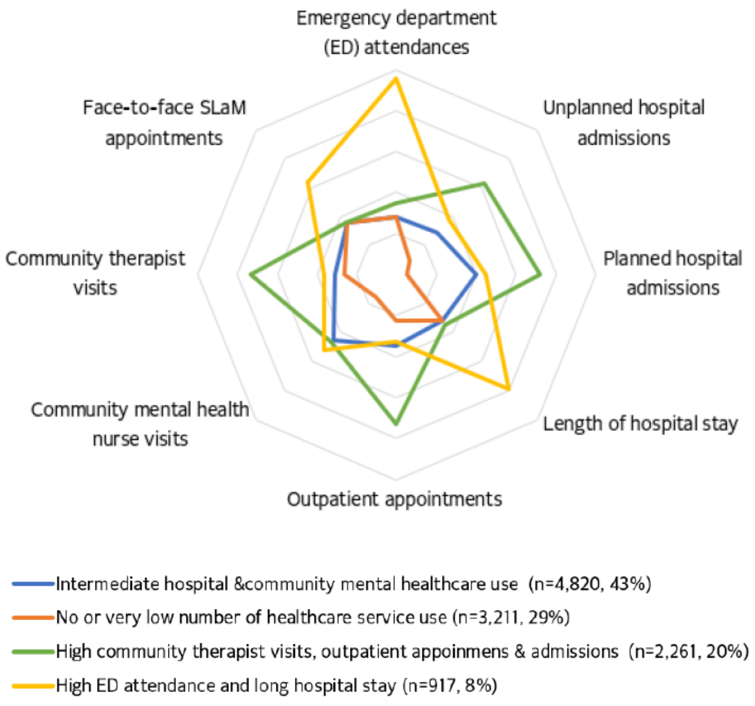


Figure: Radar plot depicting four distinct profiles of people with dementia

Three class models

	Last year of life class 1	Last year of life class 2	Last year of life class 3
	N=2,809	N=1,655	N=4,159
A&E visits	0.1 (0.3)	6.1 (14.1)	5.4 (10.5)
Unplanned hospital	1.3 (0.7)	2.9 (2.7)	2.5 (1.9)
Planned hospital admissions	0.0 (0.1)	0.1 (0.8)	0.1 (2.3)
Length of hospital stay	0.0 (0.1)	16.7 (24.4)	14.1 (18.0)

Face-to-face SLaM appointments	0.0 (0.2)	6.5 (8.3)	0.1 (0.2)
Community mental health nurse visits	0.0 (0.1)	3.4 (9.8)	0.0 (0.0)
Therapists visits	0.0 (0.1)	1.7 (5.7)	0.0 (0.0)
Outpatient appointments	0.5 (1.2)	2.7 (4.6)	3.0 (5.7)

Table. Transition probabilities of staying within class and transitioning out of class at follow-up

	Last year of life class 1 (Low healthcare use)	Last year of life class 2 (Mental health and unplanned hospital use)	Last year of life class 3 (Unplanned hospital use)
Diagnosis class 1 (Low hospital, minimal mental health use)	0.31	0.22	0.47
Diagnosis class 2 (Unplanned hospital use, minimal community mental healthcare use)	0.32	0.13	0.55
Diagnosis class 3 (Mental healthcare use)	0.30	0.35	0.35

Table. The effect of proximity to death on transition probabilities (odds ratio, 95% CIs)

	Last year of life class 1 (Low healthcare use)	Last year of life class 2 (Mental health and unplanned hospital use)	Last year of life class 3 (Unplanned hospital use)
Diagnosis class 1 (Low hospital, minimal mental health use)	1.00 (1.00,1.00)	**0.34(0.29-0.40)**	**0.66(0.58-0.74)**
Diagnosis class 2 (Unplanned hospital use, minimal community mental healthcare use)	**1.97(1.56 - 2.50)**	1.00(1.00-1.00)	1.18(0.94-1.48)
Diagnosis class 3 (Mental healthcare use)	**1.30(1.05-1.62)**	**0.47(0.37-0.59)**	1.00(1.00-1.00)

*Significant findings are bolded.

