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Determinants of emergency department attendance among people with dementia approaching the end of life.

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Determinants of emergency department attendance among people with dementia approaching the end of life

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

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Supervised by
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& Professor Catherine J. Evans

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LAY SUMMARY

Dementia is a terminal condition affecting almost one million people in the United Kingdom (UK). It is the leading cause of death in the UK today.

The quality of end-of-life care for people with dementia varies. Most will attend the emergency department (ED) towards the end of life, which is often distressing and can be harmful. To help find ways to safely reduce the need to attend the ED, this thesis aimed to understand why people with dementia attend the ED towards the end of life.

The thesis was developed based on a health planning model and linked to current policy to ensure the research could be used to make changes in the real world. The research was discussed with an expert panel of people with dementia and bereaved caregivers of relatives with dementia, to help make sense of the findings and ensure conclusions were realistic.

The thesis is made up of three parts:

1) *Interview study:* Interviews with people affected by dementia from across the UK, exploring how they were supported in the community and how this affected their use of the ED. The findings suggested that people affected by dementia use the ED because they faced barriers to care in the community. This was thought to be because the health and social care system could not adapt to the changing needs of people with dementia, partly due to the system being under strain and partly due to stigma. The time when the ED was more easily avoided was when individuals with dementia were recognised as approaching the end of life, but this was often late. Based on these findings, it was suggested people with dementia need long-term contact with services, and there needs to be better awareness of dementia as a life-limiting condition and earlier recognition of the end of life.

2) *Big data study:* Analysis of service activity and patient records from people living across England, who had died with dementia and had previously used hospital services. The results showed that younger people, those living in urban areas, and people of South Asian ethnicity had more ED visits in the last year of life, whereas people living in areas with less deprivation, and areas with more nursing home beds had fewer ED visits in the last year of life. Based on these findings, it was suggested that community support must to adapt to individual social, economic and cultural needs, greater nursing home

investment could be considered, and continuity of clinical care must be more readily available to people with dementia living in the community.

3) *Merged findings from the interview and big data studies:* A process of combining the findings from the first two parts of the thesis to develop a model of ED attendance among people with dementia approaching the end of life. The model showed that people with dementia have many characteristics that make ED visits more likely (e.g., younger age, minority ethnicity, and lower socioeconomic position), which are influenced by where they live (e.g., type of residence and geographical location). The way dementia is viewed by society and the health and social care system influences how these factors interact, which either empower people to access to clinical care in the community or force them to use the ED towards the end of life. Based on this model, it was suggested that people with dementia require regularly updated care plans based on individual need, there needs to be a minimum national standard of support from diagnosis to the end of life, and public understanding of dementia must improve.

The thesis suggests that ED visits towards the end of life are influenced by individual and geographical differences, available and accessible continuity of clinical care, and wider dementia stigma. It demonstrates that a one-size-fits-all approach fails to respond to the changing needs of people dying with dementia. This thesis provides policy, practice and research recommendations to help empower people affected by dementia and safely reduce ED visits towards the end of life.

ABSTRACT

Background: Emergency department (ED) attendance among people with dementia is common and increases towards the end of life. Attendance can be distressing for people with dementia and is associated with poorer health outcomes. Understanding the determinants of ED attendance among people with dementia approaching the end of life is essential to inform policies that aim to improve end-of-life dementia care and reduce secondary care pressures.

Aim: To conceptualise the determinants of ED attendance among people with dementia approaching the end of life. **Objectives:** 1) To explore the drivers of ED attendance among people with dementia across the illness trajectory; 2) To examine individual- and service-level factors associated with ED attendance among people with dementia in their last year of life; and 3) To develop a conceptual model of ED attendance among people with dementia towards the end of life.

Methods: Informed by pragmatism, a convergent-parallel mixed methods design was used, mapped against three phases of the PRECEDE component of the PRECEDE-PROCEED health programme planning model. The first phase (social assessment) comprised a remote qualitative interview study exploring drivers of ED attendance among people with dementia across the illness trajectory, analysed using reflexive thematic analysis. The second phase (epidemiological assessment), conducted in parallel, comprised a population-based retrospective cohort study of individual- and service-level factors associated with ED attendance among people with dementia in the last year of life, analysed using multilevel modelling. The third phase (educational and ecological assessment) comprised a mixed methods integration to develop a conceptual model of ED attendance among people with dementia approaching the end of life. This was based on successive integration of claims from phases one and two, according to predisposing, reinforcing, and enabling factors. Ongoing engagement with public representatives facilitated the development of each phase. Policy implications were threaded throughout.

Results: *Phase 1 (social assessment):* From two dyad and 33 individual interviews (people with dementia=10; current caregivers=11; bereaved caregivers=16), three themes were developed: 1) Navigating a ‘push system’, 2) ED as the ‘last resort’, and 3) Taking dementia ‘seriously’. Themes describe a discrepancy between individual priorities and the configuration of health and social care, wherein ED attendance is often the path of least resistance for people with dementia who experience barriers to accessing timely community care and support. The discrepancy may reflect wider societal stigma and a lack of systemic prioritisation of dementia.

Phase 2 (epidemiological assessment): Of 74,486 decedents, 83% had at least one ED attendance in the last year of life. Factors associated with more ED attendances included living in urban areas (IRR 1.06, 95% CI 1.04-1.08), being of South Asian ethnicity (IRR 1.07, 95% CI 1.02-1.13), and having chronic respiratory disease as the underlying cause of death (IRR 1.17, 95% CI 1.14-1.20). Factors associated with fewer ED attendances included having higher socioeconomic position (IRR 0.92, 95% CI 0.90-0.94) and being a resident in a local authority with more nursing home beds (IRR 0.85, 95% CI 0.78-0.93), but not residential home beds.

Phase 3 (educational and ecological assessment): Based on the meta-inference, ED attendance among people with dementia approaching the end of life was conceptualised as a product of multiple intersecting predisposing characteristics (e.g., ethnicity, comorbidity, socioeconomic position) that interact with local reinforcing factors (e.g., residence and geographical location). Systemic priorities and societal preconceptions influence how these factors interact and determine if a person with dementia is empowered to access community clinical care, or reliant on attending the ED towards the end of life.

Conclusions: Based on the findings of this thesis, it is posited that ED attendance is influenced by barriers to accessing timely and responsive community-based clinical continuity, which may be exacerbated among minoritised individuals and driven, in part, by a systemic failure to recognise dementia as a life-limiting illness and wider societal stigma. Findings are situated in previous literature and the current policy context, advocating an intersectional approach to policy development and practice, greater systemic prioritisation of dementia, improved post-diagnostic care that includes the end of life, and increased public education. The thesis also provides baseline observations, prioritised targets for change, and key components of an interventional programme to inform future research into safely reducing ED attendance among people with dementia.

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STATEMENT OF CONTRIBUTION

The contents of this thesis represent my own work, under the supervision of Professor Katherine Sleeman and Professor Catherine Evans. Professors Sleeman and Evans were responsible for the original design of the thesis comprising a systematic review and quantitative and qualitative workstreams, as part of a larger funding application submitted to the Alzheimer’s Society. I was responsible for thesis and workstream development, planning and execution. I was also responsible for securing funding from the King’s Centre for Doctoral Studies and recruiting and engaging with an expert panel of public representatives.

My contribution to each research component of this thesis is detailed below:

Systematic review: I developed the systematic review protocol and search strategy, and searched, screened, and selected papers. From each included paper, I extracted relevant data and assessed the study quality. I conducted the synthesis of study findings and wrote the manuscript as first author.

Phase 1 (social assessment): I developed the protocol and ethics application for the qualitative study and developed the interview topic guides and participant information sheets. I recruited participants and organised and completed interviews with each participant. I conducted the reflexive thematic analysis and wrote the manuscript as first author.

Phase 2 (epidemiological assessment): I developed the protocol and analysis strategy, completed the data application, and sourced all publicly available data. I cleaned the data and completed the statistical analyses with support from co-authors. I wrote the manuscript as first author.

Phase 3 (ecological and educational assessment): I designed and executed the mixed methods integration and developed the conceptual model.

PUBLICATION AND PRESENTATIONS

Peer-reviewed publications incorporated in this thesis

Williamson LE, Evans CJ, Cripps RL, Leniz J, Yorganci E, Sleeman KE. Factors associated with emergency department visits by people with dementia near the end of life: a systematic review. Journal of the American Medical Directors Association. 2021 Oct 1;22(10):2046-55.

Williamson LE, Leniz J, Chukwusa E, Evans CE, Sleeman KS. A population-based retrospective cohort study of end-of-life emergency department visits by people with dementia: Multilevel modelling of individual- and service-level factors using linked data. Age and Ageing. 2023 Mar 52(3):1-11.

Other relevant publications in peer-reviewed journals

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.

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.

Presentations at scientific meetings and conferences

Oral presentations

Williamson, LE. Emergency department attendance among people with dementia approaching the end of life: Research Update. Dementia Study Day, Keech Hospice Care, 29th March 2023, Online.

Williamson LE, Leniz J, Chukwusa E, Evans CJ, Sleeman KS. Individual- and service-level factors associated with end-of-life emergency department attendance among people with dementia. Marie Curie Research Conference ‘Improving End of Life for All’, 9th February 2023, Online.

Williamson LE, Evans CJ, Cripps RL, Leniz J, Yorganci E, Sleeman KE. Factors associated with emergency department attendance by people with dementia approaching the end-of-life: A systematic review. 17th World Congress of the European Association of Palliative Care, 8th October 2021, Online.

Williamson LE. Emergency department attendance by people with dementia towards the end of life. Aging and Neuroscience Translational Research Group, 24th March 2021, Online.

Poster presentations

Williamson LE, Sleeman KE, Evans CJ. "Mum had a right for her voice to be heard, and it wasn't": An interview study exploring what influences emergency department visits among people with dementia. Dementias 2023, 9th-10th February 2023, London.

Williamson LE, Evans CJ, Cripps RL, Leniz J, Yorganci E, Sleeman KE. Emergency department visits for people with dementia towards the end of life: A systematic review of individual, clinical, and environmental factors. 35th Global Conference of Alzheimer's Disease International, 9th-11th June 2022, London.

Williamson LE, Sleeman KE, Evans CJ. "Then they went to A&E. It just seemed to be the policy." Findings of an interview study involving bereaved relatives about emergency department visits by people living with dementia. 35th Global Conference of Alzheimer's Disease International, 9th-11th June 2022, London.

Williamson LE, Evans CJ, Cripps RL, Leniz J, Yorganci E, Sleeman KE. Factors associated with emergency department attendance by people with dementia approaching the end of life: a systematic review. Florence Nightingale Faculty of Nursing, Midwifery and Palliative Care PhD Conference, King's College London, 19th February 2020, London.

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"There is no such thing as a self-made (wo)man"
(George Matthew Adams)

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This thesis is dedicated to my Father, who showed me the value of hard work; my Husband, whose unfaltering support and patience makes it possible for me to explore and reach my goals; and to my past patients, whose stories I have kept with me in my pursuit for better dementia care.

TABLE OF ABBREVIATIONS

A&E	Accident & Emergency
AIC	Akaike Information Criterion
APC	Admitted Patient Care
APPG	All-Party Parliamentary Group
ASRN	Alzheimer's Society Research Network
BAME	Black, Asian, and Minority Ethnic
BIC	Bayesian Information Criterion
CCG	Clinical Commissioning Group
CSI	Cicely Saunders Institute
DCC	Dementia Carers Count
DEEP	Dementia Engagement and Empowerment Project
DNAR	Do-Not-Attempt-Resuscitation
DTSF	Dementia Training Standards Framework
ECDS	Emergency Care Data Set
ED	Emergency Department
FTE	Full-Time Equivalent
GDPR	General Data Protection Regulation
GP	General Practitioner
GRAMMS	Good Reporting of A Mixed Methods Study
GRIPP-2	Guidance for Reporting Involvement of Patients and the Public
GT	Grounded Theory
HES	Hospital Episode Statistics
ICB	Integrated Care Board
ICC	Intra-Class Coefficients
ICS	Integrated Care System
IPA	Interpretative Phenomenological Analysis
IRR	Incidence Rate Ratios
JDR	Join Dementia Research
LGBTQ+	Lesbian, Gay, Bisexual, Transgender, Queer/Questioning, more
MATCH	Multilevel Approach To Community Health
MMER	Mixed Methods Evaluation Rubric
NHS	National Health Service

NICE	National Institute for Health and Care Excellence
NIHR	National Institute for Health and Care Research
ONS	Office for National Statistics
PPI	Patient and Public Involvement
PPM	PRECEDE-PROCEED Model
PRECEDE	Predisposing, Reinforcing and Enabling Constructs in Educational / Economic Diagnosis and Evaluation
PROCEED	Policy, Regulatory, and Organizational Constructs in Educational and Environmental Development
QS	Quality Standard
REC	Research Ethics Committee
RECORD	REporting of studies Conducted using Observational Routinely collected Data
STROBE	Strengthening The Reporting of Observational Studies in Epidemiology
TA	Thematic Analysis
UK	United Kingdom
VIF	Variance Inflation Factors
VPC	Variance Partition Coefficients
WHO	World Health Organisation

GLOSSARY

Abduction	The back-and-forth process of making logical connections between data and theory, alternating between inductive and deductive reasoning.
AIC/BIC	Statistics to estimate model fit which account for the number of parameters.
Bracketing	Process of capturing diversity across findings to develop claims about the nature of the contradictions.
Bridging	Process of developing a consensus between findings.
Collinearity	When two explanatory variables are correlated.
Deductive reasoning	Making a specific inference based on existing theory and accepted premises (top-down logic).
Deviance	A goodness-of-fit statistic between the fitted model and a perfect model.
Gestalt switch	A sudden shift in perception; a change in worldview.
Inductive reasoning	Making a generalised inference based on specific observations (bottom-up logic).
Integrated Care Boards	A statutory organisation responsible for the budgeting and commissioning of NHS services.
Integrated Care Systems	Partnerships between NHS organisations, local authorities and others taking shared responsibility for the planning of services.
Intersectionality	The synergistic nature of multiple intersecting social identities (e.g., ethnicity, gender, and socioeconomic position) that position individuals in different social contexts, which may shape either privilege or oppression.
Intra-Class Coefficients	Statistic to describe how strongly outcomes in the same cluster are likely to be similar, or how strongly outcomes in different clusters are likely to be different.
Likelihood ratio test	A test of goodness-of-fit between two competing models.
Logic model	A graphic depiction of the chain of causes and effects that lead to an outcome of interest.
Meta-inferences	Theoretical statements or narrative products of successive integrated claims / inferences
NHS 111	A telephone and online triage and signposting service for urgent concerns
Offset variable	A variable used to offset the influence of different sizes of observational units (i.e., population sizes) on the outcome variable by modelling the rate rather than the count.
Overdispersion	The presence of greater variability in a data than expected based on the statistical model.

Positive predictive value	The probability that a patient with a positive (abnormal) test result has the disease.
Standard error	The standard deviation of a sample population, indicating how representative the sample is of the population.
Type 1 error	When the investigator rejects the null hypothesis in favour of a statistically significant effect when there is no true effect in the population (false-positive).
Type 2 error	When the investigator accepts the null hypothesis in favour of no statistically significant effect when there is a true effect in the population (false-negative).
Variance Inflation Factor	Measures the extent to which a variable contributes to the standard error in regression.
Variance Partition Coefficients	The percentage variance explained by a higher level in multilevel modelling.
Wald statistic	A statistic that describes whether a group of explanatory variables are collectively significant in a model.

1 INTRODUCTION

1.1 Why should we aim to reduce emergency department attendance among people with dementia who are approaching the end of life?

Dementia is the seventh leading cause of death globally,[1] with 50 million people currently living with the disease.[1] It is the leading cause of death in the United Kingdom (UK),[2] where 944,000 people are estimated to be living with dementia, with 656,000 more expected by 2050.[3] Among people dying with dementia in the UK, at least 79% will attend the emergency department (ED) at least once towards the end of life.[4]

There are strong indicators that ED attendance among people with dementia approaching the end of life is problematic. Across the illness trajectory, emergency hospitalisation increases towards the end of life,[5] with an exponential increase in ED attendance closer to death.[4, 6] For people living with dementia, attending the ED is associated with delirium, antipsychotic administration, hospital admission, and mortality.[7-9] Furthermore, with a lower threshold for sensory overload in dementia,[10] the ED environment has been described as incongruent to meeting the needs of people with dementia and contributes to distress and disorientation.[10, 11] Caregivers of people with dementia report experiencing anxiety and uncertainty during the ED attendance, feeling ignored and in limbo.[12]

It is estimated that between 1.5 and 3 million people per year attending the ED in the UK could have their needs met elsewhere in the urgent care system.[13] Meanwhile, ED overcrowding and prolonged waiting times continue to escalate with associated excess deaths.[14] There is therefore an urgent need for change, which is reflected in a long-standing policy drive to reduce ED attendances and minimise wider system pressures. The NHS Five Year Forward View identified urgent and emergency care as a priority area, acknowledging the ED is "running at full stretch", requiring better system-wide organisation and simplification.[15 (p.21)] Similarly, the NHS Long Term Plan outlined actions to facilitate patient access to support closer-to-home plans to "ensure patients get the care they need fast, relieve pressure on A&E departments, and better offset winter demand spikes".[16 (p.19)] Furthermore, it is acknowledged in the End-of-Life Care for Adults NICE Quality Standard (QS13) that 24/7 access to healthcare, as soon as the need arises, can help to prevent ED visits and hospital admissions and thus reduce unnecessary distress.[17]

Overall, there are strong individual and systemic justifications to consider ED attendance among people with dementia approaching the end of life as problematic and in need of redress. Previous literature has often focused on dichotomising ED attendances as in/appropriate or un/avoidable based on clinical reasons for attendance, or criteria based on patterns of ED attendance. While helpful to observe trends at the population-level, such terms are problematic at the individual-level, as the appropriateness of an ED attendance can usually only be determined in hindsight when the outcomes are known. Furthermore, the decision to attend or send a person to the ED is most likely ‘appropriate’ to the circumstances at the time of perceived need.[18] Arguably, questions about whether attending the ED is appropriate or not may distract efforts to improve end-of-life care for individuals with dementia. Therefore, the question, which underpins the position of this thesis, is: “how can we safely reduce ED attendance among people with dementia towards the end of life?”

2 BACKGROUND

2.1 Dementia

2.1.1 Definition

Dementia describes a collection of symptoms that manifest from a degenerative disease of the brain, sufficient to cause disruption to daily activity and function.[19] Cognitive symptoms of dementia can include amnesia, aphasia, agnosia or apraxia, while neuropsychiatric symptoms can include agitation, apathy or anxiety. However, the symptom profile depends on the stage of dementia and the underlying disease. There are over one hundred different types of dementia, with the commonest being Alzheimer's disease. The progressive and irreversible nature of all dementias means that people will become gradually dependent on others for instrumental and basic activities of daily living. Dementia is therefore profoundly debilitating on multiple levels.[20]

Deterioration in dementia is often described in stages, with the advanced or late stage typified by extreme memory, communication, motor, and functional deficits causing significant disability.[21] Average life expectancy varies between 1.1 to 8.5 years.[22] Prognostic factors of decreased survival have been sought, but these have shown little difference between people with and without dementia.[23] Unlike other terminal conditions like cancer, the trajectory of dementia is comparably protracted with deterioration that is more insidious. The inability to determine prognosis in dementia ('prognostic paralysis'[24]) means that dementia is not always recognised as a terminal illness,[25] and is subsequently associated with futile aggressive interventions, delayed palliative care input and uncontrolled symptoms leading to poorer quality of end-of-life care.[25]

2.1.2 Disability and societal preconceptions

Disability caused by dementia is increasing worldwide.[26] Living with dementia is associated with greater morbidity, with 61% of people with dementia estimated to have at least three comorbidities.[27] There are also increased risks of polypharmacy,[28, 29] undertreated pain,[30] hospitalisation for infection,[31] and reduced quality of life for the person living with dementia and family carergivers.[32] There are 1.1 billion hours of unpaid care per year in the UK,[3] which provides £3.2 billion of working time lost.[33] Families affected by dementia also fund almost two thirds of increasing social care costs.[34] With costs for health and social care for dementia expected to reach £59.4 billion by 2050,[35] dementia is a high public health priority.[36]

Although the biomedical view of disability dominates the literature,[37] there is growing appreciation for social and relational views of disability in dementia which consider the cultural barriers imposed by others,[38] as well as functional barriers of the disease,[39] respectively. Although not all people living with dementia will choose a disability label, it potentially provides an enabling identity and opportunity to assert their rights.[39] There is extensive literature detailing the prevailing societal bias against dementia, which extends beyond public members,[40] to include healthcare professionals,[40] and even people with dementia.[41] Stigma relating to ageism, cognitive frailty and mental illness have been associated with dementia,[42] leading to a source of social disadvantage.[43] This disadvantage has been observed in barriers to accessing healthcare services, with suggestion that some people with dementia are actively denied access.[43] This has been observed in access to palliative care,[44] and end-of-life support.[45]

2.2 End-of-life

2.2.1 Definition

Being at the end of life is often considered to mean that the person is likely to be in their last year of life,[46] and is the definition used in this thesis. The UK end-of-life quality standard details 16 indicators of quality end-of-life care,[47] ranging from adequate identification of the end-of-life period and communication of accessible and sensitive information to prompt safe responses to crises, in keeping with individual needs and preferences. There is an overall emphasis on care that is timely, holistic and personalised.[47] End-of-life care therefore needs to be targeted and relies heavily on healthcare professionals being able to recognise when someone is approaching the end of life.

2.2.2 End-of-life care in dementia

With difficulties in determining the prognosis of dementia, providing timely end-of-life care can be challenging, with many symptoms being undetected or undertreated,[48] and other symptoms over-investigated and aggressively managed.[49] Rather than the widely advocated person-centred approach to end of life care in dementia,[50] it can often translate to the person with dementia experiencing several distressing hospitalisations.[51] A landmark paper by Gozalo *et al.* coined the term ‘burdensome transitions’ to describe repeated hospital transfers within the last 90 days of life or any transfer in the last three days of life.[52] These transitions were associated with markers of poor end-of-life care, including intensive care unit admissions, use of feeding tubes and stage four pressure ulcers.[52] Hospitalisations earlier in the last year of life have been associated with high levels of hospital use throughout the year.[53]

Compared to other life-limiting conditions, such as cancer, dementia has been associated with poorer quality end-of-life care, including reduced anticipatory prescribing and bereavement support for next of kin.[54] In primary care, people with dementia are statistically significantly less likely to discuss end-of-life topics with their General Practitioner (GP) and engage in advance care planning, compared to people with cancer.[55] Furthermore, people with dementia are less likely to access specialist palliative care services compared to those with cancer, with barriers determined by policy, lack of staff knowledge and education, limited communication between services and individual staff characteristics.[24]

2.3 Emergency department

2.3.1 Definition

While research into end-of-life transitions typically focus on hospitalisation, attending the emergency department (ED) is arguably a phenomenon that is clinically, practically, and experientially distinct to hospitalisation. There are different types of EDs across and between countries. In the UK, there are four types of ED: type 1 is a consultant-led 24hr accident and emergency service with full resuscitation facilities, type 2 is a single-specialty accident and emergency service (i.e. eye casualty), type 3 refers to urgent treatment centres and type 4 refers to walk-in centres.[56] This thesis defines the ED using the type 1 ED definition.

2.3.2 Emergency department attendance among people with dementia

Research has shown that ED attendance can be a distressing and disorientating experience for people with dementia.[10, 11] Attending the ED is known to be associated with increased risk of delirium, antipsychotic administration, and admission,[7, 8] which poses additional risks of infections, pressures sores, and worsening neuropsychiatric symptoms.[57] Despite this, the number of ED attendances among people with dementia increases with proximity to death.[4, 6] While national quality standards for end-of-life care monitor emergency hospital admissions in the last three months of life, this does not specify ED attendance.[17] Given that 33-63% people with dementia approaching the end of life will attend the ED without being admitted into hospital,[58, 59] ED attendance towards the end of life may be a more accurate indicator of quality. However, without monitoring it is difficult to understand the determinants of ED attendance among people with dementia towards the end of life and ensure policies and service planning respond to population need.

2.4 The policy context of end-of-life emergency care in dementia

In 2017, the World Dementia Council global care statement called on all health and social care systems to provide access to high-quality, person-centred care and support based on continuous assessment and individualised care planning.[60] However, the World Alzheimer Report 2022 identified persistent challenges around post-diagnostic care, with 64% of survey respondents living with dementia having no personalised care plan, 37% receiving no information following diagnosis, and 36% of caregivers having no access to post-diagnostic support.[61] In response, there have been renewed global calls for more person-centred, culturally appropriate, gender-inclusive coordinated care, with link workers, improved efforts to challenge stigma associated with dementia, and national dementia plans to become a policy priority.[61]

In 2021, only one quarter of World Health Organisation (WHO) Member States had in place a national dementia strategy, plan, or policy, despite aiming for three-quarters of all member states by 2025.[62] In a sample of dementia strategies from across 14 countries, palliative and end-of-life care was rarely referenced, although terms such as person-centred care and continuity of care were more widely documented.[63] England and the devolved nations each have dementia strategies or action plans, and although tailored to population need and political priorities, they share common targets for improved access to post-diagnostic support, improved models of palliative and end-of-life care, and raising public awareness.[64-67] Some of these strategies are at least ten years old and in need of revision. In England, there have been calls on Government to publish a revised national dementia strategy, which remains pending.

Various other policies have been implemented across the UK that directly and indirectly influence dementia care. For example, in England, the NHS Long Term Plan sets out a clear vision for a consistent standard of support for people with dementia to live in their own homes for longer and avoid unnecessary hospital admissions.[68] It also advocates personalised and proactive planning for everyone identified as being in the last year of life, with a view to reduce emergency admissions towards the end of life.[68] To facilitate reduced secondary care use, the Plan outlines ambitions to boost provision of community-based services, building on successes of various community provider vanguards across the country as part of the NHS Five Year Forward Plan.[15] This includes provision of two-hour urgent community response to people in their usual place of residence, with virtual ward follow-up.[69] Urgent response teams for care home residents is part of the wider Enhance Health in Care Homes initiative,[70] which includes regular GP support, rehabilitation and anticipatory care.[69] This initiative has potential to reduce emergency admissions,[68] and therefore impact the 70% of care home residents who have dementia.[71]

Building on the proposals of the NHS Long Term Plan, the Health and Care Act (2022) brought about infrastructural changes to the planning, commissioning and delivery of health and social care, with greater focus on cross-service integration at the individual-, place-, and population-level.[72] This includes focus on place-based partnerships to improve local health outcomes and reduce inequalities,[73] and relates to the Government's agenda to 'level up' regional inequalities across the UK.[74] The adult social care reform is integral to these changes, which targets person-centred care with greater workforce investment, support for unpaid carers and a new website to support people to navigate the health and care system.[75] Further changes to social care include a cap in care costs. While intended to reduce unpredictable costs,[75] thresholds to meet the cap exclude local authority contributions. This caused concern that only 21% of people with dementia accessing social care would reach the cap, and socioeconomic and regional disparities would worsen.[76] Although the UK Government set out plans for social care reform in September 2021, and implementation of the cap in October 2023, these have been delayed.

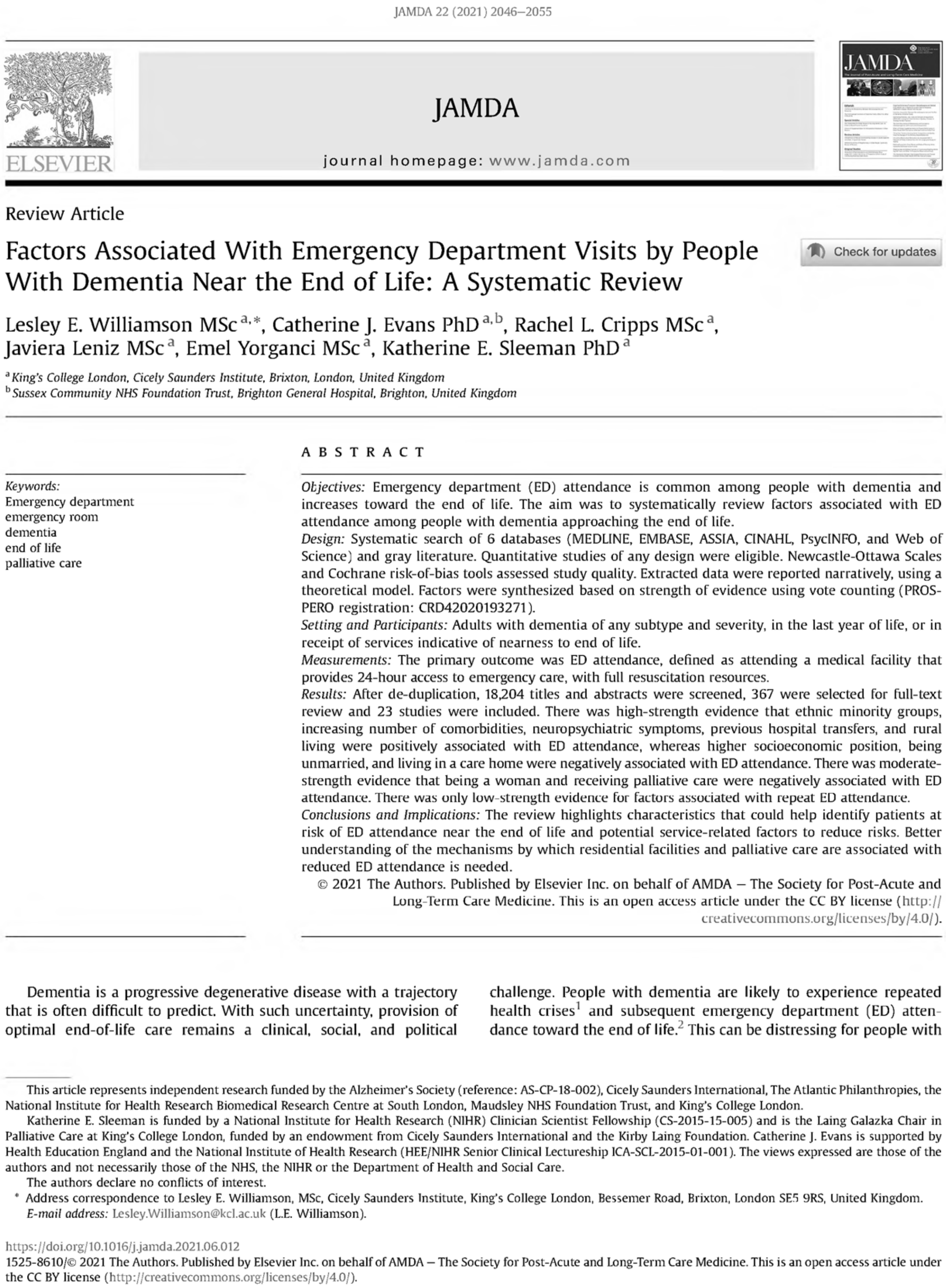
The Health and Care Act (2022) placed a new legal duty on each local commissioning board (Integrated Care Board; ICB) to commission services or facilities for palliative care (including specialist palliative care), as considered appropriate, to meet the requirements of local people.[77] This may be beneficial for people with dementia who have historically had poor access to palliative and end-of-life care, despite national ambitions for fair access.[78] This also affords opportunity to build on the 2016 national Well Pathway for Dementia. The pathway includes a 'Dying Well' domain, which prioritises place of death rather than place of care towards the end of life.[79] It is yet to be seen if the changes in legislation will move focus towards ensuring people with dementia remain in their usual place of care towards the end of life.

With recent changes in legislation, levelling up agendas, awaited social care reform and revisions to national dementia strategies, there is a timely opportunity to review and contribute to the existing evidence base to shape conversations around end-of-life dementia care.

2.5 Systematic review of the evidence into ED attendance among people with dementia approaching the end of life

2.5.1 Introduction

A review of existing evidence is useful to summarise what is already known and what is lacking to shape conversations and direct future effort. Therefore, this section reproduces a published systematic review of international evidence into ED attendance among people with dementia approaching the end of life. The review was published in the Journal of American Medical Directors Association in July 2021. Findings from 23 quantitative studies were synthesised using vote counting based on direction of effect. Results indicated that minoritised ethnicity, increasing number of comorbidities, and rural residence were associated with greater likelihood of ED attendance towards the end of life, whereas higher socioeconomic position, care home residence and community palliative care input were associated with lesser likelihood. Supplementary material for the systematic review can be viewed in Appendix A.



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Review Article

Factors Associated With Emergency Department Visits by People With Dementia Near the End of Life: A Systematic Review

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ABSTRACT

Objectives: Emergency department (ED) attendance is common among people with dementia and increases toward the end of life. The aim was to systematically review factors associated with ED attendance among people with dementia approaching the end of life.
Design: Systematic search of 6 databases (MEDLINE, EMBASE, ASSIA, CINAHL, PsycINFO, and Web of Science) and gray literature. Quantitative studies of any design were eligible. Newcastle-Ottawa Scales and Cochrane risk-of-bias tools assessed study quality. Extracted data were reported narratively, using a theoretical model. Factors were synthesized based on strength of evidence using vote counting (PROSPERO registration: CRD42020193271).
Setting and Participants: Adults with dementia of any subtype and severity, in the last year of life, or in receipt of services indicative of nearness to end of life.
Measurements: The primary outcome was ED attendance, defined as attending a medical facility that provides 24-hour access to emergency care, with full resuscitation resources.
Results: After de-duplication, 18,204 titles and abstracts were screened, 367 were selected for full-text review and 23 studies were included. There was high-strength evidence that ethnic minority groups, increasing number of comorbidities, neuropsychiatric symptoms, previous hospital transfers, and rural living were positively associated with ED attendance, whereas higher socioeconomic position, being unmarried, and living in a care home were negatively associated with ED attendance. There was moderate-strength evidence that being a woman and receiving palliative care were negatively associated with ED attendance. There was only low-strength evidence for factors associated with repeat ED attendance.
Conclusions and Implications: The review highlights characteristics that could help identify patients at risk of ED attendance near the end of life and potential service-related factors to reduce risks. Better understanding of the mechanisms by which residential facilities and palliative care are associated with reduced ED attendance is needed.

Dementia is a progressive degenerative disease with a trajectory that is often difficult to predict. With such uncertainty, provision of optimal end-of-life care remains a clinical, social, and political challenge. People with dementia are likely to experience repeated health crises[1] and subsequent emergency department (ED) attendance toward the end of life.[2] This can be distressing for people with

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dementia,[3] and has inherent risks including delirium and hospital-acquired complications such as infections, pressure sores, and worsening behavioral symptoms.[4] However, it is unclear why some people with dementia attend the ED near the end of life and others remain in their usual residence at home or care home.

Several studies and reviews have measured hospitalization of people with dementia, identifying associated factors such as carer strain,[5,6] socioeconomic position,[7] comorbidity profile,[8–10] behavioral problems,[11] medications,[9,10,12] residence type,[2,10] and location.[13,14] Although the majority of hospital admissions are via the ED,[15,16] there has been no systematic review of studies specifically focused on ED attendance by people with dementia who are approaching the end of life.

The overarching aim was to examine factors associated with ED attendance by people with dementia approaching the end of life. Specific objectives to meet this aim were as follows:

1. To identify clinical reasons for ED attendance by people with dementia approaching the end of life
2. To examine the strength of evidence for factors associated with ED attendance by people with dementia approaching the end of life
3. To explore the frequency of ED reattendance by people with dementia approaching the end of life and the factors associated with repeat attendance

Methods

This review followed the Preferred Reporting Items for Systematic Reviews and Meta Analyses (PRISMA) statement[17] (Supplementary Table 1) and was based on a registered protocol (PROSPERO registration: CRD42020193271).

Eligibility Criteria

The population comprised adults with any dementia subtype of any severity, approaching the end of life. An adult with dementia was defined as any individual with a dementia diagnosis or indicated as having dementia based on contextualized validated assessment. Adults nearing the end of life were defined as those likely to be in the last year of life,[18] or in receipt of services indicative of nearness to end of life including palliative services, home care, and residential care. Included studies had a 12-month time frame for outcome follow-up, to correspond with the definition of end of life.[18] Studies with longer time frames were included if data could be extracted for the final 12 months of follow-up. There were no specific interventions or comparators of interest.

The outcome of interest was ED attendance, defined as attending a medical facility that provides 24-hour access to emergency care, with full resuscitation resources.[19] Any type of ED attendance was accepted (ie, with or without admission). When multiple types were reported (attendance with admission, without admission, any attendance), "any attendance" was used. Where studies presented findings of stratified samples without aggregate data, each sample was treated independently. There were no restrictions by type of residential or geographical setting, or by written language or date. As few relevant qualitative studies were identified from initial scoping, only quantitative data were included. Studies of any design reporting original quantitative data were included if they were relevant to at least 1 of the review objectives (further eligibility details in Supplementary Table 2).

Information Sources

Six bibliographic databases, MEDLINE, EMBASE, ASSIA, CINAHL, PsycINFO, and Web of Science, were searched from inception to April 2020. This was supplemented by searching gray literature from OpenGrey, Alzheimer's Society, The King's Fund, and NHS Evidence.

Search and study selection

The MEDLINE strategy was first developed with input from the project team and then piloted. The syntax and subject headings were adapted for use in other databases (Supplementary Tables 3-8). To ensure literature saturation, the search included reference chaining and snowballing. Screening of titles and abstracts was overinclusive, removing only obviously irrelevant reports. Full-text articles were assessed against the eligibility criteria by L.E.W., and a 25% random sample of these were double-screened by independent reviewers J.L. and E.Y. Discrepancies were resolved by discussion.

Data Extraction

Data were extracted by L.E.W. using a bespoke template, including data on study characteristics (country, aim, design, population, sample size, recruitment and data source, time frame, any interventions and/or comparators described, outcome definitions, and statistical analysis), factors associated with ED attendance and reattendance (descriptive statistics and effect sizes with confidence intervals and P values) and reasons for ED attendance (descriptive statistics). Unadjusted estimates were only recorded when no adjusted estimates were available. For reliability, reviewers R.L.C. and A.T. independently checked the accuracy of extracted data.

Risk of Bias

Quality assessment was completed using the Newcastle-Ottawa Scale (NOS)[20] for cohort and case-control studies and the adapted version for cross-sectional studies.[21] Each study was judged against 3 categories: Selection, Comparability, and Outcome. Comparability assessed the extent to which the studies control for the most important factor. As factors differed between studies, the most important factor was identified for each study. For cross-sectional studies, self-reported outcomes scored zero, in line with the NOS cohort and case-control appraisal tools.

Studies with controlled trial designs were appraised using the Cochrane Risk of Bias (RoB 2)[22] and Risk of Bias In Non-randomised Studies of Interventions (ROBINS-I)[23] tools, as appropriate. All appraisals were completed by L.E.W. and independently checked by R.L.C. and A.T., with discrepancies resolved by discussion.

Synthesis of Results

The underpinning framework for synthesis was developed by Gomes and Higginson[24] and has since been used in systematic reviews of ED attendance toward the end of life in other patient cohorts.[25,26] Accordingly, factors associated with ED attendance were categorized into (1) individual factors (ie, stable sociodemographic and personal variables), (2) clinical factors (type of disease and comorbidities, etc), and (3) environmental factors (contextual determinants of health care input and social support).

Given the heterogeneity of studies, meaningful meta-analysis was unfeasible. For consistency, data were converted into odds ratios where possible and reported narratively, with factors synthesized by vote counting using direction of effect as the standardized metric.[27] This metric excluded statistical significance and effect size to ensure results of underpowered studies were not overlooked.[27] However, for comparability with related reviews,[25,26] a sensitivity analysis was conducted, counting direction of statistically significant results only. Consistency of findings was assessed to determine the strength of evidence using a pre-established algorithm[24] (Supplementary Figure 1). Factors with at least moderate-strength evidence were summarized in a harvest plot,[27] with all factors presented in a final conceptual model.

Results

Study Selection

After de-duplication, 18,204 titles and abstracts were screened, 367 were selected for full-text review and 23 studies were included. Figure 1 demonstrates the stages of study selection, with reasons for exclusion.

Study Characteristics

The main characteristics of each study are in Table 1. Full study details and quality scores are outlined in Supplementary Tables 9-14.

Of the 23 studies, 13 were from North America,[28–35,37,39,41,42,45] 5 from Europe,[16,38,43,46,49] 4 from Australia,[36,44,47,48] and 1 from Asia.[40] There were 18 high-, 1 moderate-,[49] and 2 low-quality studies,[37,46] with moderate risk and some concerns of bias identified in the non-randomized[48] and randomized[47] controlled trials, respectively.

Clinical Reasons for ED Attendance by People With Dementia Approaching the End of Life

Seven eligible studies reported common clinical presentations in the ED.[33,34,36–38,41,48] Each study used different terms ranging from diagnoses to individual symptoms and generalized systemic complaints. Common reasons for ED attendance included infection, injury, and respiratory problems (Table 2). One study found one-quarter of patients had initial and repeat attendances that were considered potentially preventable, and almost half of potentially preventable reattendances were for the same diagnoses as the initial ED attendance.[33]

Factors Associated With ED Attendance by People With Dementia Approaching the End of Life

Eight factors with high-strength evidence and 2 factors with moderate-strength evidence were identified (Figure 2). Information on all factors, including low-strength evidence, are in Supplementary Tables 15-17 and summarized in Figure 3.

Individual factors

There was high-strength evidence that ethnic minority groups (including African-Caribbean[16] and Hispanic[28] ethnicities) were more likely to attend the ED compared with people of white ethnicity. There was high-strength evidence that higher socioeconomic position (measured by area deprivation level,[16] household income,[28] or neighborhood income[31]) was associated with reduced ED attendances. There was moderate-strength evidence that women were less likely to attend the ED than men.[16,28,36,38] All other demographic factors such as age,[16,28,31,34,36,38] education,[28] and insurance cover[28] were of low-strength evidence.

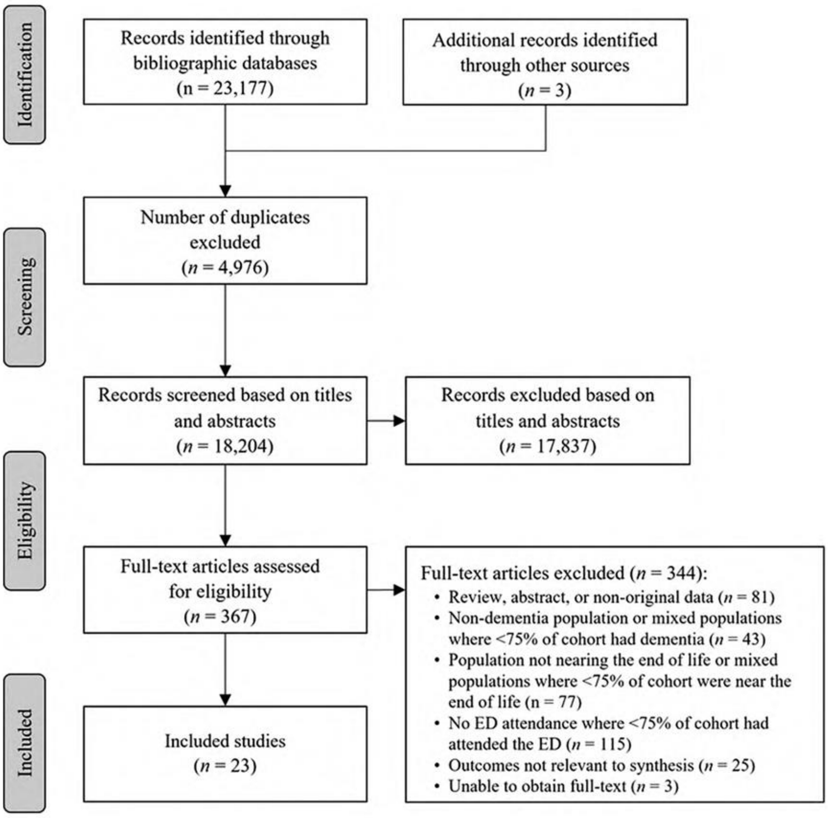

Fig. 1. PRISMA flow diagram of the study selection process.

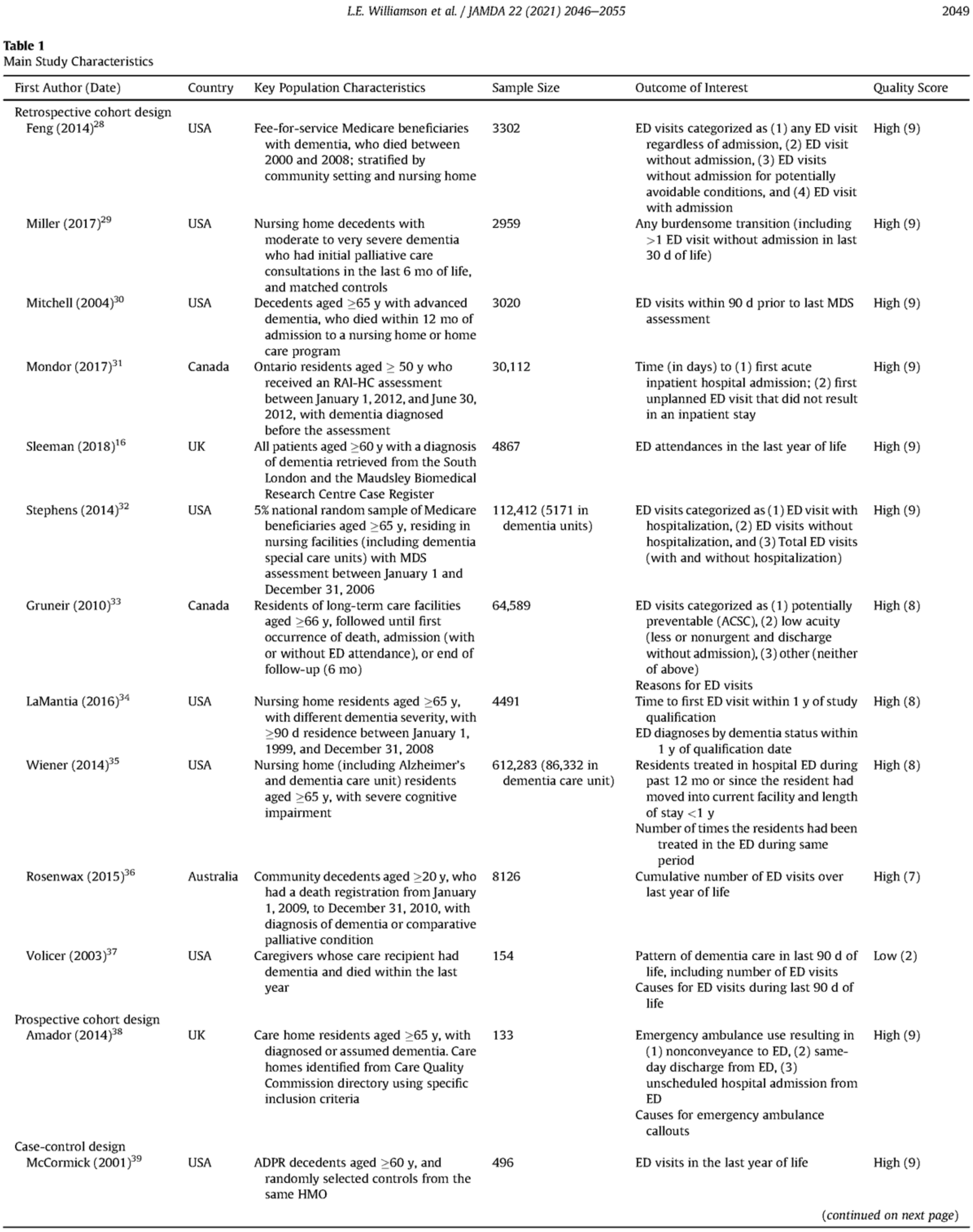

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Table 1
Main Study Characteristics

First Author (Date)	Country	Key Population Characteristics	Sample Size	Outcome of Interest	Quality Score
Retrospective cohort design					
Feng (2014)[28]	USA	Fee-for-service Medicare beneficiaries with dementia, who died between 2000 and 2008; stratified by community setting and nursing home	3302	ED visits categorized as (1) any ED visit regardless of admission, (2) ED visit without admission, (3) ED visits without admission for potentially avoidable conditions, and (4) ED visit with admission	High (9)
Miller (2017)[29]	USA	Nursing home decedents with moderate to very severe dementia who had initial palliative care consultations in the last 6 mo of life, and matched controls	2959	Any burdensome transition (including >1 ED visit without admission in last 30 d of life)	High (9)
Mitchell (2004)[30]	USA	Decedents aged ≥65 y with advanced dementia, who died within 12 mo of admission to a nursing home or home care program	3020	ED visits within 90 d prior to last MDS assessment	High (9)
Mondor (2017)[31]	Canada	Ontario residents aged ≥ 50 y who received an RAI-HC assessment between January 1, 2012, and June 30, 2012, with dementia diagnosed before the assessment	30,112	Time (in days) to (1) first acute inpatient hospital admission; (2) first unplanned ED visit that did not result in an inpatient stay	High (9)
Sleeman (2018)[16]	UK	All patients aged ≥60 y with a diagnosis of dementia retrieved from the South London and the Maudsley Biomedical Research Centre Case Register	4867	ED attendances in the last year of life	High (9)
Stephens (2014)[32]	USA	5% national random sample of Medicare beneficiaries aged ≥65 y, residing in nursing facilities (including dementia special care units) with MDS assessment between January 1 and December 31, 2006	112,412 (5171 in dementia units)	ED visits categorized as (1) ED visit with hospitalization, (2) ED visits without hospitalization, and (3) Total ED visits (with and without hospitalization)	High (9)
Gruneir (2010)[33]	Canada	Residents of long-term care facilities aged ≥66 y, followed until first occurrence of death, admission (with or without ED attendance), or end of follow-up (6 mo)	64,589	ED visits categorized as (1) potentially preventable (ACSC), (2) low acuity (less or nonurgent and discharge without admission), (3) other (neither of above) Reasons for ED visits	High (8)
LaMantia (2016)[34]	USA	Nursing home residents aged ≥65 y, with different dementia severity, with ≥90 d residence between January 1, 1999, and December 31, 2008	4491	Time to first ED visit within 1 y of study qualification ED diagnoses by dementia status within 1 y of qualification date	High (8)
Wiener (2014)[35]	USA	Nursing home (including Alzheimer's and dementia care unit) residents aged ≥65 y, with severe cognitive impairment	612,283 (86,332 in dementia care unit)	Residents treated in hospital ED during past 12 mo or since the resident had moved into current facility and length of stay <1 y Number of times the residents had been treated in the ED during same period	High (8)
Rosenwax (2015)[36]	Australia	Community decedents aged ≥20 y, who had a death registration from January 1, 2009, to December 31, 2010, with diagnosis of dementia or comparative palliative condition	8126	Cumulative number of ED visits over last year of life	High (7)
Volicer (2003)[37]	USA	Caregivers whose care recipient had dementia and died within the last year	154	Pattern of dementia care in last 90 d of life, including number of ED visits Causes for ED visits during last 90 d of life	Low (2)
Prospective cohort design					
Amador (2014)[38]	UK	Care home residents aged ≥65 y, with diagnosed or assumed dementia. Care homes identified from Care Quality Commission directory using specific inclusion criteria	133	Emergency ambulance use resulting in (1) nonconveyance to ED, (2) same-day discharge from ED, (3) unscheduled hospital admission from ED Causes for emergency ambulance callouts	High (9)
Case-control design					
McCormick (2001)[39]	USA	ADPR decedents aged ≥60 y, and randomly selected controls from the same HMO	496	ED visits in the last year of life	High (9)

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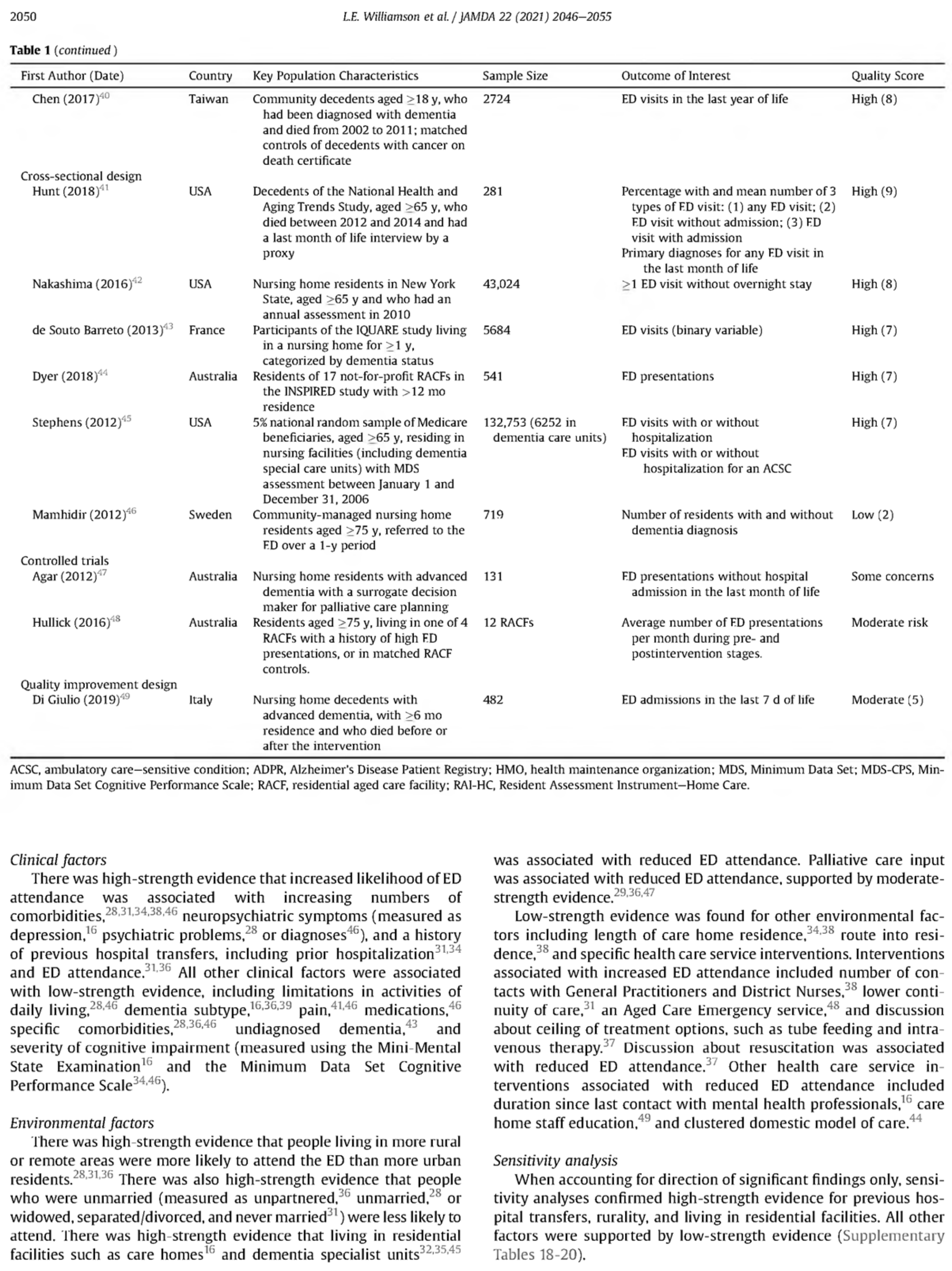

Table 1 (*continued*)

First Author (Date)	Country	Key Population Characteristics	Sample Size	Outcome of Interest	Quality Score
Chen (2017)[40]	Taiwan	Community decedents aged ≥18 y, who had been diagnosed with dementia and died from 2002 to 2011; matched controls of decedents with cancer on death certificate	2724	ED visits in the last year of life	High (8)
Cross-sectional design					
Hunt (2018)[41]	USA	Decedents of the National Health and Aging Trends Study, aged ≥65 y, who died between 2012 and 2014 and had a last month of life interview by a proxy	281	Percentage with and mean number of 3 types of ED visit: (1) any ED visit; (2) ED visit without admission; (3) ED visit with admission Primary diagnoses for any ED visit in the last month of life	High (9)
Nakashima (2016)[42]	USA	Nursing home residents in New York State, aged ≥65 y and who had an annual assessment in 2010	43,024	≥1 ED visit without overnight stay	High (8)
de Souto Barreto (2013)[43]	France	Participants of the IQUARE study living in a nursing home for ≥1 y, categorized by dementia status	5684	ED visits (binary variable)	High (7)
Dyer (2018)[44]	Australia	Residents of 17 not-for-profit RACFs in the INSPIRED study with >12 mo residence	541	ED presentations	High (7)
Stephens (2012)[45]	USA	5% national random sample of Medicare beneficiaries, aged ≥65 y, residing in nursing facilities (including dementia special care units) with MDS assessment between January 1 and December 31, 2006	132,753 (6252 in dementia care units)	ED visits with or without hospitalization ED visits with or without hospitalization for an ACSC	High (7)
Mamhidir (2012)[46]	Sweden	Community-managed nursing home residents aged ≥75 y, referred to the ED over a 1-y period	719	Number of residents with and without dementia diagnosis	Low (2)
Controlled trials					
Agar (2012)[47]	Australia	Nursing home residents with advanced dementia with a surrogate decision maker for palliative care planning	131	ED presentations without hospital admission in the last month of life	Some concerns
Hullick (2016)[48]	Australia	Residents aged ≥75 y, living in one of 4 RACFs with a history of high ED presentations, or in matched RACF controls.	12 RACFs	Average number of ED presentations per month during pre- and postintervention stages.	Moderate risk
Quality improvement design					
Di Giulio (2019)[49]	Italy	Nursing home decedents with advanced dementia, with ≥6 mo residence and who died before or after the intervention	482	ED admissions in the last 7 d of life	Moderate (5)

ACSC, ambulatory care–sensitive condition; ADPR, Alzheimer's Disease Patient Registry; HMO, health maintenance organization; MDS, Minimum Data Set; MDS-CPS, Minimum Data Set Cognitive Performance Scale; RACF, residential aged care facility; RAI-HC, Resident Assessment Instrument–Home Care.