Table. The effect of gender (0=female, 1=male) on transition probabilities (odds ratio, 95% CIs)

	Last year of life class 1 (Low healthcare use)	Last year of life class 2 (Mental health and unplanned hospital use)	Last year of life class 3 (Unplanned hospital use)
Diagnosis class 1 (Low hospital, minimal mental health use)	1.00(1.00-1.00)	**2.08(1.67-2.58)**	**1.28(1.07-1.53)**
Diagnosis class 2 (Unplanned hospital	**0.52(0.38-0.70)**	1.00(1.00-1.00)	0.76(0.57-1.01)

use, minimal community mental healthcare use)			
Diagnosis class 3 (Mental healthcare use)	0.94(0.68-1.29)	**1.57(1.15-2.14)**	1.00(1.00-1.00)

*Significant findings are bolded.

5. Modelling specifications

To deal with zero-inflated count variables that are not normally distributed, instead of a Maximum Likelihood (ML) estimator, using MLR (maximum likelihood parameter estimates with standard errors) or MLF (maximum likelihood estimation with standard errors based on the first-order derivatives) estimators is recommended. These estimators (MLR and MLF) provide robust estimation and avoid model misspecification. In large samples, such as in our sample, all estimator methods are equivalent.[27]

A z-score (standard) measures the distance between a data point and the mean using standard deviations. Z-scores can be positive or negative. The sign tells you whether the observation is above or below the mean and can be helping for understanding where a specific observation falls within a distribution.

6. Sensitivity analysis (complete case analysis – multinomial logistic regression)

Table. Patient characteristics associated with the year after diagnosis classes: reference class: Class 1Low healthcare use after diagnosis (complete case analysis, N=8,210)

Characteristic	RRR (95% CI)			
	Planned and unplanned hospital use after diagnosis		Mental healthcare use after diagnosis	
	Unadjusted	Adjusted for age & sex	Unadjusted	Adjusted for age & sex
Sex [Ref, woman]	**1.16 (1.05-1.27)**	**1.26 (1.14-1.39)**	1.09 (0.96-1.23)	0.99 (0.88-1.13)
Age at diagnosis	**1.03 (1.01-1.03)**	**1.03 (1.02-1.04)**	**0.97 (0.97-0.98)**	**0.97 (0.96-0.98)**
Dementia diagnosis [Ref, Alzheimer's disease]				
Mixed dementia	**1.50 (1.29-1.72)**	**1.45 (1.26-1.68)**	1.17 (0.95-1.45)	1.20 (0.97-1.48)
Unspecified dementia	**1.44 (1.27-1.63)**	**1.44 (1.27-1.63)**	**1.90 (1.62-2.24)**	**1.89 (1.62-2.23)**
Vascular dementia	**1.64 (1.44-1.88)**	**1.67 (1.46-1.91)**	**1.97 (1.65-2.34)**	**1.94 (1.62-2.31)**
Dementia in other diseases	**1.77 (1.44-2.18)**	**1.97 (1.60-2.43)**	**4.07 (3.26 -5.10)**	**3.75 (2.97-4.73)**
IMD Quintiles [Ref, 5 (least deprived)]				
1	**1.45 (1.17-1.79)**	**1.51 (1.22-1.87)**	**1.46 (1.10-1.93)**	**1.40 (1.06-1.86)**
2	**1.43 (1.17 -1.74)**	**1.48 (1.22-1.81)**	**1.72 (1.33-2.23)**	**1.67 (1.29-2.17)**
3	1.22 (0.98-1.49)	**1.25 (1.01-1.54)**	**1.34 (1.02-1.77)**	1.31 (1.00-1.73)
4	1.16 (0.92-1.45)	1.18 (0.94-1.48)	0.96 (0.70-1.32)	0..95(0.70-1.30)
Ethnicity groups [Ref, White]				
Mixed	**0.45 (0.23-0.88)**	**0.45 (0.23-0.89)**	0.75 (0.36-1.57)	0.71 (0.34-1.49)
Asian	0.90 (0.72-1.12)	0.95 (0.76-1.18)	**0.55 (0.39-0.77)**	**0.52 (0.37-0.73)**
Black	0.94 (0.82-1.07)	0.98 (0.86-1.13)	1.24 (0.96-1.45)	1.16 (0.99-1.36)
Other	0.91 (0.66 -1.25)	0.93 (0.67-1.28)	**0.45 (0.26-0.77)**	**0.43 (0.25-0.75)**