Clinical factors

There was high-strength evidence that increased likelihood of ED attendance was associated with increasing numbers of comorbidities,[28,31,34,38,46] neuropsychiatric symptoms (measured as depression,[16] psychiatric problems,[28] or diagnoses[46]), and a history of previous hospital transfers, including prior hospitalization[31,34] and ED attendance.[31,36] All other clinical factors were associated with low-strength evidence, including limitations in activities of daily living,[28,46] dementia subtype,[16,36,39] pain,[41,46] medications,[46] specific comorbidities,[28,36,46] undiagnosed dementia,[43] and severity of cognitive impairment (measured using the Mini-Mental State Examination[16] and the Minimum Data Set Cognitive Performance Scale[34,46]).

Environmental factors

There was high-strength evidence that people living in more rural or remote areas were more likely to attend the ED than more urban residents.[28,31,36] There was also high-strength evidence that people who were unmarried (measured as unpartnered,[36] unmarried,[28] or widowed, separated/divorced, and never married[31]) were less likely to attend. There was high-strength evidence that living in residential facilities such as care homes[16] and dementia specialist units[32,35,45] was associated with reduced ED attendance. Palliative care input was associated with reduced ED attendance, supported by moderate-strength evidence.[29,36,47]

Low-strength evidence was found for other environmental factors including length of care home residence,[34,38] route into residence,[38] and specific health care service interventions. Interventions associated with increased ED attendance included number of contacts with General Practitioners and District Nurses,[38] lower continuity of care,[31] an Aged Care Emergency service,[48] and discussion about ceiling of treatment options, such as tube feeding and intravenous therapy.[37] Discussion about resuscitation was associated with reduced ED attendance.[37] Other health care service interventions associated with reduced ED attendance included duration since last contact with mental health professionals,[16] care home staff education,[49] and clustered domestic model of care.[44]

Sensitivity analysis

When accounting for direction of significant findings only, sensitivity analyses confirmed high-strength evidence for previous hospital transfers, rurality, and living in residential facilities. All other factors were supported by low-strength evidence (Supplementary Tables 18-20).

Table 2
Common Clinical Reasons for ED Attendance by People With Dementia Near the End of Life

First Author (Date)	Leading 3 Clinical Reasons for ED Presentation		
	1	2	3
Amador (2014)[38] n = 109*	Trauma (43.1%)	Respiratory (11%)	Cardiovascular complaint (9.2%)
Gruneir (2010)[33] n = 14,884†	Fall-related injury (18.7%)	Pneumonia (7.4%)	Kidney or urinary tract infection (4.9%)
Hullick (2016)[48] n = 836‡	Fall (19.8%)	Respiratory (11.3%)	General (11%)
Hunt (2018)[41] n = 281	Septicemia (6.4%)	Cardiac arrest (5%)	Pneumonia and other respiratory disease (4.3%)
LaMantia (2016)[34] n = 3186§	Injury and poisoning (19.4%)	Diseases of the heart (8.7%)	Disease of nervous system and sense organs (7.3%)
LaMantia (2016)[34] n = 338‖	Injury and poisoning (21.9%)	Urinary tract infection (10.7%)	Open wounds (7.7%)
Rosenwax (2015)[36] n = 5261	Shortness of breath (9%)	Lower leg injury (6.7%)	Altered conscious state (5.2%)
Volicer (2003)[37] n = 71	Breathing difficulty (44%)	Infection (31%)	Injury (27%)

*Total ED attendances with and without admission.
†Total ED attendances (potentially preventable, low acuity and other).
‡Control group (beds), where diagnosis was specified.
§Early-moderate dementia, based on 47% of residents who attended ED in 1 year.
‖Advanced dementia, based on 47% of residents who attended ED in 1 year.

Frequency of ED Reattendance and Factors Associated With Repeat ED Attendance

Internationally, no patterns in frequency of ED reattendance were identified because of the small number of relevant studies and context-specific variation. The percentage of people with dementia reattending the ED varied by country and care setting. A population-based study in Taiwan found 36% of community residents reattended more than 3 times in the last year of life.[40] In contrast, only 8% of people residing in US dementia specialist units reattended more than 3 times in 1 year.[32] Among Canadian nursing home residents, 53% reattended the ED within 6 months of an attendance that did not result in hospital admission; however, only 6.4% attended the ED more than twice.[33] By contrast, 24.6% of Canadian home care recipients attended the ED at least 2 times.[31]

Only 2 studies described and measured the influence of different factors on repeat ED attendance. There was therefore low-strength evidence for each factor despite studies being of high quality. One study found fewer repeat ED attendances associated with residence in a dementia specialist unit [incidence density ratio = 0.714 (0.564-0.905), $P < .01$].[35] The second study described a higher proportion of people with unmet pain needs having multiple ED attendances in the last month of life, compared with those without unmet pain needs (26% vs 16%).[41]

Discussion

This systematic review synthesized findings from 23 studies, identifying reasons and factors associated with ED attendance among people with dementia near the end of life. Common clinical reasons for attendance included infection, injury, and respiratory problems. There was high-strength evidence that ethnic minority groups, greater number of comorbidities, neuropsychiatric symptoms, living in more rural areas, and previous hospital transfers were associated with increased ED attendance, whereas higher socioeconomic position, being unmarried, and living residential facilities were associated with reduced ED attendance. There was moderate-strength evidence that being a woman and receiving palliative care were associated with reduced ED attendance. There was only low-strength evidence for factors associated with repeat ED attendance.

Few eligible studies examined the reasons for ED attendance. Where described, most reasons could be considered as ambulatory care–sensitive conditions, such as infection, for which admission may have been averted by access to proactive community care.[50] This correlates with previous literature on hospitalization for people with dementia.[51,52] Only 1 of the studies reported delirium as a reason for attendance.[34] This may reflect the observation that delirium often goes undetected in the ED.[53] Trauma or falls were more commonly reported reasons for ED attendance. Falls and associated injuries are more prevalent among people with dementia than without, leading to hospital admission.[54,55] Polypharmacy and certain classes of medication (such as benzodiazepines and antidepressants) are common causes of falls in people with dementia,[56] who are prescribed significantly more medications than those without dementia, even after adjustment for comorbidity.[9,57] Polypharmacy is also associated with increased risk of hospitalization[10] and ED attendance within 2 years of dementia diagnosis.[12] This review identified only 1 low-quality study that investigated medication type.[46] Given this evidence gap and potential impact of medications on ED attendance, further research is indicated.

There was high-strength evidence that living in more rural areas was associated with increased ED attendance. This reflects research into end-of-life hospitalization in dementia,[14] and ED attendance in other patient groups.[25,26] The review found high-strength evidence that living in a residential facility, such as a care home or dementia specialist unit, was associated with reduced ED attendance.[16,32,35,45] Dementia specialist units were also associated with reduced repeat ED attendances, although only 1 study reported this association.[35] More research is needed to understand the mechanisms underpinning the association between residential facilities and ED attendance, and identify key service characteristics. It was not reported in the studies whether facilities had access to specialist support, which can vary between urban and rural settings.[58] Specialist support, including geriatrician and palliative care input, has been identified in qualitative literature as helping to minimize escalation to hospital.[59,60]

This review found that palliative care input was associated with reduced ED attendance in community[36] and care home settings[29,47]

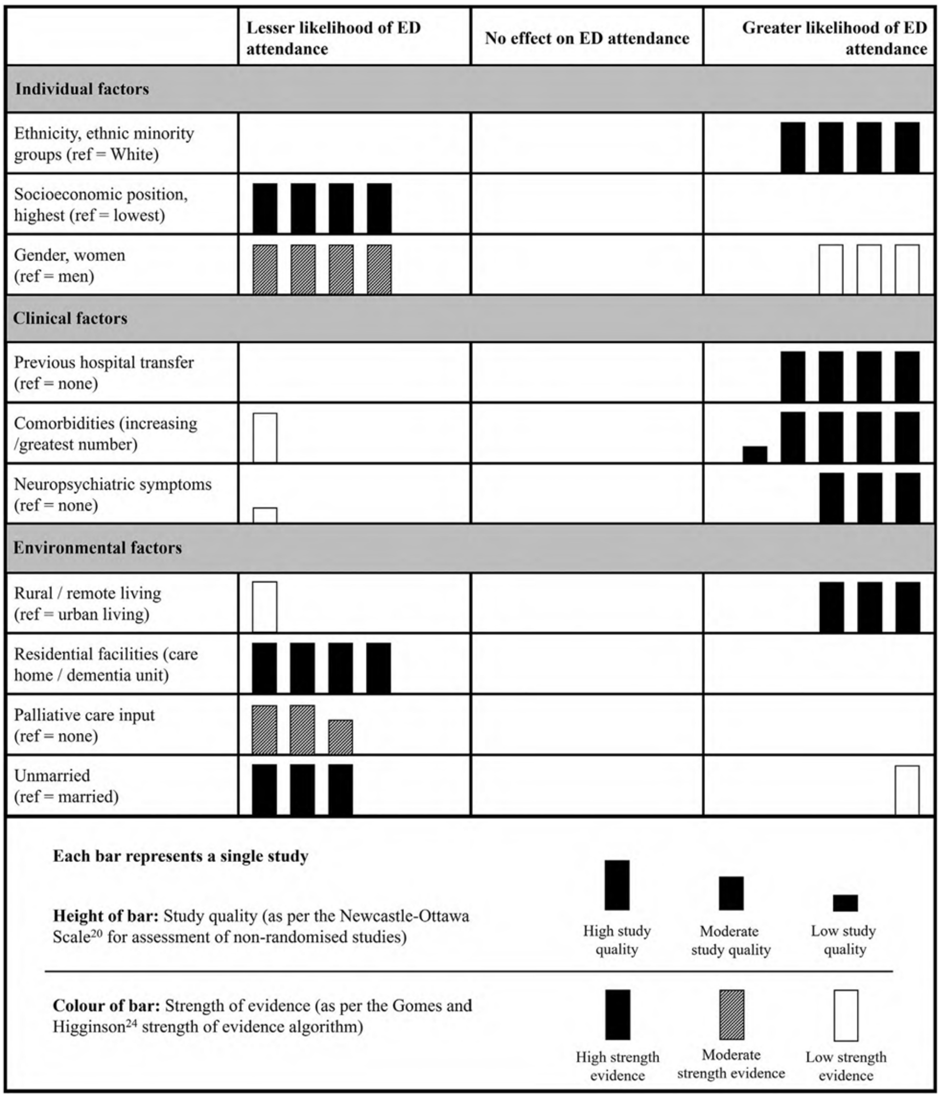

Fig. 2. Harvest plot of moderate- to high-strength evidence for factors associated with ED attendance by people with dementia near the end of life.

and was supported by moderate-strength evidence. In this review, palliative care input included family case conferencing[47] and specialist consultations.[29,36] However, there is also evidence in support of hospice care reducing hospitalizations for people with dementia.[61] Despite variation of palliative care availability and accessibility,[62,63] findings indicate that access to skilled, holistic support may help to reduce ED attendance for people with dementia toward the end of life.

There was high-strength evidence that neuropsychiatric symptoms, including depression, were associated with increased ED attendance.[16,28,46] Although included studies did not specify any other behavioral or psychological concerns, there is complementary evidence of hospitalizations associated with neuropsychiatric symptoms,[11] including depressed mood.[2,7] As well as carer distress,[64] neuropsychiatric symptoms are associated with complications such as falling and treatment noncompliance,[65] which may also precipitate ED attendance. Empirical evidence of effective treatment for depression in dementia is limited,[66] and treatment of other neuropsychiatric symptoms is often ineffective or associated with potentially harmful side effects.[67] There is growing support for person-centered psychosocial management,[67–69] which could be further investigated for impact on ED attendance toward the end of life. Overall, more research is needed to unpick the relationship between ED attendance and neuropsychiatric symptoms to provide clearer direction for clinical intervention.

Marital status was the only social support factor identified in this review.[28,31,36] It was often dichotomized,[28,36] precluding analysis into

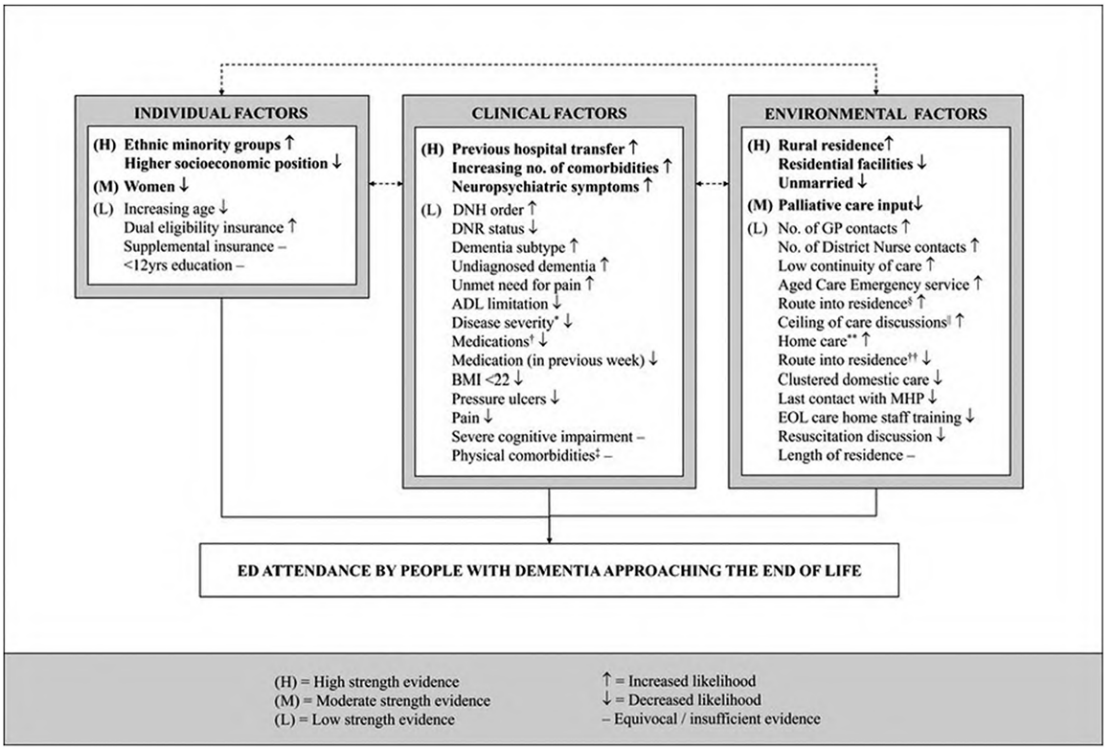

Fig. 3. Model of factors associated with ED attendance by people with dementia nearing the end of life, based on direction of effect for low-, moderate-, and high-strength evidence. Individual, clinical, and environmental factors related to emergency department (ED) attendance by people with dementia nearing the end of life. ACE, aged care emergency service; ADL, activities of daily living; DNH, do not hospitalize; DNR, do not resuscitate; EOL, end of life; GP, general practitioner; MHP, mental health professional. *Changes in Health, End-Stage Disease, Signs, and Symptoms Scale (CHESS) low, moderate, or high instability. †Neuroleptics, sedatives, antidepressants, hypnotics, and analgesia. ‡Heart and lung problems, cancer, diabetes, stroke, arthritis, hypertension, peptic ulcer disease, and poor self-rated health. §Sheltered accommodation or warden controlled. ‖Intensive care unit care, ventilation, hospital transfer, tube feeding, intravenous therapy, or antibiotics. **Compared to nursing homes. ††Relative's home/hospital/other care home.

the impact of different civil states on ED attendance. This highlights a need for better routine data collection and focused research into social support and carer-related factors. Qualitative literature shows that carers experience uncertainty in responding to changes in their relatives with dementia,[70,71] and a lack of support and limited information, which contributes to ED attendance.[71] Carers have also raised concerns over the suitability of the ED environment[72] and hospital staff competency to provide dementia-specific care.[73] However, it is unknown if these views influence ED attendance toward the end of life. Further qualitative inquiry of primary carers is thus indicated, particularly as carer strain is a recognized factor associated with hospitalization of people with dementia[6] and increases toward the end of life.[74]

Strengths and Limitations

This is the first systematic review of the literature investigating factors associated with ED attendance by people with dementia near the end of life. The review has several strengths. It was undertaken with a strong theoretical foundation, using a model previously used in reviews examining different patient cohorts.[25,26] Tight eligibility criteria were adopted wherein studies measuring "emergency admission," for example, were omitted because emergency admissions into hospital can by-pass the ED. This increased the construct validity of eligibility criteria that were applied to studies without limitation of time, language, or measures. There was also no limitation of country; however, most studies were from North America, with only 1 from Asia. This limits the generalizability of findings, as differences in cultural preferences and service structure may influence patterns of ED attendance.

Only one-quarter of full-text papers were double-screened, and data extraction was completed by 1 author. However, all extracted data were double checked to promote accuracy. The review was further limited by the impracticality of conducting a meta-analysis. Given the variation in statistical reporting, vote counting was used as the synthesis method based on the direction of effect.[27] This method does not accommodate differences in the size of studies or magnitude of effects.[75] A sensitivity analysis of statistically significant results confirmed findings, with strength of evidence reduced for some factors.

Conclusions and Implications

This review is the first to aggregate the evidence on common precipitants and factors associated with ED attendance by people with dementia nearing the end of life. The findings highlight several characteristics that may help identify patients most at risk of ED attendance near the end of life, including individuals from ethnic

minority groups, of lower socioeconomic position, from more rural communities, and those with multimorbidity. These findings may provide direction for further investigation and targeted support. Potentially modifiable factors include residential care and palliative care, implying that access to skilled community support may help people with dementia stay in their usual place of care toward the end of life. These findings provide a focus for more qualitative inquiries and intervention studies to inform service planning and clinical practice.

Limited evidence was found for factors relating to reattendance, despite strong evidence that previous hospital transfers increase the likelihood of ED attendance. With known risks associated with ED attendance for people with dementia, better understanding of why it increases toward the end of life is needed.

Acknowledgments

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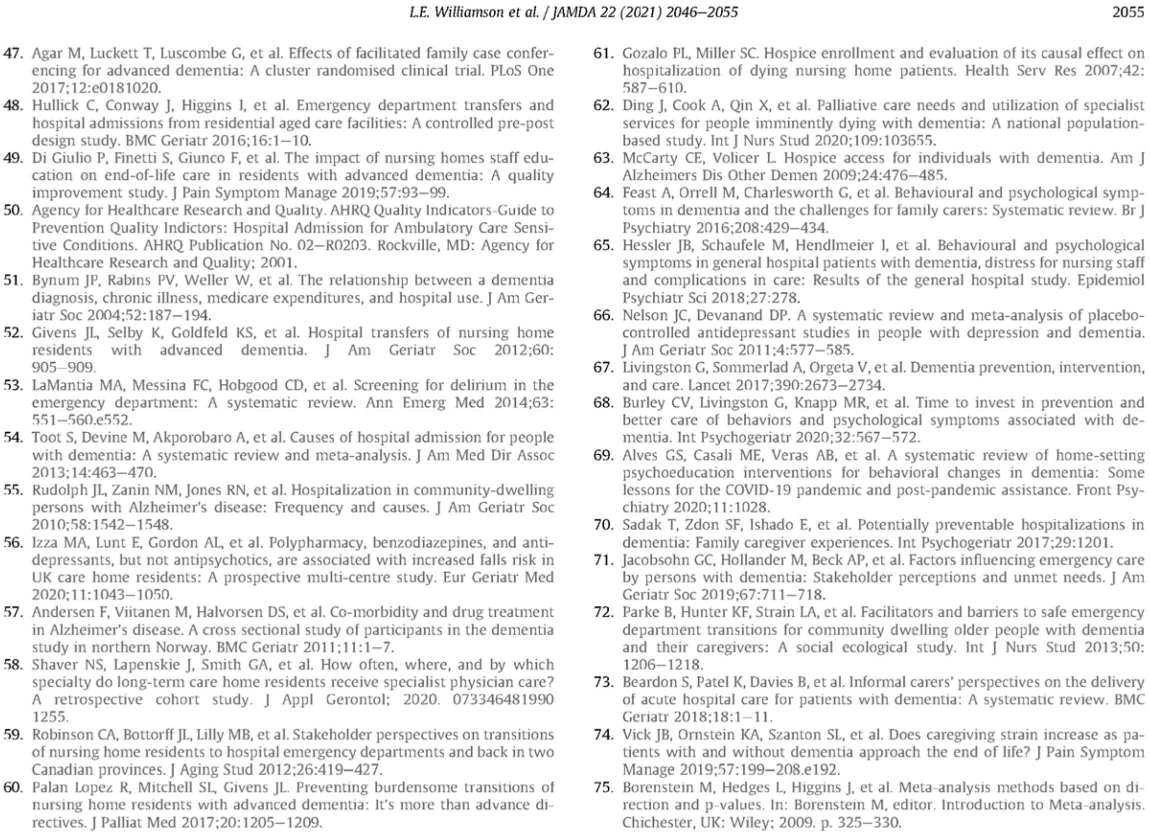

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2.6 Evidence gaps and thesis rationale

Findings from the systematic review suggest that people from minoritised ethnic groups, more comorbidities, or living in rural settings were associated with increased ED attendance towards the end of life. Having higher socioeconomic position, living in a care home, or receiving palliative care input were associated with reduced ED attendance. The systematic review concluded that timely access to skilled community support may help people with dementia to stay in their usual place of care.

The review highlighted a striking shortage of evidence from the UK. While it is expected that some factors will remain the same irrespective of setting, the health and social care system in the UK is funded and structured differently to other countries around the world. As discussed in Chapter 2.4, there have been recent changes and more expected in the UK policy context of dementia and end-of-life care. To inform the development of policies, practice, and future interventional research, it is essential to understand the determinants of ED attendance in context. This can help to identify what may mitigate the need for ED attendance and how it could be used to best support the people who are most likely to attend towards the end of life.

The review found that people from minoritised ethnic groups were more likely to attend the ED. While racial inequality in accessing end-of-life care is rife within the UK,[80] minoritised ethnic groups are heterogeneous and it remains unclear which groups, specifically, are more likely to attend and why. Understanding this is essential to inform policy and tailor services to meet needs of individuals from different minoritised ethnic groups. Similarly, the review found that people with higher socioeconomic position were less likely to attend the ED towards the end of life. Socioeconomic deprivation is known to vary across the country and is reflected in differences in quality of healthcare and patient outcomes.[81] Closer examination of the influence of socioeconomic position and geographic location is therefore needed to inform policy development.

The review found that people in rural settings were more likely to attend the ED. This contradicts UK-based literature in related areas of research,[4] prompting the need for further investigation. Rural areas in England have more residents over the age of 65yrs than urban areas (25.4 vs. 17.1%), who are more likely to reside in sparse settings.[82] This trend is similar in most devolved nations.[83, 84] A systematic review of literature identified low uptake of formal support in rural areas among people with dementia.[85] However, qualitative inquiry into people with dementia living in remote and rural Scotland show a reliance on strong small social networks, including more informal relationships with healthcare workers.[86] As dementia prevalence is greater among older than younger adults, it is important to understand how rurality influences ED attendance in the UK, and if this differs for younger people with dementia who require access to different services.

According to the systematic review, comorbidities are associated with more ED attendances towards the end of life. This suggests that there are opportunities for improved planning and management of chronic conditions. This is challenging for people with advancing dementia as their capacity to follow self-management strategies may be limited and would require support to be adapted to reflect individual need.[87] Identifying which comorbidities influence the likelihood of attending the ED may help to focus clinical efforts in advance care planning and symptom management towards the end of life.

Finally, while care homes were identified as protective in the systematic review, it is unclear in what ways they offer protection. With multiple closures of care homes and evidence of nursing homes relinquishing clinical registration due to workforce shortages,[88] there is an absolute need to understand the influence of care homes on ED attendance among people with dementia approaching the end of life. This will give insight into why investment in care homes may be needed, how it can inform new models of practice, and what, if any, features can be transferred to home care to ensure equitable access to end-of-life care for people with dementia.

2.7 End of chapter summary

There is urgent need for evidence-informed policy to safely reduce ED attendance among people living with dementia in the UK who are approaching the end of life. The systematic review highlighted gaps in the evidence needed to meet this need. This thesis will help to fill these gaps, based on the aim and objectives outlined in the next chapter.

3 AIM AND OBJECTIVES

3.1 Aim

To conceptualise the determinants of emergency department attendance among people with dementia approaching the end of life.

3.2 Objectives

(1) To explore the drivers of emergency department attendance among people with dementia across the illness trajectory.

(2) To examine individual- and service-level factors associated with emergency department attendance among people with dementia in their last year of life.

(3) To develop a conceptual model of emergency department attendance among people with dementia towards the end of life.

4 METHODOLOGICAL CONSIDERATIONS

Based on the aim and objectives outlined in the previous chapter, this thesis comprises mixed methods research using the pragmatist approach, applying the PRECEDE component of the PRECEDE-PROCEED Model (PPM) of health programme planning.[89] Integral to this component is community engagement, which was implemented throughout the development of this thesis. In line with the pragmatist approach, methodological considerations are discussed in this chapter to enable the research community to appreciate the context of this research.[90]

4.1 Paradigms and ontological, epistemological, and axiological stances

As there are many definitions of 'paradigm', it is useful to define it for use in this thesis. The concept of paradigm has been used to refer to the ontological and epistemological assumptions, as well as a shared research practice within the research community.[91] Later uses of the concept range from 'organising worldviews',[92] to 'mental models',[93] and heuristics or tools.[94, 95] While these definitions are considered 'weak' by some,[96] and potentially marginalising,[97] others have argued that as a framework, paradigms can be valuable in guiding researchers and grounding research.[98] On this basis, the thesis accepts the definition of paradigm aligned to a guiding framework of shared beliefs and practices. It assumes that ontology refers to the nature of existence, epistemology to the nature of knowledge, and axiology to the nature of value.

4.1.1 Mixed methods approach

Paradigmatic differences have frequently been used to distinguish between quantitative (positivist) and qualitative (interpretivist) research,[96] with mixed methods research representing a 'third paradigm'.[99] The purpose of conducting research within the third paradigm ultimately depends on the research question.[100] The question underpinning this research centres around conceptualising the determinants of ED attendance to better understand how we can safely reduce ED attendances among people with dementia approaching the end of life. Using a quantitative approach to underpin the thesis would limit the research to measuring associations between different immutable factors and ED attendance towards the end of life. While this would provide insight into the characteristics of people most at risk of attending the ED and identify potentially modifiable factors, the conceptualisation of ED attendance would fail to include *why* people with dementia attend the ED. Using a qualitative approach to underpin the thesis would limit the research to exploring experiences of attending the ED among individuals affected by dementia. While this would provide insight into why some people attend the ED, the conceptualisation of ED attendance would fail to include *who* is most likely to attend or *what* is most likely to mitigate attendance. Using a mixed methods approach to underpin the thesis would afford opportunity to use inferences from both quantitative and qualitative approaches, complementarily, to conceptualise ED attendance in a more comprehensive and practically useful way.

4.1.2 Pragmatist approach

Debates around compatibility between quantitative and qualitative research have posed challenges for mixed methods researchers.[101] Some strongly argue that quantitative and qualitative paradigms are polar opposites and thus incompatible.[96] This assumption was at the root of the so-called 'paradigm wars',[102] while other perspectives,[98] or 'meta-paradigms', have been established, such as pragmatism, dialectical pluralism and critical realism. As it is more productive to judge the rationale for using a specific approach rather than argue for the superiority of a single approach,[98] the justification of using pragmatism is discussed below.

This thesis uses the pragmatist approach, which focuses on human experience and gives priority to the purpose of research as social inquiry.[90] Through the cyclical interaction between belief and action, where actions inform beliefs and beliefs inform actions, human experience creates meaning that is grounded within contextual, emotional, and social influence.[90] Therefore, when a situation is interpreted as problematic, it prompts a process of inquiry which cycles between belief and action until there is satisfaction of a resolution.[90] This process underlies a search for knowledge and extends to the process of conducting research.[90] Although described as a sort of ontological experientialism and epistemological instrumentalism,[103] instead of framing research by metaphysical beliefs, the pragmatist approach frames research by beliefs that are directly linked to action.

The pragmatist approach has been considered the best approach to justify using mixed methods.[104, 105] The main source behind its popularity is the opinion that it focuses on 'whatever works' and disregards metaphysical considerations.[90, 106] This crude reduction to practicality fails to consider the 'why' questions,[90, 107] and is often a major criticism of pragmatism. However, the notion that pragmatism is value deficient removes it from its philosophical context, and is arguably a 'caricature' of the approach,[90, 107] which conflates pragmatism with expedience.[91, 108] Pragmatism is explicitly value-orientated,[99] and does not dismiss the relevance of metaphysical paradigms but rather rebuffs the top-down authority of ontology.[109] It prioritises the research question and represents different paradigms as ‘two sides of the same coin’.[90] Therefore, pragmatism provides a framework for qualitative and quantitative research as complementary social actions rather than competing metaphysical traits,[98] which is the premise used in this thesis.

The pragmatist approach is inherently context-dependent since knowledge and action are inseparable, and action and the context in which it occurs are inseparable.[90] This context dependency makes all reasoning fallible and probabilistic, as changes in context will alter the definition of a problem and the most suitable means to overcome it. Therefore, pragmatism seeks warranted assertions to orientate action and does this through the process of inquiry with ‘ends-in-view’.[103] This generates a means for directing action while acknowledging that knowledge will always be updated as circumstances change.[103] This appreciation of change and uncertainty makes it well suited to researching social complexity,[110, 111] healthcare,[112] and policy development,[111, 113] which is directly relevant to the thesis.

From the pragmatist stance, researchers’ experiences and expectations of research are emotionally- and socially-bound, as well as being context-dependent, and are thus considered to be politically and ethically orientated.[90] Pragmatism is therefore intuitively tied to social justice research on issues of equity, equality, and emancipation,[114] with a goal of developing knowledge that is extrinsically useful.[115] These axiological tenets are directly applicable to this thesis, which is not only driven by a moral commitment to improve end-of-life care for people with dementia but also to provide findings with impact and utility beyond academia.

For these reasons, the thesis was conducted within the pragmatist approach. Other approaches were considered, which are worthy of brief mention. The meta-paradigm, dialectical pluralism, is an approach used to hold multiple paradigms in a single study.[93] However, the approach is often used by a team of researchers and relies on proficiency of (Gestalt) switching between paradigms,[116] which is unsuited to the novice researcher. Critical realism assumes compatibility between mixed methods, with each strand representing an alternative perspective contributing to an approximation of a mind-independent reality.[117] While it avoids the need for paradigmatic switching, it requires separating methods from their meta-theoretical base to align them to critical realist philosophy.[118] This can be challenging,[119] and was considered unjustified without obvious philosophical need to apply critical realist tenets to the thesis. Finally, the transformative-emancipatory approach places central focus on social inquiry into marginalised groups,[120] which would apply to research into dementia care. It assumes an embedded active community approach. While community engagement was a valuable tool used to inform this thesis, co-production was not within the theoretical or economic scope of the thesis.

4.2 PRECEDE-PROCEED Model (PPM)

Within the pragmatist approach, this thesis applies the popular logic model used to guide health programme planning and evaluations, the PRECEDE-PROCEED Model (PPM).[121] This model provides a structure to organise different factors and inform the development of targeted interventions for social, behavioural, and environmental change.[122] The PPM comprises eight interdependent phases, separated by two components that start with defining the end-goal and working backwards to achieve it (Figure 4.1). The PRECEDE (Predisposing, Reinforcing and Enabling Constructs in Educational/Economic Diagnosis and Evaluation) component involves assessing the public health concern and identifying targets for change. The PROCEED (Policy, Regulatory, and Organizational Constructs in Educational and Environmental Development) component implements and evaluates the intervention against these objectives. Overall, the model helps to prioritise a problem, analyse and respond to the associated need, and provides a catalyst for change.[123] The PPM therefore serves as an agenda for action.

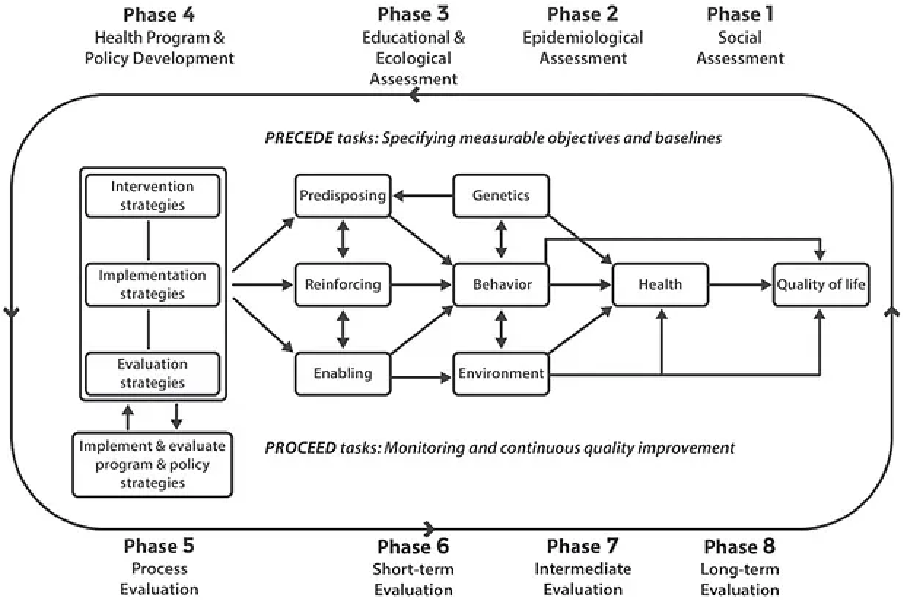


Figure 4.1 The PRECEDE-PROCEED Model (reprinted with permission of The Johns Hopkins University Press)[124]
PRECEDE component: phases 1-4; PROCEED component: phases 5-8.

4.2.1 Mapping the thesis against the PPM

Using a health planning model to frame the thesis was useful not only to advance theoretical understanding and generate further research avenues, but also to provide scope for practical application. The thesis is orientated around conceptualising determinants of ED attendance to inform policy, practice, and research suggestions for improvement, which closely aligns to the PRECEDE component of the PPM. The phases comprising this component are detailed in Table 4.1. With each completed phase of the PRECEDE component, targets for change are prioritised and elements of an intervention are identified to implement and evaluate as part of the PROCEED component. Therefore, as well as conceptualising the determinants of ED attendance among people with dementia approaching the end of life, this thesis will simultaneously lay the groundwork for future interventional research intended to safely reduce ED attendances among people with dementia approaching the end of life.

Table 4.1 Phases of the PRECEDE component
Adapted from the PRECEDE-PROCEED Model

PRECEDE phase	*Description*
Social assessment	Identify desirable outcome and subjective concerns regarding the health issue; assess readiness for change.
Epidemiological assessment	Identify (proximal, interpersonal, and distal) behaviour and (direct/indirect) environmental factors most likely to affect the health issue; identify and prioritise targets for change.
Educational and ecological assessment	Identify predisposing, reinforcing, and enabling factors influencing behaviours and environmental conditions identified in previous phases; identify and prioritise targets for change.
Health programme and policy development	Identify administrative and policy factors that may influence what can be implemented.

There are other planning models available, such as the Multilevel Approach To Community Health (MATCH) or consumer-based planning models.[125] However, these models emphasise programme implementation and business models, respectively, which do not align to the scope of the study nor context of UK healthcare. Furthermore, the PPM has been applied in over 1,200 published papers,[126] and is viewed to be one of the most useful planning models for research and practice.[127] Although resource-intensive,[126] the model can assist in the efforts to remedy a problem affecting a particular population.[128] It maintains a strong policy focus, central socio-ecological assumption and commitment to participation, which align to the scope of this thesis. All these characteristics underpin the design of the model to find common ground between the public, health scientists, professionals, and policy makers, bringing their worldviews into closer alignment,[122] which improves research impact potential.

Described as a "leading force" in socio-ecological and participatory approaches to health programme planning,[126] (p.754) the PPM works from the view that there are multifactorial determinants of health. Each phase of the PRECEDE component is an interdependent part of an ecological planning system,[122] guiding users through different layers of the system from the individual to the socio-political. Each phase builds a comprehensive needs analysis and informs priority targets for intervention. Understanding the influence of behaviour and social context is also afforded by the PPM's focus on participation of stakeholders.[122] Its design helps to maintain focus on the community's desired outcome, what they most value in a particular situation and how it lies in the context of their lives (provisionally labelled 'quality-of-life' in the PPM, although this is conceptually different to quality-of-life as a construct).[89] Therefore, the goal of the PPM is to develop a programme that promotes a health-related status by focusing on its day-to-day value as determined by the community.[89] This is particularly important, as research priorities are known to differ between researchers and people with dementia,[129] and there are growing calls for people with dementia to be 'in the driving seat' of dementia research.[130]

The model has been criticised for theoretical agonism,[131] although it has been noted for its capacity to guide the application of the most appropriate theoretical models for each phase of the inquiry.[128] Therefore, the model is a means of uniting different theories, as well as ethical principles,[126] and arguably has an extensive theoretical basis.[132] This theoretical flexibility allows the model to maintain its epidemiological focus, without discounting the influence of human agency.[126] It therefore has capacity to accommodate different theoretical applications to different levels of influence on health and wellbeing, from the individual to the socio-political, resulting in a tailored public health initiative.[126] This is conceptually coherent with a mixed methods design and aligns to the phenomenon of interest in this thesis.

The PPM has only once been applied to the topic of dementia, focusing on public education.[133] The PPM has not yet been applied to improving end-of-life care, despite international effort to incorporate a public health approach to end-of-life care.[134] Through the novel use of the PRECEDE component of the PPM, this thesis offers an original contribution to the field of end-of-life care for people with dementia. Mapped against the four phases of the PRECEDE component (Figure 4.2), the 'social assessment' phase comprises a qualitative study addressing objective one of this study. The ‘epidemiological assessment’ phase comprises a quantitative study addressing objective two. These two phases were conducted in parallel for complementarity to maximise the needs assessment. The ‘educational and ecological assessment’ phase comprised the integration of findings from the social and epidemiological assessments, addressing objective three. The ‘policy and intervention development’ is the thread that runs throughout this thesis, linking all preceding phases.

As the model should be adapted to suit the needs of populations and phenomena of study,[89] the PPM was altered for this thesis (Figure 4.2). In the social assessment, ‘quality-of-life’ was updated with the health-related issue of ED attendance among people with dementia approaching the end of life. As genetics were not deemed relevant, this was removed from the epidemiological assessment, and is consistent with several other applications of the PPM in the literature.[135] To coincide with end-of-life literature on individual- and service-related factors (Chapter 9.1), these were used to replace behavioural and environmental targets for change in the epidemiological assessment. Both the social and epidemiological assessments informed the health targets for change.

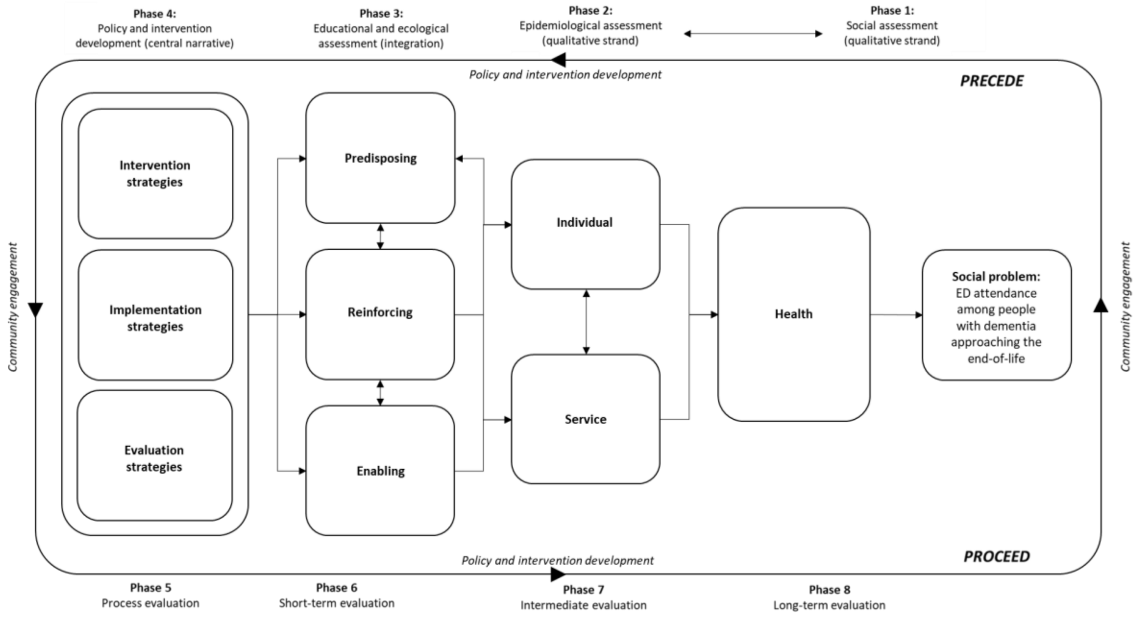


Figure 4.2 Application of the PRECEDE component

Applied to ED attendance among people with dementia approaching the end of life.

4.3 Community engagement

Community engagement was central to this thesis. Aside from cohering to pragmatist concepts of collective inquiry, democratic decision-making and pursuit of social justice,[136] community engagement is also a core priority of the PRECEDE component of the PPM. The PPM assumes the community is the "centre of gravity" for population health programmes, ensuring programme relevance, acceptability, and longevity.[89 (p.856)] Literature shows that nurturing authentic, trusting relationships with community stakeholders can increase research impact in the real-world.[137, 138] Furthermore, research has shown that engaging with people with dementia and family caregivers in research development fosters empowerment and satisfies a desire for change.[139, 140] Therefore, there was strong methodological, theoretical, and moral justification to embed community engagement into the thesis.

4.3.1 Community engagement strategy

The thesis had several engagement touchpoints that corresponded with thesis milestones. It was important that the first touchpoint was from the outset to ascertain what aspects of ED attendance among people with dementia towards the end of life were most important to the community. This involved a 'Dragons' Den' research pitch to the Cicely Saunders Institute (CSI) Patient and Public Involvement (PPI) group, with follow-up discussions using the online PPI forum, and discussions with individual members by telephone and email. This cumulated in a co-produced diagram listing aspects of the phenomenon that were considered most important (Appendix B1). This served as the starting point for the thesis and the basis for selecting variables for the epidemiological assessment and developing the interview schedule for the social assessment.

An expert panel of public representatives was later established with the financial support of the King's Centre for Doctoral Studies Public Engagement Small Grants fund. The overall aim of the expert panel was to create a guiding coalition of people affected by dementia to ensure study findings were interpreted in context, and that recommendations for improvement were grounded in the realities of living with dementia. Advertisements for public representatives were circulated using the Dementia Engagement and Empowerment Project (DEEP) and Alzheimer's Society Research Network (ASRN). Thirteen people responded. The first three people with dementia and first three people with experience of supporting a relative with dementia joined the panel. Each representative was provided with a copy of a public representative role description.

The expert panel took part in three online meetings. Meeting one (August 2022) involved formally introducing the project and each other and discussing the findings of epidemiological assessment. Meeting two (October 2022) involved discussing the findings of social assessment. Meeting three (held twice to optimise attendance; December 2022) involved discussing findings of the educational and ecological assessment. These discussions assisted in the interpretation of findings and how they related to the bigger picture of ED attendance towards the end of life among people with dementia. Discussions also informed priorities for change, which shaped further development of the PPM, and recommendations for future research, clinical practice, and policy.

To facilitate meaningful engagement, public representatives were sent a one-page written summary of study findings, presentation slides and a meeting agenda at least one week in advance. Meetings included a brief presentation, followed by a discussion about the meanings and implications of the study findings. The third meeting also included a review of an impact log, demonstrating how public representatives' contributions had influenced the research (Appendix B2). With consent, each meeting was recorded to optimise focus on discussions, ensuring each representative had opportunity to contribute, and to improve the accuracy of meeting notes. Public representatives were emailed a copy of the notes (Appendix B3) and invited to feedback if and how meetings could be improved. Public representatives were reimbursed for their time, contributions, and internet usage in accordance with National Institute of Health and Care Research (NIHR) guidance.[141]

A final evaluation was undertaken with public representatives, including a brief survey and follow-up meeting to discuss experiences and reflections of taking part in the expert panel. Public representatives were offered opportunity to document their reflections for wide dissemination. They opted to do this as a poster, inviting the PhD Fellow to add a reflection and project details (Appendix B4). A report for the Centre of Doctoral Studies and a reflective summary was written to evaluate the extent to which the aim of the panel was met and explore lessons learned (Appendix B5). The summary was informed by Guidance for Reporting Involvement of Patients and the Public (GRIPP-2) short form.[142]

4.4 End of chapter summary

Based on the aims and scope of the thesis and review of extant theory and literature, this thesis comprises mixed methods research using a pragmatist approach. Mapped against the PRECEDE component of the PRECEDE-PROCEED Model, the research was aligned to social, epidemiological, and education and ecological assessments that were informed by community engagement and applied to policy and practice. With critical consideration of methodological integrity, the following method chapters will describe the development of each assessment, starting with the social assessment.

5 METHOD 1: SOCIAL ASSESSMENT

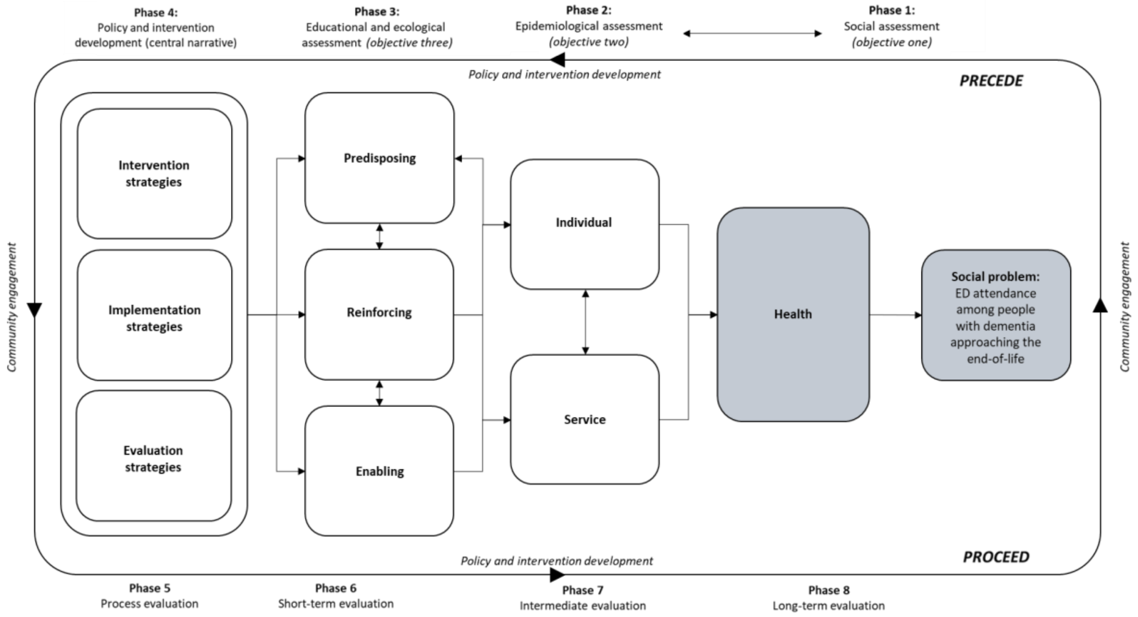


Figure 5.1 Social assessment (phase 1, in parallel with phase 2)
Objective one, to explore the drivers of emergency department attendance among people with dementia across the illness trajectory.

The social assessment is the first phase of the PRECEDE component of the PRECEDE-PROCEED Model (PPM), completed in parallel with the second phase, and meets objective 1 (Figure 5.1). The PPM advocates a needs analysis to identify and assess areas for action.[89] It involves exploration of community-defined priorities and values, and understanding the context within which they sit.[143] This chapter details the methodological and design considerations of the social assessment.

5.1 Methodological considerations

The aim of the social assessment was to explore the drivers of ED attendance among people with dementia and, in doing so, the perceptions of ED attendance. Qualitative research permits in-depth exploration of situated and contextualised influences, system-wide complexity,[144] and aspects of healthcare that are irreducible to operationalised variables.[145] The focus on context, thickness of description and emergent design also makes qualitative research compelling for policy-makers.[146] Based on these qualities, a qualitative design was favoured to meet the first objective of the thesis and complement the findings of the epidemiology assessment.

5.1.1 Critical realist approach

A critical realist approach was used, based on the aim and scope of the social assessment. Critical realism is a single paradigm of ontological realism and epistemic relativism, and therefore assumes that while there is an independent reality, its understanding is mediated by individual cultural, social and political influences.[147] It suggests that there are ‘structures, mechanisms and causal powers’ in reality, which can be explained but not always observed.[148] This situates ED attendance in several related ‘laminates’ of a stratified system, from clinical to psychosocial to sociocultural. By contrast, research with positivist ontology and epistemology adopts a reductionist approach that focuses on actual events, which may miss these deep causal relations.[149] As the aim of the social assessment is to explore the driving forces of ED attendance rather than reducible associated factors, it was considered more appropriate to use an approach that highlights the multiplicity and complexity of social reality.[150]

Since the PRECEDE component of the PPM is used to diagnose a problem, the social assessment requires an approach that will seek to explain the mechanisms underpinning the phenomenon, transferable beyond the uniqueness of the research setting. While constructivist research with its relativist ontology and subjectivist epistemology can accommodate complexity,[151] it focuses on making sense of others’ social realities that are situated in unique contexts.[152] Using this approach would therefore raise questions about the relevance of findings on which to act and base policy decisions.[153] By contrast, findings of critical realist research reflect the researcher’s current understanding of the relationship between the mechanisms observed and the contexts in which they operate.[154] Therefore, it provides theoretical generalisations to inform policy recommendations to address social problems.[155] This is another reason why the critical realist approach was considered conceptually coherent to the social assessment and was thus used as the theoretical lens.

5.2 Conceptual models of degree-of-fit and candidacy

The Penchansky and Thomas degree-of-fit model and Dixon-Woods *et al.* candidacy model informed the design and interpretation of the social assessment.[156, 157] These models encompassed the individual and wider context without restricting the design and analysis of the social assessment.

The degree-of-fit model by Penchansky and Thomas comprises five dimensions of access based on service characteristics: Acceptability (relationship between patient's preference and expectations and actual service delivery); Accessibility (relationship between location of healthcare and location of patient); Accommodation (relationship between organisation of services and patient need); Affordability (relationship between cost and patient's ability to pay); and Availability (relationship between service supply and patient demand).[156] Although these dimensions are interconnected, the model assumes that they are independent and warrant individual assessment to determine access.[156] The model focuses on components of access rather than determinants of access and is therefore less complex than other models (i.e. behavioural model[158]), without compromising the service-level approach.

Although the model's domains are based on service characteristics only, it can be used to guide patient-centred care as the model focuses on the degree of compatibility between the patient and characteristics of the healthcare service (including its workforce). It is also not confined to discrete episodes of illness, unlike other models (i.e. patient-centred model[159]). The Penchansky and Thomas model has been applied to research understanding socio-economic differences in access to palliative and end of life care,[160] and emergency and acute care.[161] Furthermore, a sixth dimension, Awareness (of services, including communication and information), was added by Saurman et al.,[162] and has been incorporated in subsequent research, including access to palliative care.[163] Given its focus on the interaction between the person and the health and social care system, and its simplicity and ease of application, it was considered useful to inform the development of the interview schedule.

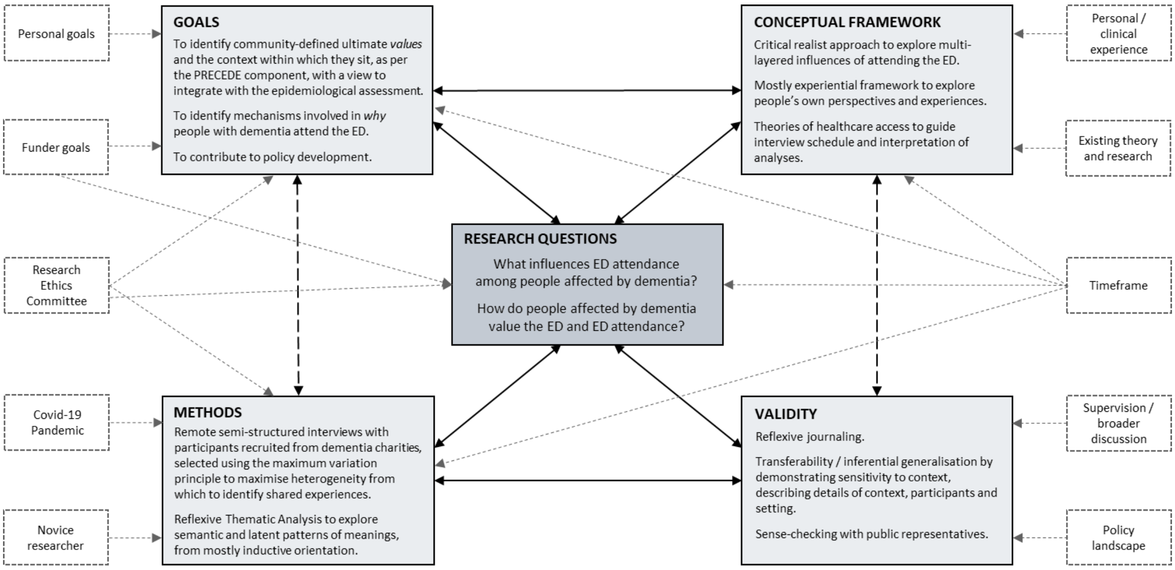
The candidacy model by Dixon-Woods *et al.* was based on the development of critical interpretive synthesis of literature on access to healthcare by socioeconomically deprived people.[157] In this model, candidacy refers to eligibility to access healthcare, which is negotiated through interactions between patients and providers, subject to the interplay of individual, social and environmental processes.[157] The model comprises synthetic constructs and second-order constructs to generate a process of identification of candidacy, navigation, the permeability of services, appearance at health services, adjudications, offers and resistance, with local influences from operating conditions and local production of candidacy.[157] The model has been used to frame data and interpret findings from several studies focusing on inequality of healthcare access. This includes research on people from ethnic minority groups,[164] older adults living in rural areas,[165] people attending the ED for primary care complaints,[166] and people seeking dementia diagnosis.[167, 168] The model also has explanatory value in research exploring how patients with long-term conditions choose between healthcare options in a health crisis, where concepts of candidacy and recursivity (influence of past experience) play an interactive role.[169]

The model has notable limitations including the premise that candidacy is negotiated, which minimises the power dynamics that shape healthcare interactions.[170] Furthermore, candidacy is considered to be mediated through public discourses around deservedness and fairness,[170, 171] and the sociocultural status attributed to specific diseases,[172] which are not easily reflected in the model. However, the model withstands development, which has included an extension of illness identity, where candidacy and access are influenced by the sociocultural representation of illnesses.[172] Research has also built on the extended model by specifying the wider contextual conditions that affect access to transport services for people with dementia, including budgetary cuts, local organisational and commissioning frameworks, and dominant disease-led services that negate person-centred care.[173] Based on the model's focus of interaction and its flexibility to extend to meso- and macro-level influences, it was considered to have strong explanatory value in the interpretation of findings from the social assessment.

There were several other models relevant to the focus of the social assessment but not applied. The behavioural model of healthcare service use is most prominent in the literature and comprises three core determinants: predisposing, enabling and need factors.[158] It has been applied to research into ED attendance at the end of life,[174] and dementia care,[175] but it conflates service use with access and reduces service use to three determinants, which may limit analyses. Unlike the behavioural model, the patient-centred model of access considers the interaction between supply and demand,[159] and has been applied to research into access to palliative and hospice care.[176] While involvement of the patient and system is a strength of this model, others argue for greater focus on service workforce.[177] The model also fails to capture the lack of integration between services, which is relevant to people with more chronic conditions.[178] Although not a model of access, the Stress Process Model for Individuals with Dementia was also applicable to the social assessment.[179] It has been successfully applied to the study of ED attendance among veterans with dementia.[180] The focus on the individual level is an advantage of this model, but it does not easily accommodate different sociodemographic characteristics that are associated with ED attendance, nor the interaction of the individual and wider care system. Overall, these models were unsuited to the scope and aim of the social assessment and therefore were not used.

5.3 Design considerations

Qualitative research does not have the well-delineated types of designs that are used in quantitative research. Aside from broad approaches, such as ethnography or case studies,[181] qualitative research designs are advocated as being reflexive and iterative processes,[182] which are flexible and nonsequential.[183] In Maxwell's (2012) interactive model of qualitative design, there are integrated and interacting components.[145] There have been more recent models for developing qualitative designs (i.e., Hopscotch building[184]); however, Maxwell's interactive model adopts a critical realist stance,[185] is well-known, prompts in-depth consideration of design, and provides a structure to help justify decisions.[145] Therefore, it was used to inform the development of the social assessment (Figure 5.2).