Care package recipient [Ref, no]	**1.14 (1.03-1.25)**	**1.16 (1.05-1.28)**	**2.35 (2.08-2.66)**	**2.33 (2.06-2.64)**
Living alone [Ref, no]	**1.55 (1.36-1.76)**	**1.53 (1.35-1.74)**	**2.04 (1.76-2.37)**	**2.16 (1.86-2.52)**
Number of medications	**1.12 (1.06-1.19)**	**1.15 (1.09-1.22)**	**2.17 (2.05-2.31)**	**2.15 (2.03-2.28)**
HoNOS cognitive problems score	**1.11 (1.05-1.18)**	**1.12 (1.05-1.18)**	1.06 (0.98-1.14)	1.06 (0.98-1.14)
HoNOS physical problems score	**1.34 (1.30-1.41)**	**1.34 (1.29-1.40)**	**1.23 (1.17-1.29)**	**1.25 (1.18-1.32)**

Abbreviations: RRR (95% CI): Relative Risk Ratio (95% Confidence Intervals), Bold findings are statistically significant (p<.005). Ref: Reference Class, IMD: Index of Multiple Deprivation * 1= Most deprived, 5 = Least deprived, HoNOS: Health of the Nation Outcome Scales

Table. Patient characteristics associated with the last year of life classes: reference class: Class 1: Low healthcare use in the last year of life (complete case analysis, N=8,204)