GOALS

To identify community-defined ultimate *values* and the context within which they sit, as per the PRECEDE component, with a view to integrate with the epidemiological assessment.

To identify mechanisms involved in *why* people with dementia attend the ED.

To contribute to policy development.

CONCEPTUAL FRAMEWORK

Critical realist approach to explore multi-layered influences of attending the ED.

Mostly experiential framework to explore people's own perspectives and experiences.

Theories of healthcare access to guide interview schedule and interpretation of analyses.

RESEARCH QUESTIONS

What influences ED attendance among people affected by dementia?

How do people affected by dementia value the ED and ED attendance?

METHODS

Remote semi-structured interviews with participants recruited from dementia charities, selected using the maximum variation principle to maximise heterogeneity from which to identify shared experiences.

Reflexive Thematic Analysis to explore semantic and latent patterns of meanings, from mostly inductive orientation.

VALIDITY

Reflexive journaling.

Transferability / inferential generalisation by demonstrating sensitivity to context, describing details of context, participants and setting.

Sense-checking with public representatives.

Figure 5.2 Social assessment design
Adapted from Maxwell's (2012) interactive model of qualitative design[145]

5.4 Participant recruitment considerations

Participants comprised people with dementia and family caregivers who had, and had not, attended the ED. A family caregiver was defined as someone "who provides care without pay and whose relationship to the care recipient is due to personal ties...".[186 (p.3)] Family caregivers comprised those with current caring responsibilities and those with former caring responsibilities following bereavement. Table 5.1 displays the eligibility criteria and is followed by critical discussion and justification for the criteria, participant number and recruitment methods.

Table 5.1 Eligibility criteria
For people with dementia and family caregivers

	Inclusion	*Exclusion*
People with dementia	Adults (≥18 years) Any subtype of dementia at any stage	People lacking mental capacity to provide informed consent to participate
Family caregiver	Adults (≥18 years) Current or bereaved caregiver of a person with dementia	Professional carers employed by an external agency

5.4.1 Recruiting people living with dementia and informal caregivers

The process of conducting the systematic review (Chapter 2.5) highlighted that no study related to ED attendance directly seeks the views of people with dementia. This is a major limitation in the evidence base, as individuals with dementia would be best placed to describe their experiences and perceptions of the ED rather than proxy accounts. Researchers have previously opted to use proxy accounts from family caregivers to detail the lived experience of dementia,[187] yet quality of life scores differ between first-hand and proxy responses,[188] with the latter often being more negative.[189] While the caregiver's perspective was sought in the social assessment, it was not intended as a proxy measure of experiences of people with dementia. Instead, inclusion of current and bereaved caregivers as well as people with dementia permitted exploration of service use across the disease trajectory, and from the different perspectives of seeking help.

The social assessment involved people with dementia who were able to demonstrate the mental capacity to decide to take part in the research study and those comfortable to discuss their experiences. Although it is possible to obtain proxy consent and assent from an individual lacking capacity to consent to participate,[190] this option was deemed unsuited to the social assessment since the aim was to understand the different influences of attending the ED. It required retrospective accounts of using health and social care services, including circumstances leading up to ED attendance where relevant. Although mental capacity is time and decision-specific and therefore not reflective of ability to share past experiences, it was considered a useful eligibility criterion to minimise undue distress. Furthermore, it was considered more ethical to include only those with mental capacity to consent given that consent and interviews were completed online and detecting dissent in participants may have been challenging.

Including both current and bereaved caregivers permitted exploration of service use not only across the different stages of dementia, but also among those unknown and known to be at the end of life. This decision was made purposively to mirror the uncertain trajectory and prognosis of dementia, and because there is low-strength evidence that increasing disease severity is associated with end-of-life ED attendance (Chapter 2.5). The social assessment also included people with and without experience of using the ED. This was intended to permit broader exploration of why some people attend the ED and others do not.

5.4.2 Number of participants

Qualitative studies have often been criticised for lacking clear justification of the sample size.[191] There are several approaches that qualitative researchers may choose from to inform the number of participants in research, including numerical guidelines, rules of thumb, statistical formulae, and conceptual models. All but conceptual models are based on concepts of ‘saturation’ and ‘emergent’ themes,[192] which are linked to Grounded Theory (GT) methodology as a specific component of the constant comparison analysis method.[193] These concepts do not readily apply to other qualitative approaches, leading to poorly justified sample sizes,[193] ‘method slurring’,[194] and haphazard ‘mashups’.[195] Conceptual models to estimate sample size are not dependent on saturation points, but assume that sample size is informed by the interaction of different study characteristics.[196] Based on this, a conceptual model approach to determining the sample size was adopted in the social assessment.

An example conceptual model involves basing sample size on ‘information power’.[193] Malterud *et al.* developed this concept as a pragmatic guide,[197] which assumes that samples hold information and the more information held, the fewer participants needed.[193] Characteristics informing the information power include: (a) the aim of the study, (b) sample specificity, (c) use of established theory, (d) quality of dialogue, and (e) analysis strategy.[193] Considering these factors helps to approximate the same size, which is determined by continuous evaluation throughout the study.[193] The approach has been contested for assuming that dimensions of information power are sufficiently predictable to apply to all studies.[196] Nevertheless, information power encourages researcher reflection on the 'richness' of data and how this interacts with the parameters of the study.[198] It also offers a pragmatic means of estimating the sample size to meet the requirements of protocols and ethics committees.[198] For these reasons, and because a priori sample sizing is problematic in qualitative research,[196] information power was used in the social assessment. An initial sample size of approximately 30 participants was determined based on the broad aim of the social assessment, the desired sample specificity discussed below, application of established theory, limited research interview experience and the analysis strategy to be used.[193] The appropriateness of the sample size was assessed as the study progressed. Recruitment ceased when the sample was considered to have sufficient information power to address the aim of the social assessment.

5.4.3 Participant selection

Participant recruitment was purposive to increase the involvement of people with experiences and insights pertinent to the research aim and objectives.[199] There are different purposive sampling approaches, including homogenous, critical case, deviant case and typical case sampling.[200] These aim to obtain a uniform sample of participants or a sample for a single case study and would therefore fail to meet the aim of the social assessment. By contrast, selection by the maximum variation principle permits both uniqueness and shared patterns in heterogeneous cases.[200] There are inconsistencies in what maximum variation means in practice.[201] In the social assessment, it involved selecting participants based on variation of key characteristics,[200] which were informed by findings of the systematic review (Chapter 2.5; Table 5.2).

Table 5.2 Key characteristics to maximise variation
Based high-strength evidence from the systematic review

Key characteristics	*Example*
Gender	Men, women, other
Ethnicity	Asian, Black, Mixed, White, other
Socioeconomic position	Self-reported level of comfort on present income
Number of comorbidities	0, 1-3, >3
Type of usual residence	Own home, care home, mixed
Nearest ED to usual residence	< 5 miles, ≥5
Number of ED visits since diagnosis	0, 1, ≥2

Maximising variation permitted diversity of the sample and identification of core experiences and shared patterns,[200] making them more transferrable beyond the participant sample and context.[199] In some purposive sampling strategies, this involves assigning target numbers of participants with key characteristics,[199] which contradicts the logic of the information power method chosen to determine sample size. As mentioned above, sample specificity is a dimension of information power, which involves selecting participants with a variety of experiences specific to the study aim.[193] Dictating the number of participants with key characteristics may guarantee broad inclusion of participants but may compromise sample specificity and thus information power of the sample. Therefore, maximum variation was a guiding principle for heterogeneity, with the flexibility to enact a more reflexive purposive strategy. This ensured coherence of participant selection to the research aim,[199] rather than using arbitrary thresholds.

5.4.4 Virtual recruitment through charities and national databases

Due to social restrictions imposed by the Covid-19 pandemic, the social assessment was conducted remotely. It therefore relied on remote methods of participant recruitment and word-of-mouth. Since the pandemic, there have been papers exploring and guiding researchers through virtual recruitment of participants to qualitative studies.[202, 203] From these reviews and case examples, there is general acceptance that while there are disadvantages of conducting qualitative research online, there are some distinct advantages. Disadvantages include the increased risk of obtaining a skewed sample of those from higher socio-economic and educational backgrounds,[204] challenges of establishing community relationships without in-person meetings,[202] being inaccessible to marginalised groups or those with limited digital footprints,[203] and the transient nature of electronic advertisements.[202] However, advantages specific to the social assessment included recruiting participants who did and did not attend the ED, and recruitment beyond geographical boundaries.[202] Participants were from across the UK, complementing the regional variation noted in the policy context (Chapter 2.4) and in preliminary findings from the epidemiology assessment (Chapter 9.1).

Although advertising for participants by social media is a useful tool, it is associated with high risk of bias due to algorithms that determine who can view postings.[205] It was also acknowledged that not all individuals with dementia or their caregivers would have access social media or choose to use it. On this basis, participants were recruited through charity organisations who had appointed ‘gatekeepers’.[206] The charity organisations were approved by the Research Ethics Committee (REC) and included the Alzheimer’s Society Research Network (ASRN), Dementia Engagement and Empowerment Project (DEEP) and Dementia Carers Count (DCC). These organisations held volunteer registers for research recruitment and engagement, which include people living with dementia and/or those who are or were dementia caregivers. Gatekeepers from the ASRN, DEEP and DCC circulated a description and/or poster to constituents by email. Participants were also recruited from National Institute of Health and Care Research (NIHR) Join Dementia Research (JDR), which involved uploading the study description for members to express interest or for those matched to the study (or their representatives) to be purposively approached.

Although volunteer registers are beneficial,[207] there are risks. Barriers to participation are lowest among people with previous participation experience.[208] Therefore, risks of self-selection bias may be more prominent when recruiting participants from volunteer registers. Furthermore, it is known that research volunteers are more likely to be women,[207, 209] be higher functioning with better cognitive baselines,[210] and have greater mental wellbeing.[211] It is also recognised that registers are likely to under-represent minoritised ethnic groups, people with lower socio-economic position and those aged over 75yrs.[207, 212] This under-representation is reflective of the wider ‘recruitment crisis’ in dementia research.[213] It was therefore important for the social assessment that concerted effort was directed to recruiting participants of different genders, from across the socioeconomic strata, different minoritised ethnic groups and different age groups.

5.5 Data collection considerations

It was important to consider theoretical and practical factors around collecting data from people with dementia and people with current and bereaved family caregivers. Qualitative interviews were used in the social assessment, as they afford balance between context-rich idiosyncrasy and broad generalisation. Interviews permit focus on a broad range of people and settings,[214] exploration of past and rare events, and experiences not documented elsewhere.[215] Furthermore, they can be sufficiently flexible to 'probe' and explore further, strengthening and complicating other data.[215] For these reasons, interviews were the most appropriate means of ascertaining the accounts of people with dementia and family caregivers about experiences that drive ED attendance. While structured interviews can overlook the emotional dimension of respondents' accounts,[216] and unstructured interviews can yield data that meanders,[215] semi-structured interviews offer a middle ground to explore without getting lost. Therefore, semi-structured interviews were used for the social assessment. Dyad interviews have been found to be beneficial for participants with dementia-specific communication difficulties.[217] Dyads were not purposively sampled for this study, as it was recognised that some caregivers can dominate interviews.[218] However, any participant preferring the support of a significant other was welcomed to facilitate the interview process.

There were alternative data collection methods available. Focus groups, for example, have been used in previous studies exploring experiences of dementia care.[219, 220] However, they often comprise a homogenous group to encourage participation and discussion of sensitive issues,[221] which is inconsistent with the aim of maximum variation. While heterogenous focus groups are possible,[222] they risk debate and potentially deviating from the aim. Furthermore, as the value of focus groups is in the types of interactions that take place during discussion,[223] their use would not match the aim of the social assessment. Observational studies were discounted on practical grounds, as it would be challenging to observe events leading to an unexpected ED attendance and would fail to provide insight into personal experiences. Case studies could offer an attempt to rectify this by including interviews as well as observation, or other means of intensively exploring experience.[224] However, they have been criticised for not being representative of people in other contexts.[225] Although this study is not aiming to obtain the views of a homogenous collective, as with focus groups, it equally does not aim to limit to the idiosyncrasies of specific cases. Therefore, semi-structured interviews were conducted, plus supply of two questionnaires to facilitate recruitment and the safety and welfare of participants.

5.5.1 Conducting remote interviews

Conducting interviews in-person is considered the gold standard approach,[226] based on scholarly tradition,[227] as well as representing the most natural conversational context.[228] Remote interviews have been described as sterile and less personable,[229] where opportunity to build rapport is severely limited,[230] with the risk of social desirability bias at its greatest.[231] Debatably, face-to-face interviews do not guarantee interviewer-interviewee rapport,[229] and there are examples of remote interviews that permit exploring sensitive issues,[229] and where interviewee anonymity minimises reticence.[232] In addition, telephone and online interviews can be conducted with individuals from geographically diverse areas without the logistical challenges or costs associated with in-person interviews.[199] There were therefore obvious advantages to conducting interviews remotely, by telephone or using online video calls, without necessarily compromising the quality of data collected. Given this, and that face-to-face interviewing was not possible during the pandemic, it was considered acceptable to conduct interviews remotely.

It is important to acknowledge the disadvantages of remote interviewing, as these needed to be transparently accounted for in the interpretation and reporting of results. Obvious disadvantages to researchers include the absence of non-verbal cues during telephone interviews, although some have argued that this is an exaggerated limitation since insights can still be gained from voice and intonation,[233] that verbal cues tend to naturally increase when non-verbal communication is limited,[234] and any lost information can be captured with specific probing questions.[234] However, for people with dementia, the disadvantages may be more legitimate, as some rely heavily on non-verbal cues,[235, 236] and communicating by telephone can be particularly challenging.[237] For current caregivers, however, the option of telephone interviewing can be more easily placed into a busy schedule and thus has potential to access those who would ordinarily be difficult to reach.[238]

There are more practical issues associated with online interviews including problems of intermittent internet connectivity and poor audio.[239] Time-lags due to connectivity have been identified as potentially hindering rapport;[240] however, others advocate that rapport is mostly influenced by interviewee personality and prior contact.[241] Notwithstanding the appeal of online interviews for their flexibility and convenience,[242] absenteeism has been noted to occur more with online than in-person interviews.[241] Furthermore, the ‘digital divide’[243] is likely to exacerbate the risk of selection bias towards white, middle-class participants that is already observed in dementia research,[213] and reinforces issues around representativeness in online interview studies.[244] While purposive recruitment was intended to mitigate this potential selection bias, it remains an important limitation of the social assessment.

5.5.2 Development of interview topic guide and questionnaires

The interview topic guide and two questionnaires were informed by the aim and objectives of the social assessment, findings from the systematic review, review of relevant theory, engagement with the Cicely Saunders Institute (CSI) Patient and Public Involvement (PPI) forum, and consultation with an individual PPI member with experience of supporting a relative with dementia. As with other semi-structured interview topic guides, the guide was loose to permit flexibility of order of questions,[245] and flow of dialogue.[246] It included open-ended questions,[247] with a view to receive interviewee answers that were detailed, spontaneous,[245] and unique to them, reflecting their personal experiences and what was important to them. Similar to other topic guides, there were two levels of questions: the main themes and follow-up prompts.[248] Specifically, there were four main themes for the interviews: Living with dementia, community support, emergency service use, and opinions about ED attendance. Pre-designed follow-up prompts were based on the domains of access to healthcare services in Penchansky and Thomas' 'degree-of-fit' model.[156] Other follow-up questions were spontaneous based on interviewees' answers and direction on dialogue, as is common in semi-structured interviewing.[248]

Following the framework developed by Kallio et al.,[248] after formulating the preliminary topic guide, it was then piloted. There are three main approaches to piloting an interview topic guide: internal testing (within a research team), expert assessment (external to the research team), and field-testing (with study participants).[248] The latter was used to pilot the interview guide and questionnaires, with a bereaved carer who was also a ASRN volunteer involved in monitoring the research within this thesis. As the field-test was conducted over the online video platform Zoom, it also permitted opportunity to test the technology, quality of sound and connectivity. Following this pilot, Wi-Fi connectivity was maximised as much as possible, the position of the audio recorder and computer volume were adjusted to optimise clarity while maintaining confidentiality, the researcher minimised their use of natural verbal probing to limit disruption during episodes of time-lag, and the topic guide was re-formatted into a diagram to afford greater flexibility of use. The topic guide continued to evolve during subsequent interviews (Appendix C5).

5.6 Analysis method considerations

The importance of using an analysis method that was conceptually coherent was prioritised in the design of the social assessment.[198] Each decision took account of the research paradigm, research goals and characteristics of the subject matter and the researchers,[249] as discussed below.

5.6.1 Reflexive Thematic Analysis

The social assessment centred on the meaning of health and social care service experiences, including the ED, for later integration with findings from the epidemiological assessment. Using qualitative analysis that focuses on patterns of meanings across data was therefore considered most logical. This excluded analytical methods that focus on biographical accounts or the nature of speech, such as narrative analysis or conversation analysis, respectively. Approaches that focus on patterns of meaning include Interpretative Phenomenological Analysis (IPA), Grounded Theory (GT) and Thematic Analysis (TA). Distinctively, IPA and GT are both methodologies with associated analytical methods. Neither methodology was conceptually coherent to the scope nor aim of the social assessment. Furthermore, while it is possible to use only the methods affiliated to these methodologies, it is generally considered poor practice and leads to limited analytic output.[250] In contrast to IPA and GT, TA is not a defined methodology and is theoretically flexible,[251] and therefore could accommodate the critical realist approach that was used in the social assessment.

Thematic analysis is an umbrella term comprising different approaches: coding reliability TA, codebook TA and reflexive TA.[252] Reflexive TA was used in the social assessment as it suits research that focuses on understanding situated meaning and interrogating interpretation.[251] Therefore, it permitted exploration of participants’ experiences of living with dementia and accessing services, as well as how they referred to dementia and accessing care. As the flexibility of reflexive TA to apply across the spectrum of orientations,[251] it was further considered conceptually coherent to the aim and scope of the social assessment. Furthermore, researcher subjectivity in Reflexive TA is regarded as an asset rather than a source of bias in need of validation.[251] Routinely reflecting on own positionings and perspectives is fundamental to the analytical process and its integrity.[253] As a research diary creates the space needed to achieve this,[254] a reflexive journal was maintained from participant recruitment to finalising the themes. Specifically, this was used to facilitate introspective reflexivity to provide insight into the interpretation of findings and motivations behind choices made, and intersubjective reflexivity to provide insight into influence of the situated dynamic of the interviewee-interviewer interaction.[253]

Alternative TA approaches were less suited to the social assessment. Specifically, codebook TA comprises framework,[255] template,[256] and matrix analyses,[257] facilitating collaborative coding within a multidisciplinary team.[258] While codebook TA can accommodate the practicalities of applied research and policy development,[259] it risks curbing the depth and flexibility of analysis that is at the core of qualitative inquiry.[252] As depth of exploration was central to achieving the aim of the social assessment, and the research did not sit within a multidisciplinary team, codebook TA was discounted. Coding reliability TA was also discounted, as this approach is used to translate languages of both qualitative and quantitative analysis,[260] which was not a requirement for the social assessment. Furthermore, while coding reliability TA permits exploration of a *topic*, the research question for the social assessment focused on exploring *meaning* and thus requires analysis that goes deeper. Finally, on a more practical note, coding reliability TA requires multiple coders to achieve satisfactory (inter-coder) reliability, whereas this study had a single coder. These reasons further supported the application of reflexive TA.

There is debate in the literature as to whether qualitative research can be generalisable to other populations and contexts, which is required to inform policy change. Aligned to reflexive TA, generalisability depends on how the reflexive researcher interprets the term and is based on a critical evaluation of the participants and research setting.[251] Although critical realism bases knowledge on situated subjective interpretations that are fallible, there is opportunity to transfer knowledge claims about generative mechanisms causing the observed event to other yet-to-be observed events. To do this within the reflexive TA approach, preserving the contextualisation of data and interpretation is essential,[251] ensuring ‘readiness for extrapolation’.[261] As this can be facilitated by locating the participant group and the context of data collection,[251] it was essential that the write up of analyses included these details.

5.7 Ethical considerations

Ethical considerations range from issues of informed consent and confidentiality, to the situational and relational ethics specific to qualitative research.[262] These latter ethical considerations are observed particularly in health services research, and include issues around minimising participant distress, exploitation, misrepresentation, and identification.[263] However, the complexity and significance of all ethical principles is intensified in research involving people with dementia,[264] with growing recognition that dementia research requires flexibility and participant-centred ethical practice.[265] As such, the social assessment first obtained approval from the King's College London Research Ethics Committee (REC; Appendix C1), with amendments informed by the DEEP Ethics Gold Standards for Dementia Research.[266]

From the REC review process, there were two risks of taking part in the social assessment: 1) risk of distress when discussing emotionally sensitive topics, and 2) risk of breaching participant confidentiality should a safeguarding concern be identified during the study. The risk of distress is apparent in any study exploring potentially negative experiences, such as recalling experiences of becoming acutely unwell, or a relative approaching the end of life. The risk is potentially greater when interviewing participants with cognitive impairment,[267, 268] those with current caregiver responsibilities,[269] or those who are bereaved.[270] It has been suggested that while qualitative interviews have potential to cause distress to participants, the risk is no greater than in everyday life,[271] and can be a cathartic experience.[270, 271] Nevertheless, it was imperative to conduct interviews sensitively in response to the vulnerabilities of individual participants and topics of discussion.[272] As well as sensitivity and flexibility of questioning, participants were reminded that they did not have to discuss anything that made them feel uncomfortable and the options to pause, postpone or stop the interview were always available. Wellbeing was checked verbally and non-verbally during and after the interview. A protocol was also developed to guide escalation in response to participant distress (Appendix C2), although this was not required.

The risk of an intentional confidentiality breach is an important ethical consideration of research with vulnerable communities, and often involves a balance between the negative consequences of breaking confidentiality and the researcher's moral values,[273] as well as ethical codes of practice to protect participants against harm.[274] By recruiting from the community rather than within the health service, there were no pre-established safeguarding policies or procedures in the event of a concern over an individual's safety and welfare. To maintain ethical research practice and protect all participants in the social assessment, one of the questionnaires collected personally identifiable data from each participant. This included the participant's name, postcode, telephone number and GP surgery. For current caregivers, data on the person with dementia was also collected, and for people with dementia, information on next of kin was collected. These details permitted escalation to relevant safeguarding teams within a participant's local authority or GP, depending on the nature of the concern. Participants were made aware of the need and reasons for collecting these details, and the risk of sharing them with others in the event of a safeguarding concern.

As previously implied, balance is needed between nonmaleficence and autonomy in dementia research ethics. It is essential that no participant is harmed in any research activity; however, the regulations to protect participants with dementia may prevent their involvement.[265, 275, 276] Blanket approaches to conducting research are considered unnecessary, as participants with dementia are often "victims of paternalism, in the name of ethics".[265 (p.8)] It was therefore considered more respectful and productive to attend to each person on individual need. This included liaising with representatives of people with dementia where specified, reducing the pace of speech during verbal consent and interviews, having interviews outside office hours to accommodate caregiver schedules, obtaining consent and conducting interviews over the telephone or online, with and without screenshare, as preferred. Similarly, to minimise the power imbalance, it was imperative to establish contact before the interview. This 'broke the ice' and provided a foundation for building a trusting relationship,[267] and a safe space in which the participant could share their personal stories.[277] To further minimise the power imbalance, the researcher conducted interviews flexibly to permit participants to discuss issues most important to them.[278]

It has been advocated that specific knowledge of dementia and interpersonal skills are paramount when managing the ethical complexity and sensitivity of dementia research.[279] While the social assessment was conducted by a novice researcher, experience working in older adult mental health services afforded a specific skillset pertinent to conducting dementia research, including empathy and sensitivity,[278] active listening skills,[280] critical thinking and reflexivity.[268] Professional backgrounds need careful consideration in the design and carrying out of qualitative studies, as they may influence participants' responses and interview interactions.[281] Boundaries can be blurred for participants when researchers are known to be healthcare professionals,[279] and they may seek advice about their condition or treatment options.[268] This was apparent in the field-test, although diverted. From this experience, and acknowledging the potential for greater power imbalance,[263] and distress,[267] it was decided that the researcher's professional identity would be confirmed only if an individual participant enquired.

5.8 End of chapter summary

Based on the first objective and scope of the thesis, review of extant theory and literature, community engagement, and consideration of participant need and the social context in which the research was situated, the social assessment used a critical realist approach to conduct a remote interview study involving people with dementia and current and bereaved caregivers. Purposive sampling based on information power was used to maximise variation of participants recruited from national charity organisations and a dementia research register. Reflexive thematic analysis was used to analyse interview responses and field notes, with the aid of a reflexive diary. With similar critical consideration of methodological integrity, the next chapter will describe the development of the epidemiological assessment.

6 METHOD 2: EPIDEMIOLOGICAL ASSESSMENT

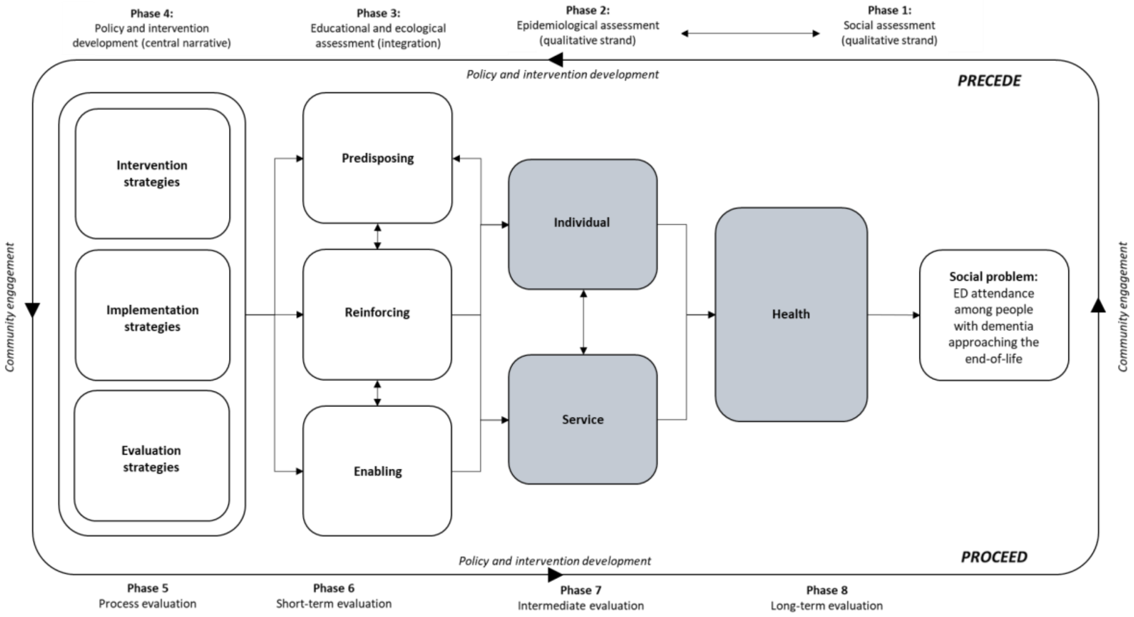


Figure 6.1 Epidemiological assessment (phase 2, in parallel with phase 1)
Objective two, to examine individual- and service-level factors associated with emergency department attendance among people with dementia in their last year of life.

The epidemiological assessment is the second phase of the PRECEDE component of the PRECEDE-PROCEED Model (PPM), completed in parallel with the first phase, and meets objective 2 (Figure 6.1). The PPM advocates using epidemiology to provide a credible way of identifying health issues that are both important and changeable.[89] It also permits direct application of findings to set priorities for change,[89] and is a cornerstone to inform health policies.[282] This chapter details the methodological and design considerations of the epidemiological assessment.

6.1 Methodological considerations

The methodological considerations of epidemiological studies are rarely specified,[283] as its reliance on quantitative data and deductive reasoning of causal effects and associations imply a positivist approach.[284] Positivism assumes a single universal truth that can be externally examined, independent of context and time. This methodological approach was considered ethically and practically useful to frame the examination of measures of association between different factors and ED attendance among people with dementia in the last year of life. Furthermore, it provided a population-based insight that complemented the individual-based insights gained from the social assessment. Approaching this study with a positivist methodology was therefore beneficial in meeting the thesis aim and objectives.

There have been concerns over epistemological hegemony,[285] where positivism is uncritically accepted as superior to other views of knowledge.[285] However, this assumed credibility often means that epidemiological findings are used to inform public policy and underpin evidence-based practice.[285] Although there are risks of "promiscuous policy mongering",[286] (p.554) the application of epidemiological findings to policy makes the positivist methodology practically valuable in meeting the study aim and maintains conceptual coherence with the PRECEDE component of the PPM. Furthermore, the utility of population-based scientific enquiry lends itself to the multilevel examination of different factors, which further broadens the implications for policy.[287]

6.2 Conceptual models of end-of-life care

The Gomes and Higginson[288] and Gao *et al.*[289] conceptual models were merged into a hybrid model to facilitate data collection and analysis for the epidemiological assessment.

The Gomes and Higginson model was developed following evidence synthesis of factors associated with place of death among people with cancer.[288] The model includes individual-related factors such as demographics and personal variables, illness-related factors such as type and duration of disease, and environmental factors, including healthcare input, social support, and macrosocial factors such as historical trends. The model has been applied to people with non-cancer palliative conditions,[290] and to understanding the factors associated with ED visits among people with cancer,[291] and older adults in general.[292] It was also used to inform the systematic review in this thesis (Chapter 2.5). While the model is more descriptive than explanatory, it is a useful tool to structure individual- and area-level factors important to end-of-life care. For the epidemiological assessment, it did not sufficiently capture the differences in service factors. Therefore, the model was adapted to incorporate service-related features of the Gao *et al.*[289]

The Gao *et al.* model (Figure 6.2) was developed specifically for population-based views of service influences on place of death.[289] It integrates aspects of the Gomes and Higginson model,[288] and behavioural, and person-centred models of access.[158, 159] The resultant model includes end-of-life care policies, which influence service commissioning and characteristics (type, capacity, location, and workforce), which influence service use and place of death. This, in turn, feeds back to inform end-of-life care policies and commissioning.[159] While the model includes patient factors (socio-demographic and disease-related characteristics), and environmental factors (social care, and family and community support), these were peripheral to service factors. Therefore, it was considered appropriate to merge the features of the Gomes and Higginson model that concern individual and environmental factors,[288] with the features of the Gao *et al.* model that concern service factors, developing a hybrid conceptual model to facilitate a more comprehensive deductive analysis.

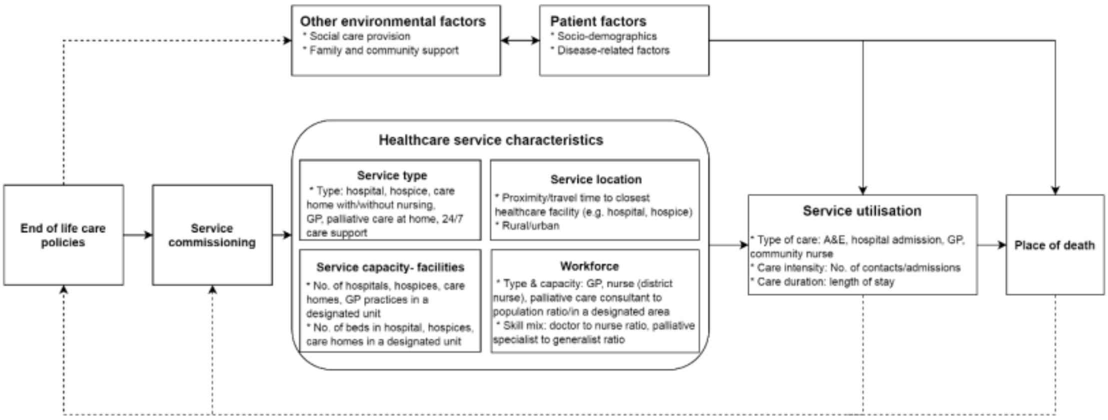


Figure 6.2 Gao *et al.* conceptual model for the role of healthcare service factors in place of death (reprinted with permission)[289]

There were other conceptual models that were considered but discounted. Briefly, these were the Penchansky and Thomas model of fit,[156] and the behavioural model of healthcare service utilisation.[158] The former was not used because, practically, there was insufficient data available to map against the model's five domains of access. Theoretically, the model is based on the concept of fit between the service and user, which was not the focus of the epidemiological study. The behavioural model was not used because although there were data available to map against the model's core features (predisposing, enabling and need factors), these features are limited by their ambiguity.[293] Furthermore, without understanding the mechanisms of associations in the data, categorisation would have been entirely subjective and thus unhelpful to inform policy recommendations.

6.3 Design considerations

The aim of the epidemiological assessment was analytical rather than descriptive. As such, a retrospective cohort study design was used. The rationale for using a cohort design was that it permits examination of multiple exposures associated with an outcome in one cohort. A cross-sectional design would have been impractical, as it involves collecting all data at a single point in time and thus would limit measurement of the number of ED attendances over the last year of life. A case-control design was also impractical, as it involves defining cases by presence of the outcome and comparing exposure to risk factors against controls without the outcome, which would have limited analysis to odds of an ED attendance for a given exposure. By contrast, cohort designs, which define groups by exposure, can accommodate measuring the odds and risk of an ED attendance for a given exposure. Cohort studies therefore permit measures of association that are more clinically intuitive and accurate when the outcome is common,[294] such as in the examination of ED attendance among people with dementia approaching the end of life.[4]

In studies examining end-of-life, there are ethical and methodological issues of collecting data prospectively, such as response burden and non-response.[295] These issues can be avoided with retrospective study designs,[295] which can also ensure a clearly defined denominator.[296] However, there is wide debate around describing cohort studies as either retrospective or prospective. Some argue that all cohort studies are prospective, as all data (whether historical or not) is followed up by moving forward in time, and only case-control studies are truly retrospective.[297] Others have used the terms prospective and retrospective to differentiate between when data is collected and when the study was conceived,[298] or when cases were selected and when data on exposures were available.[299] The 'Strengthening The Reporting of Observational Studies in Epidemiology' (STROBE) guidelines advocate either not using the terms prospective or retrospective at all, or including them with clear definitions of what is meant by their use. As per these recommendations, the epidemiological assessment adopted a *retrospective* cohort design with a cohort of decedents with dementia, *looking back* over the twelve months before death to count the number of ED attendances.

6.4 Data source considerations

6.4.1 Routinely collected administrative data

Routinely collected data is generated by administrative and clinical processes. Used as a by-product of care,[300] secondary analysis can provide important insights into health service use and opportunity to evaluate and improve care.[301] The main advantages of using routinely collected administrative data in research is that it reflects real-world processes, which enhances the generalisability and comparability of findings.[302] It is generally more economical with funding and time compared to primary data collection, and permits population-based examination at the patient-level.[4] Therefore, it was practically and conceptually useful to use routinely collected data to meet the aim of the epidemiological assessment. Most data are collected in siloes,[303] but data linkage makes it possible to combine patient data across different healthcare services. This was preferrable in this assessment, as the aim included examination of individual- and service-level factors. Routinely collected data also affords the flexibility of vertical integration with area-level data, generating richer data streams.[304] This richness is particularly useful in health systems and dementia research given the complexity and multifactorial nature of healthcare access and progression of the condition, which effect and are affected by context. Secondary analysis of routinely collected data is also useful to inform policy. It gives timely and up to date insights,[305] which are needed for priority setting, policymaking and understanding the distributional consequences of policies.[302]

While there were pragmatic and methodological justifications for using routinely collected data for the epidemiological study, there is limited availability of data pertaining to patients' preferred place of care, which may include the ED. Issues of standardisation, completeness and correctness are considered the most challenging when using routinely collected data in research.[306] Taking these issues into account, the epidemiological assessment was reported using the REporting of studies Conducted using Observational Routinely collected Data (RECORD)[307] to facilitate transparency and optimise quality.

6.4.2 Civil Registration (Death) – Secondary care cut

For mortality data, the Office for National Statistics (ONS) dataset extracts summary information from the Medical Certificate of the Cause of Death. This document informs the civil registration of a death, which is a legal requirement in the UK. Therefore, the data provides complete population coverage of deaths, which makes it a valuable source of information.

Furthermore, inaccuracies in data acquisition and coding are minimised by validation and quality checks completed by the ONS.[308]

The mortality data used in the epidemiological assessment was a ‘secondary care cut’, which is a subset of mortality data that can be linked to Hospital Episode Statistics (HES). This affords the opportunity to expand the data to permit observation of hospital activity prior to decedent death and therefore was suited to meeting the aim of the epidemiological assessment. Compared to standard mortality data, the secondary care cut does not include marital status or occupation details but includes all other data on gender, date, and cause and place of death.[309]

6.4.3 Hospital Episode Statistics

Hospital Episodes Statistics (HES) contain records of ED visits, inpatient admissions, and outpatient appointments at English NHS hospitals.[310] The HES Admitted Patient Care (inpatient) dataset includes all hospital admissions that required the use of a hospital bed, and the HES Accident & Emergency (A&E) dataset includes all ED attendances. Each dataset comprises data coded according to NHS Digital data dictionaries.[311] The main strength of using HES is its coverage, providing a large dataset across England, permitting estimates of rates and specific outcomes.[312] Preliminary findings of the social assessment indicated geographical variation in service access. Therefore, using data that permits analysis across the country was considered beneficial to completement these findings. Furthermore, it offered opportunity to advance the current evidence base since similar studies have analysed data limited to single geographical areas in England.[4]

6.5 Case identification considerations

The population comprised people who died between 01 April 2018 and 31 March 2019 with or from dementia, as evidenced by their death certificate, and who had at least one inpatient admission and/or ED attendance or at least one outpatient appointment within three years of death (01 April 2016 to 31 March 2019).

6.5.1 Using death certification to identify cases

Cases were decedents with dementia, therefore dementia diagnosis on the death certificate was used to identify cases. Dementia diagnosis was measured as either the underlying cause of death or recorded as any death mention on the certificate. Death certification is known to underestimate dementia prevalence.[313, 314] Evidence suggests that 45-50% of cases of dementia are listed on the death certificate.[315, 316] However, frequency of dementia recording has increased over time,[313] and the positive predictive value for all-cause dementia is 89% in mortality data.[317] This suggests that while death certificates may underestimate the number of people with dementia, this is likely better than in previous years and there is a high degree of certainty that those identified did in fact have dementia, which is comparable to inpatient records.[317]

It was recognised that death certificates are less likely to include dementia subtypes other than Alzheimer's disease,[313] although there is international evidence that unspecified dementia subtype is prevalent within mortality data.[318] To mitigate for potential overrepresentation, unspecified dementia on the death certificate was triangulated with comorbidities in inpatient records. Therefore, any subtype specified in the inpatient records superseded unspecified dementia on the death certificate.

6.5.2 Rationale for date range

Included decedents died between 01 April 2018 to 31 March 2019. Linked data was extracted for three years (01 April 2016 to 31 March 2019) ensuring that all cases included at least twelve months before death to permit full examination of predictors of ED visits within this timeframe. In April 2020, the HES A&E dataset was decommissioned and replaced with the Emergency Care Data Set (ECDS) which used different pseudo-identifiers from inpatient dataset. For consistency and ease of linking record-level data, date of death was therefore limited to between 2018-2019. This was also before the onset of the Covid-19 pandemic.

6.6 Variable considerations

The outcome and explanatory variables are detailed in the results (Chapter 9.1), but judgements made about their inclusion and exclusion are critically discussed in this chapter, with theoretical, conceptual, and practical considerations.

6.6.1 Primary outcome measure

The primary outcome measure was the number of ED attendances in the last year of life. It was possible to dichotomise the variable as others have done, for example, into single/multiple ED attendances,[174] or early or late transitions.[319] Although multiple ED attendances and timing of transitions are worthy of further examination, dividing number of ED attendances into these categories did not align to the aim or scope of the epidemiological assessment.[320] Without theoretical justification, categorisation would increase the risk of false positive results from multiple hypothesis testing,[321] and be vulnerable to unintentional p-hacking.[322] Additionally, the variable does not meet other criteria that would justify its segregation, such as being naturally categorical or part of extreme group analysis.[320] For these statistical reasons, to enable comparison with other literature,[4] and for conceptual coherence to the aim of the epidemiological assessment, the primary outcome was the number of ED attendances in the last year of life, modelled as a continuous variable.

6.6.2 Selection of record-level individual-related explanatory measures

Analysing data at the record level permitted examination of individual-related factors associated with the number of ED attendances in the last year of life. Selection of factors were based on evidence gaps identified in the systematic review (Chapter 2.5). For example, there was evidence that increasing age was associated with reduced likelihood of ED attendance and vascular dementia was associated with increased likelihood of ED attendance. However, this evidence was of low-strength due to the limited number of studies. Most studies in the review were also from North America with only two studies from the UK. Based on these gaps in the evidence and the national focus of this thesis, it was important to reflect all explanatory variables in the systematic review, as far as practicable from the data sources, to support or challenge the existing evidence base and contribute to new directions.

Comorbidity status could not be included as an explanatory variable, despite literature identifying multimorbidity and specific comorbidities associated with increased ED attendance towards the end of life across different cohorts,[291, 292] including dementia.[323] This is because comorbidities were recorded in the inpatient data only, and not all patients were admitted into hospital. Some studies have used death certificates to determine comorbid conditions,[324] including the number of contributory causes of death to approximate ‘comorbidity burden’,[325] and underlying causes of death to define chronic comorbidities listed in the Charlson Comorbidity Index.[326] However, inaccuracies in death certification are frequent, with major or unacceptable errors ranging between 30-50% depending on location of death.[327, 328] Certification of hospital deaths have been found to have more errors than for deaths in other settings,[327, 329] including improper reporting of secondary causes of death as the main cause.[328-330] Despite these limitations, underlying cause of death was included as a covariate and grouped in accordance with the other studies,[331] giving some indication of a patient's chronic health status.

6.6.3 Selection of area-level service-related explanatory measures

Types of area-level service-related data were informed by the aims and objectives of the epidemiological assessment, theoretical underpinnings, and the availability of service data. There is known variation of ED attendance rates across GP surgeries,[332, 333] however, there is mixed evidence that GP supply influences emergency hospital attendance.[334] Some studies have found no significant effect of GP supply,[335, 336] another found higher GP full-time equivalent (FTE) was significantly associated with fewer ED visits,[337] and another found similar findings for deprived areas only.[338] None of these studies specifically focused on people with dementia approaching the end of life. Research into this population have instead identified reduced emergency admissions associated with increased continuity of GP care,[339, 340] and identification of palliative care needs in primary care.[340] Data on GP continuity was not publicly available for the epidemiological assessment and would have required purchase of additional NHS Digital datasets, which was beyond the economical scope of the research. However, given the potential influence of GP supply on ED visits, that GPs are often the first point of contact for people affected by dementia in need of support,[341] and that GPs were frequently mentioned in the social assessment (Chapter 8.1), GP supply (FTE) at the area-level was an important covariate to include.

The influence of other primary care staff on emergency hospital attendance has received minimal attention in the evidence base. One study identified increased practice nurse FTE significantly associated with increased ED attendance by an older adult population.[337] Evidence reviews have identified central roles for practice nurses in the primary care provision of end-of-life care and dementia care, but there is insufficient evidence to detail scope of practice or impact on patient outcomes.[342-344] To advance understanding, area-level practice nurse supply (FTE) was included as an explanatory variable. Admiral Nurse workforce data was also intended for inclusion based on comments made from interviewees during the social assessment. Admiral Nurses are specialist dementia nurses commissioned locally by NHS Trusts, GP surgeries, local authorities, and charities.[345] However, workforce data showed few Admiral Nurses working across England, operating within vague local boundaries. This hindered meaningful inclusion in the study and therefore Admiral Nurse workforce data was omitted from analysis.

Adult social care plays a central role in the provision of care for people with dementia.[346] Despite political drives to increase dementia diagnoses, UK adult social care spending has fallen over recent years.[347] There is mixed evidence that adult social care spend is associated with increased emergency hospital attendance.[348, 349] Evidence is also mixed for the influence of social worker and occupational therapy input, although research shows that registered nurses in care homes likely reduce the need to transfer residents to hospital.[350] Therefore, area-level adult social care annual expenditure and workforce data were included in the epidemiological assessment, which included FTE for direct carers and professionals (nurses, occupational therapists and social workers), to better understand their potential influence on ED attendance for people with dementia at the end of life.

The systematic review (Chapter 2.5) identified high-strength evidence that care homes (with and without nursing care, and dementia specialist and non-specialist) were associated with reduced ED attendance towards the end of life for people with dementia. This is similar to literature that identified care home residence associated with fewer early and late hospital transitions towards the end of life for people with dementia.[319] This literature has led to calls for policy priority on greater investment in care home capacity to reduce pressures on emergency care.[4] Based on their influence, it was pertinent to include care homes in the epidemiological assessment. Although care home residence was unavailable at the individual-level, numbers of care homes beds, with and without nursing care, were obtainable at the area-level and therefore included in analyses. This approach has been used previously,[351, 352] and would give indication of the influence of type of care home, which has not been investigated in literature examining ED attendance towards the end of life. It was also a potential modifiable factor to inform policy change.

Service location, or ‘accessibility’, is another key domain of health service access.[156, 289, 353] Several studies have demonstrated the ‘distance decay effect’ whereby the greater the distance between the patient and service, the lesser likelihood of service use. This effect has been demonstrated with type 1 EDs.[354, 355] Similarly, there is evidence to suggest that closer proximity of GP surgeries to patients’ homes is associated with reduced ED attendance.[333, 355] Shorter distances to the GP surgery than to the hospital have also been associated with reduced ED attendance.[335] There is further evidence that living within one mile of an urgent care centre reduces the likelihood of attending the ED.[356] However, proximity as an explanatory variable in the epidemiological assessment was excluded for two reasons: 1) patients’ full postcodes were unavailable, and while straight-line distances could be calculated, these were between the individual service postcodes and the mean longitude and latitude of each patient's resident postcode district (first half of postcode). This severely diluted the accuracy of the variables; and 2) service proximity would likely be confounded by level of rurality. Instead of examining service proximity, the number of services within the local area was calculated as a proxy for service availability.

All service-related data were presented per 10,000 adults ≥65yrs old in each local authority. Standardising the data as a rate enabled comparison between local authorities whose populations ≥65yrs spanned 1,564 to 314,491[357] and negated the need for an offset variable in the analysis. Populations were limited to adults ≥65yrs to reflect those most likely to use primary and social care services.[358, 359] Service data were grouped into quintiles to permit ranking for ease of comparison.

6.6.4 Local authorities as the geographical unit of analysis

Service factors measured in this epidemiological assessment were linked to service availability, which can be sourced from administrative databases at either local authority or Clinical Commissioning Group (CCG) levels. Deciding between different geographical unit of analysis is fundamental to studies with ecological measurements.[360] Without due consideration, using artificial units of aggregated data can cause artificial spatial patterns and risk statistical bias ('modifiable areal unit problem').[361] Criteria have been proposed to guide the selection of geographical units of analysis in ecological studies, including communicability of results,[362] while others advocate weighing up the influence of various factors such as data availability and policy relevance.[360] Based on these suggestions, there were three reasons to use local authorities as the geographical unit of analysis: 1) CCGs are responsible for the commissioning of health services, whereas local authorities are responsible for the provision of social care and some community healthcare and are therefore more aligned to the scope of the study examining service availability; 2) the hybrid conceptual model used in the study focuses on workforce and capacity, which is more consistent with the remit of local authorities than with CCGs; and 3) findings at the local authority level would be more effective for communication of results,[362] and policy relevance,[360] as CCGs were replaced by Integrated Care Boards (ICBs) in July 2022 as per the new Health and Care Act (2022), with some merging and assuming new boundaries.[363]

6.7 Analysis method considerations

Although a Poisson regression model was considered since the outcome measure was continuous, the number of ED visits in the last year of life was overdispersed (*see* Figure 6.3). It was therefore appropriate to use a negative binomial regression, which allows the variance to exceed the mean. Rather than report the regression coefficient, the epidemiological assessment reported the Incidence Rate Ratio (IRR), which represented the change in outcome variable as a percentage increase or decrease from the level of 1.0. This was chosen as a common method to report results from count models, permitting comparison with related studies,[4] and ease of interpretation.

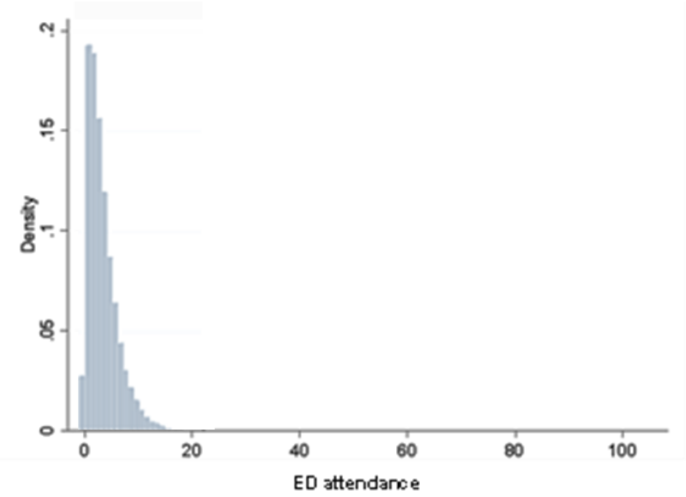


Figure 6.3 Overdispersion of ED attendance
Frequency of ED attendance in the last year of life.

Using a sample of patients from across England, it was highly likely that patients living in the same area would have common contextual factors influencing the number of ED visits, as well as having individual influences. On this basis, observations would not be independent, but may be clustered by the local authority level. This violates the assumption of independence needed for regression modelling.[364] To avoid incorrect estimations of standard errors and type 1 errors,[364] multilevel modelling was used. This permits modelling of individual- and area-level associations with the outcome.[364] Alternatives to multilevel modelling include running analyses without accounting for potential clustering effects. However, this would increase the risk of atomistic fallacy, where individual-level results are generalised to groups at the area-level. Another alternative would be to aggregate the dataset by local authority rather than the individual-level. However, this would reduce the sample size from over 74,000 to just 150.

Furthermore, the focus on aggregate estimates only would increase the risk of ecological fallacy,[364] where group characteristics are generalised to individuals.

Although statistically significant differences between null multilevel and null single-level regressions indicate area-level effects, this is an insufficient justification for the use of multilevel analysis.[365] Intra-class coefficients (ICC) and variance partition coefficients (VPC) are considered useful to convey the practical importance of clustering.[365] There is no threshold for ICCs or VPCs to dictate whether multilevel modelling is necessary.[364] Some argue that an ICC of around 0.10 with a range of 0-1.0 would indicate non-trivial clustering.[366] However, others caution against avoiding multilevel modelling based on low ICC values and advocate judgement based on data structure.[367] Considering all of this, the epidemiological assessment comprised negative binomial multilevel modelling based on: 1) the data structure of individual decedent and local authority levels,[367] 2) the significantly improved model fit between intercept-only and two-level variance-components models ($p<0.001$), and 3) that 6.5% of the variance in the model was explained by differences between local authorities (VPC=0.065), as calculated using the method described by Leckie *et al.*[365]

A zero-truncated negative binomial regression was used for the sensitivity analysis, as this used a subset of the sample comprising decedents who had at least one ED attendance in the last year of life only.

6.7.1 Selection of variables included in the final model

The selection of variables in the final model was based on managing multicollinearity and improving the model fit. Multicollinearity is the linear relationship between two or more variables. It is common in observational studies and can be implied by a high correlation between two explanatory variables.[368] Multicollinearity can overinflate standard errors and cause type 2 errors.[369] There are different methods available to assess multicollinearity, from Pearson correlations and Variance Inflation Factors (VIF).[370] Thresholds to indicate multicollinearity differ across studies, using correlation coefficients,[371, 372] and VIFs.[373] Some have advised using thresholds that are determined by consideration of practicalities and context,[374] which was used to inform variable selection in the epidemiological assessment. Adult Social Care expenditure correlated with the Carer and Professional FTE data ($r=0.67$ and $r=0.66$, respectively). As the policy implications for workforce would potentially be more useful than implications for expenditure, the latter was excluded from analyses. Adult Social

Care Professional FTE also correlated with number of nursing home beds (r=0.56). As there was more literature indicating an association of care homes on end-of-life ED attendance than for Adult Social Care professionals, the latter was excluded from analyses to augment the evidence base.

Variable selection is regarded as one of the most difficult aspects of model building.[375] Stepwise regression, such as forward selection or backwards elimination, sequentially selects explanatory variables for inclusion in multiple regression models based on statistical significance. Despite its popularity,[376] there are strong statistical arguments against using stepwise regression.[377] For example, it is said to underestimate the standard error of coefficients which can lead to overfitting the model.[378] Stepwise regression may also overlook variables that have causal effect but which are not statistically significant, and vice versa.[377] Used with big data, these issues are magnified: so-called "data-mining on steroids".[377 (p.5)] Several myths surrounding variable selection have perpetuated the use of stepwise regression,[376] and possibly the ease of computation with stepwise regression codes embedded in statistical software.[377]

Backwards elimination is generally preferred over forward selection.[376] However, neither method can adequately accommodate the complexities of 'change-in-estimate',[379] where the magnitude of association for one variable changes based on the removal of another. Forward selection is also less susceptible to issues of collinearity and starts with smaller models,[375] making it easier to manage. In either circumstance, recommendations in variable selection emphasise avoiding stepwise regression altogether, or at least first considering its necessity.[376] Alternatively, there are calls to base variable selection on theory and a priori hypotheses. While some argue that a theory-driven approach prohibits 'data to speak for themselves' and limits advancement in knowledge,[380] the importance of previous literature and theory in directing variable selection is largely advocated.[376]

As there is no universal approach for variable selection,[381] it was considered appropriate for the epidemiological assessment that forward selection was used to facilitate model building, but using previous literature and theory to dictate final exclusion of any variables with non-significant likelihood ratios. This enabled a systematic approach to model building, while prioritising the authority of theory. To monitor model stability during model building, measures of goodness-of-fit (i.e., deviance, AIC/BIC) were monitored with each iteration.[376] Four explanatory variables were subsequently queried based on statistical non-significance of the likelihood ratio: number of GP FTE, number of Primary Care Nurses FTE, number of emergency departments and number of urgent treatment centres. Based on previous literature and theories of healthcare access, all variables were included despite statistical non-significance, except the number of Primary Care Nurse FTE. The literature was relatively sparse to justify its inclusion, considering the statistical evidence of poor model fit. Therefore, this variable was excluded from analyses.

6.8 Ethical considerations

The use of big data is recognised as offering value for public health.[382] However, big data has also been subject to speculation of ethical, legal and epistemic concerns.[383] Much of the ethical controversy of big data comes from studies using social media posts,[384] or its use in political movements.[385] In public health and health sciences specifically, issues of informed consent, anonymisation and data protection have been raised.[383] As the epidemiological assessment used data from decedent records, no ethical approval was required since the General Data Protection Regulation (GDPR) only applies to identifiable living individuals and data from decedents no longer constitute personal data.[386] All hospital data used in the study were from patients who had not opted out of their data being used for purposes beyond individual care, therefore informed consent is assumed. It is possible that there is some bias in the data, as there were two months in the data when the opt-out initiative was not operational.[387] However, the influence of this on representativeness of the sample is considered negligible, as figures in March 2019 showed 2.74% of all registered patients had opted out, and the average opt-out rate among patients aged between aged 60 to 90yrs+ was 3.8%.[387]

As data was obtained at the record-level to observe patterns and frequency of ED attendance in decedents' last year of life, it was imperative that individuals could not be identified. The data received from NHS Digital was pseudonymised, where identifiable data are replaced with codes or numbers. This compares to anonymisation where identifiable data is concealed or deleted to prohibit identification of data subjects.[388] There was single flow of pseudonymised data from NHS Digital to King's College London, ensuring that only de-identified data was stored and processed at King's. This was vital to mitigate risks of identifying individual patients within the dataset. As well as using pseudonymised data, efforts to mitigate identification of decedents included presentation of results at an aggregate level, with small cell counts suppressed (n<10). Furthermore, no record-level data was shared with any third-party, in accordance with the Data Sharing Agreement with NHS Digital (Appendix D1).

It is well-recognised that accessing health and social care administrative data is a lengthy and uncertain process, as necessary for the ethical and legal provision, storage, and processing of patient data.[301] Strong governance was therefore necessary for the epidemiological assessment. This was achieved by successful completion of a comprehensive data sharing application and accreditation as an ONS Safe Researcher, and maintained with annual completion of the Data Security and Protection Toolkit, a self-assessment audit that measures departmental performance against National Data Guardian's data security standards.

6.9 End of chapter summary

Based on the second objective and scope of the thesis, review of extant theory and literature, and consideration of data availability and the social context in which the research was situated, the epidemiological assessment used a positivist approach to conduct multilevel analysis of population-based routine collected data within a retrospective cohort study design. Death certificates were used to identify cases and hospital statistics were used to measure the number of ED attendances in the last year of life and individual-level factors. Service-level data were from publicly available datasets measured at the local authority level. With similar critical consideration of methodological integrity, the next chapter will describe the development of the educational and ecological assessment.