Characteristic	RRR (95% CI)					
	Moderate healthcare use in the last year of life		High hospital use in the last year of life		Community healthcare use in the last year of life	
	Unadjusted	Adjusted for age & sex	Unadjusted	Adjusted for age & sex	Unadjusted	Adjusted for age & sex
Sex [Ref, woman]	**1.21 (1.09-1.35)**	**1.22 (1.09-1.35)**	**2.59 (2.20-3.060**	**2.51 (2.11-2.69)**	**1.77 (1.56-2.02)**	**1.69 (1.48-1.92)**
Age at diagnosis	0.99 (0.99-1.01)	1.00 (0.99-1.01)	**0.98 (0.97-0.99)**	**0.98 (0.97-0.99)**	**0.98 (0.97-0.99)**	**0.98 (0.98-0.99)**
Dementia diagnosis [Ref, Alzheimer's disease]						
Mixed dementia	**1.26 (1.08-1.48)**	**1.25 (1.07-1.46)**	**1.36 (1.06-1.75)**	**1.31 (1.02-1.67)**	**1.36 (1.06-1.74)**	1.18 (0.96-1.44)
Unspecified dementia	1.07 (0.94-1.22)	1.06 (0.94-1.21)	0.93 (0.75-1.16)	0.89 (0.71-1.11)	0.93 (0.75-1.16)	1.05 (0.89-1.240
Vascular dementia	**1.43 (1.24-1.65)**	**1.41 (1.22-1.62)**	**1.49 (1.20-1.78)**	**1.33 (1.06-1.67)**	**1.50 (1.20-1.87)**	1.04 (0.86-1.26)
Dementia in other diseases	**1.29 (1.04-1.59)**	**1.26 (1.01-1.56)**	**1.42 (1.02-1.79)**	1.12 (0.80-1.56)	**1.42 (1.02-1.98)**	**1.40 (1.07-1.81)**
IMD Quintiles [Ref, 5 (least deprived)]						
1	1.03 (0.83-1.28)	1.03 (0.83-1.28)	0.85 (0.59-1.23)	0.84 (0.58-1.20)	1.29 (0.96-1.74)	1.26 (0.93-1.70)
2	1.05 (0.82-1.28)	1.05 (0.86-1.29)	1.09 (0.78-1.51)	1.10 (0.79-1.54)	1.32 (1.00-1.75)	1.32 (1.00-1.75)
3	0.95 (0.76-1.15)	0.95 (0.77-1.18)	1.13 (0.80-1.60)	1.12-0.79-1.59)	**1.46 (1.09-1.95)**	**1.44 (1.07-1.93)**
4	0.91 (0.64-1.25)	0.92 (0.73-1.16)	1.11 (0.76-1.61)	1.14 (0.78-1.67)	1.11 (0.78-1.79)	1.13 (0.81-1.56)
Ethnicity groups [Ref, White]						
Mixed	1.04 (0.57-1.19)	1.01 (0.55-1.86)	1.08 (0.40-2.93)	0.91 (0.33-2.48)	0.73 (0.30-1.76)	0.64 (0.26-1.59)
Asian	1.06 (0.84-1.35)	1.05 (0.83-1.33)	**1.76 (1.26-2.45)**	**1.58 (1.12-2.22)**	0.85 (0.61-1.17)	0.78 (0.56-1.08)
Black	1.08 (0.94-1.24)	1.06 (0.92-1.21)	1.26 (0.99-1.57)	1.10 (0.87-1.37)	1.09 (0.92-1.31)	0.98 (0.82-1.17)
Other	**0.66 (0.47-0.93)**	**0.66 (0.47-0.92)**	1.19 (0.79-1.39)	1.09 (0.67-1.78)	**0.47 (0.28 - 0.79)**	**0.44 (0.26-0.73)**
Care package recipient [Ref, no]	0.99 (0.89-1.09)	0.99 (0.90-1.10)	0.92 (0.78-1.09)	0.94 (0.79-1.11)	**2.40 (2.11-2.74)**	**2.41 (2.15-2.77)**
Living alone [Ref, no]	0.91 (0.81-1.04)	0.93 (0.82-1.06)	**0.78 0.63-0.98)**	0.89 (0.71-1.11)	0.98 (0.82-0.98)	1.06 (0.90-1.26)
Number of medications	0.99 (0.94-1.04)	0.99 (0.94-1.05)	**0.89 (0.82-0.97)**	**0.88 (0.81-0.97)**	**1.37 (1.29-1.45)**	**1.35 (1.28-1.44)**
HoNOS cognitive problems score	0.97 (0.91-1.03)	0.97 (0.91-1.03)	**0.76 (0.68-0.82)**	**0.76 (0.69-0.83)**	**0.90 (0.84-0.98)**	**0.91 (0.84-0.99)**
HoNOS physical problems score	**1.05 (1.00-1.09)**	**1.05 (1.01-1.09)**	0.99 (0.93-1.07)	0.99 (0.93-1.07)	0.95 (0.89-1.00)	0.96 (0.90-1.01)

Abbreviations: RRR (95% CI): Relative Risk Ratio (95% Confidence Intervals), Bold findings are statistically significant (p<.005). Ref: Reference Class, IMD: Index of Multiple Deprivation * 1= Most deprived, 5 = Least deprived, HoNOS: Health of the Nation Outcome Scales

7. Transitions between classes over time (descriptive tables)

Table. Transition groups from *'low healthcare use after diagnosis'* class to the last year of life classes

	Low healthcare use in the last year of life	Moderate hospital use in the last year of life	High hospital use in the last year of life	Community mental healthcare use in the last year of life
N (4,258)	33% (1,421)	40% (1,710)	11% (463)	16% (663)
Gender				
woman	983 (69.2%)	1,118 (65.4%)	231 (49.9%)	360 (54.3%)
man	438 (30.8%)	592 (34.6%)	232 (50.1%)	303 (45.7%)
Age at diagnosis – death	81.4 (7.8) - 87.1 (7.3)	81.5 (7.6) - 86.6 (7.2)	80.8 (6.9) - 85.1 (6.7)	80.6 (7.4) - 84.9 (7.1)
Ethnicity groups				
White	1,044 (73.5%)	1,267 (74.1%)	336 (72.6%)	522 (78.7%)
Mixed	13 (0.9%)	14 (0.8%)	3 (0.6%)	5 (0.8%)
Asian	70 (4.9%)	92 (5.4%)	32 (6.9%)	28 (4.2%)
Black	206 (14.5%)	265 (15.5%)	73 (15.8%)	97 (14.6%)
Other	48 (3.4%)	28 (1.6%)	14 (3.0%)	8 (1.2%)
Not known	40 (2.8%)	44 (2.6%)	5 (1.1%)	3 (0.5%)
First dementia diagnosis				
Alzheimer's disease	603 (42.4%)	683 (39.9%)	176 (38.0%)	280 (42.2%)
Mixed dementia	178 (12.5%)	250 (14.6%)	79 (17.1%)	93 (14.0%)
Unspecified dementia	344 (24.2%)	401 (23.5%)	87 (18.8%)	156 (23.5%)
Vascular dementia	221 (15.6%)	305 (17.8%)	91 (19.7%)	94 (14.2%)
Dementia in other diseases	75 (5.3%)	71 (4.2%)	30 (6.5%)	40 (6.0%)
IMD quintiles				
1 (Most deprived)	264 (18.6%)	320 (18.7%)	68 (14.7%)	110 (16.6%)
2	491 (34.6%)	629 (36.8%)	169 (36.5%)	237 (35.7%)
3	309 (21.7%)	348 (20.4%)	112 (24.2%)	163 (24.6%)
4	195 (13.7%)	207 (12.1%)	63 (13.6%)	81 (12.2%)
5 (Least deprived)	117 (8.2%)	143 (8.4%)	39 (8.4%)	43 (6.5%)
Missing	45 (3.2%)	63 (3.7%)	12 (2.6%)	29 (4.4%)

MMSE at diagnosis mean (SD)	18.2 (6.5)	18.4 (6.3)	19.3 (6.2)	17.6 (6.8)
Hypertension	569 (40.0%)	708 (41.4%)	192 (41.5%)	326 (49.2%)
HoNOS cognitive problems				
0	13 (0.9%)	10 (0.6%)	8 (1.7%)	8 (1.2%)
1	157 (11.0%)	209 (12.2%)	75 (16.2%)	81 (12.2%)
2	594 (41.8%)	743 (43.5%)	207 (44.7%)	306 (46.2%)
3	447 (31.5%)	523 (30.6%)	124 (26.8%)	207 (31.2%)
4	119 (8.4%)	122 (7.1%)	16 (3.5%)	51 (7.7%)
Missing	91 (6.4%)	103 (6.0%)	33 (7.1%)	10 (0.6%)
Physical illness or disability problems	596 (44.8%)	735 (45.8%)	187 (43.5%)	257 (39.4%)
Problems with depressed mood	162 (12.2%)	160 (10.0%)	38 (8.8%)	72 (11.0%)
Other mental and behavioural problems	353 (26.9%)	326 (20.7%)	101 (23.8%)	176 (27.3%)
Problems with relationships	167 (12.6%)	204 (12.7%)	41 (9.6%)	102 (15.6%)
Problems with activities of daily living	757 (57.0%)	883 (55.0%)	205 (47.9%)	358 (55.0%)
Problems with living conditions	126 (9.6%)	149 (9.4%)	30 (7.0%)	50 (7.7%)
Living alone at the time of diagnosis recorded in notes				
Yes	197 (13.9%)	234 (13.7%)	62 (13.4%)	84 (12.7%)
Recorded as a care package recipient at the time of diagnosis				
Yes	522 (36.7%)	630 (36.8%)	174 (37.6%)	395 (59.6%)
Time in contact with SLaM (days) median (range)	343.0 (22.0-1075.0)	327.5 (14.0-1004.0)	691.0 (107.0-1204.0)	1273.0(936.0-1779.5)

*Numbers smaller than 10 are not reported.

Table. Transition groups from *'Planned and unplanned hospital use after diagnosis'* class to the last year of life classes