7 METHOD 3: EDUCATIONAL AND ECOLOGICAL ASSESSMENT

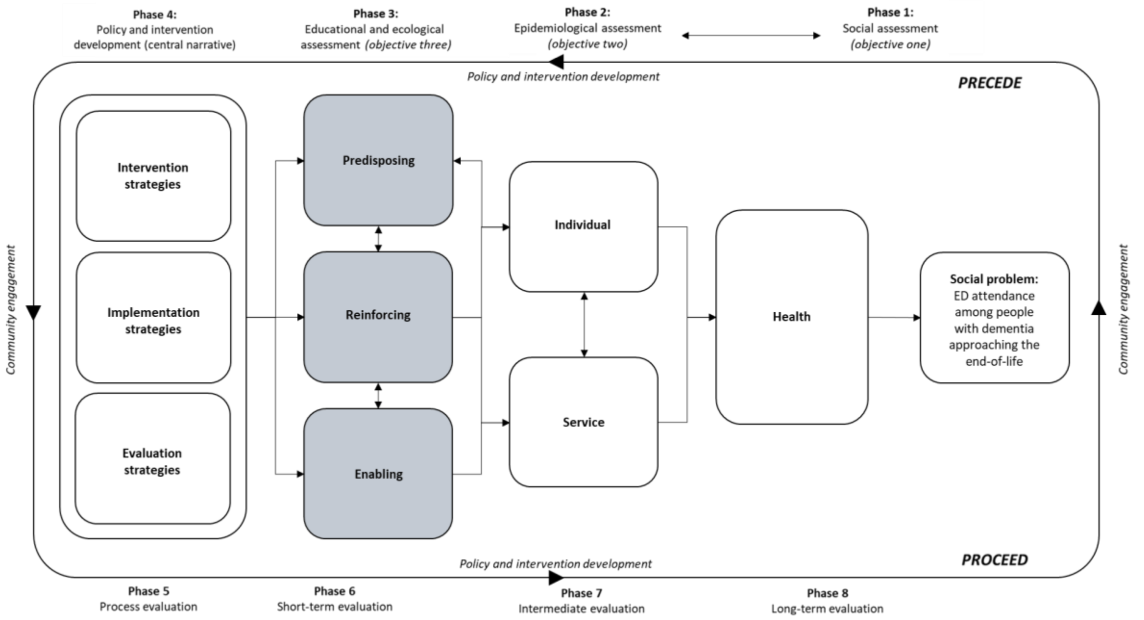


Figure 7.1 Educational and ecological assessment (phase 3)
Objective three, to develop a conceptual model of emergency department attendance among people with dementia towards the end of life.

The educational and ecological assessment is the third phase of the PRECEDE component of the PRECEDE-PROCEED Model (PPM) and meets objective 3 (Figure 7.1). The educational and ecological assessment is focused on integrating findings from the social and epidemiological assessments to identify interdependent factors that predispose, reinforce, and enable change in behaviour and environment.[389] This chapter details the design considerations of the educational and ecological assessment.

7.1 Methodological considerations

As a pragmatist approach was adopted for this thesis, the integration of findings was conducted using pragmatist principles of abduction, intersubjectivity and transferability.[109] Abduction is the back-and-forth process of making logical connections between data and theory, alternating between inductive and deductive reasoning. It is considered fundamental to pragmatist inquiry and, in this thesis, involved working back and forth between the different kinds of knowledge produced in the social and epidemiological assessments, seeking useful points of connection.[109] In doing so, alternating frames of reference were used between the subjectivity of the social assessment and the objectivity of epidemiological assessment to intersubjectively create shared meanings between them.[109] As the aim of integration was to develop a conceptual model of ED attendance, it was important that its development involved working back and forth between the context-specificity of the social assessment and generalisability of the epidemiological assessment, therefore increasing its transferability to other situations.[109] This was essential to ensure the model and its assertions were warranted and could be used to improve the social problem,[99, 390] informing policy and practice.

7.2 Intersectional ecological framework and relational model of dementia

The intersectional ecological framework and relational model of dementia were used to inform the interpretation of integrated findings and were built on in the conceptual model of ED attendance among people with dementia approaching the end of life.[39, 391] These models focus on the social identities of individuals within the wider context, which suited the context-dependent, social justice tenets of the pragmatist approach to integrating the findings of the social and epidemiological assessments.

The intersectional ecological framework is a hybrid framework drawing on intersectionality theory and Bronfenbrenner’s ecological model of development.[391] Intersectionality theory focuses on multiple intersecting social identities such as ethnicity, gender and socioeconomic position, and their interaction within the context of systemic power relations.[391] It postulates that the influence of different social identities operate synergistically (rather than additively) to position individuals in different social contexts, which may or may not be conducive to an individual’s life as privilege or oppression is shaped.[392] Bronfenbrenner’s ecological model focuses on human development as an interaction between individuals and context (ecosystems).[393] An intersectional lens was therefore applied to the Bronfenbrenner’s model in the intersectional ecological framework, which was developed within disability literature to ensure intersectionality research considers systemic influences.[391]

Although there is limited application of the intersectional ecological framework in the literature, it is conceptually coherent to the aim and scope of the thesis and educational and ecological assessment. Furthermore, the constituent intersectional and ecological components of the framework have been widely cited and are applicable to the thesis. Specifically, the main tenets of intersectionality theory underscore the principles of social justice and equity,[394] which is aligned to the pragmatist approach.[395] It provides a useful guide to investigating inequity of healthcare access,[396] and it can be used to inform policy development and social change.[397] Similarly, the ecological model has been applied to describe home service use among older adults,[398] and complexity within palliative care.[399] Furthermore, the layered ecosystems have been adopted more broadly as a part of a social ecological approach,[400] which has been used to illustrate levels of influence in accessing healthcare services among minority groups such as people with HIV/AIDS, deaf sign language users and racialised immigrants,[401-403] and applied to public mental health policy.[404] The intersectional ecological framework was also sufficiently flexible to accommodate the predisposing, reinforcing and enabling factors that underpin the educational and ecological assessment.

As introduced in Chapter 2.1.2, there are conceptualisations of disability in dementia that extend beyond the biomedical model that can advance the rights of people with dementia. The relational model of disability in dementia adopts a nuanced approach that considers disability in dementia from impairments of the disease and societal barriers.[39] This contrasts the social model of disability,[37] which only considers societal barriers and arguably falls short in accounting for the complex, multidimensional nature of dementia, and the disability experience.[405] Although social conceptualisations of dementia has moved policy focus away from the biomedical view of dementia,[406] the relational model suggests that as well as the need to empower people with dementia, policy also needs to reflect the support and safeguarding that is needed as the disease progresses.[39] The recognition of dementia as both a source of social disadvantage and as a neurodegenerative, terminal disease more comprehensively corresponded to the educational and ecological assessment, accommodating for the stigma-related findings of the social assessment and the risk-related findings of the epidemiological assessment. Therefore, a relational lens was applied to the intersectional ecological framework to inform the interpretation of the educational and ecological assessment.

Alternative models to apply to the educational and ecological assessment included the behavioural model of healthcare use,[158] and the candidacy model of access used in the social assessment.[157] While the behavioural model has similar core features to the educational and ecological assessment, this overlap was insufficient to explain ED attendance and therefore fell short of meeting the aim of developing a conceptual model. The behavioural model is also limited in its focus on service use rather than access, which may have oversimplified the phenomenon. By contrast, the candidacy model does have explanatory power for the construct of access, which goes beyond categorised factors. While this model sufficiently complemented the social assessment, it was insufficient to fully account for the complementary contribution of the epidemiological assessment in the integration of findings. Therefore, neither the behavioural nor candidacy model were used in the educational and ecological assessment.

7.3 Design considerations

7.3.1 Mixed methods approach

Mixed methods research is defined as an approach to collecting and integrating data from quantitative and qualitative methods, combining the strengths of both.[407] It is suited to research that asks real-life contextual questions, with a systemic, multi-layered focus,[408] and is one of the reasons why it is used in health services research.[409] However, there are challenges associated with mixed methods research, including methodological expertise, and achieving true integration of findings.[410] It is advocated that researchers' rationale for choosing a mixed methods approach should be transparent to facilitate quality assessment.[407, 411] While the rationale for using a mixed methods approach was discussed in Chapter 4.1.1, further details are explicitly discussed below.

7.3.2 Purpose of a mixed methods design

The purpose of conducting a mixed methods design ultimately depends on the research question,[100] and coheres with a pragmatist approach wherein the nature of the research question drives the choice of methods.[99] This study's question centred around conceptualising the determinants of ED attendance among people with dementia towards the end of life. As mentioned previously (Chapter 6.1), measuring associations between different immutable factors and ED attendance in the last year of life provides insight into the characteristics of people most at risk of attending the ED and identifies potentially modifiable factors. However, it remains unclear why people with dementia attend the ED. Similarly, exploring experiences of attending the ED and its perceived value among individuals affected with dementia gives insight into why some people attend the ED, but it is not clear who is most likely to attend or what is most likely to mitigate attendance. Complementary integration of inferences from each approach will bridge this divide, providing context and enhancing the applicability and integrity of findings, which cannot be accomplished independently. Therefore, this study used the mixed methods design for the purpose of complementarity.[412]

7.3.3 Convergent parallel mixed methods design

Due to funding requisites, the study was of a fixed design in that the quantitative and qualitative components were pre-planned, rather than emerging through the process of research. However, as most mixed methods study designs are a combination of fixed and emergent designs,[407] the research process remained open to accommodating for any unexpected findings warranting further inquiry or a change in approach. Aside from changes to individual study design due to the Covid-19 pandemic (Chapter 11.6.8), there were no major deviations in the overall mixed methods design. As the dynamic approach to design is best preserved for the more experienced researcher,[407] the design of this study was based on existing typology. There are various typologies of mixed methods study designs, as summarised by Creswell and Plano Clark.[407] (p.56-59) Although differing in description, the meanings are similar across typologies. On this basis, for simplicity and consistency of explanation, this study is described using the typology put forward by Creswell and Plano Clark,[407] and is labelled as a convergent, parallel mixed methods design (Figure 7.2).

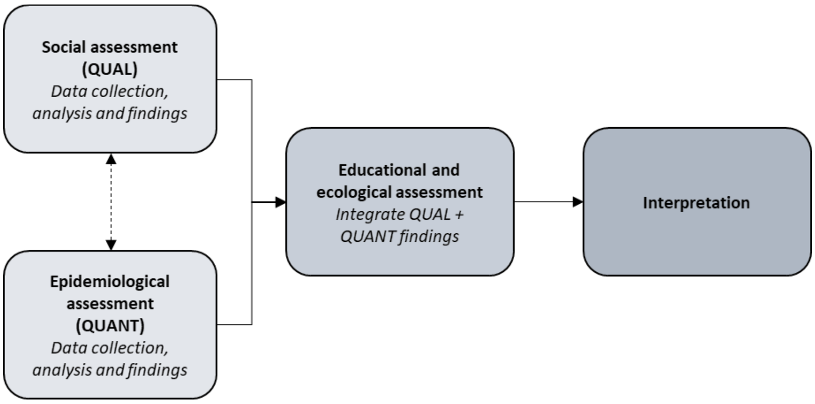


Figure 7.2 Convergent, parallel mixed methods design

Rationale for using this design is based on the priority assigned to the quantitative and qualitative components of the study, as well as the points of integration. This thesis assumed equal priority between social and epidemiological assessments (QUAL + QUANT), which was aligned to the research question and the PPM. As equal priority was assumed, the qualitative and quantitative components were completed concurrently. Other designs such as the explanatory or exploratory designs have quantitative and qualitative priority (respectively) and objectives that were not suited to the research aim. Although it could be argued that the exploratory design assists theory development and thus may facilitate developing a conceptual model, this design is better suited in the context of developing a new instrument,[413] or to identify important quantitative variables when none are known. Similarly, embedded designs are more suited to experimental or intervention studies,[413] and therefore were not conceptually coherent with this study.

7.3.3.1 Partially mixed design

Mixed methods research is viewed on a continuum from ‘not mixed’ to ‘fully mixed’, with ‘partially mixed’ residing somewhere in between.[414] Therefore, the level at which constituent studies interact is a necessary consideration to mixed methods design.[93] Fully mixed designs involve integration across all five phases of research (design, data collection, sampling, analysis and drawing inferences).[415] By contrast, in a partially mixed design, the constituent studies are conducted separately, as seen in convergent, parallel mixed methods research. Therefore, this mixed methods integration was conducted using a partially mixed design. The social and epidemiological assessments informed each other at different stages, as summarised in Table 7.1.

Using a convergent, parallel design gives opportunity to use each study to inform the other’s design and execution, preserving the pragmatist belief-action cycle. The designs of both social and epidemiological assessments prohibited integration at the sampling phase, since the epidemiological assessment used anonymised data on decedents and the social assessment included people living with dementia. Given this, ‘type 2’ multilevel sampling was used to combine probability and purposive sampling.[416] Multilevel sampling has the advantages of supporting inferences that are generalisable to other settings and populations.[415] Inferences from each assessment were juxtaposed for the purpose of integration. The rationale and quality considerations around this are discussed later (Chapter 7.4.3).

Table 7.1 Mixed methods summary
Adapted from design template from Creamer (2017)[415]

Design characteristics			
Rationale/purpose	Complementarity		
Priority	Equal status (QUAN+QUAL)		
Timing of data collection	Concurrent		
Timing of data analysis	Concurrent		
Mixed by stage	Level of integration		*Partially mixed*
	Design	✓	*Separate but linked studies*
	Data collection	--	*Multilevel sampling (different populations)*
	Data analysis	--	*Parallel-track analysis*
	Inferences	✓	*Inferences from both studies juxtaposed*

7.3.3.2 Points of interface

As the social and epidemiological assessments were conducted in parallel, it was possible to actively influence the design of one based on the development of the other. Table 7.2 provides a summary of how the two assessments interacted. Specifically, workforce capacity and service availability were included as explanatory variables in the epidemiological study based on interview responses. Concerted efforts during recruitment for the social assessment was influenced by preliminary analyses of the epidemiological assessment, which included ethnicity and care home residence. Finally, both social and epidemiological assessments showed converging themes of regional and socioeconomic differences in health and social care access. This observation gave further credence to including local area-level differences of service-related factors in the epidemiological assessment and to continue to recruit participants from across the country and explore the influence of socioeconomics on experiences of ED attendance in the social assessment.

Table 7.2 Points of interface between social and epidemiological assessments
Themes and direction of influence between social and epidemiological assessments

Social assessment	*Influence*	*Epidemiological assessment*
Admiral Nurses	⟶	Explanatory variable
Adult Social Care workforce	⟶	Explanatory variable
Urgent treatment centres	⟶	Explanatory variable
Purposive sampling	⟵	Ethnicity
Purposive sampling	⟵	Nursing/residential homes
Postcode lottery	⟶ ⟵	Regional differences
Financial stability	⟶ ⟵	Socioeconomic position

7.4 Analysis method considerations

7.4.1 Using parallel mixed analysis

The analysis strategy for the mixed methods study was a parallel mixed analysis, which suits the complementarity purpose of this mixed methods research.[417] This approach, sometimes referred to as parallel-tracks analysis,[418] involves analysing the qualitative and quantitative studies separately, with inferences (or ‘claims’[419]) integrated into meta-inferences in the final analysis.[420] This is the most used mixed methods analysis technique,[421] and cohered most with the research question, purpose and design of mixed methods research in this thesis, and structure of the PPM. It also corresponded to the complementary nature of the social and epidemiological assessments, as they provided different insights into the same phenomenon of interest.[421] Furthermore, parallel mixed analysis best suits the pragmatic approach for mixing methods,[93] preserving methodological integrity of constituent studies.[93] It also offers the advantage of avoiding premature closure of analysis.[422] Alternative analysis options included sequential mixed analysis,[417] which does not cohere to the complementarity purpose of mixing methods used in this thesis. Concurrent mixed analysis was another option, which involves using the same analytical framework with integration at the initial data analysis stage.[417] This approach was not adopted as it was inconsistent with the chosen mixed methods design and the designs of the social and epidemiological assessments.

7.4.2 Integration of claims using a joint display

Using parallel mixed analysis strategy excludes strategies that integrate at the level of data analysis, such as ‘following a thread’,[423] and the Pillar Integration Process.[424] Integration at the interpretation level involves employing a triangulation protocol, where triangulation refers to combining methods to gain a more complete picture (rather than for mutual validation).[425, 426] By juxtaposing findings of each constituent study, points of convergence, complementarity and contradiction can be ascertained.[425] This juxtaposition can be best achieved using a side-by-side joint display that provides a visual scaffold to facilitate integration and promote transparency.[427] The side-by-side joint display is the most used type of display,[428] and has previously been applied to the PPM.[429] It also aligned to the complementarity purpose of mixing methods, as it facilitates merging of inferences. Approaches other than merging, such as connecting, building, and embedding were incongruent to the chosen mixed methods design.[430] Furthermore, merging involves moving backward and forward inductively and deductively to "jointly constitute" the phenomenon of interest.[426 (p.107)] As mentioned earlier, this process of abduction is fundamental to pragmatism, which further enhanced the methodological integrity of the thesis.

Integrated claims, or inferences, are intended to reach beyond the findings of each constituent study, therefore building an argument rather than presenting an accumulation of information.[426] As a hallmark of mixed methods research, meta-inferences are theoretical statements or narrative products of successive integrated claims.[419, 431] Despite being of central importance in mixed methods research, the process of integration is often poorly documented in studies.[419] However, Schoonenboom (2022) has recently developed guidance to facilitate integration, providing instruction on the back-and-forth process of emerging successive integrative claims that culminate in a meta-inference (Figure 7.3).[419] The guidance is helpful to demonstrate transparency and robustness of the integration process and was therefore used to facilitate the mixed methods analysis.

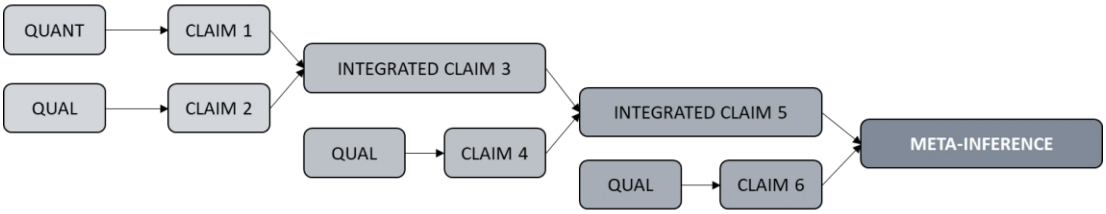


Figure 7.3 Process of integrating claims

Claims from quantitative and qualitative strands are merged to form an integrated claim, which can be further merged with a third primary claim. This process continues and culminates in a meta-inference.

According to the guidance, the nature of integrated claims is labelled: confirmation, contradiction, juxtaposition, or explanation. As well as promoting integration transparency, these labels also underscore the utility of mixed methods research, as contradiction and explanation are considered useful to develop a unique meta-inference that could not have been determined without integration.[419] To facilitate identifying contradictory integrated claims, ‘bracketing’ and ‘bridging’ methods were employed in the educational and ecological assessment.[432] Bracketing involves capturing diverse and surprising findings to develop claims about the nature of the contradictions, whereas bridging involves developing a consensus between findings.[432] Although bracketing is better suited to concurrent designs,[431] both were employed to obtain a full picture of ED attendance among people with dementia nearing the end of life.

7.4.3 Quality of integration

It has been argued that there is no need to develop a new term for validity in mixed methods research, as validity is already widely applied to both quantitative and qualitative research.[407] However, others have advocated the term ‘inference quality’ to apply validity to mixed methods research.[421, 431] For the educational and ecological assessment, attention was paid to developing a meta-inference that was theoretically-consistent, transferable, consistent with social and epidemiological assessment inferences, and cohered to the purpose of using a mixed method design.[431, 433] In line with Onwuegbuzie and Johnson (2006), ‘legitimation checks’ were considered at each stage of the mixed methods process.[434] Specifically, there are nine types of legitimation, though not all are applicable to every mixed methods study. Only those that were relevant were considered in development of this mixed methods integration (Table 7.3).

Table 7.3 Legitimation type and mitigation
Based on Onwuegbuzie and Johnson (2006) 'legitimation checks'[434]

Legitimation	*Approaches to mitigate legitimation issues*
Sample integration legitimation: Degree to which the relationship between qualitative and quantitative sampling affects the quality of meta-inferences.	Multilevel sampling was used in this study to investigate different aspects of the same phenomenon (Chapter 7.3.3.1).
Inside-outside legitimation: Degree to which the researcher accurately presents and utilises the insider's view and the observer's view.	Peer review, supervision and sense-checking with public representatives were used to confirm insider-outsider legitimation for each assessment (Chapter 4.3).
Weakness minimisation legitimation: Degree of complementarity between strengths and weaknesses of qualitative and quantitative methods.	The designs of social and epidemiological assessments were considered in relation to each other to ensure complementarity (Chapter 7.3.3.2).
Paradigmatic mixing legitimation: Degree to which metaphysical approaches in each strand are combined or blended.	The pragmatist approach avoids any concerns of competing dualisms and treats the contrasting paradigms as compatible (Chapter 4.1.2).
Commensurability legitimation: Degree to which meta-inferences reflect a fully mixed worldview that is beyond each strand viewpoints.	The pragmatist approach assumes intersubjectivity, wherein knowledge is created through joint action and shared meanings.[109] It therefore counters incommensurability issues.
Multiple validities legitimation: Degree of validity of qualitative and quantitative strands.	Both social and epidemiological assessments have been developed with critical consideration to optimising validity (Chapters 5 and 6).
Political legitimation: Degree to which stakeholders value meta-inferences derived from both strands.	Research was designed and executed with the value of utility for change. This ambition was facilitated by the application of the PPM and the priority given to community engagement (Chapter 4.3).

7.5 End of chapter summary

Based on the third objective and scope of the thesis, and review of extant theory and literature, the educational and ecological assessment used a pragmatist approach to integrate the findings of the social and epidemiological assessments within a partially mixed, convergent parallel design for the purpose of complementarity. Findings were mixed by successive integration of claims using joint display.

Having critically considered the methodological and design elements of each assessment to ensure methodological integrity, the following Results chapters present the findings of each assessment.

8 RESULTS 1: SOCIAL ASSESSMENT

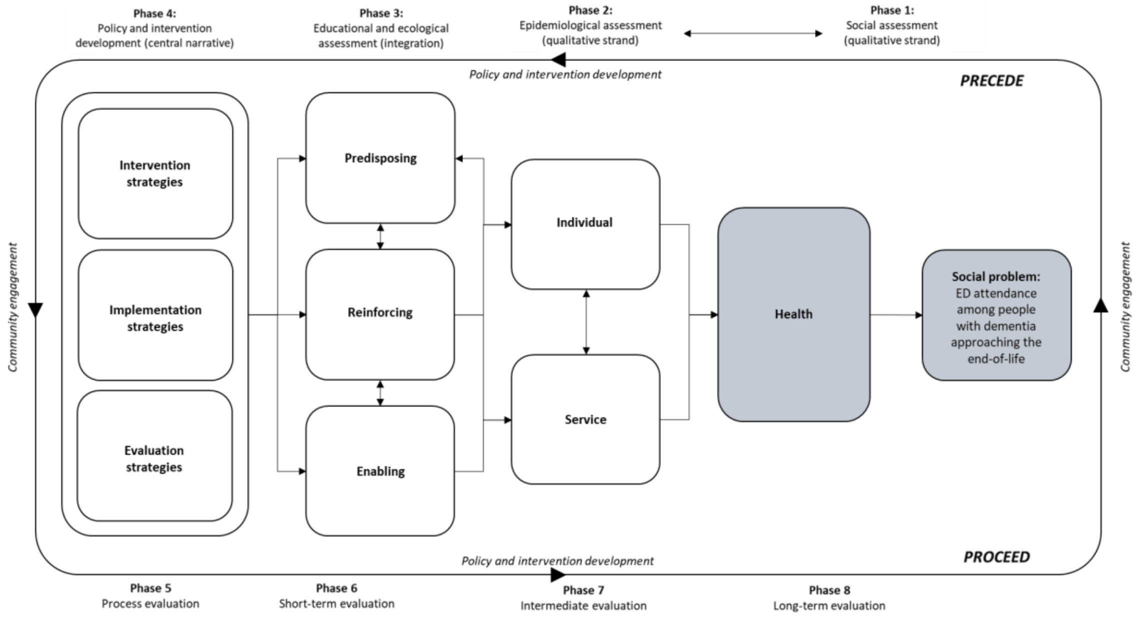


Figure 8.1 Social assessment (phase 1, in parallel with phase 2)
Objective one, to explore the drivers of emergency department attendance among people with dementia across the illness trajectory.

This chapter presents results of the social assessment, submitted as a paper to the International Journal of Geriatric Psychiatry. The social assessment is a qualitative interview study and the first phase of the PRECEDE-PROCEED Model (PPM), completed in parallel with the second phase, meeting objective 1 (Figure 8.1). Following presentation of the results, this chapter summarises feedback from public representatives of the expert panel. The findings and public representative feedback were used to inform the overall target and health targets for change, as part of the PPM's planning process.

Supplementary material for the social assessment is in Appendix C.

8.1 Drivers of emergency department attendance among people with dementia across the illness trajectory: A qualitative interview study (under peer review)

8.1.1 Introduction

Most people with dementia have at least one emergency department (ED) attendance each year, and represent almost half of all older adults attending the ED.[435] Despite this, the nature and purpose of the ED is considered incongruent to the needs of people with dementia.[11] Furthermore, ED attendance is associated with higher rates of delirium, antipsychotic administration, hospital admission, and mortality among people with dementia compared to those without.[7, 8] As reducing emergency admissions among people with dementia is a policy priority in the United Kingdom (UK),[436] it is essential that we better understand why ED attendance is so common in this population.

Research shows that increased ED attendance among people with dementia is associated with lower socioeconomic position, minoritised ethnicity,[323] multimorbidity, and polypharmacy,[437] whereas decreased attendance is associated with care home residence,[323] and continuity of care.[438] Compared to people without dementia, those with dementia are at increased odds of attending the ED for conditions that are potentially manageable in the community.[6] Limited availability and access to community support contributes to urgent care use among people with dementia.[439] Moreover, inequity of access to community support is well-recognised among people with lower socioeconomic position and from minoritised ethnic groups, which worsened during the pandemic.[440]

While dementia severity is not associated with emergency admissions,[441] rates of unplanned hospitalisations typically increase as people with dementia approach the end-of-life,[5] with number of ED attendances dramatically increasing in the last year of life.[4] Understanding why ED attendance differs across the dementia trajectory, from the perspectives of those attending, is vital to inform policy and care pathways.[442] On this basis, we aimed to explore the drivers of ED attendance among people with dementia across the illness trajectory, from the perspectives of people with dementia, and current and bereaved family caregivers.

8.1.2 Materials and method

To maximise rigour, we used Braun and Clarke's checklist[251] to prompt our engagement with the data, reflexivity, and cognisance with theoretical assumptions. We used the consolidated criteria for reporting qualitative studies (COREQ)-32 item checklist[443] to facilitate transparency in our reporting (Appendix C3).

8.1.2.1 Design and theoretical underpinning

This study was informed by critical realism, a single paradigm of ontological realism and epistemic relativism. We therefore conducted this study on the assumption that while there is an independent reality, its understanding is mediated by individual cultural, social and political influences.[147] This methodology enabled us to give a voice to people affected by dementia to describe their accounts, while also considering how their accounts were situated in the broader social and cultural context of living with dementia. Our approach to study design and analysis was informed by theories of healthcare access; namely, the Penchansky and Thomas[156] model of fit and Dixon-Woods *et al*.[157] model of candidacy. Both consider an interactive alignment between the individual and the system. However, the former comprises components of access and was used to inform the interview schedule, ensuring key domains of service access were discussed. The latter has strong explanatory value and was used to inform the interpretation of data, emphasising the complex dynamic process of healthcare access.

The study was approved by King's College London Research Ethics Committee (ref: HR/DP-20/21-21808).

8.1.2.2 Setting and selection of participants

Participants with dementia were living in the community at home. Current and bereaved caregivers discussed relatives with dementia who were or had been living either in the community in their own home, with them, or in a residential care home. We recruited using purposive sampling with maximum variation to identify uniqueness and shared patterns in heterogeneous cases.[444] This was based on self-defined socio-demographic characteristics of people living with dementia, which we had identified from previous literature: gender, ethnicity, age, socioeconomic position, rurality, dementia subtype and comorbidities.[323] We sought to identify individuals with these characteristics, monitoring recruitment to increase inclusion of under-represented characteristics. We also sought participants from across the UK.

From September 2021 to March 2022, we advertised for participants using national charitable organisations that support people affected by dementia, including the Alzheimer's Society Research Network, Dementia Engagement and Empowerment Project (DEEP), and Dementia Carers Count (Appendix C4). Gatekeepers of these charities shared study details with their members by email and/or social media, and interested individuals were asked to email or telephone LW. Participants were also recruited using Join Dementia Research, a national research register run by the National Institute for Health and Care Research (NIHR). Individuals registered with Join Dementia Research were purposively approached by LW through email, based on gender, ethnicity, and areas of socioeconomic deprivation and rurality. Participants not affiliated to the charities or Join Dementia Research were recruited by word-of-mouth. No renumeration was offered. We ceased recruitment on consideration of sufficient information power.[193]

8.1.2.3 Data collection

We used a semi-structured interview design with people living with dementia and current and bereaved family caregivers. The interview guide (Appendix C5) covered experiences of living with dementia and accessing community and emergency care, and views of the ED. The guide was informed by consultation with the Cicely Saunders Institute Patient and Public Involvement forum and included prompt questions that covered the five domains of the Penchansky and Thomas[156] model of access. The guide was piloted with a participant who was a bereaved caregiver involved in the project as a public representative. The interviewer, LW, did not know any other participant prior to initial contact. Using two questionnaires, we also collected anonymous demographic data to monitor participant heterogeneity (Appendix C6), and personal data for safeguarding purposes (Appendix C7). The questionnaires and other participant materials were developed with public representative input.

Due to ongoing social distancing restrictions of the pandemic, all contacts with participants were remote. For those responding to the study advertisement, a study information sheet was forwarded, and an online video or telephone call was arranged between LW and each prospective participant to discuss the details of the study. Following a period of at least 24hrs, LW contacted individuals again and arranged a separate call for those agreeing to take part. During this call, any queries were discussed, and verbal consent was audio recorded. Participants then completed and returned the questionnaires to LW by post or email and the interview was then arranged. Later, participants were given the option for LW to complete the questionnaires under their instruction during the call and proceed with the interview immediately thereafter. Consent, and mental capacity to consent (where appropriate), were continually assessed from point of initial contact to the end of the interview. All participants with dementia were offered the option to be accompanied during the interview. All interviews were conducted by LW by telephone or remotely using participants' preferred online communication platform.

Interviews were recorded using an encrypted audio recording device. Recordings were transcribed verbatim by either LW or an authorised third-party transcription service. Transcripts were checked against audio recordings to ensure completeness and anonymised by replacing all identifiable details with generic descriptors. Fieldnotes and reflections were documented after each interview. Verbal consent and interview audio files, fieldnotes, questionnaires, consent forms, interview transcripts, and a pseudonymisation key were stored separately on the King's College London secure server in individual password-protected files with access limited to the research team.

8.1.2.4 Data analysis

We used the reflexive thematic analysis approach,[251] as it is theoretically flexible to accommodate critical realist theory. This analysis approach was also conceptually coherent to the study aim, scope, and method, as it facilitated identifying patterns of meaning across the situated realities of participants with dementia and caregivers, before and during the pandemic, at different stages of dementia and in different regions of the country. Reflexive thematic analysis also cohered to the goal of producing analysis with actionable outcomes to inform policy and accommodates interview data.[251]

In applying reflexive thematic analysis, we mostly used an experiential framework to describe participants' experiences of living with dementia and accessing services. As the analysis progressed, we combined this with more critical elements, focusing on how participants referred to dementia and accounted for their experiences of accessing care. Our orientation to the data was mostly inductive, while our focus shifted between semantic and latent meaning. Working within six recursive phases of reflexive thematic analysis, LW critically engaged in data familiarisation and systematically, inclusively, and repeatedly engaged data items during the coding process, which evolved through multiple rounds of review and refinement using QSR NVivo 1.6. Using visual maps, LW revised and reworked candidate themes, comparing back to coded items and the dataset, and sense-checked with CE and KS. As we considered the themes within the wider evidence base, we deductively used the candidacy model of access [157] to deepen our explanatory interpretation. Furthermore, we presented our analyses and reflected on feedback from public representatives.

We reflexively approached the analysis from our own social and cultural contexts as a team of three white women researchers: two clinical professors in palliative care (CE and KS) and a PhD fellow with a clinical background in psychiatry and experience of qualitative interviewing (LW). Using a reflexive diary and fieldnotes, we interrogated our assumptions and responses to the data to further enhance our analyses.[251]

8.1.3 Results

We received expressions of interest from 52 individuals and consented 38 participants. Of those who did not take part, seven were unreachable after initial contact, four were not recruited to maximise variation, and three declined (due to paperwork, collection of sensitive data, and participating in other studies). One current caregiver withdrew due to competing commitments; therefore 37 participants took part in an interview (10 people with dementia, 11 current caregivers and 16 bereaved caregivers). Participants were from across 10 regions of the UK (7 English regions and the three devolved nations), including urban (n=16) and rural areas (n=19); 8 participants had relatives with dementia who had resided in a care home. The sample included variation in ED attendance (from 0, n=8 to ≥1, n=27) and age groups (50-69, n=11; 70-89 n=18; and 90+, n=6), but not ethnicity with only 3 participants from minoritised ethnic groups (Table 8.1). Four participants with dementia were accompanied by a relative, with one relative taking part in the interview as a consenting participant. Two caregivers sharing caregiving responsibilities were interviewed together. There were therefore two dyad interviews and 33 individual interviews. Most interviews took place online (n=26) and lasted an average 1hr20mins (43mins to 2hr4mins). Two participants had interviews over two intervals less than one week apart.

Table 8.1 Key dimensions of variation

Characteristics of person with dementia (number of participants)			
No. of ED attendances	0 ED attendance (8)	1 ED attendance (7)	≥1 ED attendance (20)
Age group	50-69 (11)	70-89 (18)	90+ (6)
Dementia subtype	More common† (29)	Less common‡ (6)	
Comorbidities	0-1 (6)	2-4 (22)	≥5 (5)
Gender	Women (24)	Men (11)	
Ethnicity	White ethnicity (32)	Black, Asian & Minority ethnicity (3)	
Socioeconomic position	Living comfortably – coping (35)	Difficult – Very difficult (0)	
Residence	Care home residence (8)	Community residence (27)	
Nearest ED	<5 miles (16)	≥5 miles (19)	

†Alzheimer's disease, vascular dementia, mixed dementia; ‡Parkinson's' disease dementia, Dementia with Lewy Bodies, Posterior Cortical Atrophy, Behavioural variant frontotemporal dementia

We developed three themes: 1) Navigating a 'push system', 2) ED as the 'last resort', and 3) Taking dementia 'seriously'. Each theme is described and illustrated with data extracts from people with dementia (PWD), bereaved carers (BC) and current carers (CC). Additional extracts are in the Appendix C8. Collectively, these themes tell a story of how the needs of the health and social care system are weighted against the needs of people with dementia and family caregivers, who push for support and reluctantly attend the ED when there are no accessible alternatives. Contributing to this is a lack of prioritisation of dementia in the system, underscoring a systemic bias that reflects wider societal stigma.

8.1.3.1 Navigating a 'push system'

This theme focuses on how participants pushed through a fragmented, crisis-weighted health and social care system with minimal guidance, as needs continued to increase. Illustrative quotes are presented in table 8.2.

Participants identified community support as imperative to living well with dementia, providing routine, social connectedness, distraction, and purpose. Family was central to facilitating this support. Family caregivers were the first point of contact for people with dementia, who worked hard to navigate the system and advocate for their relatives. However, this was particularly challenging in the absence of a formal pathway of post-diagnostic support. Specifically, mainstream diagnostic services (memory clinics) were described as having "washed their hands of you" (CC1) following diagnosis. Family caregivers described feeling alone in navigating a health and social care system that was likened to “swimming through porridge” (BC1); a “nigh impossible” (CC2) task of sourcing and chasing support, while often feeling “incredibly ignorant” (BC2) of dementia, and “making uninformed decisions” (BC12).

Many participants expressed a need for more “joined up thinking” (BC3) between services, as the lack of integration was “a nightmare” (CC2) in coordinating services, chasing services for support, escalating concerns, and supporting people with dementia to manage their care. Professionals’ poor system knowledge and sharing of information was also experienced as a hindrance, including restricted communication with family caregivers based on services “hiding behind” (BC4) patient confidentiality. Participants described geographical inconsistency in service provision, making navigation of the wider system more challenging. Those with young-onset dementia encountered barriers to support from age restricted services. Participants often sought support from the voluntary sector, which increased awareness of local services, as well as informal peer support and formal training that were practically and emotionally valuable.

In a system “geared towards someone at crisis point” (CC4), with primary care having “never been one to be forward” (PWD8), accessible support was considered to be more reactive than proactive, where it is “probably more luck than judgement that more elderly don't end up in A&E” (CC2). Participants described an under-resourced system as “too rigid… to be able to respond really effectively” (BC1), and too slow to respond to increasing needs. As dementia progressed, greater accommodation was required of the system, which was not always easily available, including timely primary care access, face-to-face clinical reviews, continuity of care, needs-based personal care, and access to dementia expertise. This was made more challenging for those in more rural areas relying on public transport. Family caregivers used combative language to describe their persistence in accessing support for their relatives; confronting professionals, having to “fight my corner” (BC5) and describing how they “stuck to my guns” (BC6) and “stood my ground” (BC7).

With the socioeconomic privilege of financial stability, education, systemic knowledge, and “clout” (CC5), some participants were better able than others to navigate, challenge, and “play the system” (CC7). Expendable finance enabled some participants to by-pass the lengthy waiting lists and purchase support from outside the system, including equipment and additional carers for “extra shifts…completely unofficial[ly]” (BC8). Financial support was available to participants living with dementia and family caregivers, but the application processes comprised "so much red tape and paperwork" (BC3) which posed a barrier for people with less time, education, or fewer connections. Financial support was also restricted to needs stipulated by the system rather than the recipients.

Table 8.2 Navigating a 'push system' – illustrative quotes
CC=Current carer; BC=Bereaved carer; PWD=Person with dementia

ID	*Quote*
CC1	"That the whole support for people with dementia it's much like, I suppose you could argue it's not a pull system, it's a push system. And it relies very much on the support that those people are receiving because, you know, to get the best treatment and help for them. Yeah, it's not a pull system. You have to get very pushy. It's quite hard I think to navigate."
PWD7	"…'Oh well this is the way we do it.' Well, that's not helpful to me because I can get my repeat prescription, but I need to get that one from somewhere else… if I went further down the line with dementia, and it did start progressing in a certain way, that wouldn't be helpful for me as I wouldn't know what to do. It's just, it's not helpful. If we could have a truly joined up service that would be, that would help everybody. It wouldn't just help people with dementia."
BC5	"and then we waited for the social workers to finally pick the case up and then you get into that fight of well, I've now got him in the day centre, we've not got him settled in this day centre as much as he didn't want to go, he's now settled, but they don't want to pay for that because he's outside the area and so they wanted him to be moved to a day centre in the area, at which point I had to fight my corner for that. And you know, it's that constant round of you know, the services not being there when you actually need them and then when they do finally pick you up, there's that bum-fight about who should be paying for what and when, so yeah, the whole thing's really quite challenging."
CC5	"I mean when I was on this course, which was run by the Alzheimer's Society I think, there was some family came in there, it was husband and wife, the wife had dementia, Alzheimer's – very like mum, in complete denial that there was anything wrong – and then the daughter would come as well. But when you looked at them, because they weren't from upper-middle class highly educated lives, you thought, how on earth do they face up to professionals trying sort-of, not, not, I could imagine for a person of that level of society that the professionals could be overbearing and not take notice of what they're trying to tell them. It wouldn't be everywhere, but I think they would more easily be railroaded than somebody like me with [brother] behind me."
BC13	"I had a lady called [name], who was an ex-nurse… they'd set up a local domiciliary care agency and I was given her details by a social worker who we were dealing with on a different problem, and she said, 'she's very good, because you're self-funding', you know, 'if you go through our assessment, I'll probably point you towards [ex-nurse] anyway, and you'll still have to pay for her, but you'd have lost three months', so, you know."

8.1.3.2 ED as the 'last resort'

This theme focuses on the risks associated with attending the ED, and how family caregivers fought to keep relatives with dementia out of the ED, unless it was deemed necessary. Illustrative quotes are presented in table 8.3.

There was clear consensus among participants that the ED should be avoided. Concerns of catching "hospital bugs" (BC8) and Covid-19 were firm deterrents, as was the ED environment. The noise and bustle, and other patients in the ED made it "everything that dementia doesn't like" (PWD1). The lengthy waits on "hard seats" (PWD2) or "in a trolley in a corridor" (BC6), with no food or drink, or any certainty over what was happening reinforced the need to avoid the ED "at all costs" (BC10). When attending the ED alone, participants with dementia described feeling vulnerable, with no-one "to have your back" (PWD3) or "to be your voice" (PWD1), while family caregivers described feeling anxious. There was also "the fear of being made an inpatient" (PWD4) and being "stuck in" (CC6) hospital with no control. As the acute hospital "isn't really equipped" (CC3) to meet the needs of people with dementia, participants were mindful that dementia status could be poorer on discharge than before admission.

Participants were clear that ED attendance would be a "last resort" (BC8), only accessed in times when the person with dementia was critically unwell or required interventions that were only accessible in hospital. However, participants found that efforts to avoid attendance were sometimes unsuccessful, where their voice was unheard and plans to only attend for investigation fell through. Family caregivers described having limited options during points of decline, particularly out-of-hours. They described the ED as an easy option for healthcare staff, driven by "flippant" (CC6) clinical decisions made in primary care. Care homes without nursing staff would go "by the book rather than by the needs" (BC7) or preferences of residents, due to limited access to clinical support and being "so risk averse" (BC1). Family caregivers "protested against" (BC7) routine ED transfers, advocating for the needs and wishes of their relatives. These disputes emphasised the needs of the system weighted against the needs and preferences of participants. For participants, this was a question of quality of life; for the system, it was perceived to be a question of ease of access and "preservation for the sake of it" (CC3).

Participants wanting to avoid the ED found less resistance from healthcare staff when the person with dementia was recognised as approaching the end-of-life. This though was often when death was imminent. Participants recognised there was a "tipping point" (BC6) when the risks of attending the ED outweighed the benefit. However, "to actually weigh up when it makes sense not to fight and when it makes sense to fight is, is difficult" (BC11) and bound by ethical complexities and clinical uncertainties, which underscored the need for clinical guidance. Participants generally spoke in favour of end-of-life care planning to support decisions around attending the ED. While advance care plans empowered family caregivers to advocate their relatives' wishes, these were not always observed in the healthcare system, as plans were sometimes overlooked or disregarded. Furthermore, access to community end-of-life care was challenging and often unsuccessful unless initiated at the point of hospital discharge.

Table 8.3 ED as the 'last resort' – illustrative quotes
CC=Current carer; BC=Bereaved carer; PWD=Person with dementia

ID	*Quote*
PWD3	"All the noise, the machines bleeping, a lot of background noise. People talking all over the place becomes really, it makes your disorientation ten times worse. Because you can't focus on anything, there's just so much going on."
BC11	"…my eyes filled up with tears that the fact that nobody suggested where were could get – we were there all day basically, waiting around for this, that and the other, and no-one – I don't know if they even knew he had dementia but we had nothing to eat, nothing to drink, I couldn't even go to the loo in peace because I didn't know if he would wander off or if they would come, when I was not there, so I just remember it as a totally miserable day, when there was nobody, nobody sort of taking care of us."
PWD6	"Because the A&E isn't any place for someone with dementia. Hospital isn't any place for someone with dementia. We need to be in our own environment. We need to have hospital at home, if you like, simply because you go in the hospital, you don't come out at the same level as you were when you went in. I have seen it with so, so many of my friends. Just the noise, the lack of routine, lack of knowledge, lack of understanding, makes it just an alien environment. And that's why I simply won't go in anymore."
BC10	"in out-of-hours, you've got nobody because you got – I got no contact from the memory clinic for an out-of-hours service and so you're relying on triple 1 [integrated urgent care telephone service] and they don't want to know if it's dementia because there's nothing they can do. They know that they'll be here for hours if they come to someone's house and there's delirium going on, they've got other calls to make, and they know they're going to get stuck, and they can't do anything. So, we end up, the last thing is an ambulance to A&E. And really, it's that bit there when these things – they seem to forget that these issues with dementia people don't happen during office hours, they happen at the worst possible times, seven o'clock at night, when the sundown thing comes on, or whenever, or they wake up during the night when, and then you're stuck at four o'clock in the morning. And there's nowhere else to go."
BC1	"And then, when he was in the care home, we had a double layer of that because we had the care home who didn't want to take the risk of not sending him to hospital, and we had the paramedics who came in who propped them up and said, 'oh, no, no, no, we've got to take him in' or whatever… one of the paramedics said to me, 'it's just not worth my job not to take you in', and I said, 'isn't it worth his life and his quality of life?' And he sort of just looked at me and said 'Sorry, I understand but he's going to have to go in', and off we went for another eight-hour stint. You know, in A&E."

8.1.3.3 Taking dementia 'seriously'

This theme focuses on the experiences of dementia as a poorly prioritised condition within the health and social care system, reflective of wider societal stigma around dementia. Illustrative quotes are presented in table 8.4.

Participants repeatedly identified a lack of parity between dementia and other life-limiting conditions, noting that "there is nobody who will be continuous with me… will go through my life with dementia" (PWD5). Unlike other conditions, dementia was described as not sitting neatly in the health and social care system. Participants were often “caught between medic and mental” (BC10), passed between professionals, where dementia was reduced to “a hot potato; no-one wants to hold on to it and handle it” (PWD4). Most participants with rarer dementias accessed multidisciplinary teams through psychiatry services and specialist clinical research centres. Those with more common dementias had no specialist follow-up. While ‘Admiral Nurses’ (specialist dementia nurses) were a highly commended intermediary, their availability was limited by a “postcode lottery” (PWD4) based on the priority assigned to dementia care at the local commissioning level.

Participants noted a lack of clinical oversight and responsive clinical care in dementia compared to other medical conditions. Most family caregivers requesting referrals to palliative care were refused, despite this option being available to people with other life-limiting conditions. Participants described not being “taken seriously” (CC6); unheard and passed off in the system where dementia often denoted poor quality of life and end-stage disease, and where needs were often met with “token gesture” (PWD1) initiatives that often missed the mark. Behavioural manifestations of physical illness were believed to have been seen as no more than a progression of dementia. Participants also described a clinical preoccupation with urinary tract infections as the limit of clinical workups, while neuropsychiatric causes of physical complaints were misdiagnosed and undertreated. Some caregivers, again, had to “fight and fight and fight” (CC6) to access clinical support, with success determined by having expertise in dementia, or having “threatened” to complain (CC1). Despite “a lack of faith, definitely” (PWD4), participants were generally sympathetic towards staff and recognised competency boundaries in non-specialists. There was appreciation that “dementia itself is a complicating factor” (BC1) in diagnosing and managing illness. However, there were strong calls for more training, particularly around “the ‘living with’ side” of dementia (PWD6) and ways to improve equity.

The natural language used and reported by participants with dementia and caregivers to describe dementia reinforced a persistent conceptualisation that focuses on neuropsychiatric presentations, and corroborated participants’ views that societal perceptions of dementia are centred around the stigma of mental illness: “nutter / going bananas / dottled / away with the fairies / do-lally / crazy / backward / gaga / looney”. Participants described widespread misunderstanding and taboo surrounding dementia, where dementia “is Uncle Fred disappearing into the asylum and never coming out" (PWD6), and where people with dementia are socially excluded, their symptoms are trivialised, and opportunities to discuss the disease are cancelled. While some participants preferred not to publicly disclose their diagnosis to avoid judgement, others openly confronted the stigma, asking: “Is it a disgrace to have dementia? Is it?” (PWD5).

Table 8.4 Taking dementia ‘seriously’ – illustrative quotes
CC=Current carer; BC=Bereaved carer; PWD=Person with dementia

ID	*Quote*
PWD7	I won’t say it’s insulting, but it is not given the seriousness that I think that the disease should have. Its only when you’re the older gentleman or older lady walking down the middle of the road in your pyjamas not knowing where you're living that ‘argh, argh bless, poor thing, they don’t know they have Alzheimer’s’, or ‘they don’t know they have some sort of dementia’. And its, when you're in early onset trying to talk about it with people is really, really difficult, and they have no concept. They can’t understand.”
BC7	“Mum had a right for her voice to be heard and it wasn’t and she was ignored, totally. And my concerns on exactly the same issue were dismissed. Yeah. I mean, very nicely, they weren’t rude when they said, but from their point of view, they had no choice. It was something you – there was no choice.”
PWD8	“Sometimes I just want people to take me, what I say, at face value rather than thinking, ‘Maybe what she's saying isn't quite true’. ‘Maybe she doesn't remember what she's doing’. And I hate people making me feel like I'm stupid, which sometimes people do that without meaning to… Health professionals don't mean to, but they do tend to act that way sometimes because the judgement takes over what they think.”
CC3	“this is a massive problem that is going to be facing a huge amount of people worldwide with dementia that have no longer got a voice to say, ‘I don't want you to do that’, whereas somebody with a terminal diagnosis of cancer or motor neurone disease or some of the very debilitating neurological conditions, at some point, can say ‘withdraw the treatment, I'm done with it’. And then they detract mindfully and respectfully and comfortably because they have a voice to say that, whereas from when my dad did his paperwork years ago to where he is now, his voice is no longer present… He made everybody aware that as he could that ‘this is not what I want’, and lo and behold, this is what he's having to have and that just cannot be right in anybody's world.”
CC1	“we had this problem with the excoriation… They were looking at it from there being a physical cause for it, rather than psychological or well, not psychological, but related to the dementia…until this Admiral Nurse pointed out that it was delusional behaviour. …We went practically a year, being backwards and forwards to the dermatologist and this cream and these bandages and being dressed by a nurse and all that, as this got progressively worse and worse and worse and more ingrained in his thinking, or whatever he was experiencing, so we went for nearly a year before it got to the point where I had to say, I'm going to make a complaint to the health authority or whatever before a psychiatrist came out. And then it was sorted within less than a week.”

8.1.4 Discussion

Our analyses show that people with dementia are disadvantaged by both the nature of the condition and the health and social care system. Multiple barriers to timely, responsive access to community health and social care mean ED attendance, while considered a last resort, is frequently the path of least resistance. This disadvantage is driven by operational limitations of a stretched system to respond to increasing need, and ingrained preconceptions about dementia that are part of a wider societal intolerance.

The ‘candidacy’ model of access[157] has some explanatory value in our analyses. The model refers to how individuals’ eligibility to access healthcare is negotiated through interactions with providers, which are subject to the interplay of multiple influences. Accordingly, vulnerabilities are created when there is a lack of alignment between individual priorities and systemic configuration.[157] Our study suggests that vulnerabilities arose when the changing needs of people with dementia were at odds with the structural, legal, and cultural constraints of the system.

In our study, community support was central to people with dementia remaining well at home; however, participants described being largely uninformed while navigating a poorly integrated system. This is supported in previous literature, where community support is known to influence urgent care use,[439] with access impeded by limited awareness and service fragmentation.[11, 445] Our analyses showed that people affected by dementia encounter additional barriers to accessing community health and social care. The nature of dementia demands time, familiarity, and routine, with additional needs that increase over time. In contrast, the structural configuration of services limits carer contact time, home visiting availability, and staff continuity, which are often slow to access. As reflected in this study, comorbidities are common in people with dementia yet healthcare is configured for single diseases and does not easily accommodate multimorbidity,[446] especially for people with dementia.[447] However, our analyses suggest that people with socioeconomic privilege have the means to overcome some of these barriers. This highlights how a system that requires people to push, or fight, for support is inherently skewed and may predispose some towards ED attendance. While the value of post-diagnostic support is well-established,[61] the system must do more to pull people into services to improve equitable access.

Our analyses suggest that general healthcare may take a blinkered view of illness in dementia, where behavioural change is attributed to dementia progression, physical illness is assumed to be the cause of physical complaints, and clinical workups are limited to exclusion of urinary tract infections. There are high rates of potentially avoidable ED attendances among people with dementia,[6] and undetected physical illnesses that manifest as neuropsychiatric changes.[448] Comprehensive clinical assessments are therefore imperative for early intervention, yet they often rely on collateral histories. Our analyses showed that caregivers with greater dementia literacy were better able to articulate their candidacy and prompt clinical intervention. This echoes evidence that limited health literacy is associated with fewer primary care visits and more ED visits.[449] Based on intersecting determinants, health literacy mediates self-care, healthcare access, and communication between healthcare professionals and patients.[450] Therefore, accessible caregiver education to recognise and communicate red flags should be prioritised in post-diagnostic support, to empower decision-making in seeking early intervention and enhance asserted candidacy to secure clinician engagement.

In our study, people with dementia encountered barriers in accessing alternative services to the ED. In residential care homes, participants considered ED transfers being initiated at low thresholds by protocol-driven decisions. Literature shows that ED transfers from residential care homes can result from challenges around detecting early-acute changes,[451] late requests for primary care support,[452] and limited resources to support additional care needs.[451] Our analyses suggest that these challenges may be common in residential care homes without nursing care, consistent with other studies.[453] This is an important distinction, as most people with dementia who live in residential care homes are in homes that do not provide nursing care.[454] Given this, the movement towards 'enhanced health in care homes'[16] must consider the value of clinical continuity from on-site registered nurses in mitigating ED visits for people with dementia, and work to mirror this in the support available to residential care homes.

In our study, people with advanced dementia were less able to articulate their needs and preferences. They therefore relied on family caregivers and advance care plans to assert their priorities, which were often overridden by protocols for ED transfer. This 'candidacy by-proxy' underscores the vulnerability of people lacking mental capacity, as legally, healthcare staff need only consult advance care plans or caregivers in the absence of capacity and a Lasting Power of Attorney. Only when end-of-life was recognised were ED transfers reduced and, at times, replaced with urgent community response teams. Since it can be challenging to recognise when someone with dementia is approaching the end-of-life,[455] as suggested in this study, responsive clinical support must be made accessible to people with dementia whose wishes are to avoid the ED where possible. Furthermore, as we have shown that caregiver voice is not always heard, there may be a role for independent advocacy. This may be afforded by Admiral Nurses whose triadic relationship-centred approach facilitates shared decision-making between the person with dementia, their family caregivers, and staff.[456]

Participants described an absence of follow-up care and single point of contact, as well as limited financial and social support. While observed in other studies,[440, 445] our analyses suggest this is driven by a systemic lack of parity of esteem between dementia and other life-limiting illnesses. Although dementia is often perceived as an end-stage disease, participants were declined palliative care upon request. There are known associations between palliative care and reduced ED visits towards the end-of-life among people with dementia;[323] however, access based on illness type is well-recognised and barriers for people with dementia are noted.[44] Work on illness identity has concluded that conditions like cancer have greater social significance than others, which makes services easier to access.[172] Aligned to this, we suggest that people with dementia are not only impeded by a systemic sympathy towards cancer and other such conditions, but also by a systemic antipathy towards dementia. Our analyses show a persistent societal bias towards dementia, which is reminiscent of the stigmatisation of mental illness. This is consistent with literature that describes dementia as a source of social disadvantage,[43] influenced by mental illness-stigma and ageism.[457] We suggest that this is reflected in the general health and social care system, which gives greater credence to physical illness over mental distress and fails to legitimise dementia as a life-limiting illness with adequate post-diagnostic support.

A step towards giving dementia due esteem could start with the ED. There have already been advances to care practices in the ED for people with dementia, including dementia inclusive bays and communication tools.[458] However, priority areas identified in this study included improved ergonomics for people with reduced cognitive reserve, including clear signage and quiet areas; improved communication from staff that is respectfully sensitive to the needs of individuals with dementia; reduced time to assessment to avoid worsening anxiety, consideration of community-based investigations to avoid admission where possible, and being accompanied by a family caregiver or familiar other. Fundamentally, participants were keen for people with dementia to be taken as individuals and treated without assumption.

8.1.4.1 Strengths and limitations

Our study has included the experiences and perspectives of people living with dementia as well as current and bereaved family caregivers. This provided insight into dementia from across the illness trajectory from people living with early/moderate dementia to those with more advanced dementia. This is a novel contribution to this area of research, which steers away from typical end-stage assumptions of dementia. Engaging people with dementia also complements research that has explored this topic from the views of family caregivers and service providers.[11] This study further contributes to the literature having explored experiences of people affected by dementia using health and social care before and during the Covid-19 pandemic, and from across the UK. There is a recognised ‘postcode lottery’ of community services available to people in the UK. While this was reflected in the interviews, using a broad sample provided insight into shared experiences on which to base recommendations for policy and practice.

The study has important limitations. It was reliant on retrospective accounts from participants, which are subject to recall bias. As we recruited from charities and a research register, there is likely an over-inclusion of people adept in managing the health and social care system. Furthermore, the dependency on remote recruitment and interviewing likely excluded people with poor technological access and/or literacy. This was reflected in the whole sample identifying as ‘living comfortably’ or ‘coping’ financially. However, this subjective measure likely reflects social comparison rather than an approximation of socioeconomic position,[459] which accounts for the variations in financial circumstances described between participants. Despite concerted effort to target geographical areas with high ethnic diversity, most participants reported being of white ethnicity. Future research must specifically engage with community partners working with people affected by dementia from minoritised ethnic groups to enable meaningful representation in research. It is known that minoritised ethnic groups are underserved by healthcare, experience barriers to accessing community support,[460] and are more likely to use the ED, particularly towards the end-of-life.[323] Their unique experiences in the health and social care system will be essential to future service planning.