	Low healthcare use in the last year of life	Moderate hospital use in the last year of life	High hospital use in the last year of life	Community mental healthcare use in the last year of life
N (2,939)	31% (908)	51% (1,489)	8% (225)	11% (317)
Gender				
woman	598 (65.9%)	905 (60.8%)	71 (31.6%)	183 (57.7%)
man	310 (34.1%)	584 (39.2%)	154 (68.4%)	134 (42.3%)
Age at diagnosis – death	83.4 (7.4) - 88.3 (7.0)	82.7 (7.4) - 86.9 (7.2)	80.3 (7.7) - 84.3 (7.7)	82.0 (7.4) - 85.9 (7.1)
Ethnicity groups				
White	701 (77.2%)	1,138 (76.4%)	150 (66.7%)	242 (76.3%)
Mixed	*	*	*	*
Asian	42 (4.6%)	62 (4.2%)	20 (8.9%)	17 (5.4%)
Black	116 (12.8%)	218 (14.6%)	41 (18.2%)	48 (15.1%)
Other	20 (2.2%)	29 (1.9%)	*	*
Not known	26 (2.9%)	37 (2.5%)	*	*
First dementia diagnosis				
Alzheimer's disease	317 (34.9%)	434 (29.1%)	61 (27.1%)	100 (31.5%)
Mixed dementia	136 (15.0%)	234 (15.7%)	38 (16.9%)	62 (19.6%)
Unspecified dementia	243 (26.8%)	370 (24.8%)	50 (22.2%)	83 (26.2%)
Vascular dementia	157 (17.3%)	346 (23.2%)	55 (24.4%)	53 (16.7%)
Dementia in other diseases	55 (6.1%)	105 (7.1%)	21 (9.3%)	19 (6.0%)
IMD quintiles				
1 (Most deprived)	168 (18.5%)	303 (20.3%)	36 (16.0%)	71 (22.4%)
2	352 (38.8%)	574 (38.5%)	97 (43.1%)	116 (36.6%)
3	188 (20.7%)	288 (19.3%)	47 (20.9%)	71 (22.4%)
4	98 (10.8%)	171 (11.5%)	28 (12.4%)	34 (10.7%)
5 (Least deprived)	56 (6.2%)	97 (6.5%)	11 (4.9%)	15 (4.7%)
Missing	46 (5.1%)	56 (3.8%)	6 (2.7%)	10 (3.2%)
MMSE at diagnosis mean (SD)	18.5 (6.2)	18.0 (6.4)	19.9 (5.2)	18.0 (6.1)
Hypertension	371 (40.9%)	621 (41.7%)	107 (47.6%)	160 (50.5%)
HoNOS cognitive problems				
0	6 (0.7%)	12 (0.8%)	*	*

1	83 (9.1%)	153 (10.3%)	34 (15.1%)	41 (12.9%)
2	365 (40.2%)	603 (40.5%)	99 (44.0%)	128 (40.4%)
3	316 (34.8%)	518 (34.8%)	63 (28.0%)	118 (37.2%)
4	70 (7.7%)	125 (8.4%)	13 (5.8%)	*
Missing	68 (7.5%)	78 (5.2%)	28 (12.5%)	25 (8.2%)
Physical illness or disability problems	495 (58.9%)	893 (63.3%)	143 (68.1%)	168 (53.5%)
Problems with depressed mood	107 (12.7%)	167 (11.9%)	32 (15.2%)	47 (15.0%)
Other mental and behavioural problems	210 (25.5%)	456 (32.9%)	48 (23.2%)	75 (24.1%)
Problems with relationships	99 (11.8%)	207 (14.7%)	31 (14.9%)	61 (19.4%)
Problems with activities of daily living	555 (66.5%)	931 (66.2%)	121 (57.6%)	196 (62.6%)
Problems with living conditions	115 (14.0%)	207 (14.9%)	20 (9.5%)	40 (12.9%)
Living alone at the time of diagnosis recorded in notes				
Yes	187 (20.6%)	279 (18.7%)	40 (17.8%)	68 (21.5%)
Recorded as a care package recipient at the time of diagnosis				
Yes	375 (41.3%)	613 (41.2%)	89 (39.6%)	203 (64.0%)
Time in contact with SLaM (days) median (range)	151.5 (0.0-673.0)	159.0 (5.0-601.0)	452.0 (34.0-1056.0)	1141.0 (857.0-1559.5)

* Numbers smaller than 10 are not reported.