8.1.5 Summary of social assessment

Our analyses of interviews with people with dementia and current and bereaved family caregivers show that, across the illness trajectory, the ED is regarded as the last resort for care. However, due to barriers in accessing timely and responsive care, ED attendance often becomes the path of least resistance. These barriers reflect an implicit bias against dementia, driven by persistent preconceptions of mental illness in the system and wider society. We advocate that a committed prioritisation of post-diagnostic care is urgently needed to increase equitable access to community services and clinical continuity for people with dementia, at home and in care homes, and for caregivers to be better supported as health navigators through timely access to skilled services, advocacy, and interventions for dementia health literacy. However, we argue that until there is parity of esteem between dementia and other life-limiting illnesses within the system, people with dementia will continue to experience disadvantage and attend the ED against their wishes, putting them at risk of poorer health outcomes.

8.2 Public representative responses to the social assessment

The findings of the social assessment were presented to the expert panel of public representatives for discussion (Appendix B3). Public representatives agreed with findings that dementia is not taken seriously in wider society, describing their own experiences of encountering stigma and observations that dementia seems to be of low priority in the health and care system. Public representatives called for greater public education about dementia and the marginalisation experienced. Public representatives suggested this would help the public appreciate why dementia needs to be a higher priority in the health and social care system. There was agreement among public representatives that barriers to accessing community support, including GPs, influenced ED attendance. Furthermore, barriers encountered by people from minoritised ethnic groups were discussed and considered to be due to not having a voice, primarily because of language-barriers for non-English speaking individuals, which compound disease-related difficulties in articulating need.

There was consensus among public representatives that end-of-life planning was valuable for the person with dementia, as well as for caregivers. However, there were concerns that plans are not always adhered to in practice. Discussions extended to a general mistrust in care home staff and questions if residents with dementia would be treated appropriately, with reference to blanket Do-Not-Attempt-Resuscitation (DNAR) decisions during Covid-19. Public representatives shared experiences of wanting to raise safeguarding concerns but either did not know how to or feared that their relatives would be penalised by staff as a result. It was strongly endorsed by public representatives that an advocate should be available to help mediate discussions between staff and caregivers/people with dementia.

8.3 Influence of the social assessment and public representative feedback on the applied PRECEDE-PROCEED Model (PPM)

Aligned to the PPM, priority targets for intervention are informed from each phase of the PRECEDE component. Based on findings from the social assessment, and public representative feedback, the overall target and health targets of the PRECEDE component have been developed, including points to consider for policy and intervention development (Figure 8.2).

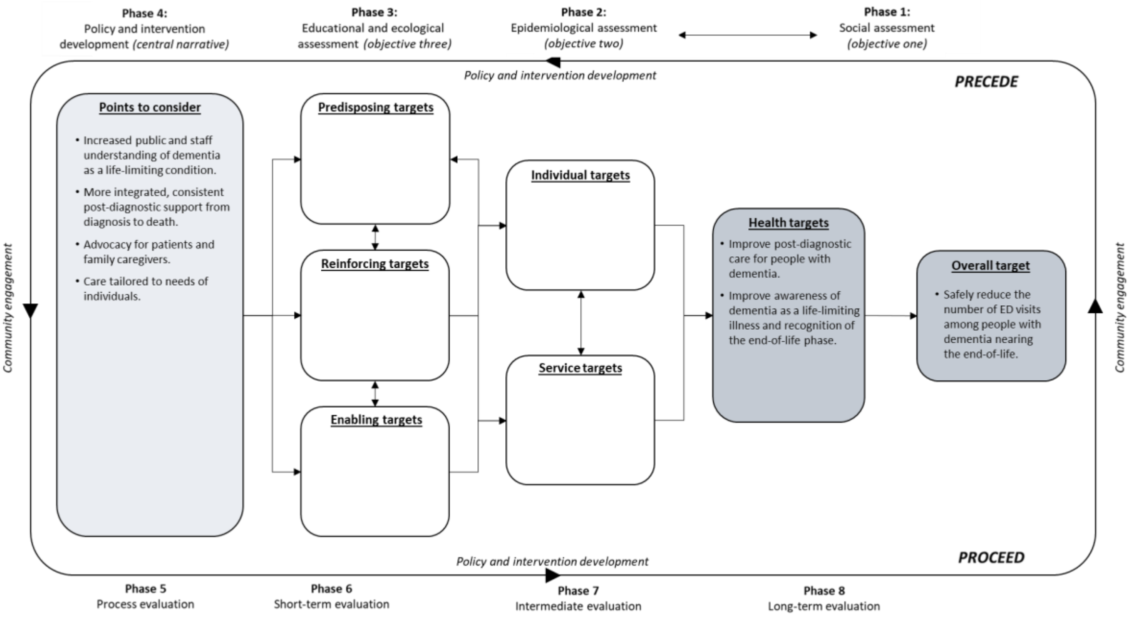


Figure 8.2 Developing the applied PRECEDE-PROCEED Model (PPM)
Overall and health targets for intervention, with points to consider for policy and intervention development, informed by findings of the social assessment and public representative feedback.

While this thesis is underpinned by the research question of how ED attendance can be safely reduced among people with dementia approaching the end of life, findings from the social assessment and public representative feedback confirmed this as a priority. It therefore forms the basis of the overall target of the model. The social assessment highlighted that although people affected by dementia did not ordinarily choose to attend the ED, it was the path of least resistance when clinical input was required in the community. This was considered, in part, to be driven by the inconsistent post-diagnostic support available. Therefore, one of the health targets is to improve post-diagnostic care for people with dementia. This is intended to account for timely and responsive care, both pre-emptively care at the point of decline, which were both implicated in the social assessment. As public representatives corroborated that limited access to community support increases the likelihood of ED attendance, improving access is expected to help meet the overall target of safely reducing ED attendance towards the end of life.

Stigma and general misunderstanding of dementia was identified as a priority area for change, based on findings of the social assessment and discussions with public representatives. It is anticipated that re-framing dementia as a life-limiting condition will increase awareness of the severity of the disease and the eligibility of people with dementia for palliative care input, as this was often overlooked by clinicians according to participants of the social assessment.

Consequently, the second health target is to improve recognition of dementia as a life-limiting condition. Similarly, health targets include increased awareness of end-of-life in dementia. Findings from the social assessment suggested that determining when to initiate end-of-life care required clinical input. While clinical confirmation of the end-of-life period resulted in fewer ED attendances, recognition was late and often when death was imminent. Given this, improved recognition is expected to contribute to achieving the overall target.

Based on feedback from public representatives and the findings of the social assessment, important points to consider for policy and intervention include the need for advocacy, and the flexibility of services to provide care that is tailored to individual needs of people with dementia, more integrated post-diagnostic support and increased public understanding of dementia to challenge societal preconceptions that are thought to influence access to health and social care.

8.4 End of chapter summary

Informed by the candidacy and degree-of-fit models of access, the findings of the social assessment suggest that while the ED is perceived as the last resort for care, barriers to timely and responsive community clinical care make ED attendance the path of least resistance. Barriers were based on the structural, legal, and cultural configuration of the health and care system that fails to position dementia on par with other life-limiting conditions. Public representatives of the expert panel agreed with findings, particularly those implicating systemic and societal bias against dementia, and called for independent advocacy for people affected by dementia. These findings and public representative feedback have informed the development of the PPM by confirming the overall target and identifying health targets. Components of policy and intervention development have also been identified, including integrated post-diagnostic support, needs-based care and advocacy. The following chapter will continue to build on the PPM with findings and public representative feedback from the epidemiological assessment.

9 RESULTS 2: EPIDEMIOLOGICAL ASSESSMENT

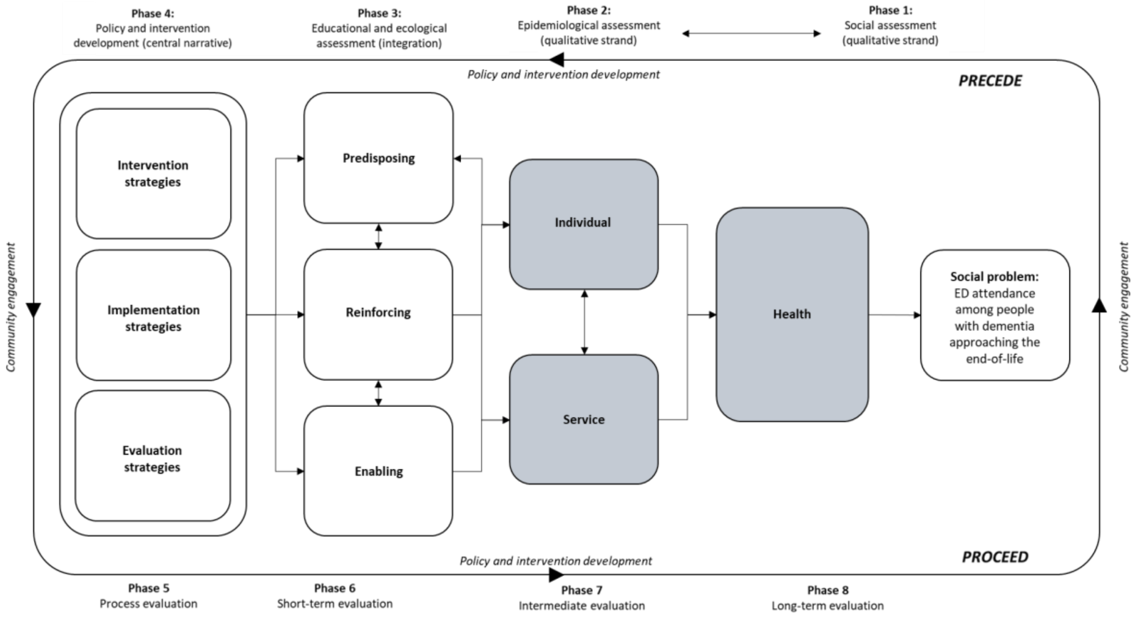


Figure 9.1 Epidemiological assessment (phase 2, in parallel with phase 1)
Objective two, to examine the patient- and service-level factors associated with emergency department attendance among people with dementia in their last year of life.

This chapter presents the results of the epidemiological assessment, reproducing a peer-reviewed paper published in Age and Ageing in March 2023. The epidemiological assessment is a retrospective cohort study and the second phase of the PRECEDE-PROCEED Model (PPM), completed in parallel with the first phase, meeting objective 2 (Figure 9.1). Following presentation of the results, this chapter summarises feedback from public representatives of the expert panel. The findings and public representative feedback were used to inform individual, service and health targets for change, as part of the PPM's planning process.

Supplementary material for the epidemiological assessment is in Appendix D.

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RESEARCH PAPER

A population-based retrospective cohort study of end-of-life emergency department visits by people with dementia: multilevel modelling of individual- and service-level factors using linked data

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Abstract

Background: emergency department (ED) visits have inherent risks for people with dementia yet increase towards the end-of-life. Although some individual-level determinants of ED visits have been identified, little is known about service-level determinants.

Objective: to examine individual- and service-level factors associated with ED visits by people with dementia in the last year of life.

Methods: retrospective cohort study using hospital administrative and mortality data at the individual-level, linked to health and social care service data at the area-level across England. The primary outcome was number of ED visits in the last year of life. Subjects were decedents with dementia recorded on the death certificate, with at least one hospital contact in the last 3 years of life.

Results: of 74,486 decedents (60.5% women; mean age 87.1 years (standard deviation: 7.1)), 82.6% had at least one ED visit in their last year of life. Factors associated with more ED visits included: South Asian ethnicity (incidence rate ratio (IRR) 1.07, 95% confidence interval (CI) 1.02–1.13), chronic respiratory disease as the underlying cause of death (IRR 1.17, 95% CI 1.14–1.20) and urban residence (IRR 1.06, 95% CI 1.04–1.08). Higher socioeconomic position (IRR 0.92, 95% CI 0.90–0.94) and areas with higher numbers of nursing home beds (IRR 0.85, 95% CI 0.78–0.93)—but not residential home beds—were associated with fewer ED visits at the end-of-life.

Conclusions: the value of nursing home care in supporting people dying with dementia to stay in their preferred place of care must be recognised, and investment in nursing home bed capacity prioritised.

Keywords: dementia, end-of-life, emergency department, emergency care, community care, care homes, older people

Key Points

- Being resident in a local authority with more nursing home beds (but not residential home beds) was associated with fewer emergency department (ED) visits.
- There was a negative dose–response association between emergency department (ED) visits and increasing socioeconomic position.
- Being of South Asian ethnicity was associated with more emergency department (ED) visits in the last year of life.
- Access to clinical continuity may help to reduce reliance on emergency department (ED) visits for people with dementia who are nearing the end-of-life.

Introduction

Emergency department (ED) visits are common among people with dementia who are nearing the end-of-life [1]. The number of ED visits is observed to increase with proximity to death, with a quarter made within the last month of life [2]. These visits can be distressing [3], and risk secondary complications in hospital [4].

A recent systematic review of international literature identified moderate-to-high strength evidence that having lower socioeconomic position, being from ethnic minority backgrounds and living in more rural settings were associated with higher ED visits among people nearing the end-of-life (defined as likely to be in the last year of life [5]), whereas care home residence and palliative care input were associated with lower ED visits [6]. The review concluded that community services may have a role in mediating end-of-life ED visits. Improving community care to reduce hospitalisation is a policy priority [7, 8], but understanding how to achieve this is limited.

Although community service use is associated with ED visits towards the end-of-life [9], this has only been examined at the individual level. Area-level service factors, such as workforce and service capacity, are likely to influence end-of-life service use [10]. Given the 'postcode lottery' of access to health and social care in England, a population-based examination of potentially modifiable service factors could inform policy to improve end-of-life care for people with dementia. We therefore aimed to examine individual- and service-level factors associated with ED visits by people with dementia in the last year of life.

Methods

Study design and settings

This retrospective cohort study used routinely collected data to examine factors associated with ED attendance in last year of life. Socio-ecological models of end-of-life care [10, 11] and previous population-based studies of end-of-life service use [2, 9, 12] informed the reporting of results as sociodemographic, clinical and service factors, with the latter comprising workforce and capacity.

We used the REporting of studies Conducted using Observational Routinely-collected Data (RECORD) extension of STrengthening the Reporting of OBservational studies in Epidemiology (STROBE) guidelines [13].

Data sources

We used routinely collected administrative data from national Hospital Episode Statistics (HES) from National Health Service (NHS) Digital, linked with Civil Registrations of Deaths from the Office of National Statistics (ONS). The HES database comprises data reporting patient contacts with care delivered by all NHS hospitals in England. We used two HES datasets: ED attendance (HES Accident & Emergency) and inpatient care (HES Admitted Patient Care). Mortality data from Civil Registrations of Deaths were available as a 'secondary care cut', which linked to the HES datasets. This cut limited mortality data to date, place and cause of death (including underlying cause of death and any mention), and decedent gender [14].

Data on service-level factors were from publicly available health and social care service datasets (Supplementary data S1). We derived primary care and adult social care workforce data from NHS Digital [15] and Skills for Care [16], respectively. We derived bed numbers in care homes, with and without nursing care, from the Care Quality Commission (CQC) [17]. We obtained the number of General Practitioner (GP) surgeries from NHS Digital [15] and type 1 EDs (consultant-led department providing 24-h emergency care [18]) from NHS Digital in response to a Freedom of Information request posted online [19]. We obtained numbers of urgent care centres, minor injury units and walk-in centres from the CQC [17] and categorised them as 'urgent treatment centres' for simplicity.

Data access, cleaning and linkage

Individual-level data were linked using encrypted patient identifiers, with the quality of each match ranked from one (highest quality match) to eight (lowest quality match). Similar to other studies [12], we removed data with match ranks three to eight, as these data are partially matched or matched using less reliable measures [14]. We also removed cases with addresses outside England. We removed cases where the only hospital contact was an outpatient appointment, as these cases comprised mortality data only.

We used Upper Tier Local Authorities as the geographical unit of analysis, retrieved from the ONS Geoportal [20]. Local authorities are areas of local government responsible for protecting and improving health and wellbeing of the local population [21]. When datasets did not include local authority details, data were linked to local authorities by postcode, using the ONS Postcode Directory file, November 2019 version [22]. The ONS Postcode Directory comprises all UK postcodes linked to local authorities, electoral wards, Clinical Commissioning Groups and Lower Layer Super Output Areas (LSOAs).

Ethical approval and other permissions

There was a single flow of linked pseudonymised record-level data from NHS Digital to King's College London, under Data Sharing Agreement DARS-NIC-365602-V5H3Z. As we used previously collected, non-identifiable information from decedents, the study did not require ethical approval.

Study sample

The cohort comprised adults (aged $\geq$18 years) who: (i) died between 01 April 2018 and 31 March 2019; (ii) had a diagnosis of dementia recorded on the death certificate, as either the underlying cause of death or any mention as a cause of death, using filters based on ICD-10 codes F00*-03* and G30* as used elsewhere [23]; and (iii) had at least one HES record between 01 April 2016 and 31 March 2019. We included contacts over 3 years to increase the sample size.

Primary outcome

The primary outcome was the count of ED visits in the last year of life. We defined ED visits as any unplanned visit to any type 1 ED.

Explanatory variables

The ED and inpatient datasets provided gender (male, female), and 19 ethnicities from which we recoded as White, Black, South Asian, Mixed, Other and unknown/not stated ethnicities (Supplementary data S2). We derived age at death by calculating the difference between recorded dates of birth and death from ED and mortality data and centred by median age. We omitted civil status as an explanatory variable, as this was available in the inpatient dataset only. We derived settlement of usual residence (urban/rural) from aggregating results from the 2011 Rural–Urban Classification, which is an ONS measure used to distinguish urban and rural areas based on settlements of more or less than 10,000 resident population [24]. We derived socioeconomic position from the Index of Multiple Deprivation, which uses LSOA geography of usual residence to compare neighbourhood deprivation in England [25]. We derived region of usual residence from the Local Authority District to Region (April 2019) dataset, from the ONS Geoportal [26].

Dementia subtype was based on dementia ICD-10 codes in the mortality data, recorded as either the underlying cause of death or a cause of death mention. As most dementias are recorded as unspecified on death certificates [27], we triangulated the 'unspecified dementia' ICD-10 code (F03) with all dementia ICD-10 codes in inpatient data. Underlying causes of death in mortality data were grouped according to previous studies [28]: dementia, chronic lower respiratory disease (ICD-10 J40–47), cancer (ICD-10 C00–97, D00–48), cardiovascular disease (ICD-10 I00–52, I70–99), cerebrovascular disease (ICD-10 I60–69), chronic neurological disease (ICD-10 G12, G20, G35) and 'other' (remaining ICD-10 codes).

Service workforce included full-time equivalent (FTE) numbers of GPs, and Adult Social Care workers providing direct care. Service capacity included number of nursing home beds (residential facility with partial or full nursing care) and residential home beds (residential facility without nursing care), urgent treatment centres and type 1 EDs in local authority areas. In each local authority, we expressed service workforce and capacity data as totals per 10,000 at-risk population. We used the number of adults $\geq$65 years in each local authority as the denominator to denote the at-risk population [29], as this population is more likely to have dementia and to use primary [30] and social care services [31] than younger populations. The estimated counts per 10,000 of at-risk population were grouped into quintiles, ranging from 1 (lowest) to 5 (highest).

We also measured FTE numbers of primary care nurses and Adult Social Care regulated professionals (nurses, occupational therapists and social workers), Adult Social Care expenditure and proximity of EDs, urgent treatment centres and GP surgeries, in line with existing models [10]. However, we excluded these from the final model due to issues of collinearity and poor model fit.

Statistical analyses

We used frequencies and percentages to describe the cohort and ED visits. As the primary outcome (number of ED visits) was overdispersed, we used a negative binomial regression model with a random intercept at the local authority level to account for correlation within local authorities. Explanatory variables were selected based on improved model fit ($P < 0.01$) and a priori hypotheses. Missing GP FTE data ($<$1%) were imputed using local authority median number of FTEs. The strength of association was described using Incidence Rate Ratios (IRRs) and 95% confidence intervals (95% CIs) at the $P < 0.05$ significance level. As the sample excluded decedents who had no contact with secondary care in the preceding 3 years, we completed a sensitivity analysis with a subset cohort of patients with at least one ED visit in the last year of life using zero-truncated negative binomial regression, with robust cluster variance. Analyses were performed using Stata, version 17 (StataCorp, College Station, TX, USA).

Results

There were 86,137 patients who had at least one hospital contact between 01 April 2016 and 31 March 2019 and who died with or from dementia between 01 April 2018 and 31 March 2019. After removing cases based on eligibility criteria, including two cases with anomalous numbers of ED visits in the last year of life (349 and 269 visits), the final cohort comprised 74,486 patients (Figure 1). Most decedents in the final cohort (Table 1) were women (n = 45,072, 60.5%) and of white ethnicity (n = 65,180, 87.5%). The mean age at death was 86.9 (SD: 7.1). The most common specified dementia subtype was Alzheimer's disease (n = 25,701, 34.5%). Compared with national averages, the cohort was less deprived [32] with similar rural–urban distribution [33]. Table 2 displays summary statistics of service factors, by local authority.

In the last year of life, 82.6% (n = 61,491) of the final cohort visited the ED 154,508 times, with 53.2% (n = 39,596) attending at least twice (Supplementary data S3). For 58.1% (n = 89,776) of all visits in the last year of life, the ED outcome was hospital admission. For 0.5% (n = 840), the ED outcome was death in the department. The proportion of visits that were in the month before death was 23.9% (n = 36,849), and for 66.7% (n = 24,569) of these, the ED outcome was hospital admission. Most

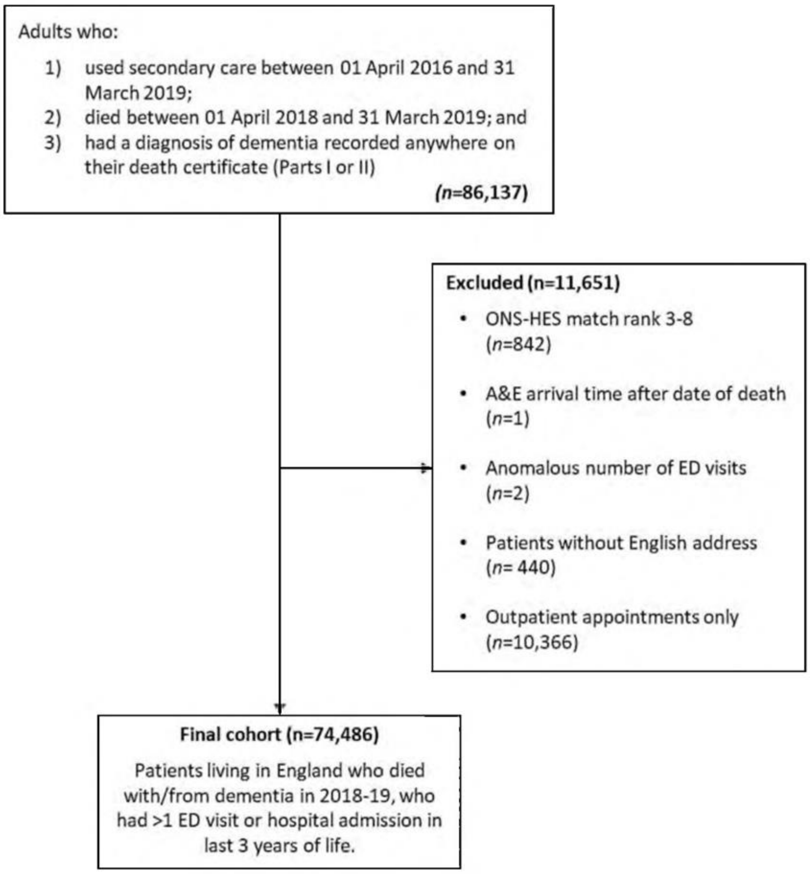


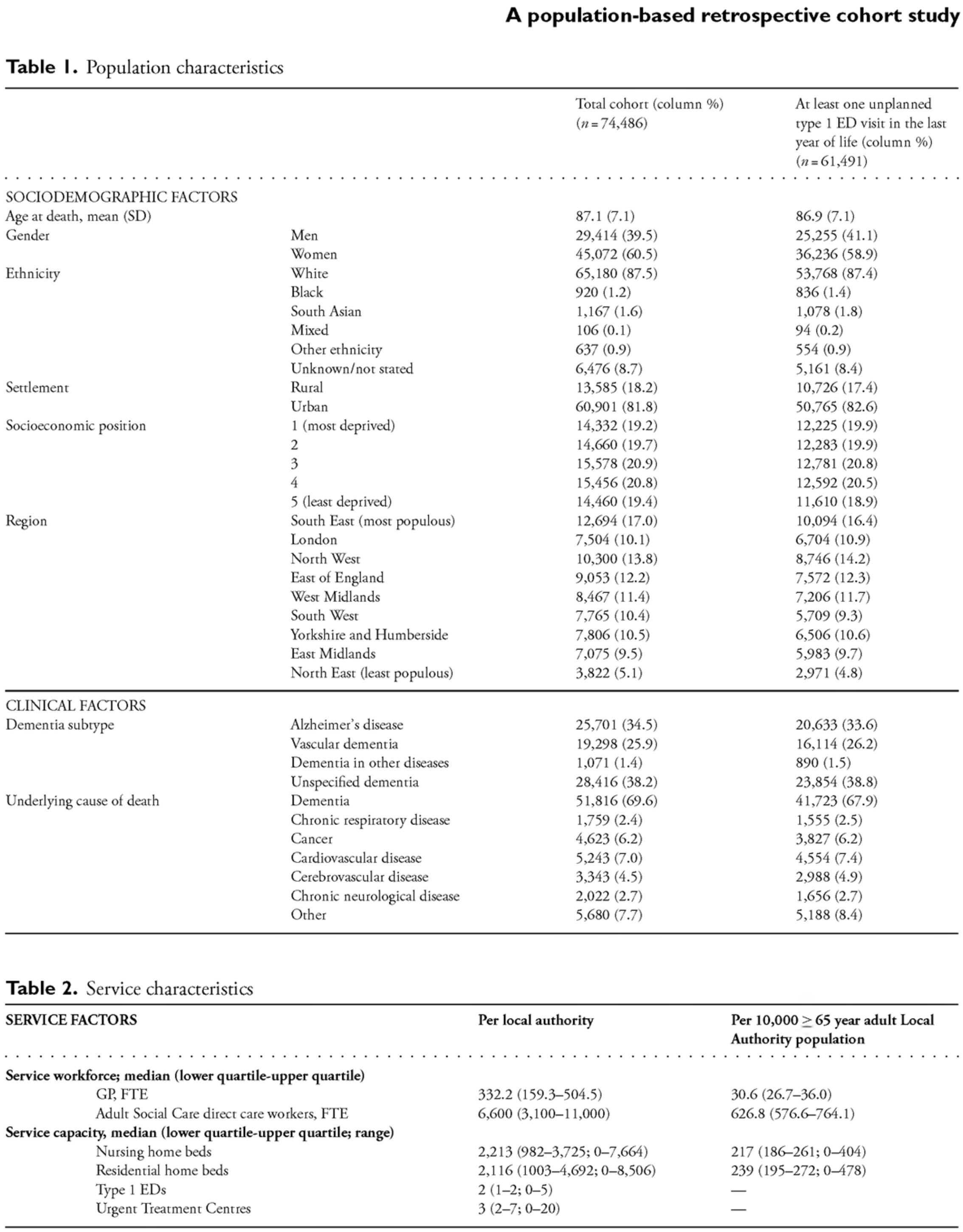
Figure 1. Flow chart of study population selection

patients attended by ambulance (89.6%) with just over half attending out-of-hours (defined as 8 pm–8 am weekdays and anytime weekends and Bank Holidays [2]; 54.2%). Common classifiable primary diagnoses included respiratory conditions (excluding asthma; 11.6%) and urological conditions, including cystitis (11.3%).

Factors associated with ED visits in the last year of life

In the unadjusted analysis (Supplementary data S4), all covariates were statistically significantly associated with the primary outcome, except mixed ethnicity and the third quintile of nursing home beds. In the adjusted multilevel model (Table 3, model 1; Figure 2), factors that were statistically significantly associated with fewer end-of-life ED visits included: older age (IRR 0.99, 95% CI 0.99–0.99, $P < 0.01$), female gender (IRR 0.84, 95% CI 0.82–0.85, $P < 0.01$), unknown ethnicity (IRR 0.86, 95% CI 0.84–0.88, $P < 0.01$) and living in the South West (IRR 0.80, 95% CI 0.72–0.89, $P < 0.01$). Factors that were statistically significantly associated with higher end-of-life ED visits included: South Asian ethnicity (IRR 1.07, 95% CI 1.02–1.13, $P < 0.01$), diagnosis of vascular dementia (IRR 1.14, 95% CI 1.13–1.16, $P < 0.01$) or unspecified dementia (IRR 1.12, 95% CI 1.10–1.14, $P < 0.01$), underlying cause of death as chronic respiratory (IRR 1.33, 95% CI 1.28–1.38, $P < 0.01$), cardiovascular (IRR 1.17, 95% CI 1.14–1.20, $P < 0.01$), or cerebrovascular disease (IRR 1.14, 95% CI 1.11–1.18, $P < 0.01$), other underlying causes of death (IRR 1.22, 95% CI 1.19–1.25, $P < 0.01$), being a resident in an urban settlement (IRR 1.06, 95% CI 1.04–1.08, $P < 0.01$) and selected regions. There was a negative dose–response association between ED visits and increasing socioeconomic position (IRR 0.92, 95% CI 0.90–0.94, $P < 0.01$). Being a resident in a local authority with more nursing home beds was statistically significantly associated with fewer ED visits (IRR 0.87, 95% CI 0.80–0.95, $P < 0.01$). Results for number of GP FTE and type 1 EDs were less clear.

Sensitivity analysis with the subset cohort of patients who had at least one ED visit in the last year of life showed similar results (Table 3, model 2), except that some variables became



A population-based retrospective cohort study

Table 1. Population characteristics

		Total cohort (column %) (*n* = 74,486)	At least one unplanned type 1 ED visit in the last year of life (column %) (*n* = 61,491)
SOCIODEMOGRAPHIC FACTORS			
Age at death, mean (SD)		87.1 (7.1)	86.9 (7.1)
Gender	Men	29,414 (39.5)	25,255 (41.1)
	Women	45,072 (60.5)	36,236 (58.9)
Ethnicity	White	65,180 (87.5)	53,768 (87.4)
	Black	920 (1.2)	836 (1.4)
	South Asian	1,167 (1.6)	1,078 (1.8)
	Mixed	106 (0.1)	94 (0.2)
	Other ethnicity	637 (0.9)	554 (0.9)
	Unknown/not stated	6,476 (8.7)	5,161 (8.4)
Settlement	Rural	13,585 (18.2)	10,726 (17.4)
	Urban	60,901 (81.8)	50,765 (82.6)
Socioeconomic position	1 (most deprived)	14,332 (19.2)	12,225 (19.9)
	2	14,660 (19.7)	12,283 (19.9)
	3	15,578 (20.9)	12,781 (20.8)
	4	15,456 (20.8)	12,592 (20.5)
	5 (least deprived)	14,460 (19.4)	11,610 (18.9)
Region	South East (most populous)	12,694 (17.0)	10,094 (16.4)
	London	7,504 (10.1)	6,704 (10.9)
	North West	10,300 (13.8)	8,746 (14.2)
	East of England	9,053 (12.2)	7,572 (12.3)
	West Midlands	8,467 (11.4)	7,206 (11.7)
	South West	7,765 (10.4)	5,709 (9.3)
	Yorkshire and Humberside	7,806 (10.5)	6,506 (10.6)
	East Midlands	7,075 (9.5)	5,983 (9.7)
	North East (least populous)	3,822 (5.1)	2,971 (4.8)
CLINICAL FACTORS			
Dementia subtype	Alzheimer's disease	25,701 (34.5)	20,633 (33.6)
	Vascular dementia	19,298 (25.9)	16,114 (26.2)
	Dementia in other diseases	1,071 (1.4)	890 (1.5)
	Unspecified dementia	28,416 (38.2)	23,854 (38.8)
Underlying cause of death	Dementia	51,816 (69.6)	41,723 (67.9)
	Chronic respiratory disease	1,759 (2.4)	1,555 (2.5)
	Cancer	4,623 (6.2)	3,827 (6.2)
	Cardiovascular disease	5,243 (7.0)	4,554 (7.4)
	Cerebrovascular disease	3,343 (4.5)	2,988 (4.9)
	Chronic neurological disease	2,022 (2.7)	1,656 (2.7)
	Other	5,680 (7.7)	5,188 (8.4)

Table 2. Service characteristics

SERVICE FACTORS	**Per local authority**	**Per 10,000 ≥ 65 year adult Local Authority population**
Service workforce; median (lower quartile-upper quartile)		
GP, FTE	332.2 (159.3–504.5)	30.6 (26.7–36.0)
Adult Social Care direct care workers, FTE	6,600 (3,100–11,000)	626.8 (576.6–764.1)
Service capacity, median (lower quartile-upper quartile; range)		
Nursing home beds	2,213 (982–3,725; 0–7,664)	217 (186–261; 0–404)
Residential home beds	2,116 (1003–4,692; 0–8,506)	239 (195–272; 0–478)
Type 1 EDs	2 (1–2; 0–5)	—
Urgent Treatment Centres	3 (2–7; 0–20)	—

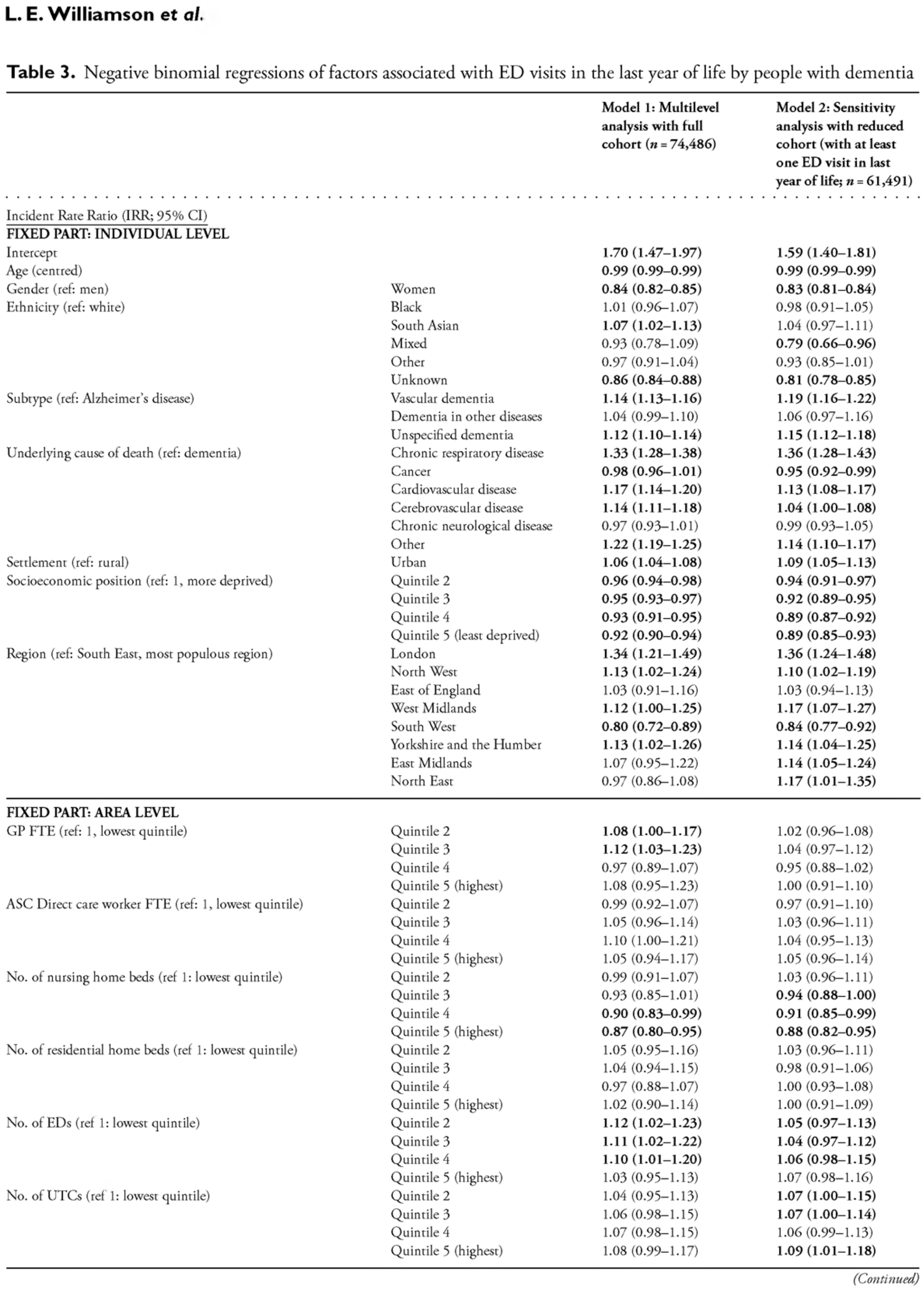


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Table 3. Negative binomial regressions of factors associated with ED visits in the last year of life by people with dementia

		Model 1: Multilevel analysis with full cohort (*n* = 74,486)	**Model 2: Sensitivity analysis with reduced cohort (with at least one ED visit in last year of life; *n* = 61,491)**
Incident Rate Ratio (IRR; 95% CI)			
FIXED PART: INDIVIDUAL LEVEL			
Intercept		**1.70 (1.47–1.97)**	**1.59 (1.40–1.81)**
Age (centred)		**0.99 (0.99–0.99)**	**0.99 (0.99–0.99)**
Gender (ref: men)	Women	**0.84 (0.82–0.85)**	**0.83 (0.81–0.84)**
Ethnicity (ref: white)	Black	1.01 (0.96–1.07)	0.98 (0.91–1.05)
	South Asian	**1.07 (1.02–1.13)**	1.04 (0.97–1.11)
	Mixed	0.93 (0.78–1.09)	**0.79 (0.66–0.96)**
	Other	0.97 (0.91–1.04)	0.93 (0.85–1.01)
	Unknown	**0.86 (0.84–0.88)**	**0.81 (0.78–0.85)**
Subtype (ref: Alzheimer's disease)	Vascular dementia	**1.14 (1.13–1.16)**	**1.19 (1.16–1.22)**
	Dementia in other diseases	1.04 (0.99–1.10)	1.06 (0.97–1.16)
	Unspecified dementia	**1.12 (1.10–1.14)**	**1.15 (1.12–1.18)**
Underlying cause of death (ref: dementia)	Chronic respiratory disease	**1.33 (1.28–1.38)**	**1.36 (1.28–1.43)**
	Cancer	**0.98 (0.96–1.01)**	**0.95 (0.92–0.99)**
	Cardiovascular disease	**1.17 (1.14–1.20)**	**1.13 (1.08–1.17)**
	Cerebrovascular disease	**1.14 (1.11–1.18)**	**1.04 (1.00–1.08)**
	Chronic neurological disease	0.97 (0.93–1.01)	0.99 (0.93–1.05)
	Other	**1.22 (1.19–1.25)**	**1.14 (1.10–1.17)**
Settlement (ref: rural)	Urban	**1.06 (1.04–1.08)**	**1.09 (1.05–1.13)**
Socioeconomic position (ref: 1, more deprived)	Quintile 2	**0.96 (0.94–0.98)**	**0.94 (0.91–0.97)**
	Quintile 3	**0.95 (0.93–0.97)**	**0.92 (0.89–0.95)**
	Quintile 4	**0.93 (0.91–0.95)**	**0.89 (0.87–0.92)**
	Quintile 5 (least deprived)	**0.92 (0.90–0.94)**	**0.89 (0.85–0.93)**
Region (ref: South East, most populous region)	London	**1.34 (1.21–1.49)**	**1.36 (1.24–1.48)**
	North West	**1.13 (1.02–1.24)**	**1.10 (1.02–1.19)**
	East of England	1.03 (0.91–1.16)	1.03 (0.94–1.13)
	West Midlands	**1.12 (1.00–1.25)**	**1.17 (1.07–1.27)**
	South West	**0.80 (0.72–0.89)**	**0.84 (0.77–0.92)**
	Yorkshire and the Humber	**1.13 (1.02–1.26)**	**1.14 (1.04–1.25)**
	East Midlands	1.07 (0.95–1.22)	**1.14 (1.05–1.24)**
	North East	0.97 (0.86–1.08)	**1.17 (1.01–1.35)**
FIXED PART: AREA LEVEL			
GP FTE (ref: 1, lowest quintile)	Quintile 2	**1.08 (1.00–1.17)**	1.02 (0.96–1.08)
	Quintile 3	**1.12 (1.03–1.23)**	1.04 (0.97–1.12)
	Quintile 4	0.97 (0.89–1.07)	0.95 (0.88–1.02)
	Quintile 5 (highest)	1.08 (0.95–1.23)	1.00 (0.91–1.10)
ASC Direct care worker FTE (ref: 1, lowest quintile)	Quintile 2	0.99 (0.92–1.07)	0.97 (0.91–1.10)
	Quintile 3	1.05 (0.96–1.14)	1.03 (0.96–1.11)
	Quintile 4	1.10 (1.00–1.21)	1.04 (0.95–1.13)
	Quintile 5 (highest)	1.05 (0.94–1.17)	1.05 (0.96–1.14)
No. of nursing home beds (ref 1: lowest quintile)	Quintile 2	0.99 (0.91–1.07)	1.03 (0.96–1.11)
	Quintile 3	0.93 (0.85–1.01)	**0.94 (0.88–1.00)**
	Quintile 4	**0.90 (0.83–0.99)**	**0.91 (0.85–0.99)**
	Quintile 5 (highest)	**0.87 (0.80–0.95)**	**0.88 (0.82–0.95)**
No. of residential home beds (ref 1: lowest quintile)	Quintile 2	1.05 (0.95–1.16)	1.03 (0.96–1.11)
	Quintile 3	1.04 (0.94–1.15)	0.98 (0.91–1.06)
	Quintile 4	0.97 (0.88–1.07)	1.00 (0.93–1.08)
	Quintile 5 (highest)	1.02 (0.90–1.14)	1.00 (0.91–1.09)
No. of EDs (ref 1: lowest quintile)	Quintile 2	**1.12 (1.02–1.23)**	**1.05 (0.97–1.13)**
	Quintile 3	**1.11 (1.02–1.22)**	**1.04 (0.97–1.12)**
	Quintile 4	**1.10 (1.01–1.20)**	**1.06 (0.98–1.15)**
	Quintile 5 (highest)	1.03 (0.95–1.13)	1.07 (0.98–1.16)
No. of UTCs (ref 1: lowest quintile)	Quintile 2	1.04 (0.95–1.13)	**1.07 (1.00–1.15)**
	Quintile 3	1.06 (0.98–1.15)	**1.07 (1.00–1.14)**
	Quintile 4	1.07 (0.98–1.15)	1.06 (0.99–1.13)
	Quintile 5 (highest)	1.08 (0.99–1.17)	**1.09 (1.01–1.18)**

(Continued)

Table 3. Continued

	Model 1: Multilevel analysis with full cohort ($n = 74{,}486$)	Model 2: Sensitivity analysis with reduced cohort (with at least one ED visit in last year of life; $n = 61{,}491$)
RANDOM PART		
Local authority intercept variance	0.00	—
Marginal statistics		
Marginal variance	2.14	—
Patient	3.63	—
Local authority	0.09	—
Patient VPC	3.54	—
Local authority VPC	0.02	—
Fit statistics		
Deviance	277065.93	209669.91

GP = general practitioner; FTE = full-time equivalent; ASC = adult social care; EDs = type 1 emergency department; UTCs = urgent treatment centres; VPC=variance partition coefficients. Bold values = statistically significant ($P < 0.05$).

statistically non-significant although the direction of effect remained the same.

Discussion

In this large population-based study, we identified individual- and service-level factors associated with ED visits at the end-of-life. At the individual-level, we found that fewer ED visits were associated with higher socioeconomic position, whereas more ED visits were associated with living in urban areas, being of South Asian ethnicity and having chronic respiratory, cardiovascular and cerebrovascular diseases as underlying causes of death. Of all the service-level factors we measured, only nursing home beds were associated with fewer ED visits.

We found a significant association between higher numbers of nursing home beds and fewer end-of-life ED visits. We found no significant association with numbers of residential home beds. Associations between care home residence and reduced end-of-life ED attendance have been identified in the literature [6], but not variation by care home type. The potentially 'protective' effect of nursing homes has important policy implications and underlines the importance of timely clinical input in community care [34]. However, community care workforce capacity to support clinical continuity is tentative, with staff turnover in social care highest among registered nurses [35]. Therefore, it is essential that community care is supported with appropriate local workforce planning, including primary care, ensuring clinical continuity for people with dementia, irrespective of setting.

We found that living in urban rather than rural areas was associated with more end-of-life ED visits. This contradicts findings of international literature [6], but is similar to English studies examining hospitalisation of people with dementia [36]. The difference may therefore be explained by contextual variation between countries. We also observed a stepwise reduction in visits with higher socioeconomic position. These findings are not new in end-of-life literature [37], but they are concerning. People affected by dementia in England are disproportionately disadvantaged, self-funding 60% of social care costs, which are projected to increase [38, 39]. Attempts to 'level-up' quality-of-life across the country must extend to quality of end-of-life, with focus on people with dementia, who are disproportionately impacted.

We found that South Asian ethnicity was associated with more ED visits in the last year of life. This is consistent with evidence that minority ethnicity was associated with increased ED visits [6]. Our findings have important clinical implications, as South Asian people are more likely to receive substandard end-of-life care [40] and are less likely to access dementia care [41]. The number of people with dementia from minority ethnic communities is expected to double in the next 40 years, with disproportionate increase in South Asian communities [42]. Therefore, there is urgent need for resources to support end-of-life care discussions with people from South Asian communities, and provision of accessible, culturally sensitive end-of-life dementia care.

In this study, urinary tract infections and respiratory conditions were common ED diagnoses. These conditions can often be treated with community support, minimising the need for burdensome transitions [43]. To improve end-of-life care for people with dementia, we echo recommendations for continuity of primary care [44], and for clinicians to optimise community-based management of chronic respiratory conditions and prioritise vaccination for individuals with dementia [45, 46]. Respiratory infections such as pneumonia should also prompt clinicians to initiate advance care planning discussions [47]. Addressing palliative care needs in people with dementia is associated with fewer end-of-life hospitalisations [44]. However, inequitable access to palliative care is well-recognised for people with dementia [48], with issues of service integration, training, and recognising dementia as a terminal illness [48]. As palliative care is not routinely monitored in England, we could not include it in our analyses. This is a missed opportunity in need of urgent redress.

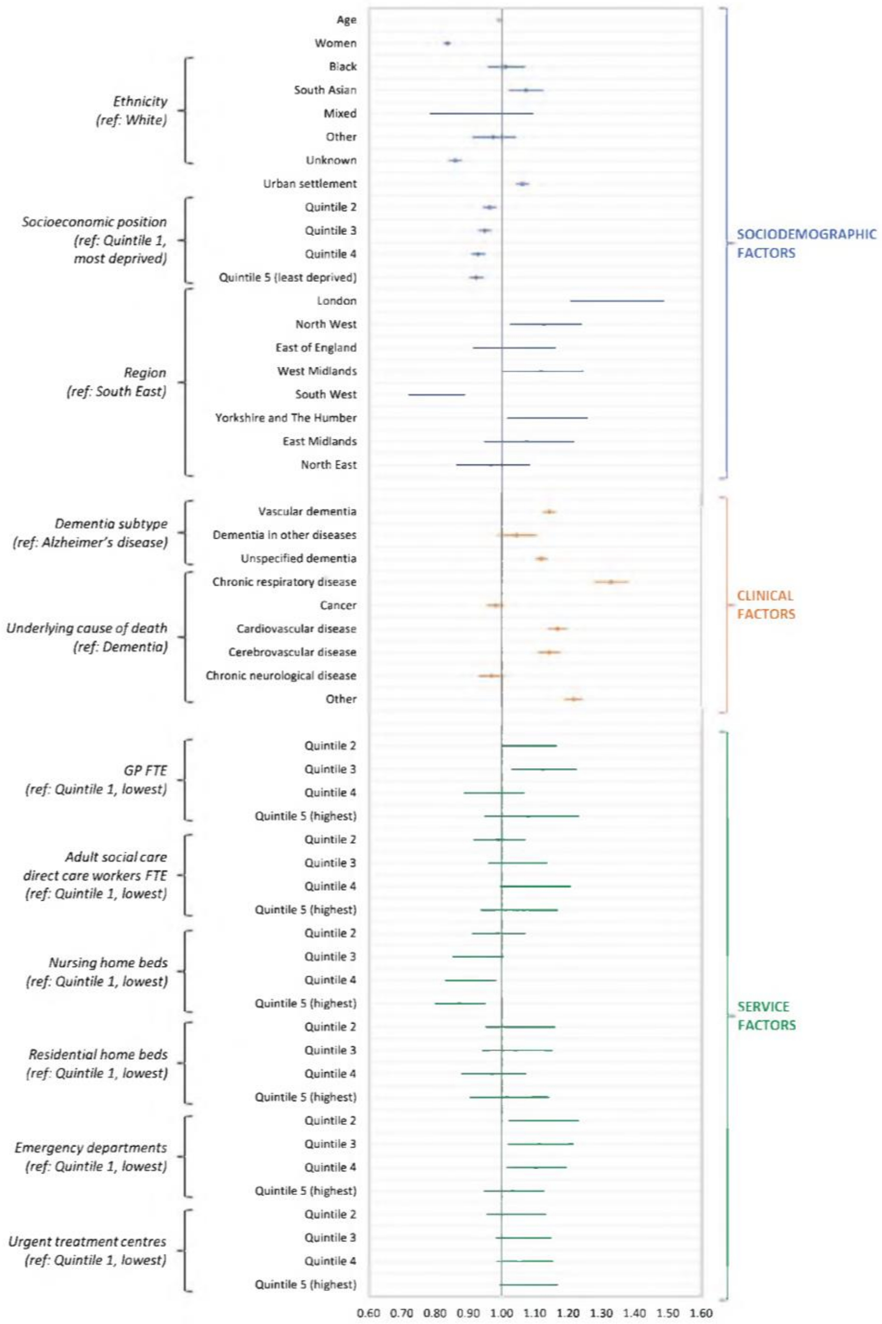

Figure 2. Sociodemographic, clinical and service factors associated with number of ED visits in the last year of life for people with dementia (IRR and 95% CI of estimates for each explanatory variable from the adjusted model)

Strengths and limitations

This study is novel in its use of nationwide routinely collected data and record linkage with several databases to examine individual- and service-level factors associated with end-of-life ED visits by people with dementia. However, there are limitations. Using mortality data may bias case identification due to incomplete death certification [23] and underreporting of dementia compared with hospital records [49]. Despite attempts to tighten specificity of dementia subtype, 'unspecified dementia' remained most prevalent. This is consistent with data from other countries [50], suggesting broader issues around subtype diagnosis and documentation. Due to data limitations, we were unable to include care home admission or residence, comorbidities, or civil status, despite high-strength evidence of their influence on ED attendance [6]. We were also unable to include voluntary service, specialist community palliative care, or primary care data. Future studies should incorporate these data, where available, to better understand the influence of wider community services.

Our sample comprised people with hospital contact within 3 years of death. As prior hospital use is associated with end-of-life ED visits [6], it is possible that people visiting the ED in the last year of life are over-represented in this study. However, we are reassured that the proportion of the final cohort attending the ED in the last year of life is similar to other studies [2] (82.6 vs. 78.6% respectively), and we observed similar results in the sensitivity analysis.

Conclusions

Individual- and service-level factors are associated with end-of-life ED visits by people with dementia. These data address an important gap in the evidence base and may aid clinicians to identify those most likely to attend the ED towards the end-of-life. Our findings underscore the value of services that are tailored to the needs of individuals from different minoritised ethnic groups, and identify policy priorities for investment in nursing home bed capacity and enhanced community models of care to better support people dying with dementia.

Declaration of Conflicts of Interest: None.

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Data Availability Statement: The data supporting the findings of this study are available within the article and in supplementary files in Age and Ageing online. This includes links to resources for all service-level data used.

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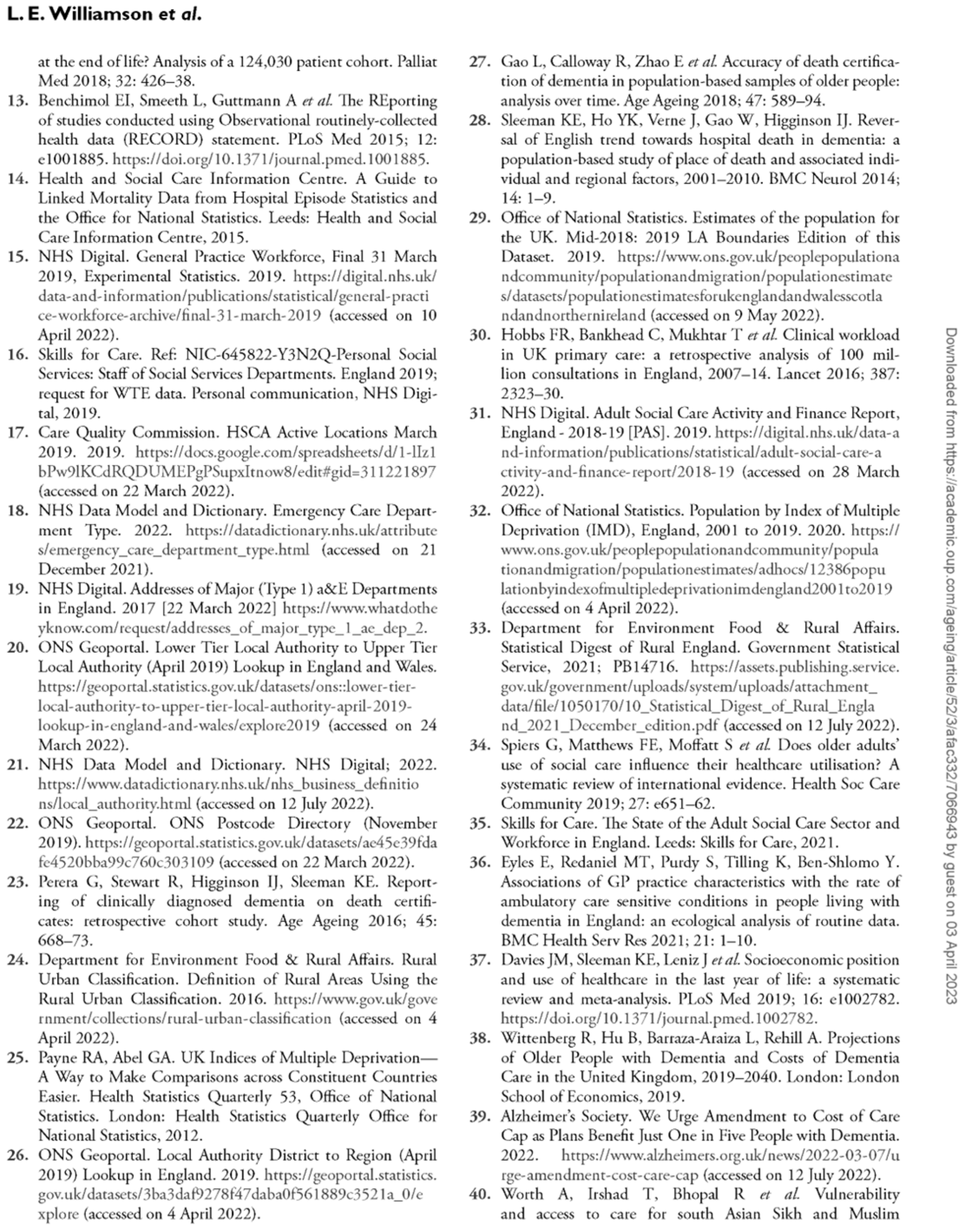

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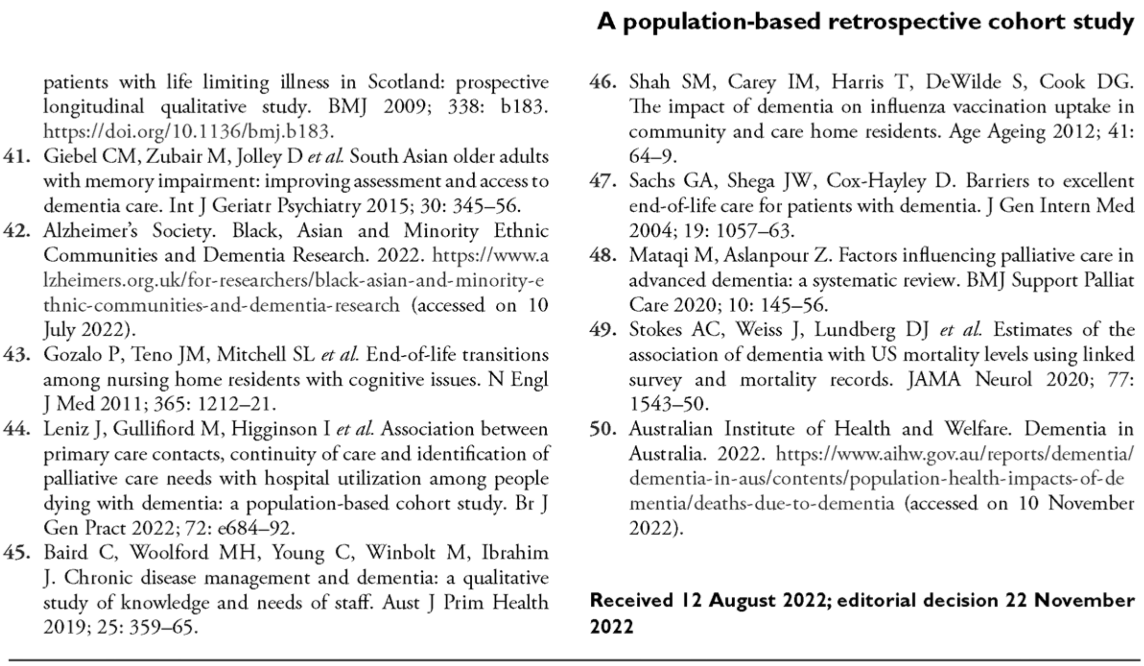

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9.2 Public representative responses to the epidemiological assessment

The findings of the epidemiological assessment were presented to the expert panel of public representatives for discussion (Appendix B3). Public representatives discussed the influence of care homes and how homes without nursing staff on site rely on administrative processes to care for people with dementia, which was considered to increase the likelihood of ED attendances for residents. Emphasis was placed on having a family caregiver accompany the relative with dementia to the ED to advocate for their relative and support staff to provide optimal care. This included assistance with communication among people with dementia from South Asian ethnic backgrounds specifically.

Public representatives also discussed the need for more integrated care, although expressed doubts that this would be achievable. There were calls for greater communication between primary, secondary and community services. Public representatives spoke about the efforts made by different services to be 'dementia friendly', which were considered largely ineffective, and that members of staff need training to understand how to best support people with dementia. Clinical staff in hospitals were found to overlook the additional functional requirements of people with dementia.

9.3 Influence of the epidemiological assessment and public representative feedback on the applied PRECEDE-PROCEED Model (PPM)

Aligned to the PPM, priority targets for intervention are informed from each phase of the PRECEDE component. Based on findings from the epidemiological assessment, and public representative feedback, individual and service targets of the PRECEDE component have been developed, as well as additional health targets, and points to consider for policy and intervention development (Figure 9.2).

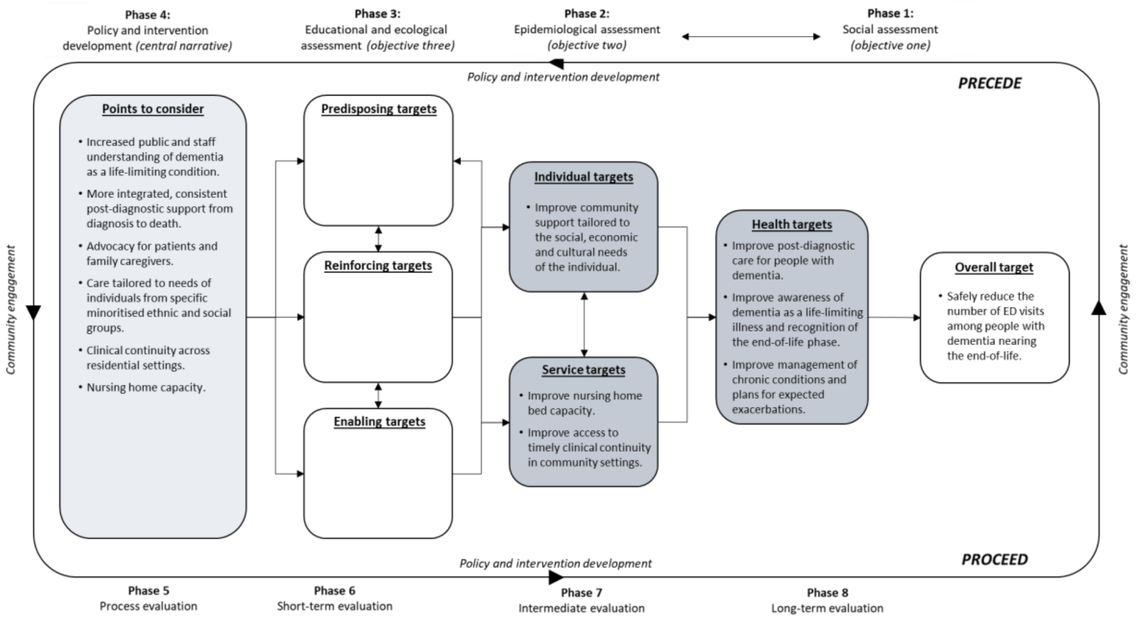

Figure 9.2 Developing the applied PRECEDE-PROCEED Model (PPM)
Individual and service targets, additional health targets, and points to consider for policy and intervention development, informed by findings of the epidemiological assessment and public representative feedback.

As the epidemiological assessment identified common ED diagnoses and found increased ED attendance associated with chronic respiratory and cerebrovascular and cardiovascular disease as underlying causes of death, an additional health target is to improve the management of chronic conditions in the community and to plan for expected exacerbations. With better recognition of end-of-life, it is expected that as the person with dementia approaches the end of life, plans for exacerbations will be tailored according to present need and advanced preferences to safely reduce ED attendance.

Findings from the epidemiological assessment identified specific sociodemographic characteristics that were associated with increased ED attendance. Furthermore, barriers to accessing care that are encountered by people from minoritised ethnic groups were discussed by public representatives as particularly problematic. Therefore, an individual target is community support that is tailored to the social, economic, and cultural needs of individuals as a key priority for change. This is expected to improve individual access to and benefit from community health and social care and therefore help to safely reduce ED attendance towards the end of life.

Service targets include increasing nursing home bed capacity, in accordance with findings of the epidemiological assessment. While the findings may be due to differences in local funding and demographics, situating the findings in the wider literature and from discussion with public representatives, continuity of clinical care afforded in nursing homes may improve recognition of end-of-life and acute deterioration, as well as mobilise higher-levels of clinical support, as needed. As regular clinical input for people living in the community (and in care homes without nurses) relies on GPs and NHS 111, this can be challenging for some to access, especially when requiring a timely response. Therefore, a second service target is to improve access to clinical continuity in community settings.

Based on feedback from public representatives and the findings of the epidemiological assessment, points to consider for policy and intervention development have been amended and extended. Findings from the epidemiological assessment show that South Asian ethnicity was associated with increased ED attendance, while higher socioeconomic position was associated with decreased ED attendance. Therefore, development of an intervention must consider provision of care that can be tailored specifically to the needs of individuals from different minoritised ethnic and social groups. It was also important to consider interventions that permit access to clinical continuity across residential settings, while also appreciating the value of increased capacity of nursing homes.

9.4 End of chapter summary

Informed by a hybrid model of end-of-life care, the epidemiological assessment identified individual-level factors associated with increased ED attendance in the last year of life, including South Asian ethnicity. Of all the service-level factors measured, only increasing number of nursing home beds was statistically significantly associated with fewer ED attendances. Public representatives of the expert panel discussed language barriers between the care staff and South Asian people and identified limited clinical expertise in residential homes.

Findings and public representative feedback have informed the development of the PPM, elaborating on health targets, and identifying individual and service targets. Components of policy and intervention development have also been developed further, highlighting cultural and social needs, clinical continuity, and nursing home capacity. The following chapter will continue to build on the PPM with findings and public representative feedback from the education and ecological assessment.

10 RESULTS 3: EDUCATIONAL AND ECOLOGICAL ASSESSMENT

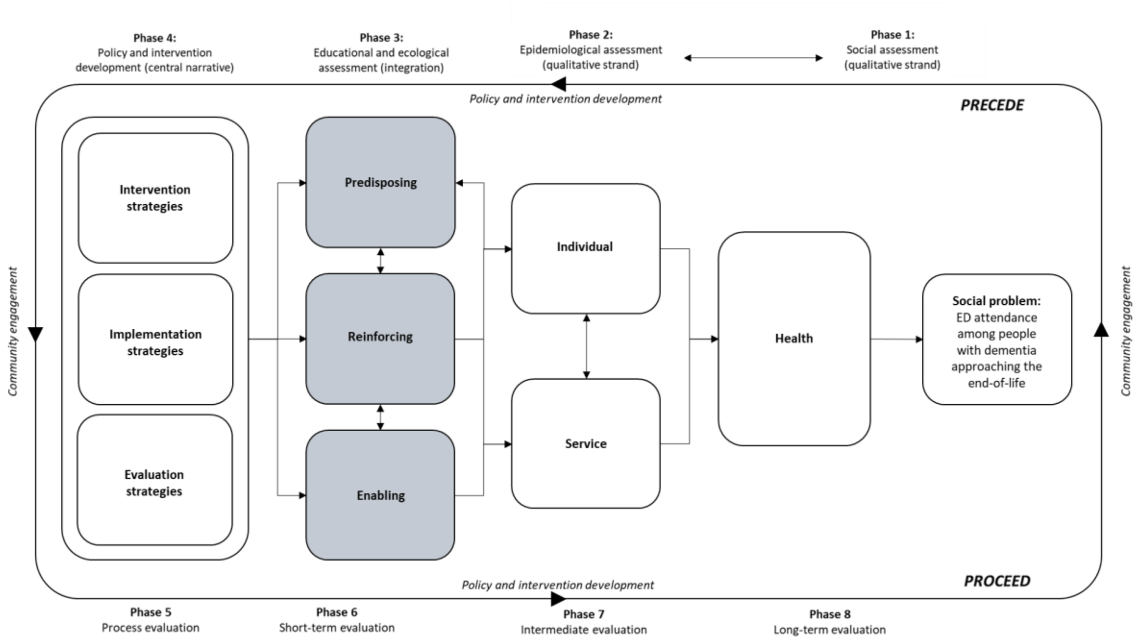

Figure 10.1 Educational and ecological assessment (phase 3)
Objective three, to develop a conceptual model of emergency department attendance among people with dementia towards the end of life.

This chapter presents the results of the educational and ecological assessment. This is a mixed methods integration and the third phase of the PRECEDE-PROCEED Model (PPM), meeting objective 3 (Figure 10.1). Following presentation of the results, this chapter summarises feedback from public representatives of the expert panel. The findings and public representative feedback were used to inform predisposing, reinforcing, and enabling targets for change, as part of the PPM's planning process.

10.1 A conceptual model of emergency department attendance among people with dementia approaching the end of life: A mixed methods integration

10.1.1 Introduction

Emergency department (ED) attendance is common among people with dementia who are approaching the end of life. While attendance remains relatively stable throughout the illness trajectory,[5] it increases towards the end of life.[4] This affects at least 79% of people with dementia who will attend the ED at least once in the last year of life.[4] Attending the ED can be very distressing for people with dementia and is associated with complications and poorer health outcomes.[7, 8, 10, 461]

Previous literature and current policy implicate community health and social care as playing a central role in reducing emergency hospitalisations.[5, 16, 462] Among people with dementia, evidence shows that limited availability and access to community support contributes to greater urgent care use.[439] An evidence-informed conceptual understanding of the relationship between ED attendance and access to community care will help to identify ways to safely reduce attendances, informing future development of policies and care pathways. Therefore, the aim is to develop a conceptual model of ED attendance among people with dementia approaching the end of life.

10.1.2 Methods

10.1.2.1 The PRECEDE-PROCEED Model

The thesis has been mapped against the first three phases of the PRECEDE component of the PRECEDE-PROCEED Model (PPM): social assessment, epidemiological assessment, and educational and ecological assessment. In this thesis, the social assessment was a qualitative interview study exploring drivers of ED attendance among people with dementia across the illness trajectory. The epidemiological assessment was a quantitative observational study examining individual- and service-level factors associated with ED attendance in the last year of life. The educational and ecological assessment is the integration of the findings from both social and epidemiological assessments. The results of the educational and ecological assessment are reported in this chapter, which has been informed by the Good Reporting of A Mixed Methods Study (GRAMMS) guidelines.[411]

According to the PPM, the educational and ecological assessment identifies factors that were found to be important in the social and epidemiological assessments, underscoring the reciprocal relationship between the individual and the environment in determining health-related problems.[89] Findings from the social and epidemiological assessments are integrated to identify predisposing, reinforcing, and enabling factors influencing the phenomenon of interest, helping planners identify and understand the multilevel factors that can bring about change.[89] The mixing of methods also complements the aim of developing a conceptual model, as mixed methods integration affords merging complementary quantitative and qualitative studies to enhance the applicability and integrity of findings that cannot be accomplished independently.[426]

10.1.2.2 Theoretical underpinning

The intersectional ecological framework,[391] and relational model of disability,[39] were used to inform the interpretation of integrated findings and the development of the conceptual model of ED attendance among people with dementia approaching the end of life. The intersectional ecological framework conceptualises how individuals may encounter marginalisation based on their multiple intersecting social identities that interact with different systemic levels, from the microsystem (individual) to the macrosystem (society).[391] It provides a representation of how social advantage and disadvantage can arise from interactions between social identity and social context.[391] The relational model of disability describes how people with dementia may encounter disability due to the functional impairment of the disease and the social disadvantage imposed by societal bias against dementia.[39]

10.1.2.3 Design

Using a convergent-parallel, partially mixed methods design, the social and epidemiological assessments were run in parallel to investigate ED attendance among people with dementia from qualitative and quantitative positions, respectively. Although their designs were mutually informative, they were conducted and analysed independently with equal priority. Methods for the two assessments are detailed elsewhere (Chapters 5 and 6) and summarised in Figure 10.2.

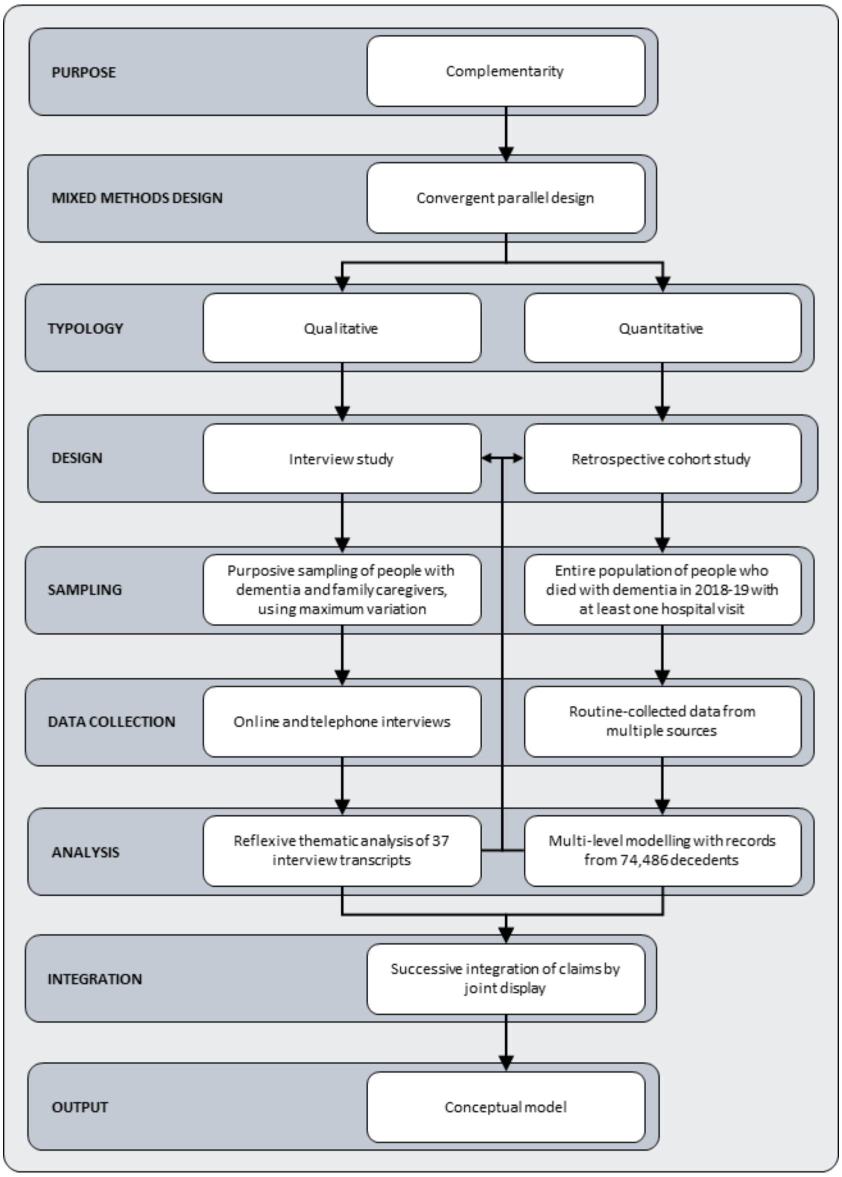

Figure 10.2 Mixed methods study design
Purpose, priority and sequence of methods, and the sampling, data collection and analysis methods for each strand.[411]

10.1.2.4 Integration method

The PPM does not advocate a specific method to integrate findings from the social and epidemiological assessments. Therefore, the method of integration was informed by mixed methods research literature. Specifically, integration followed the ‘successive integration of claims’ method,[419] where ‘claims’ are inferences from the social and epidemiological assessments. The rationale for using this method of integration is discussed elsewhere (Chapter 7.4). Briefly, this method offers a robust and transparent means of integrating inferences from qualitative and quantitative research for the purpose of complementarity, which suits the convergent, parallel mixed methods design used in this thesis.

10.1.2.5 Integration procedure

Using a joint display, claims from the social and epidemiological assessments are presented on one side of the display (constituent claims), with integrated claims presented on the other. As per the stepwise approach, a claim from the social assessment is merged with a corresponding claim from the epidemiological assessment, forming an integrated claim, which may be explanatory, contradictory, or juxtaposing in nature:

- *Explanatory integrated claims:* when constituent claims jointly enhance understanding and are separated by the word **because** within the integrated claim.
- *Contradictory integrated claims:* when constituent claims contradict each other and are separated by the word **but** within the integrated claim.
- *Juxtaposing integrated claims:* when constituent claims are related but are neither explanatory nor contradictory and are separated by the word **and** within the integrated claim.

Two constituent claims can also be from the same assessment. All constituent claims are merged into integrated claims, which can be further integrated with additional constituent claims or other integrated claims. The stepwise sequence is continued until the researcher determines when to stop the integration, with the final integrated claim representing the meta-inference.[419] This final step was not included in this integration, as not all claims between the social and epidemiological assessments corresponded and therefore could not be included in the successive process of integration. However, their relevance to the aim of the educational and ecological assessment warranted their inclusion. This mandated that the meta-inference derive from a more global analysis instead.

Aligned to the structure of the educational and ecological assessment, claims were categorised into predisposing factors (individual factors that predispose to ED attendance), reinforcing factors (physical and social factors that reinforce ED attendance), and enabling factors (conditions that act as facilitators or barriers to ED attendance).[89] Due to this categorisation, it was considered pertinent to conduct a cross-integration of claims across the three categories. As explaining contradictions in research findings is considered to be the essence of mixed methods research,[419] cross-integration prioritised clarifying any contradictions to advance explanations.

10.1.2.6 Public involvement

Public representatives of the thesis informed the interpretation of the integrated findings and development of the conceptual model (Chapter 10.2).

10.1.2.7 Ethical considerations

The study did not require ethical approval because data are inferences from other studies, based on primary aggregated and anonymised data that are available in the public domain.

10.1.3 Results

10.1.3.1 Successive integration of claims

Following the stepwise integration procedure, 34 claims were utilised, comprising constituent claims from the social assessment (n=13) and epidemiological assessment (n=6), and 15 integrated claims.

Based on available corresponding inferences from the social and epidemiological assessments, predisposing factors were limited to socioeconomic position and dementia subtype, comprising four explanatory and one contradictory integrated claim. Reinforcing factors were limited to residence and geographical location, comprising six explanatory and one contradictory integrated claim. Enabling factors were limited to health and social care priorities and societal bias, comprising three juxtaposing integrated claims (Table 10.1).

Table 10.1 Joint display of predisposing, reinforcing, and enabling claims

Constituent claims from social and epidemiological assessments [x], merged into integrated claims [ICx], with nature of connection

Constituent claims		Integrated claims	
Strand	***Claim***	***Integrated claim***	***Connection***
		Predisposing factors	
Epidem.	[1] Fewer ED attendances are associated with higher socioeconomic position	[IC3] Fewer ED attendances are associated with higher socioeconomic position **because** people with dementia and caregivers with the socioeconomic privilege of financial stability, education and systemic knowledge are better able to navigate and challenge the system, securing financial support, and access community social support.	Explanatory
Social	[2] People with dementia and caregivers with the socioeconomic privilege of financial stability, education and systemic knowledge are better able to navigate and challenge the system, securing financial support, and access community social support.		
Mixed	[IC3] Fewer ED attendances are associated with higher socioeconomic position because people with dementia and caregivers with the socioeconomic privilege of financial stability, education and systemic knowledge are better able to navigate and challenge the system, securing financial support, and access community social support.	[IC5] Fewer ED attendances are associated with higher socioeconomic position, which may be **because** people with dementia and caregivers without the socioeconomic privilege of financial stability, education, and systemic knowledge to better navigate and challenge the system, secure financial support, and access community social and clinical support, must instead rely on lengthy waiting lists to statutory services which are directed towards managing a crisis.	Explanatory
Social	[4] Waiting times for statutory services are lengthy and support is directed towards managing a crisis.		
Epidem.	[6] Vascular and unspecified dementia subtypes were associated with more ED visits than Alzheimer's disease.	[IC8] People with vascular and unspecified dementia subtypes are more likely to attend the ED, which may be **because** they are more likely to have physical complications and comorbidities associated with the dementia subtype that predispose to acute deterioration.	Explanatory
Epidem.	[7] Cerebrovascular, cardiovascular, and chronic respiratory disease as the underlying cause of death was associated with increased ED visits.		
Mixed	[IC8] People with vascular and unspecified dementia subtypes are more likely to attend the ED towards the end of life than people with Alzheimer's disease because they are more likely to have physical complications and comorbidities associated with the dementia subtype that predispose to acute deterioration.	[IC10] People with vascular and unspecified dementia subtypes are more likely to attend the ED towards the end of life than people with Alzheimer's disease because they are more likely to have physical complications and comorbidities associated with the dementia subtype that predispose to acute deterioration, **but** most participants with rarer dementias accessed multidisciplinary teams through psychiatry services and specialist clinical research centres across the country.	Contradictory
Social	[9] Most participants with rarer dementias accessed multidisciplinary teams through psychiatry services and specialist clinical research centres across the country.		
Epidem.	[7] Cerebrovascular, cardiovascular, and chronic respiratory disease as the underlying cause of death was associated with increased ED visits in the last year of life.	[IC12] People with dementia and comorbid chronic conditions are more likely to attend the ED towards the end of life, which may be **because** healthcare does not easily accommodate people with dementia who have escalating needs and multimorbidity.	Explanatory
Social	[11] Healthcare does not easily accommodate people with dementia who have escalating needs and multimorbidity.		
		Reinforcing factors	
Epidem.	[13] Living in an area with more nursing home beds (but not residential home beds) was associated with fewer ED visits in the last year of life.	[IC15] Living in an area with more nursing home beds (but not residential home beds) was associated with fewer ED visits in the last year of life, which may be **because** clinical input is needed to recognise and plan for the end of life.	Explanatory
Social	[14] Family caregivers need clinical input to recognise and plan for the end of life.		
Social	[16] End-of-life care support was difficult to access from within the community.	[IC17] End-of-life care support was difficult to access from within the community, which may be **because** waiting times for statutory services are lengthy and support is directed towards managing a crisis.	Explanatory
Social	[4] Waiting times for statutory services are lengthy and support is directed towards managing a crisis.		
Epidem.	[13] Living in an area with more nursing home beds (but not residential home beds) was associated with fewer ED visits in the last year of life.	[IC18] Living in an area with more nursing home beds (but not residential home beds) was associated with fewer ED visits in the last year of life, which may be **because** end-of-life care is difficult to access from within the community due to prolonged waiting times for statutory services that are directed towards managing a crisis.	Explanatory
Mixed	[IC17] End-of-life care support was difficult to access from within the community because waiting times for statutory services are lengthy and support is directed towards managing a crisis.		

Social	[19] Residential homes transfer residents to the ED based on low-threshold protocols	[IC21] Residential home residents attend the ED based on low-threshold protocols, which may be **because** they do not have access to clinical continuity.	Explanatory
Social	[20] Residential homes do not have access to clinical continuity.		
Mixed	[IC15] Living in an area with more nursing home beds (but not residential home beds) was associated with fewer ED visits in the last year of life, which may be because clinical input is needed to recognise and plan for the end of life.	[IC22] Living in an area with more nursing home beds (but not residential home beds) was associated with fewer ED visits in the last year of life, which may be **because** residential home residents attend the ED based on low-threshold protocols because they do not have timely access to clinical input or clinical continuity needed to recognise and plan for the end of life.	Explanatory
Mixed	[IC21] Residential home residents attend the ED based on low-threshold protocols because they do not have timely access to clinical input.		
Epidem.	[23] There were regional differences in number of ED attendances in the last year of life.	[IC25] There were regional differences in number of ED attendances, which may be **because** there is geographical variation of available community-based support services, making the system difficult to navigate.	Explanatory
Social	[24] There was geographical variation of available community-based support services, making the system difficult to navigate.		
Epidem.	[26] Living in urban rather than rural area was associated with more ED attendances.	[IC28] Living in urban rather than rural area was associated with more ED attendances, **but** people with dementia and caregivers living in rural areas must travel further and may rely on public or other means of transport to attend primary and outpatient care and social activities.	Contradictory
Social	[27] People with dementia and caregivers living in rural areas must travel further and may rely on public or other means of transport to attend primary and outpatient care and social activities.		
		Enabling factors	
Mixed	[IC8] People with vascular and unspecified dementia subtypes are more likely to attend the ED because they are more likely to have physical complications and comorbidities associated with the dementia subtype that predispose to acute deterioration.	[IC30] People with vascular and unspecified dementia subtypes are more likely to attend the ED because they are more likely to have physical complications and comorbidities associated with the dementia subtype that predispose to acute deterioration **and** general healthcare may take a blinkered view of illness in dementia, reflecting wider societal stigma.	Juxtaposing
Social	[29] General healthcare may take a blinkered view of illness in dementia, reflecting wider societal stigma.		
Mixed	[IC17] End-of-life care support was difficult to access from within the community, which may be because waiting times for statutory services are lengthy, and support is directed towards managing a crisis	[IC32] End-of-life care support was difficult to access from within the community, which may be because waiting times for statutory services are lengthy, and support is directed towards managing a crisis, **and** there is a systemic lack of parity of esteem between dementia and other life-limiting illnesses, **and** a blinkered view of illness in dementia, reflecting wider societal stigma.	Juxtaposing
Social	[31] There is a systemic lack of parity of esteem between dementia and other life-limiting illnesses.		
Social	[29] General healthcare may take a blinkered view of illness in dementia, reflecting wider societal stigma.		
Mixed	[IC5] Fewer ED attendances are associated with higher socioeconomic position, which may be because people with dementia and caregivers without the socioeconomic privilege of financial stability, education, and systemic knowledge to better navigate and challenge the system, secure financial support, and access community social and clinical support, must instead rely on lengthy waiting lists to statutory services which are directed towards managing a crisis.	[IC34] Fewer ED attendances are associated with higher socioeconomic position, which may be because people with dementia and caregivers without the socioeconomic privilege of financial stability, education, and systemic knowledge to better navigate and challenge the system, secure financial support, and access community social and clinical support, must instead rely on lengthy waiting lists to statutory services which are directed towards managing a crisis, **and** there is an inequitable absence of follow-up care and single point of contact for people with common dementias.	Juxtaposing
Social	[33] There is an inequitable absence of follow-up care and single point of contact for people with common dementias.		

10.1.3.2 Successive cross-integration of claims

Including the contradictory integrated claims from table 10.1, cross-integration provides a final integrated claim of explanatory and juxtaposing nature (Table 10.2).

Table 10.2 Joint display of cross-integration of claims
Constituent integrated claims [ICx] and final integrated claim [ICx], with nature of connection

Constituent claims		**Integrated claims**	
Strand	***Claim***	***Final integrated claim***	***Connection***
Mixed*	[IC10] People with vascular and unspecified dementia subtypes are more likely to attend the ED towards the end of life than people with Alzheimer's disease because they are more likely to have physical complications and comorbidities associated with the dementia subtype that predispose to acute deterioration, but most participants with rarer dementias accessed multidisciplinary teams through psychiatry services and specialist clinical research centres across the country.	[IC35] People with vascular and unspecified dementia subtypes are more likely to attend the ED towards the end of life because they are more likely to have physical complications and comorbidities associated with the dementia subtype that predispose to acute deterioration, but people with rarer dementias access multidisciplinary teams through psychiatry services and specialist clinical research centres across the country. This may be **because** access is mediated by geographical variation of available community-based support services that can make the system difficult to navigate and increases ED attendance, **and** rurality of residence that may require people with dementia and caregivers living in rural areas to travel further and rely on public or other means of transport to attend primary and outpatient care and social activities, **and** residence type, where nursing homes provide the clinical input needed to recognise and plan for the end-of-life, while clinical continuity is not easily accessible elsewhere. This may be influenced by socioeconomic position, as without the socioeconomic privilege of financial stability, education, and systemic knowledge to better navigate and challenge the system, secure financial support, and access community social and clinical support, people with dementia and caregivers must rely on lengthy waiting lists to statutory services directed towards managing a crisis. This may be driven by inequitable access to end-of-life and follow-up care for common dementias, driven by a systemic lack of parity of esteem between dementia and other life-limiting illnesses and a blinkered view of illness in dementia, reflecting wider societal stigma.	Explanatory, juxtaposing
Mixed	[IC25] There were regional differences in number of ED attendances, which may be because there is geographical variation of available community-based support services, making the system difficult to navigate.		
Mixed*	[IC28] Living in urban rather than rural area was associated with more ED attendances, but people with dementia and caregivers living in rural areas must travel further and may rely on public or other means of transport to attend primary and outpatient care and social activities.		
Mixed	[IC22] Living in an area with more nursing home beds (but not residential home beds) was associated with fewer ED visits in the last year of life, which may be because residential home residents attend the ED based on low-threshold protocols because they do not have timely access to clinical input or clinical continuity needed to recognise and plan for the end of life.		
Mixed	[IC34] Fewer ED attendances are associated with higher socioeconomic position, which may be because people with dementia and caregivers without the socioeconomic privilege of financial stability, education, and systemic knowledge to better navigate and challenge the system, secure financial support, and access community social and clinical support, must rely on lengthy waiting lists to statutory services which are directed towards managing a crisis, **and** there is an inequitable absence of follow-up care and single point of contact for people with common dementias.		
Mixed	[IC32] End-of-life care support was difficult to access from within the community, which may be because waiting times for statutory services are lengthy, and support is directed towards managing a crisis, **and** there is a systemic lack of parity of esteem between dementia and other life-limiting illnesses, **and** a blinkered view of illness in dementia, reflecting wider societal stigma.		

**Contradictory claims*

10.1.3.3 Final integrated claim and meta-inference

Using successive integration of claims from the social and epidemiological assessments, findings showed explanatory and contradictory inferences concerning predisposing and reinforcing factors and juxtaposing inferences concerning enabling factors. Cross-integration of integrated claims clarified contradictions between predisposing and reinforcing factors, while enabling factors continued to augment explanations. From this process, the final integrated claim explained that while people with rarer dementias have greater follow-up care from community specialist teams compared to people with Alzheimer's disease, they may be more likely to attend the ED towards the end of life as access to community support is influenced by several predisposing factors such as comorbidity profile, age, and socioeconomic position, mediated by residence type and geographical location, and driven by disparities in care that reflects wider societal stigma that prioritises physical illness over mental distress.

Deviating from the integration method, this final integrated claim is not accepted as the meta-inference of the educational and ecological assessment. To avoid reducing the phenomenon of interest to differences between rarer and common dementias, the meta-inference is based on a global analysis of the integrated findings and patterns of integration. Accordingly, the meta-inference is:

ED attendance among people with dementia approaching the end of life is influenced by several predisposing factors that are mediated by local reinforcing factors and driven by systemic priorities that can enable or disable access to timely and responsive community care and reduce or increase the need to attend the ED.

10.1.4 Conceptual model of ED attendance among people with dementia approaching the end of life

From this meta-inference, and drawing on feedback from public representatives and existing intersectional ecological theory,[391] a conceptual model of ED attendance among people with dementia approaching the end of life was developed (Figure 10.5). The model illustrates how people with dementia have multiple overlapping characteristics (e.g., age, subtype, socioeconomic position) that interact with the local context (e.g., residence and geographical location). Systemic priorities and societal preconceptions determine how these factors interact to empower people with dementia to access timely and responsive clinical care in the community. Those who are not empowered are more likely to attend the ED towards the end of life.

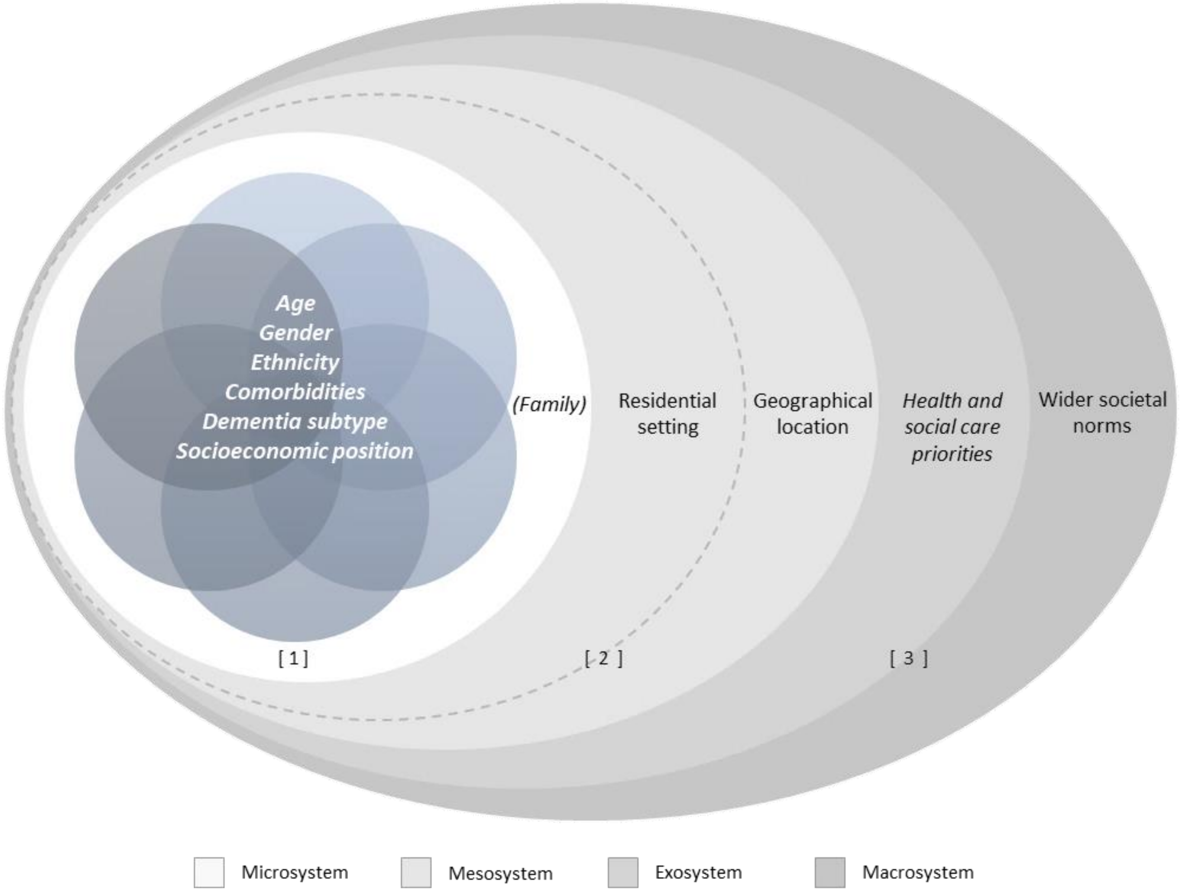

Figure 10.3 Conceptual model of ED attendance among people with dementia approaching the end of life

[1] Predisposing characteristics, [2] Reinforcing factors, and [3] Empowering influence.

The epidemiological assessment supported previous evidence that factors such as ethnicity, gender and age influence ED attendance among people with dementia towards the end of life.[323] This model assumes that these factors are social identities that synergistically interact across different levels of the wider system. Figure 10.3 includes all potential predisposing factors identified in the systematic review (Chapter 2.5) and the epidemiological assessment (Chapter 9.1). However, predisposing factors comprise all other identities that are necessary for a specific individual,[391] including any advocating family caregivers. The social assessment confirmed family caregivers play a central health navigator role and striving for access to health and social care, consistent with other studies.[11, 463] The influence of caregivers' own intersecting identities on caregiver burden and access to support have been identified in previous literature.[316, 464] This conceptual model locates their influence at the microsystem level, as advocates for people with dementia.

Aligned to the intersectional ecological framework,[391] it is at the mesosystem level of the conceptual model where reinforcing factors of local context, including residence type and geographical location, interact with intersecting social identities to influence access to community healthcare. For example, the mixed methods integration suggested that nursing homes were associated with reduced ED attendance because they afforded direct access to clinical continuity needed to recognise the end of life and facilitate care. By contrast, the availability of clinical continuity was more variable in the community depending on local service structures and proximity, with access influenced by predisposing factors such as dementia subtype and socioeconomic position. This is consistent with evidence showing limited access to support in rural areas for people with rarer dementias,[465] lower continuity of primary care in urban settings and areas of greater deprivation,[466] and potential regional bias in the provision of palliative and end-of-life care.[467]

The social assessment highlighted the influence of service configuration on access to community support for people affected by dementia. Local commissioning and national policy priorities that influence service configuration are at the exosystem level of the model, where the potential for discrimination is high.[391] Previous literature shows how political agendas determine the categorisation of dementia under medical, social or integrated care,[468] and influence commissioning priorities.[469] In the conceptual model, these agendas and priorities have potential to either express or suppress empowering influence over the interaction between intersecting predisposing factors and reinforcing factors. To illustrate, the recent Health and Care Act 2022 included changes to the eligibility criteria for capped social care costs.[77] These changes were expected to disproportionately impact people with greater care needs, such as those with vascular dementia and multimorbidity, and impact those with lower socioeconomic position.[76] This impact may have also been reinforced by area of residence, as there are regional differences in public funding and social care availability across the UK,[470, 471] and in the number of people with dementia expected to reach the cap.[76] While the Government have since delayed the implementation of the care cap, its eventual introduction is likely to unduly impact people with dementia and other marginalised identities across different residential and geographical locations.

As illustrated in the social assessment, integration and elsewhere, there is societal stigma towards people with dementia.[40, 43, 457] In the conceptual model, the influence of this bias is at the macrosystem level.[391] Societal inequality at the macrosystem level permeates through other subsystems and “sets the stage” for interactions between intersecting social identities and all other subsystems.[391 (p.148)] The notion that societal stigma negatively affects the care received by people with dementia has been observed in the 'culture of dementia care' in acute care settings,[472] which disregards the needs and preferences of people with dementia,[473] and places them at a lower priority than others with less complex needs.[474] Drawing on this evidence and the relational view of disability,[39] the model assumes that the voices of people with dementia may be lost from progression of the disease at the microsystem level, unheard from the absence of local support at the mesosystem level, overlooked from pressures and priorities of stretched health and social care at the exosystem level, and cancelled from stigma at the macrosystem level. Therefore, intersecting with other social identities across these socioecological subsystems, people with dementia and their caregivers may experience complex discrimination in accessing timely and responsive community care to meet unstable distressing symptoms and concerns. This makes ED attendance towards the end of life more likely.

The findings of the educational and ecological assessment have important implications to policy and practice. Findings suggest that an individual affected by dementia will have different social identities that will result in advantage or disadvantage depending on context. Therefore, a one-size-fits-all approach to policy development is inadequate to address ED attendance towards the end of life. However, policy that focuses on a specific marginalised group is as likely to be ineffective. Previous literature has identified that sole focus on topical or favoured marginalised groups perpetuates privilege among a small subset of the population and leads to competition between other marginalised groups.[475] As explained by the conceptual model, an intersectional approach to policy would serve to respond to all people with dementia as members of any marginalised group, reducing inequity of access to community health and social care and reliance on the ED.

International standards of post-diagnostic dementia care advocate services that are 'culturally competent' and 'gender inclusive'.[61] The conceptual model presented here underscores the value of adopting an approach which services go beyond the 'competence' needed to interact with different people, and instead to be deliberate and adaptive to how different facets of a person's identity may converge with different social structures to result in their advantage or disadvantage.[476] This intersectional approach may also serve to advance service delivery towards person-centred care, which aligns to national healthcare strategy,[16] national clinical guidelines for dementia care,[477] and global public health priorities in response to dementia.[62]

Finally, whether or not policies, service configurations or individual exchanges are approached intersectionally, the model emphasises the need to appreciate the overarching influence of the macrosystem level, and recognising it as the most challenging to change.[391] While there have been national and international attempts to de-stigmatise dementia, some are at best weak and at worst marginalising.[39] Aligned to the relational view of dementia, an equalities-based approach to combating stigma is required by recognising the marginalisation of different people with dementia.[39] This approach would better set the stage for interactions between intersecting identities in different subsystems and safely reduce ED attendance towards the end of life.

10.1.5 Strengths and limitations

This educational and ecological assessment has filled a gap in the evidence base by completing a mixed methods integration using formal methods and conceptualising ED attendance among people with dementia towards the end of life. The work is strengthened by using a formal method of integration, the framework of a well-known programme planning model (PPM), and by applying established theory and public representative feedback.

There are some limitations. The method used to integrate the social and epidemiological assessments stipulates labelling the final integrated claim as the meta-inference. This final step was not followed, as some claims could not be integrated due to the unavailability of a corresponding claim. Therefore, using the final integrated claim as the meta-inference would have compromised the conceptualisation of ED attendance. The meta-inference was instead based on a global analysis of the patterns of integration. It is acknowledged that this analysis may obscure the transparency that was originally sought from using the method of successive integration.

It is further acknowledged that categorising claims according to predisposing, reinforcing, and enabling factors may have restricted the mixed methods integration. While it is possible that some inferences from either assessment may not have been integrated as they were not perceived as relating to predisposing, reinforcing, or enabling factors, categorisation was flexible to complement the available corresponding claims. Furthermore, the use of these categories is informed by the planning model and are intended to assist with future intervention development.[89] The categories also enabled the development of the conceptual model with explanatory value, which was consistent with the aim of the educational and ecological assessment.

The central assumption of the educational and ecological assessment is that ED attendance among people with dementia approaching the end of life is based on limited access to clinical care in the community. While public representatives and previous literature support this assumption,[439] it is possible that there are other reasons for ED attendance which have not been identified from the process of integration. For example, some people may choose to attend the ED for instant access to care, or to access the wider system. Findings from the social assessment suggest that for people with dementia, the ED was used as a last resort if they required investigations only available in the ED, or if they would become critically unwell without ED intervention. While it is accepted that the conceptual model presents only this view, it has been developed robustly and is consistent with previous literature and public representative input. Therefore, the educational and ecological assessment is considered to contribute to current understanding around end-of-life care for people with dementia, offering insight into some of the key components of care that may help to safely reduce ED attendance.

10.1.6 Summary of education and ecological assessment

Findings from this mixed methods integration show that there are predisposing, reinforcing, and enabling factors that may influence ED attendance among people with dementia towards the end of life. Informed by previous literature, theory and public representative feedback, ED attendance has been conceptualised as a product of intersecting predisposing characteristics that interact with reinforcing contextual factors, which, underpinned by systemic priorities and societal norms, determine if a person with dementia is empowered to access community clinical care, or reliant on attending the ED towards the end of life. This conceptualisation identifies clinical continuity as a key component of dementia care and advocates a systemic, intersectional approach to policy and practice.

10.2 Public representative responses to the educational and ecological assessment

The findings of the educational and ecological assessment were presented to the thesis public representative group for discussion (Appendix B3). Public representatives provided feedback on the conceptual model, appreciating the link between theory and practical application, and its comprehensive approach, suggesting that it could include economic and quantitative data to have more impact with policymakers. Public representatives provided valuable feedback on the terminology used in the conceptual model. Specifically, they advised against the use of terms ‘enabling/disabling’ to avoid perpetuating stigma and division, preferring ‘empowering/not empowering’. Public representatives agreed with the importance of representation and diversity, with reference to minoritised ethnic backgrounds, as well as different dementia subtypes and stages of dementia.

It was pertinent to check with public representatives if it was appropriate to develop the model with a central assumption that ED attendance was due to limited access to community support. Public representatives agreed with this assumption. It was noted by representatives that GP access can be difficult and if successful, there was a sense that GPs would refer people with dementia to the ED due to not having the time needed to complete the assessment. Community-based support was considered limited, with geographical differences noted in post-diagnostic support especially for those living alone in the community. There was suggestion that the charity sector could provide more support to people with dementia, but that funding was tentative.

There were discussions about care homes and how public representatives believed there is a lack of meaningful training for staff about dementia, and that staff often make assumptions about people with dementia and family members. There were also comments from public representatives about observable inconsistencies in operational processes between private and local authority-run care homes, and how, in general, there were too few care workers to provide the one-to-one support required for people with dementia.

10.3 Influence of the educational and ecological assessment and public representative feedback on the applied PRECEDE-PROCEED Model (PPM)

Aligned to the PPM, priority targets for intervention are informed from each phase of the PRECEDE component. Based on findings from the educational and ecological assessment, and public representative feedback, predisposing, reinforcing, and empowering targets of the PRECEDE component have been developed, and points to consider for policy and intervention development (Figure 10.4).

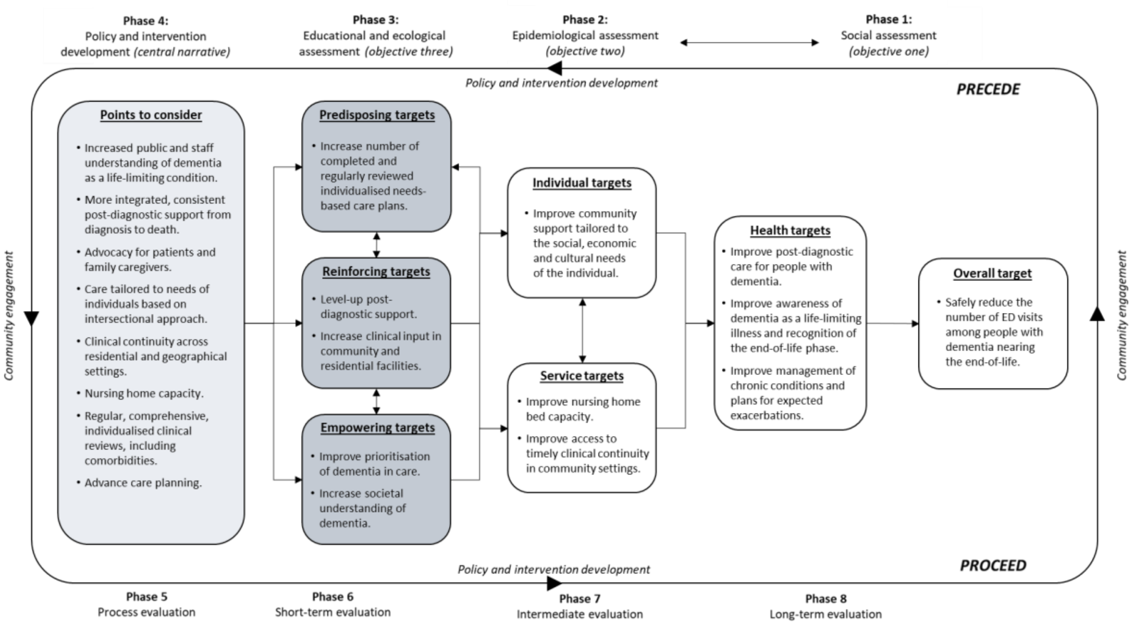

Figure 10.4 Developing the applied PRECEDE-PROCEED Model (PPM)
Predisposing, reinforcing and empowering targets, with points to consider for policy and intervention development, informed by findings of the educational and ecological assessment and public representative feedback.

As intersectionality was central to the educational and ecological assessment, the target in relation to predisposing factors focuses on improving provision of individualised, needs-based care plans. This is intended to take an intersectional approach to optimise awareness of and response to the potential influence of the different backgrounds of individuals, and to use this to inform provision of patient-centred care. It is known that social identities alter over time and context,[476] therefore regular review of these individualised care plans is also advocated as a target for change. Targets in relation to reinforcing factors include levelling up the geographical differences in post-diagnostic support, as it was highlighted in the educational and ecological assessment that this can reinforce or mitigate against barriers to accessing support in the community. This corresponds to current political agendas, as discussed in Chapter 2.4. Similarly, the assessment also identified residence type as a reinforcing factor. As clinical input is more easily and quickly accessible in a nursing home than in the community or residential homes (without nursing staff), increasing availability and accessibility of clinical input in community and residential homes was another target in relation to reinforcing factors.

Directly informed by public representative feedback, the educational and ecological assessment includes targets in relation to empowering rather than enabling factors. Based on the findings of the assessment and public representative discussions, targets towards empowerment involve improving the prioritisation of dementia in the health and social care system and tackling societal stigma by improving public understanding of dementia. It is expected that these targets will be mutually reinforcing, facilitating efforts to meet targets from the epidemiological and social assessments.

As well as changing enabling to empowering, the label 'educational and ecological assessment' has been queried. Although the 'ecological' aspect of the label effectively describes the findings of the assessment, the 'educational' aspect was examined, as this assumes a deficit model in health policy whereby patients are expected to require education to inform effective decision-making. While awareness of services is a recognised domain of access,[162] it was shown in the social assessment and has been postulated elsewhere that this may be an oversimplification of how patients choose between different services.[169] As there was emphasis in both the assessment and public representative feedback of a need to educate the public, people with dementia, and health and social care staff about dementia, the label 'educational and ecological assessment' was still considered applicable.

Based on feedback from public representatives and the findings of the educational and ecological assessment, considerations of policy and intervention have been amended in the PPM and extended. Any policy or intervention must adopt an intersectional approach to facilitate personalised care. Intersectionality is further emphasised in the suggestion of clinical reviews and advance care planning that prioritise individualisation. Given the findings relating to geographical location as a reinforcing factor, another consideration for policy and intervention development to include availability and access to clinical continuity across geographical areas, as well as residence types.

10.4 End of chapter summary

Informed by the intersectional ecological framework and relational model of dementia, findings of the educational and ecological assessment and subsequent conceptual model suggest that people with dementia have intersecting predisposing factors associated with ED attendance, which are mediated by reinforcing contextual factors. Systemic priorities and societal preconceptions about dementia determine how these factors interact to empower people with dementia to access timely and responsive community clinical care and reduce the need to use the ED. Public representatives of the expert panel echoed findings that access to community services directly influences ED attendance. Findings and public representative feedback have continued to inform the development of the PPM, identifying predisposing, reinforcing, and empowering targets for change. Components of policy and intervention development have been elaborated further, emphasising geographical differences and the need for an individualised, intersectional approach to models of care.

The following chapter will summarise the main findings of all three assessments and discuss key findings with implications for policy, practice, and future research. The latter will include review of the final PPM with components for policy and intervention development.

11 DISCUSSION

11.1 Summary of main findings

Using mixed methods research, this thesis advances understanding of the determinants of ED attendance among people with dementia approaching the end of life. It addresses important gaps in the evidence base and offers original methodological contributions. Based on the social, epidemiological, and educational and ecological assessments of the PRECEDE component of the PRECEDE-PROCEED Model (PPM), and informed by public representative input, this thesis presents robust evidence to inform policy, practice, and future research to safely reduce ED attendance among people with dementia approaching the end of life.

11.1.1 Social assessment

By exploring the drivers of ED attendance among people with dementia across the illness trajectory, with people with dementia and current and bereaved family caregivers, analyses identified ED attendance as the path of least resistance. The analyses showed that the malalignment between individual priorities and systemic configuration presents barriers to accessing community health and social care at points of need. This was less problematic if it was clinically recognised that the individual with dementia was approaching the end of life. It was concluded that dementia should be prioritised as a life-limiting condition to improve access to post-diagnostic care, recognition of the end of life, and help to reduce reliance on the ED.

11.1.2 Epidemiological assessment

Analyses showed individual- and service-level factors associated with emergency department attendance among people with dementia in their last year of life. More ED attendances were associated with living in urban areas, being of South Asian ethnicity and having chronic respiratory, cardiovascular, or cerebrovascular diseases as underlying causes of death. Fewer ED attendances were found to be associated with higher socioeconomic position and areas with more nursing home beds. It was concluded that services must adapt to the needs of individuals from different minoritised groups, and further investment is needed in nursing home capacity and enhanced community models to provide continuity of clinical care.

11.1.3 Educational and ecological assessment

From mixed methods integration, a conceptual model of ED attendance among people with dementia approaching the end of life was developed. The model shows ED attendance as a product of intersecting predisposing factors that interact with reinforcing contextual factors. Systemic priorities and societal biases determined if a person with dementia is empowered to access community clinical care, or reliant on attending the ED towards the end of life. It was concluded that a systemic, intersectional approach to policy and practice was needed to help safely reduce ED attendance among people with dementia approaching the end of life.

11.2 Discussion of key findings

The key findings presented here are based on those identified as being of high priority among public representatives of the expert panel. These findings suggest a potential link between ED attendance and limited access to timely and responsive clinical continuity from within the community. This may minimise the likelihood that a person with dementia is recognised as approaching the end of life or that end-of-life care plans are agreed and implemented. While there may be other contributing factors to the phenomenon, such as personal preference, these findings nevertheless represent some of the key components of care that may help to inform policy and practice to safely reduce ED attendance.

11.2.1 Individual differences

Throughout this thesis, individual-level influences on ED attendance, and access to community health and social care, have been highlighted. In the epidemiological assessment, increased ED attendance was associated with being a man, being of South Asian ethnicity, having lower socioeconomic position, or having vascular or unspecified dementia. The social assessment explored how people with different characteristics, such as lower socioeconomic position, encountered additional barriers to accessing timely and responsive community health and social care, which increased reliance on the ED as the last resort for support. The educational and ecological assessment conceptualised these individual characteristics as overlapping and leading to either systemic advantage or disadvantage based on their interaction with wider contextual influences. In summary, this thesis has addressed several evidence gaps identified from the systematic review, including examining the heterogeneity of minoritised ethnic groups and socioeconomic position and exploring the mechanisms behind their association with ED attendance. As a result, this thesis concludes that the intersection of different identities may predispose to ED attendance towards the end of life.

It is widely accepted that *"if you've met one person with dementia, you've simply met one person with dementia"*.[478] (p.2) Dementia presents uniquely in each individual who will have unique needs that will evolve over the illness trajectory. Therefore, in researching people with dementia, it is pertinent to acknowledge the heterogeneity of the condition and of the affected population. Populations most at-risk of developing dementia include people with lower socioeconomic position,[479] and people from minoritised ethnic communities.[480] This thesis suggests that these populations can also encounter barriers to accessing community health and social care and are more likely to attend the ED towards the end of life. This situates the 'inverse care law' within dementia and end-of-life care literature, in which those who most need care are least likely to receive it.[481] By clarifying group differences in ED attendance among people with dementia towards the end of life, findings from this thesis underscore the need for public health interventions to be flexible to tailor to the unique needs and systemic vulnerabilities of individuals from different minoritised groups most at risk of ED attendance towards the end of life.

11.2.2 Protective influence of nursing homes and clinical continuity

From the systematic review, care homes were identified as potentially protective against ED attendance among people with dementia towards the end of life. Considering multiple care home closures across the UK,[88] it was considered important to understand how care homes offered protection, however, the evidence base was lacking. This thesis has contributed towards addressing this gap. The epidemiological assessment found an association between reduced ED attendance and living in an area with more nursing home beds, but no association with the number of residential home beds. Furthermore, the social assessment suggested that care homes with limited access to clinical support elsewhere often operate by protocol rather than by resident need. The educational and ecological assessment conceptualised the influence of residential setting as reinforcing the degree of access to clinical continuity and end-of-life care, which is inconsistently available in residential homes and in the community. In sum, this thesis concludes that clinical continuity available in nursing homes may help to mitigate against the need for ED attendance among people with dementia approaching the end of life.

There are known challenges with end-of-life decision-making within the care home setting, particularly for homes without nursing support.[482] These include difficulties in initiating end-of-life care,[483] affecting residents' advanced decisions,[484] and making confident decisions without fear of litigation.[484] Further evidence suggests difficulties may arise from variable access to external support,[485] and a dichotomous culture that nurtures tensions between medical and social care.[486] The findings of this thesis are therefore potentially important to the provision of end-of-life care to residents with dementia, as clinical continuity is assumed to improve recognition of when an individual is approaching the end of life or acutely deteriorating, and mobilise additional clinical support if required. This finding that may help to inform new models of residential home practice and models of community care, prioritising provision of timely access to clinical continuity to ensure equity of end-of-life care for people with dementia, regardless of residential setting.

11.2.3 Geographical differences

Findings from this thesis have drawn attention to the influence of geographical differences in ED attendance among people with dementia approaching the end of life. The social assessment highlighted a 'postcode lottery' of available community health and social care services, offset by community support and innovative ways of working in more rural areas. The epidemiological assessment showed regional differences in ED attendance in the last year of life and an association between increased ED attendance and living in urban settings. The educational and ecological assessment conceptualised geographical location as another reinforcing influence on the degree of access to community health and social care. This evidence helps to address a gap in the evidence base regarding why the geographical area has been observed to influence ED attendance among people with dementia, which may be used to inform how service availability can be delivered across different areas of the country.