Table. Transition groups from *‘Mental healthcare use after diagnosis’* class to the last year of life classes

	Low healthcare use in the last year of life	Moderate hospital use in the last year of life	High hospital use in the last year of life	Community mental healthcare use in the last year of life
N (1,426)	30% (427)	34% (490)	5% (66)	31% (443)
Gender				
woman	289 (67.7%)	319 (65.1%)	36 (55%)	230 (51.9%)
man	138 (32.3%)	171 (34.9%)	30 (45%)	213 (48.1%)
Age at diagnosis – death	80.1 (8.5) - 85.7 (8.2)	79.8 (7.7) - 84.8 (7.9)	78.6 (7.2) - 82.9 (6.9)	79.3 (8.0) - 83.2 (7.7)
Ethnicity groups				
White	289 (67.7%)	365 (74.5%)	47 (71%)	341 (77.0%)
Mixed	333 (78.0%)	*	*	-
Asian	*	19 (3.9%)	*	10 (2.3%)
Black	10 (2.3%)	92 (18.8%)	15 (23%)	88 (19.9%)
Other	78 (18.3%)	*	-	*
Not known	*	*	-	-
First dementia diagnosis				
Alzheimer’s disease	133 (31.1%)	117 (23.9%)	16 (24%)	110 (24.8%)
Mixed dementia	49 (11.5%)	54 (11.0%)	*	47 (10.6%)
Unspecified dementia	130 (30.4%)	129 (26.3%)	24 (36%)	123 (27.8%)
Vascular dementia	78 (18.3%)	114 (23.3%)	18 (27%)	92 (20.8%)
Dementia in other diseases	37 (8.7%)	76 (15.5%)	6 (9%)	71 (16.0%)
IMD quintiles				
1 (Most deprived)	80 (18.7%)	84 (17.1%)	12 (18%)	84 (19.0%)
2	175 (41.0%)	226 (46.1%)	27 (41%)	186 (42.0%)
3	79 (18.5%)	98 (20.0%)	14 (21%)	102 (23.0%)
4	45 (10.5%)	35 (7.1%)	*	35 (7.9%)
5 (Least deprived)	27 (6.3%)	28 (5.7%)	*	22 (5.0%)
Missing	21 (4.9%)	19 (3.9%)	*	14 (3.2%)
MMSE at diagnosis mean (SD)	18.0 (6.5)	17.3 (6.9)	18.6 (6.2)	17.9 (7.0)
Hypertension	237 (55.5%)	228 (46.5%)	37 (56%)	245 (55.3%)
HoNOS cognitive problems				
0	*	12 (2.4%)	*	11 (2.5%)

1	42 (9.8%)	54 (11.0%)	*	64 (14.4%)
2	182 (42.6%)	192 (39.2%)	34 (52%)	189 (42.7%)
3	144 (33.7%)	184 (37.6%)	24 (36%)	130 (29.3%)
4	45 (10.5%)	12 (2.4%)	*	46 (10.4%)
Missing	*	48 (9.8%)	-	*
Physical illness or disability problems	229 (54.3%)	271 (55.8%)	39 (59%)	246 (55.9%)
Problems with depressed mood	70 (16.6%)	87 (17.9%)	10 (15%)	91 (20.7%)
Other mental and behavioural problems	153 (36.5%)	156 (32.4%)	21 (32%)	155 (35.6%)
Problems with relationships	122 (28.9%)	135 (27.8%)	23 (35%)	124 (28.2%)
Problems with activities of daily living	297 (70.9%)	338 (69.5%)	43 (65%)	294 (67.1%)
Problems with living conditions	83 (20.0%)	85 (17.6%)	*	70 (16.1%)
Living alone at the time of diagnosis recorded in notes				
Yes	120 (28.1%)	112 (22.9%)	11 (17%)	103 (23.3%)
Recorded as a care package recipient at the time of diagnosis				
Yes	252 (59.0%)	286 (58.4%)	37 (56%)	302 (68.2%)
Time in contact with SLaM	568.0 (251.0-1134.0)	515.0 (250.0-1030.0)	772.5 (449.0-1254.0)	1120.0 (826.0-1601.0)
Number of medications with strong anticholinergic effects Median (range)	1.0 (0.0-2.0)	1.0 (0.0-2.0)	1.0 (0.0-2.0)	2.0 (1.0-3.0)

* Numbers smaller than 10 are not reported.

THE END