Previous literature has shown how variation of ED attendance and emergency hospital admissions are influenced by area-level employment, socioeconomic deprivation and urbanicity, which is presumed to be partly explained by higher levels of disease prevalence in these areas.[487] The observation that people living in rural areas have fewer ED attendances than people in urban areas has been correlated with increased access to GP services in rural areas.[487] Notably, research studies have also recognised a difference between age and socioeconomic position of individuals living in rural or urban areas, which suggest differences in drivers for ED attendance.[488] This supports the conclusions of the educational and ecological assessment that geographical location has a reinforcing influence over intersecting individual-level characteristics, which influence ED attendance among people with dementia approaching the end of life.

11.2.4 Dementia stigmatisation

This thesis offers an original contribution to the field of end-of-life care for people with dementia, as findings suggest that dementia stigmatisation may play a role in ED attendance. While research into bias and discrimination towards people affected by dementia is not new,[457] findings of this thesis are novel in their application of stigma to accessing to community health and social care towards the end of life. The social assessment showed that dementia was not regarded on par with other life-limiting illnesses in the health and social care system. It was considered a source of disadvantage in a system inflexible to accommodate increasing and unpredictable needs of people dying with dementia, driven by systemic pressures and societal misconceptions around dementia in older adults. The educational and ecological assessment conceptualised health and social care priorities and wider societal norms as having the capacity to empower individuals with dementia to access responsive health and social care in the community, or failing to empower and increasing reliance on the ED. This thesis therefore concludes that dementia stigma may have indirect influence on ED attendance among people with dementia approaching the end of life.

A recent survey of 2,133 adults, representative of all UK adults, found that only 42% understood that dementia is a terminal illness, and 17% recognised dementia as the leading cause of death in the UK.[489] In this same opinion poll, only 8% of the respondents had heard of Admiral Nurses, compared to 84% for Marie Curie Nurses and 91% for Macmillan Nurses.[489] These results are aligned to the findings of this thesis and echo the feedback from the expert panel of public representatives. The thesis concludes that any public health intervention aiming to safely reduce ED attendance and improve access to health and social care in the community must consider public education of dementia. Moreover, as per public representative feedback, and as others have argued,[39] initiatives that focus on promoting dementia-*friendly* communities may be counterproductive, albeit well intended. Based on the findings of this thesis, it is proposed that initiatives should move towards educating the public about dementia, challenging preconceptions, and caricatures to build a dementia-*empowering* society and health and social care system.

11.3 Implications for policy

11.3.1 Using an intersectional approach to policy development

Although a 2016 declaration from the Department of Health and Social Care acknowledged that there is no one-size-fits-all for dementia post-diagnostic support,[490] evidence from this thesis and elsewhere suggests that personalised post-diagnostic care is still lacking for people with dementia,[491] some more than others,[440, 491] and lags behind other life-limiting conditions like cancer.[492] Since there is widespread confusion as to what post-diagnostic support entails,[493] it is advocated that national dementia strategies clearly define post-diagnostic support, which must span from diagnosis to (and including) the end of life, and detail a national minimum standard to minimise geographical disparity. Furthermore, it is advocated that an intersectional lens is applied to the development of the dementia strategy and other relevant policies to reduce reliance on the ED towards the end of life. The World Alzheimer Report 2022 stipulates care should be culturally appropriate and gender inclusive,[61] however, reviewing characteristics such as ethnicity and gender independently risks overlooking heterogeneity and the mutually constitutive nature of inequalities,[494] limiting adequate policy responses to health inequalities.[495] Thesis findings strongly suggest that an intersectional approach to dementia and end-of-life policy is warranted. This would move beyond ethnicity and gender mainstreaming,[496] towards policy that empowers all members of any minoritised group to access community support and safely reduce ED attendance towards the end of life.

Lack of meaningful data risks perpetuating health inequities in evidence-based policy development.[495] Therefore, it is recommended that routine collected data broadly encompass individual-level characteristics, ensuring quality indicators of end-of-life care can accommodate intersectional analyses. The epidemiological assessment of this thesis demonstrated the value of recognising heterogeneity of minoritised ethnic groups, demonstrating nuanced differences between minoritised ethnic groups in ED attendance. This compares to the homogenisation of minoritised ethnic groups as simply White and Non-White, or Black, Asian, and Minority Ethnic (BAME), which is more often used in analyses that inform policy development. In addition to improved routine monitoring of individual-level data, it is recommended that policies based on analyses of this data are developed using an intersectionality-based policy analysis framework, ensuring implicit biases against minoritised groups, including people with dementia, are identified and reframed.[497]

11.3.2 Recognising dementia in the health and social care system

Despite the growing prevalence of dementia and associated burden of suffering towards the end of life,[498] findings of this thesis suggest that inconsistent community support can influence ED attendance towards the end of life. With the recent development of Integrated Care Systems (ICSs), there is promise of greater integration between healthcare, social care, and voluntary services to provide person-centred community-based care. This affords a major opportunity to replace the fragmentation, inconsistencies and gaps in current provision that can precipitate ED attendance with a cross-sector, assets-based, coordinated approach. Based on the findings of this thesis, ICSs must recognise the increasing prevalence and needs of people with dementia that increase towards the end of life, ensuring health and social care in statutory and voluntary sectors work collaboratively to improve availability and access to community end-of-life support for people with dementia.

This thesis has highlighted important findings relating to the influence of geography on ED attendance among people with dementia, including regional variation, more ED attendances associated with urban living, and the perceived influence of a postcode lottery on the availability of community health and social care services. Levelling up inequalities across the country is a key strategic priority in the UK, with ICSs aiming to tackle local challenges, such as supporting people to stay well, caring for those with chronic conditions and multiple needs, and supporting timely access to care.[73] Findings from this thesis show that ED attendance among people with dementia approaching the end of life crosses all these challenges. However, in tackling local health inequalities, people with dementia are not considered a priority population and dementia is not included as a clinical area of focus for accelerated improvement.[499] This is a missed opportunity for people with dementia and for the wider health and social care system. Therefore, it is recommended that in national and local plans to level-up health inequalities, dementia is given due regard as a societal priority.

National benchmarks for dementia care include advance care planning and person-centred care towards the end of life, including access to palliative care.[477] However, this thesis adds to the evidence showing that these standards are not consistently met. Barriers to accessing end-of-life support has been attributed to the stigma of dementia and lack of its recognition as a life-limiting illness.[500] It is essential that dementia takes a more central focus in the culture of the health and care system. This requires strong leadership and more comprehensive staff training, which encourages respect for dementia as a life-limiting, neurodegenerative disease, and highlights the need to recognise and plan for when an individual is approaching the end of life. While the Dementia Training Standards Framework (DTSF) incorporates end-of-life dementia care,[501] there are barriers to accessing training in the social care sector,[502] with only 44% of social care staff with a record of training in dementia.[503] This emphasises the need for improved recognition of dementia in the system, ensuring Trusts, local authorities and independent care providers recognise the importance of protected time to develop a dementia-empowering workforce.

11.3.3 Strengthening the health and social care workforce

This thesis has suggested that clinical continuity in the community may help to reduce ED attendance among people with dementia approaching the end of life. This relies on a strong workforce of sufficient skill mix to deliver care proactively and at the point of decline. However, across the NHS, there is a shortage of almost 100,000 full-time equivalent staff, with nursing staff accounting for 36% of vacancies in England.[504] The turnover rate of registered nurses in adult social care is four times higher than that in the NHS, with marked regional differences, and is associated with poorer quality care.[505] The shortage of registered nurses has forced some care homes to renounce their registration to provide nursing care.[88] A recent report by the All-Party Parliamentary Group (APPG) for Dementia calls for "immediate action to address the retention and recruitment crisis in social care".[502 (p.15)] Drawing on the findings of this thesis, it is advocated that responses to this call give due consideration to the skill mix of teams as well as the numbers of staff comprising them.

As numbers of deaths in care homes are projected to increase, care homes will become the most common place of death by 2040.[506] Based on this projection and the findings of this thesis, better access to clinical care in residential homes where there are no registered nurses must be given precedence. While Urgent Response Teams that are part of the Enhanced Health in Care Homes initiative may bridge access to clinical care at the point of decline,[16] it is recommended that care staff are trained to recognise early signs of deterioration in residents with dementia. Although there is available training in end-of-life and dementia care, it is neither mandated nor culturally valued,[507] and therefore not widely adopted in social care settings.[502] As this thesis highlights the importance of clinical input in reducing end-of-life ED attendance among people with dementia, national and local workforce strategies must stipulate foundational competencies of care home workers to recognise when and how to escalate concerns about individuals with dementia for early intervention and to consider if they are approaching the end of life.

As well as timely, responsive clinical care at the point of decline, findings of this thesis call for greater proactive healthcare for people with dementia. It is a contractual requirement of all GP surgeries to complete annual dementia reviews for all patients with a diagnosis.[508] However, evidence shows this is not often completed,[509, 510] with concerns of missed opportunities to support community-dwelling people in with dementia,[509, 511] and questions over whether this role should lie with primary care.[511] With greater investment and capacity, it is possible that annual reviews could be conducted by psychiatry services, or other dementia specialists, such as Admiral Nurses. The Admiral Nurse workforce has potential to provide clinical case management that can support the management of comorbidities among people with dementia,[512] facilitate equitable access to timely palliative and end-of-life care,[513] reduce hospital admission towards the end of life,[456, 513] initiate advance care planning discussions,[456] and provide essential support to family caregivers supporting a relative approaching the end of life.[514] Given that this thesis identified an undersized workforce of Admiral Nurses, but one that is highly commended by people affected by dementia, it is recommended that workforce strategies and commissioning plans consider the value of community-based Admiral Nurses, or other clinically competent dementia specialist, to support local people dying with dementia.

This thesis has demonstrated a need for services to tailor to individual needs, advocating the intersecting influences of different minoritised groups on access to community care and ED attendance. Therefore, the health and care workforce must be demographically diverse to authentically respond. Workforce analyses indicate longstanding disparities in gender, ethnicity, and disability. People from ethnic minority communities account for one in five of the adult social care workforce and women account for four in five, whereas senior roles tend to be occupied more by white people and men.[505] The NHS recruitment process sees more candidates diminish with each round of selection among those of minoritised ethnic groups, and those who declare disability.[515] Given that workforce diversity can play a key role in reducing health inequalities,[516] it is essential that it is at the fore of workforce development, from management to frontline roles. Efforts must be made to represent the diversity of people with dementia,[502] to meet their individual needs towards the end of life and safely reduce ED attendance.

11.4 Implications for practice

11.4.1 Using an intersectional approach to patient-centred care

This thesis suggest that dementia is a source of disadvantage in an inflexible health and social system that does not easily adjust to changing need. Findings also suggest that different characteristics such as higher socioeconomic position affords easier and quicker access to community support, while lower socioeconomic position and South Asian ethnicity is associated with more ED attendances among people with dementia towards the end of life. Failure of clinicians to recognise and respond to an individual's intersecting social identities may perpetuate their marginalisation.[476] Like recommendations for an intersectional approach to policy development, it is advocated that an intersectional approach is applied to clinical practice for people dying with dementia. Intersectionality is not well understood by clinicians and is uncommon in clinical guidelines.[517] However, it has the potential to enhance the clinical consultation, facilitating the provision of person-centred care,[518] and a good death for all.[519]

An intersectionality approach requires clinicians to reflect on the structural and institutional influences that can lead to marginalisation based on intersecting identities.[476] It facilitates reflection on individual privilege and oppression, learning from and collaborating with the patient and family to appreciate their individual circumstances.[476] This is particularly important for people with dementia, as memories of discrimination and hostility against specific characteristics may be foregrounded by dementia and cause distress.[502] It may also be used to help understand and support an individual's personhood, which again, is central to achieving person-centred dementia care.[520] Intersectionality can aid the tailoring of clinical interventions and developing individualised care plans to promote end-of-life support,[521, 522] which is a national quality indicator of care of dying adults.[523] It has also been postulated to facilitate clinician assessment and reducing diagnostic overshadowing,[524] which, as observed in the social assessment, is commonly perceived in the care of people with dementia due to complexity of clinical presentations and systemic preconceptions of dementia.

Based on the learning from this thesis, an intersectionality approach to clinical practice is advocated to help clinicians respond to the background, vulnerabilities and needs of the individual dying with dementia to safely reduce reliance on ED attendance. This will require including intersectionality as a clinical competency in training curricula. Findings of the thesis also emphasised the importance of family caregivers in supporting people with dementia. Therefore, it is recommended that this intersectional approach is not only applied to care for people with dementia but also extended to those surrounding the person who will also have individual vulnerabilities and needs.

11.4.2 Improving dementia prognostication

Findings from the social assessment suggested that ED attendance reduced when the person with dementia was clinically recognised as being near the end of life, which was more often when death was imminent. Accurate prognostication is important to inform advance care planning discussions and to meet preferences for place of care and place of death.[525] However, research shows that prognostication in dementia is challenging, given the unpredictable illness trajectory, complex presentations, and reduced verbal articulation of need. As the disease trajectory is insidious with several intermittent crises,[455] and there is no consistent post-diagnostic support or formal follow-up, it is postulated that the end of life is more often unnoticed in people with dementia until signs of dying are obvious.

The European Association of Palliative Care White Paper details expert consensus that timely recognition of when a person with dementia is approaching the end of life is a research priority to guide appropriate palliative care, which should be available across all stages of dementia.[526] A recent systematic review into the definition of end-of-life shows there is little consistency across dementia research and most studies focus on cognition and functionality without addressing the complexity of other factors.[527] While there are attempts to improve recognition of the end of life in dementia with the development of assessment tools, these have limited application,[525, 528, 529] and there is no guidance on when to use them in clinical practice. Consistent with previous literature,[527] it is advocated that people with dementia should be provided with needs-based personalised care to facilitate assessments of whether or not the person is approaching the end of life. Since up to 83% of people with dementia attend the ED towards the end of life and attendance increases with proximity to death (Chapter 9.1), it is suggested that clinicians also use ED attendance as a prompt to assess if the individual may be approaching the end of life. This may facilitate the initiation of important discussions with the person and/or family and referrals to other services, as needed.[530]

11.4.3 Improving pre-emptive care for people with dementia

Considering the findings of the social and epidemiological assessments, precipitants of ED attendance included infections, complications of dementia (i.e., seizures in posterior cortical atrophy) and injury from falling. Furthermore, chronic respiratory disease as an underlying cause of death was associated with more end-of-life ED visits. Dementia is a risk factor for complications in chronic respiratory disease,[531] in which infective exacerbations are common. Despite this, barriers to vaccinations persist for people with dementia,[532] particularly in community versus care home settings.[533] Moreover, models of care for chronic conditions and self-management strategies often fail to meet specific needs of people with dementia.[87] The annual dementia review template includes a review of physical, emotional and medication needs (falls, continence, skin, and nutrition).[534] Based on thesis findings, it is advocated that this template should extend to assessment of known comorbidities and consideration of immunisation. An awareness of comorbidity status may help focus clinical efforts in advance care planning and symptom management towards the end of life. In addition to this, health professionals must tailor symptom management to the functional and social needs of individuals with dementia to optimise effectiveness.[87] It is expected that increased understanding of dementia among healthcare professionals and caregivers will facilitate dementia-empowering management strategies.

Advance care planning was favoured among participants in the social assessment. However, the initiation of discussions or implementation of plans were late in the disease trajectory, with plans being overlooked in acute care settings. When to initiate discussions with people with dementia have been subject to debate and review,[535-537] although there is general consensus that it should be completed early in the disease trajectory.[537] This is particularly important in dementia since research shows, at best, moderate agreement between people with dementia and their family caregivers in preferences for end-of-life care.[538] Given the evidence in favour of advance care planning in dementia,[539] and that plans can be overlooked or delayed in practice, it is advocated that to prompt discussion and initiation of plans, dementia is normalised as a life-limiting illness among health and social care professionals, as well as people with dementia and their family caregivers.

This thesis corroborates previous literature that identifies barriers to accessing palliative care for people with dementia.[44] The social assessment suggested that palliative care was denied by clinicians while the systematic review showed evidence that it may reduce ED attendance towards the end of life. Evidence shows that men, older people, those from minoritised ethnic groups, lower socioeconomic position and those who do not have cancer are less likely to access community palliative care services.[540] Inequalities to accessing end-of-life care become more visible with more conversations about death and dying.[519] Similarly, evidence shows that people with dementia and family caregivers are more open to palliative care input in the later stages of the disease if clinicians first discuss with them the disease trajectory.[541] This places the emphasis back on improving post-diagnostic care, and relies on broader awareness among clinicians that palliative care is applicable for people with dementia. From July 2022, Integrated Care Boards (ICBs) in England have a legal responsibility to monitor and respond to local palliative and end-of-life care needs,[77] which must be inclusive of dementia as a life-limiting illness. Clinicians will be instrumental in communicating this need with appropriate referrals to palliative care teams for people with dementia.

11.5 Implications for future research

11.5.1 Using an intersectional approach to research

Based on reflections of this thesis, it is essential that future research justifiably involves people from different minoritised groups and addresses the heterogeneity within different communities. There is growing acknowledgement that palliative care research is fundamentally racially biased.[80] Others have criticised the gendered assumptions that persist within dementia research.[542, 543] Therefore, efforts must be made towards more inclusive research to increase awareness of the different potential barriers to accessing end-of-life care. Like others,[544, 545] it is recommended that this involves investigating how these characteristics may intersect with other sources of social difference. This requires wider use of data linkage to cross-reference different variables such as level of education, income, housing tenure and quality,[544] and examine the processes that create disadvantage,[545] using statistical methods such as latent-class analyses.[546] It also requires applying qualitative research methods, such as life-story interviewing and shadowing, which permits insights into intersecting social identities and multi-layered experiences.[547] Approaching future research in this way will facilitate and broaden understanding of the disadvantages people with dementia and other characteristics may encounter and the resources needed to mitigate against their effects,[547] addressing inequalities in dementia and end-of-life care.[519]

11.5.2 Continuing research as part of the PRECEDE component

Aligned to the pragmatist assumption that all reasoning is fallible and is to be expanded with changes in context, there are further opportunities to research the determinants of ED attendance among people with dementia approaching the end of life, which are not fully conceptualised in this thesis. Based on the reflections above, research must explore the experiences of people affected by dementia from minoritised groups, such as ethnic, sexual, and socioeconomic groups, examining the intersection of these groups and their intersection with other areas of social difference. To be successful, qualitative inquiry will need to adopt flexible and culturally sensitive recruitment strategies,[548] which must involve approaching local groups that provide support for people from minoritised communities.

It is important that future research looks at determinants of ED attendance other than access to community services. The systematic review in Chapter 2.5 found that care homes and community palliative care input were associated with reduced ED attendance and provided initial suggestion that timely access to community support may be beneficial to people with dementia approaching the end of life. The epidemiological assessment gave credence to the role for nursing homes while the social assessment provided insight into the influence of access to community care. Furthermore, public representative input and previous literature supports this link, which was explored more fully in the educational and ecological assessment. Nevertheless, within the pragmatist approach, it is likely there are other contexts in which to research, which may further add to the evidence base. This may be the case with more diverse samples of people affected by dementia, and with samples of health and social care providers.

While others have researched ED attendance among people with dementia from the perspectives of multiple providers,[11] this has not extended to the end of life, nor a full complement of professionals and other workers involved in the end of life care of people with dementia. Participants in the social assessment mentioned the involvement of GPs, paramedics, Admiral Nurses, mental health nurses, psychiatrists, occupational therapists, general physicians, physiotherapists, social workers, police, NHS 111 call handlers, hospice staff, care home staff (including managers), domiciliary carers, volunteers, and clinical staff in the ED. Future research in this area must consider including members of this multidisciplinary workforce to gain insight into the potential barriers in providing end-of-life care in the usual place of residence for a person with dementia. Furthermore, examining policymakers’ views will provide wider context to ED attendance among people with dementia approaching the end of life, and may help to enhance research impact potential.[549]

11.5.3 Implementing the PROCEED component

From the pragmatic perspective, the only way to assess inferences is through action.[90] By applying the PRECEDE component of the PPM in this thesis and completing a comprehensive assessment of the health-related problem, priority targets for change have been identified. This informs the next steps of the model, which are to implement an interventional programme using the phases of the PROCEED component. It is unlikely that a single programme will be a panacea given the variability of dementia and variability of local resource and population need. Therefore, the intervention proposed is not a standalone programme, but a description of programme features that are considered integral to safely reducing ED attendance among people with dementia approaching the end of life, based on the findings of this thesis. This ensures a flexible place-based and assets-focused application in any residential setting or area of the country.

As illustrated in Figure 11.1, the proposed intervention includes a post-diagnostic support programme that is undertaken by a clinical team with dementia expertise. This includes case management for people with dementia in the community and in care homes, involving holistic, individualised, needs-based annual reviews, from diagnosis to the end of life. Reviews include discussions and updates of advance care plans, which are implemented and overseen by the clinical case manager when the individual is assessed and assumed to be approaching the end of life. Whether case managers are Admiral Nurses or community palliative care teams, the key components of the intervention include clinical continuity, dementia expertise, and independence from primary and secondary care to ensure capacity for advocacy but integrated into the community multidisciplinary team in which to coordinate care. To support this, a component of the intervention must focus on improving understanding of dementia as a life-limiting and life-threatening illness across the health and social care workforce and the public.

A review of the evidence base and matching, adapting, patching, and blending intervention strategies will facilitate the development of comprehensive programme and pathway to implementation and evaluation.[89] The baseline findings and the priorities for change identified from this thesis provides a theoretically informed, evidence-based approach to developing a strategy to safely reduce ED attendance among people with dementia approaching the end of life.

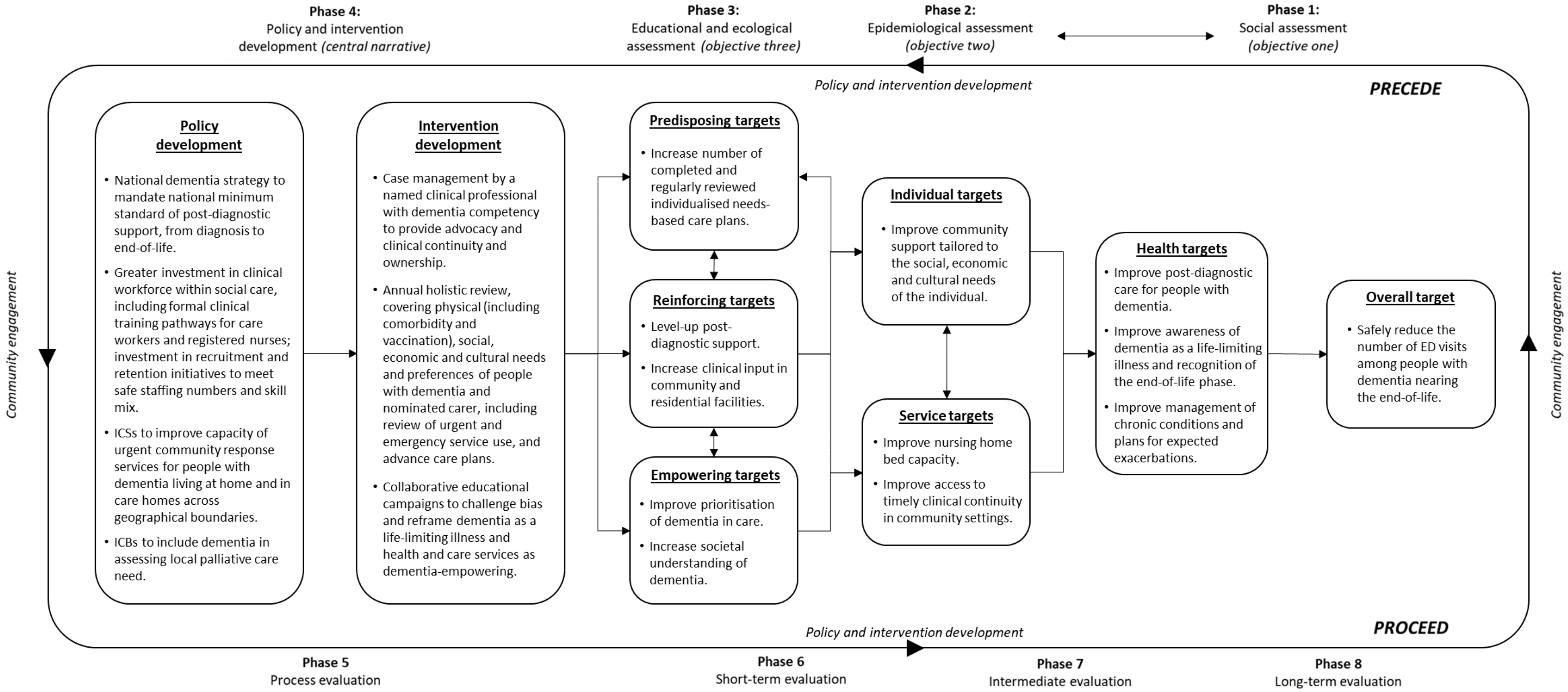

Figure 11.1 Applied PRECEDE-PROCEED Model (PPM)

Policy and intervention components and targets, informed by collective findings of the PRECEDE component and public representative feedback.

11.6 Reflections on strengths, limitations and lessons learned

The mixed methods research design adopted for this thesis has afforded a comprehensive review of ED attendance among people with dementia approaching the end of life. While the social and epidemiological assessments provide valuable insights into population-level factors and individual-level experiences of ED attendance in this cohort, their integration in the educational and ecological assessment provides a richer picture of the phenomenon. This contributes to current understanding of the determinants of ED attendance and highlights key components of dementia care and dementia end-of-life policy that may help to safely reduce ED attendance in this cohort. Therefore, the aim of the thesis has been met through the application of a mixed methods design.

It is essential that strengths, limitations, and lessons learned from this research are not only transparently reported to aid interpretation of findings but are shared within the research community to enhance further inquiry.[90] There are several evaluative frameworks to facilitate the quality assessment of mixed methods research. The Mixed Methods Evaluation Rubric (MMER) was developed to facilitate scoring of mixed methods studies.[415] Although scoring is not required for the purpose of reflecting on the strengths and limitations of the thesis, the rubric offers a comprehensive assessment. Other frameworks tend to focus solely on transparency and mixing,[411, 550] or on mixing and interpretative comprehensiveness.[434] The MMER covers all these domains, as well as a fourth foundational domain. Table 11.1 details responses to these domains, followed by more detailed reflections on specific strengths and limitations of this thesis, and the lessons learned.

Table 11.1 Mixed Methods Evaluation Rubric (MMER)
Based on Creamer (2017)[415]

Evaluation criteria	*Relevant thesis chapters*
Transparency: at least one reason why mixed methods were used or what was gained	Chapter 4 explicitly details this thesis as adopting a mixed methods design, in which equal priority was assigned to social (qualitative) and epidemiological (quantitative) assessments, with the complementary purpose of mixing methods in a concurrent parallel sequence, with integration at the design and inference levels. Chapters 5-7 detail the design and rationale for the social, epidemiological, and educational and ecological assessments, respectively. Chapters 4-7 make clear the pragmatist approach was used in this thesis and details the meta-theoretical bases of the social, epidemiological, and educational and ecological assessments. Chapters 8-10 address the strengths and limitations of the social, epidemiological, and educational and ecological assessments, respectively, and general reflections of thesis strengths and limitations are below.
Amount of mixing: amount and quality of integration throughout research process	Chapter 7.3 describes the mixing of the social and epidemiological assessments at the design and inference levels. It also provides clear rationale for this mixing, including the impracticality of mixing the assessments at the data collection and analysis levels.
Interpretative comprehensiveness: several viewpoints incorporated throughout research process	Chapter 7.3.3 details the points of interface between the social and epidemiological assessments. This chapter also includes discussion of the quality of integration and the approaches taken to mitigate identified legitimation issues. It also details the approach to analysis that included 'bracketing' and 'bridging' to explain discrepancies and consensus of findings between the social and epidemiological assessments, which were directly relevant to the construction of the warranted meta-interpretation in Chapter 7.4.2. Chapters 8-10 incorporate public representative viewpoints in the social, epidemiological, and educational and ecological assessments, respectively.
Methodological foundation: authors demonstrate expertise in the mixed methods employed	Chapters 8-11 situate the research in the relevant literature, which increases the credibility of the thesis conclusions.[415] The thesis also offers an original contribution to the mixed methods literature (*see below*).

11.6.1 Methodological reflections

From the outset of developing the thesis, the pragmatist approach was philosophically and practically justified for conducting the mixed methods research. Critical realism was another approach that was considered and, like pragmatism, is social justice orientated and assumes belief is fallible. Unlike pragmatism, critical realism is committed to the notion that social events are determined by multiple interacting causal powers, including structure and agency.[551] It upholds ontological realism and epistemic relativism and therefore would have required separating methods from their meta-theoretical bases in the social and epidemiological assessments.[118] The lack of philosophical justification to use critical realism suggested that this separation was not necessary. In hindsight, it could be argued that the integration of findings from the social and epidemiological assessments may have been enhanced with a critical realist lens.

Critical realism is underpinned by the concept of a stratified reality. From this approach, disability, or any other social event, is a ‘necessarily laminated system’ in which mechanisms at the biological, psychological, psychosocial, socioeconomic, and cultural levels interact to produce the experience of disability.[552, 553] This approach looks at how prevailing ideologies and structures interact with individual agency to generate oppression.[554] It is believed to offer a more adequate understanding of the complexity of dementia,[39] and had it been applied to the educational and ecological assessment of this thesis, may have deepened connections between intersecting identities of people with dementia and the prevailing ideologies and macro-level structures of the health and social care system.[554]

Pragmatism has been criticised for obscuring the influence of macro-level influences of institutions.[551] Critics have stated that pragmatists’ focus on agency overshadows causal influences of social structures, which can be better embraced by the critical realist approach.[551] However, pragmatism does not limit inquiry exclusively to the level of individual social action but extends to how individual social action contributes to meso- and macro-level mechanisms.[115] Pragmatism is flexible in accommodating systemic influence rather than making it the central focus.[555] In mixed methods research, this flexibility can accommodate macro-level influences by using the most relevant methodology to conduct the quantitative and qualitative strands. Therefore, if the belief is that social actions of individuals are interacting with macro-level structures, it is prudent to develop warranted assertions about this phenomenon by using an approach to inquiry that permits its exploration.[556] This was demonstrated in this thesis by using critical realism in the social assessment.

Based on these reflections, it is accepted that critical realism may have led to a more layered model of causal mechanisms underlying ED attendance among people with dementia approaching the end of life. However, it is maintained that the flexibility of pragmatism permitted sufficient exploration of structure and agency to warrant assertions about the nature of their influence and interaction. Pragmatism also permitted integration of findings from social and epidemiological assessments while maintaining meta-theoretical integrity. Whether pragmatism or critical realism was used to underpin this thesis, it is contended that the implications of the resultant conceptual model would have been the same: a one-size-fits-all approach to health and social care does not fit people who are dying with dementia.

11.6.2 PRECEDE-PROCEED Model (PPM) reflections

This thesis was strengthened by the application of the PRECEDE component of the PPM. Using conceptual models and frameworks to facilitate mixed methods research increases the transferability of integrated findings.[557] Using a health programme planning model ensured that the thesis remained solution-based and population-focused,[89] contributing to the applied nature of the research and scope for potential impact. Using the PPM specifically ensured a socioecological view of ED attendance with a strong policy focus, which accentuated the practical applications of this thesis. Although the time and cost-implications of the PPM have been subject to criticism,[126] the thesis benefitted more from the comprehensive approach advocated in the model.

As well as strengthening the thesis, using the PPM has demonstrated its utility to apply to a social problem that focuses on end-of-life. This was a novel approach that made an original contribution to the health programme planning and end-of-life care literature. One of the hallmarks of the PPM is its flexibility to adapt to the purpose and scope of the social problem.[89] This flexibility permitted adaptation of the factors associated with ED attendance in the epidemiological assessment from genetics, behavioural, and environmental, to individual and service factors. While maintaining focus on the individual and environment in the PPM, this amendment reflected end-of-life care conceptual frameworks and thus ensured the thesis remained located in the end-of-life literature. Additionally, while predisposing, reinforcing, and enabling factors were used in the educational and ecological assessment, they were tailored to suit the findings from the epidemiological and social assessments. For example, predisposing factors comprised sociodemographic and clinical factors associated with ED attendance, which are not normally included in the educational and ecological assessment because they are non-modifiable.[89]As these factors explained most of the variance in the epidemiological study, they were included in the integration and have been instrumental to guide targets for intervention.

Finally, the PPM was sufficiently flexible to facilitate developing a conceptual model of ED attendance with more explanatory than descriptive value, which is useful for policy and intervention development.[558] Previous literature exploring ED attendance towards the end of life has typically focused on advancing existing conceptual models, such as the behavioural model of healthcare service use,[291] or the Gomes and Higginson model.[559] Using the PPM as a roadmap for the thesis meant that the most relevant conceptual models could be applied to each phase of the PRECEDE component, maintaining methodological integrity of each assessment. This was also afforded by using a pragmatist approach to the research. The benefit of this was that it helped to build a larger strategy for socio-ecological change and is thus primed to inform policy and practice development.[126] Therefore, by using the PPM, this thesis offers a unique contribution to the field of end-of-life dementia care, providing evidence to inform strategies that may help to safely reduce ED attendances among people with dementia approaching the end of life.

11.6.3 Community engagement reflections

A major strength of this thesis was that community engagement was embedded throughout. The involvement of public representatives not only aided the planning of the social and epidemiological assessments but also enhanced the findings from each assessment. The discussion with public representatives were immensely valuable and, to some extent, unexpectedly so. The insights public representatives brought to discussions had direct influence on the interpretation of the social assessment. This ensured findings were interpreted in context,[89] and those that were most pertinent to public representatives were prioritised. Community engagement also ensured that recommended interventions were grounded in the realities of living with dementia and engaging with care services, which is considered valuable to improving the chances of successful implementation.[89] This has been noted to be based on increased community ownership that is afforded by their involvement.[560]

There were some challenges in the process of engaging with the community. Securing the necessary funding for the expert panel of public representatives required two attempts. The first application was rejected on the grounds that it failed to specify how the findings of the panel process would be used to benefit broader audiences and the project could have gone further to ensure an engaging experience for members. This was useful feedback and underscored the importance of ensuring the benefits of community engagement are mutually beneficial. Reciprocity is a key principle of co-production,[561] and facilitates trust and contributions from public members.[562] The second application drew on this and was successful in securing funding required for three meetings with the expert panel. Feedback with an impact log was prioritised and shared with public representatives to enhance reciprocity.[563] The value of public representative feedback and the positive influence it had on this thesis outweighed the additional time required to apply for funding and organise and facilitate the meetings. Further details on community engagement can be reviewed in the report written for the funder, which can be found in the Appendix B5.

A limitation in the development of this thesis was the absence of ongoing engagement with policymakers and practitioners. The PPM advocates finding common ground between the public, professionals, and policymakers to bring about action.[89] While policy briefs were developed and shared when appropriate, targeted efforts made to regularly engage with health and social care policymakers and professionals were unsuccessful. This included cold calling teams to arrange presentations at team meetings, which were met with reticence and escalating administrative tasks. A survey was developed with a short video to electronically circulate to different staff groups. However, as services were responding to unprecedented pressures from the Covid-19 pandemic by this time, this method of engagement was deemed to be of limited benefit. Conference presentations did reach clinical delegates who were prompted to email positive feedback and offer to facilitate dissemination of findings through care networks and newsletters. Discussion with members of the policy team at the Alzheimer’s Society also helped to situate the research in current policy context. However, the challenges to engage regularly with policymakers and professionals highlighted the importance of identifying key stakeholders early and securing stakeholder engagement activities into project timelines from the outset. It also highlighted the importance of having prior contact with teams of health and social care professionals, with whom authentic and trusting working relationships are well-established. This is known to facilitate enduring and sustainable research collaboration.[564]

11.6.4 Reflections on remote study participation

This thesis contributes to the literature by recruiting and interviewing people with dementia remotely. Although remote participation is not unique, as many studies have interviewed people with dementia over the telephone,[440, 565] and more recently online,[566] there is opportunity for reflective learning from the process of recruiting and conducting interviews virtually.

The recruitment process for the social assessment was protracted, comprising several touch points with potential participants to ensure ethical compliance. On reflection, this was also helpful to facilitate rapport-building, which is considered by some as particularly difficult to achieve remotely.[230] Recruitment comprised several email exchanges and video or telephone calls. Although there were clear agendas for each call, such as discussing study details and obtaining verbal consent, each call was laying the interpersonal groundwork for the interview.[241] Furthermore, what may have seemed trivial conversational exchanges during these calls, on reflection, they were integral to building a trusting relationship. While rapport is considered to shape interview outcomes,[567] it is also considered important that a balance is established between laying necessary groundwork for the interview and conducting a recruitment process that becomes laborious for participants (and the researcher). For the social assessment, the separation of touchpoints between obtaining verbal consent and conducting the interview was removed for participants who preferred to complete the questionnaires during the call. This helped to streamline the process and was preferred by most participants. Therefore, it is important that when designing remote interview studies, the recruitment process purposively permits sufficient time for groundwork without posing a barrier to participation.

Flexibility was also identified as a key component for successful recruitment and interviewing of people with dementia and current caregivers. The option for telephone or online calls, in and out of office hours, provided convenience and accommodated specific needs and preferences. This was found to facilitate recruitment, particularly of current caregivers who were timing interviews around caring and work commitments. This flexibility was also considered important to help mitigate any perceived inequalities between the interviewer and participant. Further effort to reduce perceived inequality in power relations included the choice of background for online interviews. A virtual background was not used during online calls to promote authenticity. While all personal information was removed from view, the homely appearance was considered important to break down any perceived power inequality and to help to nurture trust and rapport.

The unpredictability of technical issues with online interviews, such as internet connectivity and poor audio,[239] have been observed to hinder rapport and compromise data quality.[240, 568] It is therefore essential that preparation is prioritised as much as it would be for an in-person interview. Additional checks for online interviewing included internet connectivity, the position of the camera, the background view, the speaker and microphone volume, and the position of the audio-recorder. While technical problems did arise during some interviews, having made these checks a part of the interview process likely minimised their frequency. This helped to remain present during the interview, with full attention directed towards the participant and their story, which facilitated the interview process.[568] Preparatory checks, therefore, are considered another essential component of conducting online interviews with people with dementia, in addition to flexibility and a well-thought through recruitment process.

11.6.5 Reflections on the inclusion of minoritised groups

One of the limitations of the social assessment was the limited number of participations from minoritised ethnic groups, despite concerted recruitment effort. On reflection, these efforts may have been misplaced, as focus was on targeted recruitment from mainstream charities and the research register, Join Dementia Research. Echoing the view that there are no ‘hard-to-reach’ groups, rather those that are ‘seldom heard’,[569] it is reckoned that recruitment should have also been directed towards localised community groups that specifically support people from different minoritised ethnic backgrounds. Like the reflections of stakeholder engagement, recruitment is likely to be more successful if there are existing, trusting relationships between the researcher or academic institute and these community groups.[570] A recent systematic review identified several factors contributing to limited representation of minoritised ethnic groups in research, including a distrust of academics, concerns of systemic discrimination, limited understanding of dementia and research, and logistical constraints involving transport and finances.[571] Therefore, future recruitment strategies must include identifying specific community partners from which to recruit people from minoritised backgrounds, with ongoing engagement to nurture these partnerships and maintain trust and longevity.

Only one participant in the social assessment identified as gay. The influence of being from the LGBTQ+ community on access to healthcare was discussed as part of the interview and highlighted a potential barrier to receiving equitable quality care. This experience was incorporated as part of a wider issue of stigma and therefore was not a primary inference. Previous literature shows that people from the LGBTQ+ community have unique needs towards the end of life,[572] experience heteronormative assumptions in health and social care,[572] and receive care from professionals who have limited awareness of their specific needs.[573] Therefore, ED attendance among people with dementia approaching the end of life requires a light shining on the experiences of people from the LGBTQ+ communities to better understand their unique barriers to access. It also emphasises the need for an intersectional approach to policy and practice.

11.6.6 Reflections on the use of routine collected data

There were some challenges around using routine collected data. The data was limited in variable availability resulting in some being omitted, such as comorbidity or care home residence. It is also acknowledged that case identification using death certification may have underestimated the number of decedents with dementia.[313] Despite these limitations, the use of routine collected data ensured broad coverage of decedents to facilitate cross-country analyses, which were important in conceptualising the determinants of ED attendance among people with dementia approaching the end of life. Furthermore, population-based data can be used for evidence-based health policymaking,[302] providing information on the size and equitability of the problem, and on modifiable factors to inform problem preventability.[305] It also lays the foundation for later intervention effectiveness,[305] as findings from the epidemiological assessment provide baseline observations of ED attendance to which to compare during the PROCEED component of the PPM.[89]

Policy decisions are informed by economic costs,[305] however, the epidemiological assessment did not include cost data. Most data on service expenditure were unavailable for analysis, except adult social care annual net expenditure. These data were highly correlated with workforce data, and as workforce was considered more useful to inform policy development, expenditure was excluded. While a reasonable justification, the absence of any economic analysis is a limitation of the thesis. However, there are recent studies that have quantified the cost of end-of-life care for people with dementia, which shows fewer total and informal costs for people residing in care homes than in the community.[574] This echoes feedback from public representatives, and underscores the crucial importance of including economic value in any intervention to inform decisions around policy and service commissioning.

11.6.7 Reflection on the integration of findings

Findings from the social and epidemiological assessments were integrated using the ‘successive integration of claims’ method.[419] This was selected to optimise the robustness of integration, to cohere with the complementarity purpose of mixing, and to counter criticisms that mixed method research often lacks transparency in reporting integration.[419] While using a formal method of integration was a strength of the educational and ecological assessment, the choice of method was found to be too reductionist to accommodate the nature of the available inferences. Specifically, the integration method stipulates labelling the final integrated claim as the meta-inference. However, there were some claims from the social and epidemiological assessment that could not be merged. Therefore, assigning the final integrated claim as the meta-inference would have restricted the interpretation to only the claims that could be integrated, potentially losing valuable information. The final step in the integration process was not followed for this reason.

The absence of claims from the integration was due to ‘silence’ rather than ‘dissonance’ between social and epidemiological assessments.[575] Silence is when one study has an inference, but the other study is silent.[575] In this case, while the epidemiological assessment found that South Asian ethnicity was associated with increased ED attendance, there were no inferences relating to ethnicity in the social assessment. Similarly, while the social assessment reported the value of Admiral Nurses in supporting people with dementia in the community, there were no inferences relating to Admiral Nurses in the epidemiological assessment. This may be a consequence of the limitations of each assessment, but it is also to be expected since different methods were being used to examine different aspects of the same phenomenon.[425] However, the successive integration of claims method seemed not to account for expected silences. Therefore, strictly adhering to this method by using the final integrated claim as the meta-inference would have delimited the conceptualisation of ED attendance. Instead, a global analysis of the patterns of integration was conducted, though this was only made possible by the transparency of integration process.

There is general agreement that the process of integration is often poorly reported.[426] While there continues to be a growing number of integration methods developed, few apply to the convergent parallel design. Triangulation protocol has been recommended,[425] however, the richness of a meta-inference based on triangulation of inferences obscures how the meta-inference has been developed. By contrast, as discovered in the educational and ecological assessment, clearly demonstrating how the meta-inference has been developed from stepwise integration restricts the richness of the meta-inference. A balance is required. It is postulated that drawing on methods for syntheses in mixed method systematic reviews could offer compromise between the need for systematisation and richness, for example, thematic synthesis, or meta-aggregative synthesis for a more policy-relevant application. Nevertheless, the global analysis used in the educational and ecological assessment is believed to be a satisfactory complement to the method of integration used and has highlighted important learning for future integration. These insights serve to advance understanding of integration in convergent parallel mixed method designs, underscoring the advice from Morgan (1998): *“Until, we, as researchers, investigate what it takes to combine qualitative and quantitative methods, we will never know what is possible”* [576 (p.374)] and what is not.

11.6.8 Reflections on the impact of Covid-19

The social distancing restrictions and lockdowns during the Covid-19 pandemic started three months into the research underpinning this thesis. This caused disruption to the planning of the social assessment and execution of the epidemiological assessment. The social assessment was originally intended to involve recruitment of people with dementia who had been admitted into hospital from the ED, exploring the events leading to attendance. However, research in hospitals was prohibited to reduce the spread of Covid-19. It was unclear when social distancing restrictions would relax, therefore, the aim and design of the social assessment were altered. While this caused delays in the thesis timeline, opportunities to strengthen the thesis were optimised. For example, online interviews broadened the sample to include bereaved caregivers who could detail ED attendances towards the end of life, as well as people who had not attended the ED and people living across the UK, in different areas of socioeconomic deprivation and rurality, and in different residential settings.

The social distancing restrictions also hindered access to the data required for the epidemiological assessment. Remote access to the data was needed, which was not included in the original Data Sharing Agreement and required additional liaison with NHS Digital to demonstrate appropriate data security measures. Once accepted and data was obtained, remote access was reliant on an active desktop, which was disrupted with overnight power outages. Although resolved with ongoing liaison with IT colleagues, the process caused delays in the data cleaning and analysis process. However, it is likely that without these delays, the service-level data would not have been considered for linkage in multilevel analysis. The addition of service-level data enhanced the epidemiological assessment and facilitated the integration of findings with the social assessment. Therefore, while the pandemic posed several challenges which impacted the thesis schedule, the experience underscored the value of being flexible and agile to identify opportunities when faced with uncertainty in research.

An additional advantage to researching during a pandemic was that it shone a light on existing systemic deficiencies and discrimination. For some of the interviewees of the social assessment, many of the issues experienced before the pandemic were accentuated during the pandemic: challenges navigating and accessing timely support, increased ED attendance, and inconsistent social distancing practices prohibiting some caregivers from accompanying relatives with dementia to the ED or visiting them in their care home. In the wider literature, the stress-test imposed by the pandemic exposed disparities between services, with the care home sector being disproportionately affected. The number of resident deaths increased by 220% in the first wave of the pandemic compared to 90% in hospitals,[577] with some questioning if care homes were sacrificed in the national response.[578] There were also concerns regarding cases of blanket Do-Not-Attempt-Resuscitation (DNAR) decisions being made for older adults with dementia.[579] These discriminatory reactions to circumstances of rationed resources underscore the relevance of the meta-inference from the educational and ecological assessment.

11.6.9 Reflexivity

Within a pragmatist approach, the process of inquiry is a social experience, and interrogating the cultural and historical influences of the researcher's habits is a key component of inquiry.[580] Therefore, as the author of this thesis, it is important that I reflect on the influence that my experiences and beliefs may have had on the research. I have interrogated these influences in developing the thesis, sense-checking my assumptions and interpretations with public representatives and the research community.

My professional background includes working as a junior doctor in psychiatry, the most underfunded sector of healthcare, caring for some of the most vulnerable and socioeconomically deprived individuals in society, in one of the 10% most deprived areas of England. From these experiences, my perception of inequality is acute. Although I experienced graduate-entry medical training as a mature, state-educated, first-generation graduate, I recognise my relative privilege to have trained in and practiced medicine. Similarly, while I have enjoyed the privilege of undertaking this PhD and the luxury afforded by working in academia, I retain a heightened sensitivity to the influence of minoritised groups and the disadvantage imposed by closed cultures and institutional infrastructure. This may have shaped the direction of this thesis and interpretation of findings. That said, I recognised that my relative privilege as a white person working in academia likely blindsided my recruitment strategy for the social assessment and limited recruitment from mainstream sources. This is something I have reflected on and will approach differently in future.

My experience working as a junior doctor was affected by the pressures of the healthcare system. However, I also have an appreciation of a systems approach to healthcare based on additional training, service improvement work, and previous roles in the then local Primary Care Trust and later in the National Medical Director's Clinical Fellowship programme. These varied insights and experiences developed my interest in healthcare service provision and will have situated this thesis in applied research using the pragmatist approach. In addition, during the PhD, I worked part-time for ten months as a Parliamentary Research intern for a Peer in the House of Lords, assisting work towards the Health and Care Bill. This experience undeniably informed the development of the thesis, using policy as a central thread. It is also important to note that all these lived and learned experiences may have had some influence on identifying the effects of the systemic pressures on the phenomenon of interest, with a sympathetic focus towards health and social care staff.

Introspective and intersubjective reflexivity are familiar from my psychiatric training, and I have worked to maintain a reflexive approach throughout this thesis. I had not used a reflexive diary before but found this helpful in the social assessment. Although I was aware that my professional background likely heightened my sensitivity to recognising mental illness stigma, using the diary to facilitate my critical reflection and discussing the theme with the expert panel of public representatives provided assurance in my interpretation of the interview data. Using the diary also helped me to process and interrogate my emotional responses to the interviews. Participant responses during the qualitative interviews, at times, challenged my values or were emotionally provocative. Privately, there were occasions when I felt affronted, disconcerted, or deeply saddened by some of the interview responses. Although it was demanding to manage these emotional reactions, using a reflexive diary, taking time to distance myself from the interview and reflect on the interaction, and discussing my responses with my peers and supervisors helped me to process and interrogate my assumptions, which I believe improved the analysis and interpretation.

12 CONCLUSIONS

This thesis has addressed important gaps in current understanding of the determinants of ED attendance among people with dementia approaching the end of life. While personal characteristics predispose individuals to attend the ED towards the end of life, attendance also differs depending on place and type of residence. It is posited that ED attendance is more likely among those who encounter barriers to accessing timely and responsive community clinical care, which may be driven, in part, by a systemic failure to recognise dementia as a life-limiting illness.

This thesis makes several contributions to the literature, developing suggestions of a link between ED attendance towards the end of life and barriers to accessing community care. The thesis has updated the literature on the characteristics of people who are most at risk of attending the ED towards the end of life. The known protective influence of care homes on ED attendance has been explicated by identifying a difference between care homes with and without nursing staff, implicating the value of clinical continuity for people dying with dementia. Furthermore, the thesis offers a distinctive contribution, implying that stigma influences end-of-life emergency department attendance among people with dementia.

Aside from advancing the literature on the phenomenon of interest, this thesis also provides useful methodological insights with transferrable value. For example, the thesis has demonstrated application of a public health planning model to end-of-life dementia care. It also provides reflections on methods of integration in convergent, parallel mixed methods research, suggesting alternatives for future evaluation. It augments existing literature on involving people affected by dementia in research and conducting dementia research online. The thesis has also demonstrated valuable learning around optimising maximum sample variation in recruitment strategies.

These contributions have potential to inform wider policy and practice, with practical application directed towards greater prioritisation of dementia, post-diagnostic care spanning diagnosis and end-of-life, and public education of dementia. The thesis also provides a springboard for further research, providing baseline observations, prioritised targets for change, and key components of an interventional programme to inform continued efforts towards safely reducing ED attendance among people with dementia.

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14 APPENDICES

Appendix A: Supplementary materials for the systematic review

A1 – Table S1: PRISMA Checklist

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	Title page
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.	1-2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	3
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	3-4
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.	4
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.	4
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.	5
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	5 (S3-8)
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).	5
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.	5
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	5
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.	6
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	7
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.	6-7
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.	7
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.	7 (S9)
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).	7 (S10-14)
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	7-10 (Table 1)
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]).	10
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).	11-14
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
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.	Title page

A2 – Table S2: Eligibility criteria

	Inclusion criteria	Exclusion criteria
Population: ***- Dementia***	Where the sample is not stratified, >75%* of population with any dementia, determined by clinical diagnosis or validated criteria	Unspecified proportion or <75%* with dementia, where the sample is not stratified
- End of life	Where the sample is not stratified, >75%* of sample must be within last year of life, or live in long-term care/nursing home, or in be receipt of hospice/palliative/home care	Unspecified proportion or <75%* nearing end of life, where the sample is not stratified
Outcome:	>75%* of ED attendances, where the sample is not stratified	Unspecified proportion or <75%* of ED attendances, where the sample is not stratified
Study design:	All quantitative studies reported in any language, of any time period	Case-series, case reports or qualitative studies; editorials, commentaries, reviews, non-original data, protocols, presentations, or poster abstracts

** 75% threshold consistent with a previous systematic review measuring ED attendance at the end of life*[i]

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[i] Henson LA, Gao W, Higginson IJ, Smith M, Davies JM, Ellis-Smith C, Daveson BA. Emergency department attendance by patients with cancer in their last month of life: a systematic review and meta-analysis. Journal of Clinical Oncology. 2015 Feb 1;33(4):370-6.

A3 – Tables S3-8: Search strategy

Table S3: Ovid MEDLINE(R) ALL 1946 to April 22, 2020

1. exp Dementia/
2. dement*.mp or alzheimer*.mp or (lewy* adj2 bod*).mp or (chronic adj2 cerebrovascular).mp or (cerebr* adj2 deteriorat*).mp or (cerebral* adj2 insufficient*).mp or (pick* adj2 disease).mp or huntington*.mp or binswanger*.mp.
3. 1 or 2
4. exp Terminally Ill/
5. Palliat*.mp or End of life.mp or dying.mp or end stage.mp or ((terminal* or palliative or dying or hospice* or end of life or endstage or advanced or late or last or end or final) adj2 (stage* or phase*)).mp or (life* adj2 end).mp or EOL.mp or life limit*.mp or terminal*.mp or advanced.tw or (Last adj4 life).mp
6. exp Terminal care/ or exp Palliative care or exp Hospice care/ or exp "Hospice and Palliative Care Nursing"/ or exp Advance care planning/
7. (hospice care or palliative care or terminal care or (hospice and palliative care nursing) or (advance care planning or hospice)).mp or (end of life* or hospice* or advance care plan* or palliat*).tw
8. exp Home health nursing/ or exp Home health aides/ or exp Case management/ or exp Homebound persons/ or exp Home care services/ or exp Social support/
9. (home health nursing or home health aides or case management or homebound persons or home care services or social support).mp or "support services".tw
10. exp Long term care/
11. (Long term care or nursing home or homes for the aged).mp or (care home* or nursing home or long term care).tw.
12. or/4-11
13. exp Emergency Service, Hospital/ or exp Emergency medical services/ or exp Emergency medicine/ or exp Emergencies/
14. "accident and emergency".mp or "accident & emergency".mp or emergency service*.mp or hospital emergency service*.mp or (emergenc* adj3 (department* or ward* or service* or unit* or room* or hospital* or care or healthcare or patient* or visit*)).mp or (emergency or emergencies).jn or Hospitali?*.mp or A&E.mp or Unplanned.tw or Non-elective.tw or Unscheduled.tw or Urgent.tw or Acute care.tw or Acute admission.tw or Acute visit*.tw.
15. 13 or 14
16. 3 and 12 and 15

Table S4: Embase 1974 to 23 April 2020 (Week 16)

1. exp Dementia/
2. dement*.mp or alzheimer*.mp or (lewy* adj2 bod*).mp or (chronic adj2 cerebrovascular).mp or (cerebr* adj2 deteriorat*).mp or (cerebral* adj2 insufficient*).mp or (pick* adj2 disease).mp or huntington*.mp or binswanger*.mp.
3. 1 or 2
4. exp Terminally ill patient/
5. Palliat*.mp or End of life.mp or dying.mp or end stage.mp or ((terminal* or palliative or dying or hospice* or end of life or endstage or advanced or late or last or end or final) adj2 (stage* or phase*)).mp or (life* adj2 end).mp or EOL.mp or life limit*.mp or terminal*.mp or advanced.tw or (Last adj4 life).mp
6. exp Terminal care/ or exp Palliative therapy or exp Hospice care/ or exp Hospice nursing/ or exp Advance care planning/

7. (hospice care or palliative care or terminal care or (hospice and palliative care nursing) or (advance care planning or hospice)).mp or (end of life* or hospice* or advance care plan* or palliat*).tw
8. exp Home care/ or exp Case management/ or exp Homebound patient/ or exp Home care services/ or exp Social support/
9. (home health nursing or home health aides or case management or homebound persons or home care services or social support).mp or "support services".tw
10. exp Long term care/
11. (Long term care or nursing home or homes for the aged).mp or (care home* or nursing home or long term care).tw.
12. or/4-11
13. exp Emergency Service, Hospital/ or exp Emergency health service/ or exp Emergency medicine/ or exp Emergency/
14. "accident and emergency".mp or "accident & emergency".mp or emergency service*.mp or hospital emergency service*.mp or (emergenc* adj3 (department* or ward* or service* or unit* or room* or hospital* or care or healthcare or patient* or visit*)).mp or (emergency or emergencies).jn or Hospitali?*.mp or A&E.mp or Unplanned.tw or Non-elective.tw or Unscheduled.tw or Urgent.tw or Acute care.tw or Acute admission.tw or Acute visit*.tw.
15. 13 or 14
16. 3 and 12 and 15

Table S5: APA PsycINFO 1806 to 27 April (Week 3) 2020

1. exp Dementia/
2. dement*.mp or alzheimer*.mp or (lewy* adj2 bod*).mp or (chronic adj2 cerebrovascular).mp or (cerebr* adj2 deteriorat*).mp or (cerebral* adj2 insufficient*).mp or (pick* adj2 disease).mp or huntington*.mp or binswanger*.mp.
3. 1 or 2
4. exp Terminally Ill Patients/ or exp “Death and Dying”/
5. Palliat*.mp or End of life.mp or dying.mp or end stage.mp or ((terminal* or palliative or dying or hospice* or end of life or endstage or advanced or late or last or end or final) adj2 (stage* or phase*)).mp or (life* adj2 end).mp or EOL.mp or life limit*.mp or terminal*.mp or advanced.tw or (Last adj4 life).mp
6. exp Palliative care or exp Hospice/ or exp Advance directives/
7. (hospice care or palliative care or terminal care or (hospice and palliative care nursing) or (advance care planning or hospice)).mp or (end of life* or hospice* or advance care plan* or palliat*).tw
8. exp Home care/ or exp Case management/ or exp Homebound/ or exp Home visiting programmes/ or exp Social support/
9. (home health nursing or home health aides or case management or homebound persons or home care services or social support).mp or "support services".tw
10. exp Long term care/
11. (Long term care or nursing home or homes for the aged).mp or (care home* or nursing home or long term care).tw.
12. or/4-11
13. exp Emergency Services/ or exp Emergency medicine/
14. "accident and emergency".mp or "accident & emergency".mp or emergency service*.mp or hospital emergency service*.mp or (emergenc* adj3 (department* or ward* or service* or unit* or room* or hospital* or care or healthcare or patient* or visit*)).mp or (emergency or emergencies).jn or Hospitali?*.mp or A&E.mp or Unplanned.tw or Non-elective.tw or Unscheduled.tw or Urgent.tw or Acute care.tw or Acute admission.tw or Acute visit*.tw.
15. 13 or 14
16. 3 and 12 and 15

Table S6: Ovid CINAHL 1986 to 27 April 2020

1. MH “Dementia+”
2. TX Dement* or TX alzheimer* or TX (lewy* adj2 bod*) or TX (chronic adj2 cerebrovascular) or TX (cerebr* adj2 deteriorat*) or TX (cerebral* adj2 insufficient*) or TX (pick* adj2 disease) or TX huntington* or TX binswanger*
3. 1 or 2
4. MH “Terminally Ill Patients+”
5. TX Palliat* or TX End of life or TX dying or TX end stage or TX ((terminal* or palliative or dying or hospice* or end of life or endstage or advanced or late or last or end or final) N2 (stage* or phase*)) or TX life* N2 end or TX EOL or TX life limit* or TX terminal* or TI, AB advanced or TX last N4 life
6. MH “Terminal Care+” or MH “Palliative Care+” or MH “Hospice Care+” or MH “Hospice and Palliative Nursing+” or MH “Advance Care Planning+”
7. TX (hospice care or palliative care or terminal care or (hospice and palliative care nursing) or (advance care planning or hospice)) or TI, AB (end of life* or hospice* or advance care plan* or palliat*)
8. MH “Home Nursing+” or MH “Home Health Aides+” or MH “Case Management+” or MH “Homebound Patients+” or MH “Home Health Care+”
9. TX (home health nursing or home health aides or case management or homebound persons or services or social support) or TI, AB (support services)
10. MH “Long Term Care+” or MH “Nursing Home Patients+”
11. TX (Long term care or nursing home or homes for the aged) or TI, AB (care home* or nursing home or long term care)
12. or/4-11
13. MH “Emergency service+” or MH “Emergency medicine+” or MH “Emergency patients+”
14. TX "accident and emergency” or TX "accident & emergency" or TX emergency service* or TX hospital emergency service* or TX (emergenc* N3 (department* or ward* or service* or unit* or room* or hospital* or care or healthcare or patient* or visit*)) or SO (emergency or emergencies) or TX Hospitali#* or TX A&E or TI, AB (Unplanned or Non-elective or Unscheduled or Urgent or Acute care or Acute admission or Acute visit*)
15. 13 or 14
16. 3 and 12 and 15

Table S7: Web of Science Core Collection 1900 – 22 April 2020

1. TS=(Dement*) or TS=(alzheimer*) or TS=(lewy* NEAR /2 bod*) or TS=(chronic NEAR /2 cerebrovascular) or TS=(cerebr* NEAR /2 deteriorat*) or TS=(cerebral* NEAR /2 insufficient*) or TS=(pick* NEAR/2 disease) or TS=(huntington*) or TS=(binswanger*)
2. TS=(Palliat*) or TS=(End of life) or TS=(dying) or TS=(end stage) or TS=(terminal* or palliative or dying or hospice* or end of life or endstage or advanced or late or last or end or final NEAR/2 stage* or phase*) or TS=(life* NEAR/2 end) or TS=(EOL) or TS=(life limit*) or TS=(terminal*) or TI=(advanced) or AB=(advanced) or TS=(last NEAR/4 life)
3. TS=(hospice care or palliative care or terminal care or (hospice and palliative care nursing) or (advance care planning or hospice)) or TI=(end of life* or hospice* or advance care plan* or palliat*) or AB=(end of life* or hospice* or advance care plan* or palliat*)
4. TS=(home health nursing or home health aides or case management or homebound persons or home care services or social support) or TI=(support services) or AB=(support services)
5. TS=(Long term care or nursing home or homes for the aged) or TI=(care home* or nursing home or long term care) or AB=(care home* or nursing home or long term care)
6. or/2-5
7. TS=("accident and emergency") or TS=("accident & emergency") or TS=(emergency service*) or TS=(hospital emergency service*) or TS=(emergenc* NEAR/3 (department* or ward* or service* or unit* or room* or hospital* or care or healthcare or patient* or visit*)) or SO=(emergency or emergencies) or TS=(Hospitali?*) or TS=(A&E) or TI=(Unplanned) or AB=(Unplanned) or TI=(Non-elective) or AB=(Non-elective) or TI=(Unscheduled) or AB=(Unscheduled) or TI=(Urgent) or AB=(Urgent) or TI=(Acute care) or AB=(Acute care) or TI=(Acute admission) or AB=(Acute admission) or TI=(Acute visit*) or AB=(Acute visit*)
8. 1 and 6 and 7

Table S8: ASSIA 1986 to 27 April 2020

1. MAINSUBJECT.EXACT.EXPLODE("dementia")
2. Dement* or alzheimer* or lewy* NEAR /2 bod* or chronic NEAR /2 cerebrovascular or cerebr* NEAR /2 deteriorat* or cerebral* NEAR /2 insufficient* or pick* NEAR/2 disease or huntington* or binswanger*
3. 1 or 2
4. MAINSUBJECT.EXACT.EXPLODE("Terminally Ill People") or MAINSUBJECT.EXACT.EXPLODE("Dying") or MAINSUBJECT.EXACT.EXPLODE("End of life decisions")
5. Palliat* or "End of life" or dying or "end stage" or life* NEAR/2 end or "EOL" or "life limit*" or terminal* or **ti**(advanced) or **ab**(advanced) or terminal* OR palliative OR dying OR hospice* OR "end of life" OR endstage OR advanced OR late OR last OR end OR final NEAR/2 stage* OR phase* or last NEAR/4 life
6. MAINSUBJECT.EXACT.EXPLODE("Hospices") OR MAINSUBJECT.EXACT.EXPLODE("Palliative care") OR MAINSUBJECT.EXACT.EXPLODE("Terminal care") OR MAINSUBJECT.EXACT.EXPLODE("Nursing homes") OR MAINSUBJECT.EXACT.EXPLODE("Care plans")
7. **noft(end of life*) OR noft(hospice*) OR noft(advance care plan*) OR noft(Palliat*)**
8. MAINSUBJECT.EXACT.EXPLODE("Home health care") OR MAINSUBJECT.EXACT.EXPLODE("Home health aides") OR MAINSUBJECT.EXACT.EXPLODE("Case management") OR MAINSUBJECT.EXACT.EXPLODE("Housebound people") OR MAINSUBJECT.EXACT.EXPLODE("Social support")
9. noft(case manage*) OR noft(Social Support*)
10. MAINSUBJECT.EXACT.EXPLODE("Long term care") MAINSUBJECT.EXACT.EXPLODE("Retirement homes") or MAINSUBJECT.EXACT.EXPLODE("Nursing homes")
11. noft(care home*) OR noft(nursing home*) OR noft(long term care)
12. or/4-11
13. MAINSUBJECT.EXACT.EXPLODE("Accident and Emergency Departments") or MAINSUBJECT.EXACT.EXPLODE("Emergency admission") or MAINSUBJECT.EXACT.EXPLODE("Emergency")
14. "accident and emergency" or "accident & emergency" or "emergency service*" or "hospital emergency service*" or (emergenc* NEAR/3 (department* or ward* or service* or unit* or room* or hospital* or care or healthcare or patient* or visit*)) or JN(emergency or emergencies) or Hospitali?* or "A&E" or **ab(**(Unplanned or Non-elective or Unscheduled or Urgent or Acute care or Acute admission or Acute visit*)) or ti**(**(Unplanned or Non-elective or Unscheduled or Urgent or Acute care or Acute admission or Acute visit*))
15. 13 or 14

14\. 3 and 12 and 15

A4 – Figure S1: Strength of evidence algorithm

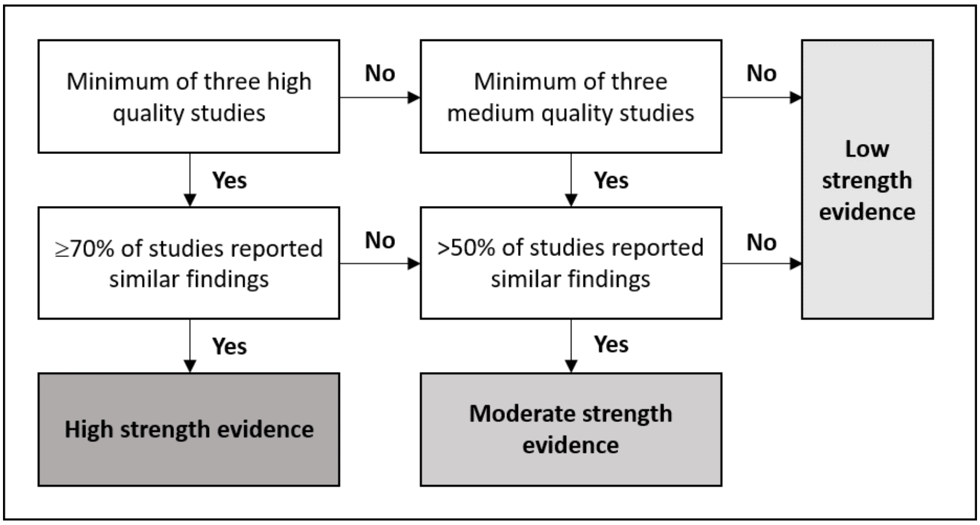


Figure S1: Strength of evidence assessment from published algorithm[ii]

[ii] Gomes B, Higginson IJ. Factors influencing death at home in terminally ill patients with cancer: systematic review. BMJ. 2006 Mar 2;332(7540):515-21.

A5 – Table S9: Study characteristics

First author, date	Study design	Country	Key population characteristics	Dementia / EOL classification	Sample size	Outcome of interest	Analysis	Descriptive statistics	Key findings (bold indicates significance, as per p<0.05)
Feng (2014)	Retrospective cohort study	USA	Fee-for-service Medicare Beneficiaries with dementia, who died between 2000 and 2008; stratified by community setting and nursing home.	Dementia diagnosis or validated HRS-based measure / decedents, last year of life	3,302 (community decedents: 2,667, nursing home decedents: 635)	1) Any ED visit regardless of admission 2) ED visit, outpatient only 3)Potentially avoidable ED visit 4) ED visit resulting in admission	Logistic regression	Any ED visit for community residents (adjusted prevalence): 81.1% (dementia) vs 79.8% (no dementia)	***Adjusted odds ratio (p value) for any ED visit: (no 95% CI provided or p value for non-significant associations)*** ***Community residents:*** Dementia (ref = no dementia) 1.090 Age (ref = 65-69yrs) **70-74yrs = 1.618 p<0.05**; Age 75-79yrs = 1.296; **80-84yrs = 1.557 p<0.05**; 85-89yrs = 1.379; 90yrs+ = 1.456 **Female (ref = male) 1.436 p<0.01** Ethnicity (ref = White, non-Hispanice): Black, non-Hispanic = 1.378; Hispanic = 1.224; Other = 0.659 Low education <12 years (ref = ≥12yrs of education): 0.881 Unmarried (ref = married) = 0.861 Number of ADL limitations = 0.953 Number of conditions = 0.891 Diabetes (ref = no diabetes) = 1.449 Cancer (ref = no cancer) = 0.767; Lung disease (ref = no lung disease) = 1.410 Heart problems (ref = no heart problems) = 1.193 Stroke (ref = no stroke) = 1.190 Psychiatric problems (ref = no psychiatric problems) = 1.167 Arthritis or rheumatism (ref = no arthritis or rheumatism) = 1.358 Poor self-rated health (ref = good/excellent self-rated health) = 0.907 Insurance (ref = Medicare only): Dual eligible = 1.209; Supplemental insurance = 0.920 Income (ref = income quartile 1; bottom) Q2 = 1.332; Q3 = 1.227; Q4 = 0.985 **Urban (ref = rural): 0.638 p<0.001** Region (ref = Pacific region): New England = 1.019; Middle Atlantic = 0.881; East North Central = 1.200; West North Central = 0.893; South Atlantic = 0.964; East South Central = 1.200; West South Central = 0.877; Mountain = 1.187 Year of death (ref = 2000) 2001 = 0.823; 2002 = 1.333; 2003 = 1.182; 2004 = 1.265; 2005 = 1.283; 2006 = 0.995; 2007 = 0.983; 2008 = 1.238
								Any ED visit for nursing home residents (adjusted prevalence): 69.2% (dementia) vs 75.0% (no dementia)	***Adjusted odds ratio (p value) for any ED visit: (no 95% CI provided or p value for non-significant associations)*** ***Nursing home residents:*** Dementia (ref = no dementia) = 0.713 Age (ref = 65-69years): 70-74yrs = 1.068; 75-79yrs = 0.453; 80-84yrs = 0.358; 85-89yrs = 0.578; 90yrs+ = 0.465 **Female (ref = male) = 0.546 p<0.05** Ethnicity (ref = White, non-Hispanic): **Black, non-Hispanic = 2.161 p<0.05**; Hispanic = 1.063; Other = 1.025 Low education <12 years (ref = ≥12yrs of education) = 1.277 Unmarried (ref = married) = 1.332 Insurance (ref = Medicare only): Dual eligible = 1.035; Supplemental insurance = 1.608 **Number of ADL limitations = 0.841 p<0.05** Number of conditions = 1.336 Diabetes(ref = no diabetes) = 0.897 Cancer (ref = no cancer) = 1.256 Lung disease (ref = no lung disease) = 0.576 Heart problems (ref = no heart problems) = 1.331 Stroke (ref = no stroke) = 0.603 Psychiatric problems (ref = no psychiatric problems) = 1.037 Arthritis or rheumatism (ref = no arthritis or rheumatism) = 0.533 Poor self-rated health (ref = good/excellent self-rated health) = 1.192 Income (ref = income quartile 1; bottom): Q2 = 0.699; Q3 = 1.066; Q4 = 0.786 Urban (ref = rural) = 1.013.

									Region (ref = Pacific Region) **East North Central = 3.346 p<0.01**; New England = 1.208; Middle Atlantic = 1.420; West North Central = 0.519; South Atlantic = 1.783; East South Central = 3.209; West South Central = 1.782; Mountain = 0.852 Year of death (ref = 2000): 2001 = 1.240; 2002 = 1.005; 2003 = 0.720; 2004 = 1.440; 2005 = 0.931; 2006 = 1.272; 2007 = 0.937; 2008 = 0.995
Miller (2017)	Retrospective cohort (propensity score-matched)	USA	Nursing home decedents with moderate-to-very severe dementia who had initial palliative care consultations in the last 6 months of life, and matched controls.	Dementia diagnosis / decedents, last 6 months of life	2,959 (203 and 2,756 controls)	Any burdensome transition (including >1 ED visit without admission in last 30 days of life).	Weighted multivariate logistic regression	ED visits in last 30 days of life, with early PC consultations = 5.5%, without early PC consultations = 17.6%	***Adjusted Average Individual Rate Differences*** *ED visits in last 30days of life, with and without PC consultations = -11.9% (-20.7%, -3.1%)*
Mitchell (2004)	Retrospective cohort study	USA	Decedents aged ≥65yrs with advanced dementia, who died within 12 months of admission to a nursing home or home care programme.	Dementia diagnosis and MDS-CPS / decedents, last year of life	3,020 (nursing home = 2,730; Home care = 290)	ED visits within 90 days prior to last MDS assessment.	Bivariate analyses	NA	***Unadjusted chi-squared test (p value only)*** ED visit within previous 90 days: Home care = 13.1%, Nursing home = 11.4%, p=0.41
Mondor (2017)	Retrospective cohort study	Canada	Ontario residents aged ≥50yrs who received a RAI-HC assessment between 01 January 2012 and 30 June 2012, with dementia diagnosed before the assessment.	Diagnosis, medications / EOL by proxy	30,112	Time (in days) to 1) first acute inpatient hospital admission; 2) first unplanned ED visit that did not result in an inpatient stay.	Fine and Gray proportional sub-hazards regression	34% of study sample attended the ED as their first event during the 1yr follow-up: 25% with 0-1 chronic conditions; 40% with >5 conditions	***Adjusted sub-hazard ratio, p value (95% CI)*** **Level of multi-morbidity (Ref = 0-1 chronic condition (CC)): 2 CCs = 1.15 (1.05, 1.26) p=0.002**; **3 CCs = 1.29 (1.18, 1.40) p<0.001; 4 CCs = 1.43 (1.31, 1.56) p<0.001, 5+ CCs = 1.63 (1.51, 1.77) p<0.001** **Sex (Ref = Women): Men = 0.94 (0.90, 0.99) p=0.011** Age (continuous): 1.00 (1.00, 1.00) p=0.453 **Income quintile (Ref = Q5/high): Q1 (low) = 1.07 (1.00, 1.14) p=0.035; Q2 = 1.13 (1.06, 1.20) p<0.001;** Q3 = 1.05 (0.98, 1.12) p=0.138; Q4 = 1.04 (0.97, 1.11) p=0.246 **Marital status (Ref = Married): Widowed = 0.95 (0.90, 0.99) p=0.021**; Separated/divorced = 0.93 (0.86, 1.02) p=0.121; **Never married/other = 0.87 (0.78, 0.96) p=0.005** **Residence (Ref = Urban): Rural = 1.18 (1.12, 1.25) p<0.001** Continuity of care (Ref = High/≥median): Low (<median) = 1.03 (0.99, 1.07) p=0.159 **Prior hospitalisations (Ref = None): 1 = 0.94 (0.89, 0.98) p=0.010;** ≥2 = 1.04 (0.98, 1.11) p=0.203 **Prior ED visits (Ref = None): 1 = 1.36 (1.30, 1.43) <0.001; ≥2 = 1.94 (1.85, 2.04) p<0.001** **MDS-HSI (continuous) = 2.36 (2.13, 2.62) p<0.001** **CHESS scale (Ref = No instability):** Minimal instability = 1.01 (0.96, 1.06) p=0.709; **low instability = 0.93 (0.88, 0.98) p=0.011; moderate instability = 0.89 (0.83, 0.96) p=0.003; High to very high instability = 0.82 (0.73, 0.92) p=0.001**
Sleeman (2018)	Retrospective cohort	UK	All patients aged ≥60yrs with a diagnosis of dementia retrieved from the South London and the Maudsley Biomedical Research Centre Case Register.	Diagnosis of dementia / decedents, last year of life	4,867	ED attendances in the last year of life.	Negative binomial regression analysis	78.6% had >1 EDA in last year of life; 44.5% had >1 EDA in last month of life; 20.9% had EDA in last week of life. Mean number of attendances per patient in last year of life = 2.1 (SD 2.3, range 0-54)	***Adjusted incident rate ratio, p value (95% CI):*** Age at death = 1.00 (0.99, 1.00) p=0.208 **Gender (Ref = female): Male = 1.16 (1.09, 1.24) p<.001** Ethnicity (ref = white British): Other White = 0.99 (0.89, 1.09) p=0.776, African Caribbean = 1.07 (0.95, 1.19) p=0.255, Other = 1.08 (0.92, 1.27) p=0.327, Not known = 1.19 (0.84, 1.69) p=0.326 Dementia subtype (ref = Alzheimer's Disease): **Vascular dementia = 1.16 (1.07, 1.26) p<.001,** Unspecified dementia = 1.07 (0.99, 1.17) p=0.105, Other dementia = 1.04 (0.94, 1.16) p=0.441, Lewy body dementia = 1.03 (0.76, 1.40) p=0.849 **CI severity (MMSE score; per unit increment): 1.01 (1.00, 1.01) p=0.021** HoNOS score: Physical health = 1.04 (0.96, 1.12) p=0.346, **Depression = 1.12 (1.01, 1.24) p=0.030**, Other mental health = 1.01 (0.94, 1.09) p=0.707 **Care home residence = 0.81 (0.75, 0.87) p<.001** Problem HoNoS scores (subscale scores 2–4): Living Conditions 1.04 (0.95-1.15) P=0.391 IMD quintile (Ref = 1/Most deprived): 2 = 0.92 (0.85, 0.99) p=0.036; **3 = 0.85 (0.77, 0.93) p=0.001;** 4 = 0.94 (0.83, 1.05) p=0.268**; 5 (Most affluent) = 0.79 (0.69, 0.91) p=0.001**

Stephens (2014)	Retrospective cohort	USA	5% national random sample of Medicare Beneficiaries aged ≥65yrs, residing in nursing facilities (including dementia special care units) with MDS assessment between 01 January and 31 December 2006.	Residents of dementia specialist units / EOL by proxy	112,412 (5,171 in dementia units)	Number of ED visits (with or without hospitalisation) per year	Over-dispersed Poisson regression (person-years of observation)	49,643 NH residents attended the ED 8993 (8%) had >3 EDAs without hospitalisation	***Adjusted incident rate ratio (95% CI) of total ED visits per year*** Dementia special care unit = 0.78 (0.75–0.82) p<0.0001
						Number of hospitalisations after ED visit	Logistic regression	Average number of ED visits per year: a) without hospitalisation (1.89); b) with hospitalisation (1.66)	***Adjusted odds ratio (95% CI) of ED with hospitalisation*** Dementia special care unit = 0.89 (0.81–0.98)
Gruneir (2010)	Retrospective cohort study	Canada	Residents of long-term care facilities aged ≥66yrs, followed until first occurrence of death, admission (with/out ED attendance), or end of follow-up (6 months).	Dementia diagnosis or medications / EOL by proxy	64, 589 (80% dementia)	ED visits during follow-up, classified as: 1) potentially preventable (ACSC), 2) low acuity (less / non-urgent and discharge without admission); 3) Other (neither of above)	Descriptive statistics only	***Unadjusted % (95% CI) of Total ED visits:*** 21,773 ED visits - rate = 77.2 (95% CI 5 76.2–78.3) visits per 100 resident-years >1 ED = 23%; 2-4 EDAs = 6.4% Potentially preventable = 24.5%; low acuity = 10.6% ***Unadjusted % (95% CI) of Initial ED visits:*** 14,884 initial visits - rate = 56.7 (95% CI 5 55.8–57.6) initial visits per 100 resident-years Potentially preventable = 24.6%; low acuity = 11.0% Same-day physician contact = 12.9% (95% CI 5 12.4–13.4) Ambulance transport: Potentially preventable = 90.4 (89.4, 91.4); Low acuity = 72.5 (70.3, 74.7); Other = 87.3 (86.6, 88.0); All initial visits = 86.4 (85.8, 87.0) Timing of EDA: Weekday = 42.0% (41.2, 42.8); weekend days = 15.4% (14.8, 16.0); week nights = 23.8% (23.1, 24.5); weekend nights = 18.8% (18.2, 19.4) Triaged as emergency: Potentially preventable = 35.3%, (33.8, 36.9); Other = 25.2% (24.3, 26.1) ***Unadjusted % (95% CI) of Repeat ED visits:*** Potentially preventable **repeat** ED visit (n=1204): Initial visit potentially preventable = 40.9 (38.1–43.7), Initial visit low acuity = 5.1 (3.9–6.3), Other initial visit = 53.9 (51.1–56.7); Mean (SD) days between initial and repeat ED visit = 39.5 (37.6); 1–3 days = 10.1 (8.4–11.8); 4–7 days = 8.7 (7.1–10.3); 8–14 days = 13.4 (11.5–15.3); 15–28 days = 19.8 (17.5–22.1); ≥ 29 days = 48.0 (45.2–50.8); Same ED = 75.6 (73.2–78.0); Discharge location: Died in ED = 0.9 (0.4–1.4); Hospitalized = 63.9 (61.2–66.6); Returned to LTC facility = 34.9 (32.2–37.6); Discharged elsewhere = 0.3 (0–0.6); Died within 30 days of visit = 26.5 (24.0–29.0); No. of residents whose initial and repeat visits were the same type = 234; Same diagnosis at both visits = 47.5 (41.1–53.9) Low acuity **repeat** ED visit (n=447): Initial visit potentially preventable = 10.3 (7.5–13.1); Initial visit low acuity = 15.9 (12.5–19.3); Other initial visit = 73.8 (69.1–77.9); Mean (SD) days between initial and repeat ED visit = 37.4 (39.1); 1–3 days = 20.6 (16.9–24.3); 4–7 days = 7.8 (5.3–10.3); 8–14 days = 11.0 (8.1–13.9); 15–28 days = 13.7 (10.5–16.9); ≥ 29 days = 47.0 (42.4–51.6); Same ED = 79.6 (75.9–83.3); Discharge location: Returned to LTC facility = 100; Died within 30 days of visit = 6.3 (4.1–8.9); No. of residents whose initial and repeat visits were the same type = 16; Same diagnosis at both visits = 22.5 (2.04–43.0) Other **repeat** ED visits (n= 2,723): Initial visit potentially preventable = 20.5 (19.0–22.0); Initial visit low acuity = 6.0 (5.1–6.9); Other initial visit = 73.6 (71.9–75.3); Mean (SD) days between initial and repeat ED visit = 36.1 (37.0); 1–3 days = 17.1 (15.7–18.5); 4–7 days = 8.3 (7.0–9.0); 8–14 days = 13.4 (12.1–14.7); 15–28 days = 17.9 (16.5–19.3); ≥ 29 days = 43.4 (41.5–45.3); Same ED = 73.2 (71.5–74.9); Discharge location: Died in ED = 1.4 (1.0–1.8); Hospitalized = 45.1 (43.2–47.0); Returned to LTC facility = 53.2 (51.3–55.1); Discharged elsewhere = 0.3 (0.1–0.5); Died within 30 days of visit = 19.6 (18.1–21.1); No. of residents whose initial and repeat visits were the same type = 326; Same diagnosis at both visits = 16.3 (12.3–20.3) All **repeat** ED visits (n=4,374): Initial visit potentially preventable = 25.1 (23.8–26.4); Initial visit low acuity = 6.8 (6.1–7.6); Other initial visit = 68.2 (66.8–69.6); Mean (SD) days between initial and repeat ED visit = 37.2 (37.4); 1–3 days = 15.5 (14.1–16.6); 4–7 days = 8.4 (7.6–9.2); 8–14 days = 13.1 (12.1–14.1); 15–28 days = 17.9 (16.8–19.0); ≥ 29 days = 45.0 (43.5–46.5); Same ED = 74.5 (73.2–75.8); Discharge location: Died in ED = 1.1 (0.8–1.4); Hospitalized = 45.7 (44.2–47.2); Returned to LTC facility = 52.9 (51.4–54.4); Discharged elsewhere = 0.2 (0.1–0.3); Died within 30 days of visit = 20.1 (18.9–21.3)	

						Reasons for EDA	Descriptive statistics only	***Ten Most Commonly Reported Main Reasons for the Initial Emergency Department Visit (%)*** Potentially preventable (n=3,658): Pneumonia = 30.1; Kidney or urinary tract infection = 20.3; Congestive heart failure = 15.9; Chronic obstructive pulmonary disease = 10.1; Dehydration = 7.5; Diabetes mellitus = 4.1; Gastroenteritis = 3.0; Cellulitis = 2.7; Angina pectoris = 1.7; Hypertension = 1.6 Low-acuity visits (n=1,637): Fall-related injury = 37.0; Non-fall-related injury = 10.4; Fitting and adjustment of other devices = 2.0; Haemorrhage from respiratory passages = 1.9; Joint disorders, not elsewhere classified = 1.9; Soft tissue disorders, not elsewhere classified = 1.9; Other medical care = 1.7; Abdominal and pelvic pain = 1.2; Attention to artificial openings = 1.2; Other anaemias = 1.2 Other visits (n=9,589): Fall-related injury = 22.7; Pain in throat and chest = 3.5; Other diseases of digestive system = 3.4; Abnormalities of breathing = 3.4; Abdominal and pelvic pain = 3.1; Other symptoms and signs involving cognitive functions and awareness = 2.6; Non-fall-related injury = 2.6; Malaise and fatigue = 2.2; Stroke, not specified as haemorrhage or infarction = 2.0; Other anaemias = 1.8	
LaMantia (2016)	Retrospective cohort	USA	Nursing home residents aged ≥65yrs, with different dementia severity, with ≥90 days' residence between 01 January 1999 and 31 December 2008.	MDS-CPS / EOL by proxy	4491 (78% dementia)	Time to first ED visit within one year of study qualification	Cox proportional hazards regression model	47% of all residents had >1 EDA over one year. 36.4% were admitted; 63.1% were discharged; 0.52% died. Median time to first EDA: advanced dementia = 258 days; early-mod dementia = 250 days; no dementia = 2020 days	***Adjusted estimated hazard ratio, p value (95% CI):*** Dementia (advanced) vs no CI = 1.05 (0.87, 1.27) p=0.6165 Dementia (early-moderate stage) vs no CI = 0.98 (0.87, 1.09), p=0.6568 **Age at qualification (years) = 0.98 (0.98, 0.99), p<0.0001** Female gender = 1.05 (0.95, 1.15), p=0.3610 **Race-overall = p0.0061** **Black vs white = 1.13 (1.03, 1.24), p=0.0104** **Other vs white = 1.46 (1.04, 2.06), p=0.0294** **Do not resuscitate order = 0.91 (0.82, 1.00), p=0.0488** Number of years in nursing home until qualification = 1.02 (0.97, 1.08), p=0.4642 **Number of hospitalisations in year prior to qualification = 1.29 (1.24, 1.35), p<0.0001** **Number of comorbidities = 1.12 (1.09, 1.15), p<0.0001**
						ED diagnoses by dementia status within 1yr of qualification date	Fisher exact tests	NA	***Unadjusted %, p value - Advanced dementia vs. Early-Mod dementia vs. No dementia:*** Infectious and parasitic diseases = 3.0 vs 3.4 vs 2.2, p=0.473 Septicaemia = 3.0 vs 2.9 vs 1.8, p=0.390 Neoplasms = 1.8 vs 1.5 vs 2.2, p=0.544 Endocrine, nutritional and metabolic diseases and immunity = 5.3 vs 4.8 vs 4.2, p=0.797 Diabetes mellitus with complications = 1.2 vs 1.7 vs 0.9, p=0.435 Fluid and electrolyte disorders =1.8 vs 1.3 vs 1.6, p=0.670 Diseases of the blood and blood-forming organs = 0.6 vs 1.5 vs 2.4, p=0.242 **Anaemia = 0 vs 1.1 vs 2.4, p=0.038** Mental illness = 3.0 vs 3.1 vs 2.2, p=0.660 Delirium, dementia, and amnestic and other cognitive disorders = 2.4 vs 1.5 vs 0.7, p=0.191 Diseases of the nervous system and sense organs = 4.1 vs 7.3 vs 6.5, p=0.300 Epilepsy; convulsions = 1.8 vs 1.9 vs 0.4, p=0.055 Convulsions = 1.8 vs 1.9 vs 0.4, p=0.055 Eye disorders = 0.6 vs 1.7 vs 2.2, p=0.419 Diseases of the heart = 5.9 vs 8.7 vs 10.5, p=0.191 Congestive heart failure; non-hypertensive = 2.4 vs 2.3 vs 2.0, p=0.911 Diseases of arteries, arterioles and capillaries = 0 vs 0.8 vs 1.8, p=0.082 Respiratory infections = 4.7 vs 5.1 vs 5.6, p=0.919 Gastrointestinal haemorrhage = 3.0 vs 1.3 vs 1.3, p=0.225 **Urinary tract infections = 10.7 vs 5.0 vs 4.9, p=0.015** Diseases of the musculoskeletal system and connective tissue = 3.6 vs 5.2 vs 7.6, p=0.087 **Injury and poisoning = 21.9 vs 19.4 vs 12.9, p=0.003** **Open wounds = 7.7 vs 3.7 vs 3.1, p=0.037** Symptoms, signs and ill-defined conditions and factors = 2.4 vs 5.4 vs 7.1, p=0.062 Nausea and vomiting = 0 vs 0.9 vs 1.3, p=0.329

									Abdominal pain = 0 vs 1.1 vs 1.8, p=0.155
Wiener (2014)	Retrospective cohort study	USA	Nursing home (including Alzheimer's / Dementia Care Unit) residents aged ≥65yrs, with severe cognitive impairment.	Dementia diagnosis or >3/7 related symptoms / EOL by proxy	612, 283 (86,332 in dementia care unit)	Residents treated in hospital ED during past 12 months or since the resident had moved into facility and length of stay <1yr (yes/no)	Logistic regression	Total proportion with ED visits = 35.5% (SD 0.8) Living in dementia care unit (DCU) = 35.6% (SD 2.0)	*Adjusted odds ratio, p value (95% CI)* ED visit in last 12 months with severe CI = 0.858 (.0729, 1.009), p<0.10; if also controlling for DCU residence = 0.907 (0.769, 1.069) **ED visit in last 12 months from DCU = 0.714 (0.564, 0.905), p<0.05**
						Number of times residents had been treated in ED during same period (count)	Negative Binomial regression		Number of ED visits in last 12 months with severe CI = 0.929 (0.851, 1.014), p<0.10; if also controlling for DSU residence = 0.914 (0.832, 1.005), p<0.10 Number of ED visits in last 12 months from DSU = 1.094 (0.957, 1.251)
Rosenwax (2015)	Retrospective cohort	Australia	Community decedents aged ≥20yrs, who had a death registration from 01 January 2009 to 31 December 2010, with diagnosis of dementia or comparative palliative condition.	Dementia diagnosis / decedents, last year of life	8126	Cumulative number of ED visits over last year of life	Nelson-Aalen cumulative hazard function	***Mean number of ED visits (SD) in last year of life:*** Dementia cohort = 1.9 (2.1); Comparative cohort = 2.0 (2.3)	
						Any ED visit	Flexible parametric proportional hazards survival regression.	Any visit to ED in last year of life: Dementia cohort = 73%; Comparative cohort = 76.3%	***Adjusted hazard ratio (95% CI) p value*** **Age at death** (80-89 = ref): <60= 1.20 (0.95, 1.51) p=0.126, 60–69= 1.01 (0.86, 1.17) p=0.883, 70–79= 1.07 (0.99, 1.15) p=0.080, **90–99= 0.87 (0.82, 0.92) p<0.001**, **>100= 0.71 (0.55, 0.89) p=0.003** **Gender (Male): 1.16 (1.10, 1.23) p<0.001** Dementia subtype (ref = Alzheimer's Disease): Vascular dementia = 1.08 (0.98, 1.19) p=0.105, **Dementia in other diseases = 1.28 (1.10, 1.49) p=0.002**, **Dementia unspecified = 1.18 (1.10, 1.25) p<0.001** Comorbidities: **Peptic ulcer disease = 1.62 (1.36, 1.92) p<0.001, Malignancies = 1.66 (1.49, 1.83), p<0.001** **Hypertension = 2.63 (2.00, 3.45) p<0.001, Chronic pulmonary disease = 1.51 (1.33, 1.71) p<0.001** Accessibility and Remoteness Index of Australia (ref = major city): Inner regional = 1.03 (0.95, 1.11), p=0.417, **Outer regional = 1.23 (1.13, 1.36) p<0.001, Remote = 1.30 (1.07, 1.57) p=0.008,** Very remote = 0.95 (0.74, 1.21) p=0.663 **Marital status (ref = no partner/unknown): Partnered = 1.10 (1.0, 1.2) p=0.001** Service contact in first 130 days of LYOL (ref = community-based palliative care): **Regular care in private residence = 1.9 (1.4, 2.5), Regular care in a care facility = 1.4 (1.1, 1.9)** Service contact in last month of life (ref = community-based palliative care): **Regular care in private residence = 6.7 (4.7, 9.6), Regular care in a care facility = 3.1 (2.2, 4.2)** **Prior ED visits in year = 1.12 (1.07, 1.16) p<0.001**
Volicer (2003)	Retrospective survey	USA	Caregivers whose care recipient had dementia and died within the last year.	Dementia organisations / caregivers of decedents	156	Pattern of dementia care in last 90 days of life, including number of ED visits.	t-test	71 (58%) care recipients reported as having attended the ED.	***Unadjusted mean (SD; p value) number ER visits after discussion about:*** Resuscitation: 0.83 (1.59) vs. no discussion 1.39 (1.94), p<0.1 ITU: 1.65 (2.54) vs. no discussion 0.95 (1.49), p < 0.1 **Ventilation: 1.52 (2.29) vs. no discussion 0.87 (1.41) p<0.05** Transfer to hospital: 1.43 (2.39) vs.no discussion 0.93 (1.36) Tube feeding: 1.13 (2.14) vs. no discussion 1.07 (1.48) IV therapy: 1.17 (2.17) vs. no discussion 1.05 (1.45) Antibiotics: 1.11 (2.09) vs. no discussion 1.08 (1.43)
						Reasons for ED visits	Descriptive statistics only	***Causes of ED visits in last 90 days of life*** Breathing difficulty: 44%, Infection: 31% Injury: 27% Dehydration: 22% Heart problem: 15% Other behavioural problems: 13%	
Amador (2014)	Prospective cohort study	UK	Care homes residents aged ≥65yrs, with diagnosed or assumed	Dementia diagnosis or care worker	133	Emergency ambulance use, resulting in 1)	Logistic regression	Proportions of emergency ambulance contact	***Adjusted odds ratio, p value (CI 95%)*** Age = 1.067 (0.997, 1.142) p=0.060 Gender (ref = male): Female = 0.661 (0.385, 1.135) p=0.133

			dementia. Care homes identified from Care Quality Commission directory using specific inclusion criteria.	assessment / EOL by proxy		non-conveyance to ED, 2) same day discharge from ED, 3) unscheduled admission from ED		resulting in non-conveyance = 24.3%, same-day discharge = 32.6% and unscheduled admission = 43.1%	Length of residency = 0.965 (0.735, 1.266) p=0.796 No. of comorbidities = 1.207 (0.879, 1.655) p=0.245 **Admission route** (ref = own home) **Relative's home = 0.092 (0.017, 0.493) p=0.005**; Hospital = 0.556 (0.136, 2.283) p=0.416; Other care home = 0.284 (0.063, 1.277) p=0.101; Sheltered housing/Warden controlled = 1.055 (0.349, 3.186) p=0.925 **No. of GP contacts = 1.170 (1.012, 1.351) p=0.034** No of District Nurse contacts = 1.003 (0.926, 1.086) p=0.943
									Main reasons and outcomes of emergency ambulance call outs to care homes: SAME-DAY D/C (n=47): Trauma* = 23, Respiratory = 4, CVS complaint = 3, GI complaint = 1, GU complaint = 8, Altered mental state = 3, Non-specific complaint = 2, Cerebrovascular complaint = 1, MSK no trauma = 2, seizure = 0, Circulatory complaint = 0, ENT problem = 0, Unknown = 0 UNPLANNED ADMISSION (n=62): Trauma* = 24, Respiratory = 8, CVS complaint = 7, GI complaint = 7, GU complaint = 0, Altered mental state = 4, Non-specific complaint = 2, Cerebrovascular complaint = 4, MSK no trauma = 2, seizure = 3, Circulatory complaint = 1, ENT problem = 0, Unknown = 0 NON-CONVEYANCE (n=35): Trauma* = 13, Respiratory = 1, CVS complaint = 0, GI complaint = 0, GU complaint = 0, Altered mental state = 0, Non-specific complaint = 2, Cerebrovascular complaint = 0, MSK no trauma = 0, Seizure = 0, Circulatory complaint = 0, ENT problem = 1, Unknown = 18 *only 3 out of 60 emergency ambulance call outs for trauma were unrelated to falls in the home
Chen (2017)	Case-control study	Taiwan	Community decedents aged ≥18yrs, who had been diagnosed with dementia and died from 2002 to 2011. Matched controls of decedents with cancer on death certificate.	Dementia diagnosis / EOL by proxy	2724 (Dementia = 908; Cancer = 1816)	Frequency of ED visits in last year of life.	Logistic regression	Proportion of patients visiting the ED: Dementia = 46 (50.22), Cancer = 977 (53.80) <3 ED visits per person: Dementia = 287 (62.94), Cancer = 613 (62.74) >3 ED visits per person: Dementia = 169 (37.06), Cancer = 364 (37.26)	***Adjusted odds ratio, p-value (95% CI)*** Visiting the ED = 0.87 (0.73, 1.02), p=0.0778 Frequency of visiting ED (ref = <3 times): >3 times = 0.90 (0.70, 1.15), p=0.9431
McCormick (2001)	Case-control study	USA	ADPR decedents aged ≥60yrs, and randomly selected controls from the same HMO.	Dementia register and MDT / decedents, last 3yrs of life (last 1yr reported)	496	ED visits in last year of life.	Chi-squared test	NA	***Unadjusted mean number ED visits (p value vs. controls):*** ED visits in last year of life: **Alzheimer's disease = 0.5, p<0.05; Other dementia = 0.4, p<0.05;** Controls = 0.8
Nakashima (2016)	Cross-sectional study	USA	Nursing home residents in New York State, aged ≥65yrs and who had an annual assessment in 2010.	Dementia diagnosis / EOL by proxy	43.024 (62%)	ED visit without overnight stay >1 times in last 90 days.	Logistic regression	Number of ED visits was 1.526 in last 90 days. 3.6% of people with dementia had >1 ED visits without overnight stay in last 90 days	***Adjusted odds ratio, p value (95% CI):*** No DNH (DNH) order (Ref = DNH): All residents = 1.25 (0.98 to 1.59) p=0.07; Dementia status (Ref = dementia) = 1.03 (0.92 to 1.15) p=0.60; Dementia only = 1.20 (0.9 to 1.59) p= 0.21
de Souto Barreto (2013)	Cross-sectional study	France	Participants of the IQUARE study living in a nursing home for ≥1 year, categorised by dementia status.	Dementia diagnosis / EOL by proxy	5684 (dementia diagnosis = 2,422, potential dementia without diagnosis = 605, no dementia = 2,657)	ED visits (binary variable)	Mixed effects logistic regression	Proportion of people attending the ED: Total = 18.8%, diagnosed dementia = 19.9, potential dementia without diagnosis = 23.8%, no dementia = 16.7%	***Adjusted odds ratio, p value (95% CI)*** Model 1 (adjusted for resident characteristics; Ref = dementia): No dementia = 1.15 (0.95, 1.39) p=0.15, **Potential dementia without diagnosis = 1.25 (0.99, 1.57) p=0.06** Model 2 (adjusted for resident and nursing home characteristics; Ref = dementia): No dementia = 1.44 (0.95, 1.40) p=0.15, Potential dementia without diagnosis = 1.25 (0.99, 1.59) p=0.061 Model 3 (adjusted for resident, nursing home characteristics living in particular nursing home as random-effect; Ref = dementia): No dementia = 1.16 (0.94, 1.43) p=0.16, Potential dementia without diagnosis = 1.22 (0.95, 1.57) p=0.11

Dyer (2018)	Cross-sectional study	Australia	Residents of 17 not-for-profit RACFs in the INSPIRED study with >12 months residence.	Dementia diagnosis or PAS-Cog >5 / EOL by proxy	541 (With dementia or PAS-Cog >5: standard care = 333 (79%); clustered domestic model = 120 (100%))	Number of ED presentations.	Random effect Poisson regressions	Adjusted means (95% CI): Clustered domestic = 0.114 (0.053, 0.244); Standard care = 0.417 (0.285, 0.610)	***Adjusted rate ratio (95% CI), p value*** **ED presentations = 0.27 (0.14, 0.53), p<0.001**
Stephens (2012)	Cross-sectional study	USA	5% national random sample of Medicare Beneficiaries, aged ≥65yrs, residing in nursing facilities (including dementia special care units) with MDS assessment between 01 January and 31 December 2006.	Dementia specialist residence / EOL by proxy	132,753 (6,252 in dementia care units)	Any ED visit (yes/no) and any ED visit with or without hospitalisation for an ACSC (yes/no)	Logistic regressions	Dementia special care unit: 43.8% any ED visit; 16.6 ACS ED visit	***Adjusted odds ratio, p value (95% CI)*** **Dementia special care unit: Any ED visit = 0.72 (0.67, 0.76), p<0.0001; ACS ED visit = 0.77 (0.72, 0.83), p<0.0001**
Mamhidir (2012)	Cross-sectional follow-up study	Sweden	Community-managed nursing home residents aged ≥75yrs, referred to the ED over a one-year period.	Diagnosis and/or MDS-CPS / EOL by proxy	719 baseline (209 referred to ED; 36% dementia diagnosis)	1) Dementia diagnosis/ no referred to ED 2) Dementia diagnosis/ referred to ED 3) No dementia diagnosis / not referred to ED	Kruskal-Wallis test (mean SD) and Chi-square test	NA	***Unadjusted %, p value (no CI)*** Dementia: Referred = 59 (23%); not referred = 199 (77%) vs. No dementia: Referred = 150 (33%); not referred = 311 (68%), p=0.010 Dementia/no referral vs. Dementia/referral vs. No dementia/No referral: Psychiatric diagnosis: 40 (20) vs 8 (13) vs 70 (22) p=0.279; Cardiovascular diagnosis: 100 (51) vs 36 (61) vs 181 (58) p=0.299; **Multi-morbidities (1-4 comorbidities: 166 (84) vs 50 (85) vs 237 (76); 5+ comorbidities: 31 (16) vs 9 (15) vs 50 (16)) p<0.001**; **CPS-sum: 4.45+1.3 vs 4.27+1.2 vs 2.18+2.1 p<0.001; ADL-sum: 10.96+5.3 vs 9.56+5.1 vs 8.88+5.3 p<0.001**; Daily pain: 54 (27) vs 11 (19) vs 99 (32) p=0.140; Pressure ulcer: 13 (7) vs 3 (4) vs 20 (6) p=0.931; BMI <22: 83 (42) vs 19 (32) vs 106 (34) p=0.051; Drug use in the previous week: 6.81+9.8 vs 5.49+2.6 vs 7.59+8.3 p=0.176; **Neuroleptics: 47 (24) vs 12 (20) vs 33 (11) p<0.001;** Sedatives: 60 (31) vs 12 (20) vs 58 (19) p=0.066; **Antidepressants: 71 (36) vs 20 (34) vs 91 (29) p=0.500; Hypnotics: 47 (24) vs 12 (20) vs 94 (30) p=0.032**; Diuretics: 82 (42) vs 25 (42) vs 158 (51) p=0.092; Analgesics: 80 (41) vs 20 (34) vs 133 (43) p=0.432
Hunt (2018)	Mortality follow-back study	USA	Decedents of the National Health and Aging Trends Study, aged ≥65yrs, who died between 2012 and 2014 and had a last month of life interview by a proxy.	Validated algorithm / decedents, last month of life	281	Percentage with and mean number of three types of ED visit: 1) any ED visit; 2) ED visit without admission; 3) ED visit with admission	Poisson regression	Last month of life: Any ED visit = 151 (56.6%); mean number of visits = 0.75 (SD 0.76); ED visit without admission = 40 (14.4%); mean no. without admission = 40 (SD 14.4); ED visit with admission = 126 (46.5%); no. with admission = 0.57 (SD 0.68) Pain in last month of life: Mean number of ED visits = 0.72 (SD 0.75); No pain = 0.72 (SD 0.75). Unmet need for pain management in last month of	***Adjusted incident rate ratio, p value for significant findings only (95% CI)*** Pain in last month of life (ref = no pain) = 0.86 (0.63, 1.17) Unmet need for pain management in last month of life (ref = no unmet need) = 1.46 (1.07, 1.99) p<0.05 10 most frequent primary diagnoses (and rates per 100 persons) for any ED visit in last month of life: 1. Septicaemia (6.4), 2 = Cardiac arrest (5.0), 3 = Pneumonia / other resp disease (4.3), 4 = Malignancy (4.0), 5 = Congestive heart failure (4.0), 6 = Cerebrovascular disease (3.6), 7 = Cystitis / other urological infections (2.9), 8 = Hip and other bone fractures (2.9), 9 = Stomach / intestinal disorder (2.5), 10 = Fluid and electrolyte disturbance (2.1)

								life: Mean no. of ED visits = 1.02 (SD 0.78); No unmet need = 0.71 (SD 0.75)	
Agar (2012)	Two arm parallel cluster randomised controlled trial	Australia	Nursing home residents with advanced dementia with a surrogate decision-maker for palliative care planning.	Dementia diagnosis / FAST >6a and AKPS >50	131 (Usual care = 64; FCC = 67)	ED presentations without hospital admission in the last month of life.	Descriptive only	***Unadjusted % (no p value; 95% CI)*** ED presentation without hospital admission: Usual care = 6 (10%), FCC = 6 (9%); total = 12 (9%)	
Hullick (2016)	Controlled pre- and post- study	Australia	Residents aged ≥75yrs, living in one of four RACFs with a history of high ED presentations, or in matched RACF controls.	Dementia specialist residence / EOL by proxy	12 RACF (1,289 beds; intervention beds = 453; control beds = 836; dementia specific intervention = 345; dementia specific control = 660)	Average number of ED presentations per month during pre- and post-intervention stages.	Generalised estimating equations	Annual ED presentation: Pre-control cohort = 653; Pre-intervention cohort = 604; Post-control cohort = 468; Post-intervention cohort = 525 Presenting problems (% controls): Fall = 19.8, Resp = 11.3, Abdo = 8.6, General = 11, Cardiac = 8, Pain = 8, Other = 33.3 Presenting problems (% intervention): Fall = 19.9, Resp = 11.6, Abdo = 11.6, General = 6.9, Cardiac = 8.8, Pain = 6.5, Other = 34.6	***Unadjusted odds ratio, p value*** Group x Time interaction: 1.17, p=0.56
Di Giulio (2019)	Quality improvement study	Italy	Nursing home decedents with advanced dementia, with ≥6 months' residence and who died before or after the intervention.	FAST >7c / decedents before and after intervention	482 (pre-intervention group: 245; post-intervention group: 237)	Number of ED admissions in seven days before death	T-test	NA	***Unadjusted t-test, proportion and p value only*** Pre-intervention ED visits: 9 (3.7%); Post-intervention ED visits: 2 (0.8); p=0.522

A6 – Tables S10-14: Quality appraisal scores

Table S10: Newcastle-Ottawa Scale for cohort studies

First author (date)	**Selection: (Max 5 stars)**				**Comparability: (Max 2 stars)**	**Outcome: (Max 3 stars)**			**Total number of stars**			
	1) Representativeness of the exposed cohort	**2) Selection of the non-exposed cohort**	**3) Ascertainment of exposure**	**4) Demonstration that outcome of interest was not present at start of study**	**1) Comparability of cohorts on the basis of the design or analysis controlled for confounders**	**1) Assessment of outcome**	**2) Was follow-up long enough for outcomes to occur**	**3) Adequacy of follow-up of cohorts**	**Selection**	**Comparability**	**Outcome**	**Total**
Amador (2014)	a) truly representative of the average exposure in the community *	a) drawn from the same community as the exposed cohort *	a) secure record (eg surgical records) *	a) yes *	c) study controls for main and additional factors **	a) independent / blind assessment (inc. medical records) *	a) yes *	a) complete follow up - all subjects accounted for *	4	2	3	9
Feng (2014)	b) somewhat representative of the average exposure in the community *	a) drawn from the same community as the exposed cohort *	b) structured interview *	a) yes *	c) study controls for main and additional factors **	b) record linkage *	a) yes *	a) complete follow up - all subjects accounted for *	4	2	3	9
Gruneir (2010)	a) truly representative of the average exposure in the community *	a) drawn from the same community as the exposed cohort *	a) secure record (eg surgical records) *	a) yes *	b) study controls for any additional factor (see comments) *	b) record linkage *	a) yes *	b) subjects lost to follow up unlikely to introduce bias - see comments *	4	1	3	8
Hunt (2018)	a) truly representative of the average exposure in the community *	a) drawn from the same community as the exposed cohort *	b) structured interview *	a) yes *	c) study controls for main and additional factors (see comments) **	a) independent / blind assessment (inc. medical records) *	a) yes *	a) complete follow up - all subjects accounted for *	4	2	3	9
LaMantia (2016)	b) somewhat representative of the average exposure in the community *	a) drawn from the same community as the exposed cohort *	a) secure record (eg surgical records) *	a) yes *	c) study controls for main and additional factors (see comments) **	b) record linkage *	a) yes *	d) no statement	4	2	2	8
Miller (2017)	b) somewhat representative of the average exposure in the community *	a) drawn from the same community as the exposed cohort *	a) secure record (eg surgical records) *	a) yes *	c) study controls for main and additional factors (see comments) **	b) record linkage *	a) yes *	a) complete follow up - all subjects accounted for *	4	2	3	9
Mitchell (2004)	b) somewhat representative of the average exposure in the community *	b) drawn from a different source (see comments)	a) secure record (eg surgical records) *	a) yes *	c) study controls for age and additional factors **	b) record linkage *	a) yes *	a) complete follow up - all subjects accounted for *	3	2	3	8
Mondor (2017)	b) somewhat representative of the average exposure in the community *	a) drawn from the same community as the exposed cohort *	a) secure record (eg surgical records) *	a) yes *	c) study controls for main and additional factors (see comments) **	b) record linkage *	a) yes *	a) complete follow up - all subjects accounted for *	4	2	3	9
Rosenwax (2015)	a) truly representative of the average exposure in the community *	a) drawn from the same community as the exposed cohort *	a) secure record (eg surgical records) *	a) yes *	b) study controls for any additional factor (see comments) *	b) record linkage *	a) yes *	d) no statement	4	1	2	7
Sleeman (2018)	b) somewhat representative of the average exposure in the community *	a) drawn from the same community as the exposed cohort *	a) secure record (eg surgical records) *	a) yes *	c) study controls for age and additional factors **	b) record linkage *	a) yes *	a) complete follow up - all subjects accounted for *	4	2	3	9
Stephens (2014)	b) somewhat representative of the	a) drawn from the same community as the exposed cohort *	a) secure record (eg surgical records) *	a) yes *	c) study controls for age and additional factors **	b) record linkage *	a) yes *	a) complete follow up - all	4	2	3	9

	average exposure in the community *							subjects accounted for *				
Wiener (2014)	a) truly representative of the average exposure in the community *	a) drawn from the same community as the exposed cohort *	a) secure record (eg surgical records) *	a) yes *	c) study controls for age and additional factors **	b) record linkage *	a) yes *	d) no statement	4	2	2	8

Table S11: Newcastle-Ottawa Scale for case control studies

First author (date)	**Selection: (Max 5 stars)**				**Comparability: (Max 2 stars)**	**Outcome: (Max 3 stars)**			**Total number of stars**			
	1) Is the case definition adequate?	**2) Representativeness of the cases**	**3) Selection of Controls**	**4) Definition of Controls**	**1) Comparability of cases and controls on the basis of the design or analysis**	**1) Ascertainment of exposure**	**2) Same method of ascertainment for cases and controls**	**3) Non-Response rate**	**Selection**	**Comparability**	**Outcome**	**Total**
McCormick (2001)	a) yes, with independent validation *	a) consecutive or obviously representative series of cases*	a) community controls *	a) no history of disease (endpoint) *	c) study controls for most important factor and any additional factor **	a) secure record (eg surgical records) *	a) yes *	a) same rate for both groups *	4	1	3	8
Chen (2017)	a) yes, with independent validation *	a) consecutive or obviously representative series of cases *	a) community controls *	a) no history of disease (endpoint) *	b) study controls for any additional factor *	a) secure record (eg surgical records) *	a) yes *	a) same rate for both groups *	4	1	3	8

Table S12: Newcastle-Ottawa Scale for cross-sectional studies

First author (date)	**Selection: (Max 5 stars)**				**Comparability: (Max 2 stars)**	**Outcome: (Max 3 stars)**		**Total number of stars**			
	1) Representativeness of the sample	**2) Sample size**	**3) Non-respondents**	**4) Ascertainment of the exposure (risk factor)**	**1) The subjects in different outcome groups are comparable, based on the study design or analysis.**	**1) Assessment of the outcome**	**2) Statistical test**	**Selection**	**Comparability**	**Outcome**	**Total**
de Sousa Barreto (2013)	a) Truly representative of the average in the target population. * (all subjects or random sampling)	b) Not justified.	a) Comparability between respondents and non-respondents characteristics is established, and the response rate is satisfactory. *	b) Non-validated measurement tool, but the tool is available or described.*	c) The study controls for the most important factor and additional factors **	a) Independent blind assessment. *	a) The statistical test used to analyse the data is clearly described and appropriate, and the measurement of the association is presented, including confidence intervals and the probability level (p value). *	3	2	2	7
Dyer (2018)	b) Somewhat representative of the average in the target population. * (nonrandom sampling)	a) Justified and satisfactory. *	c) No description of the response rate or the characteristics of the responders and the non-responders.	b) Non-validated measurement tool, but the tool is available or described.*	c) The study controls for the most important factor and additional factors **	b) Record linkage. *	a) The statistical test used to analyse the data is clearly described and appropriate, and the measurement of the association is presented, including confidence intervals and the probability level (p value). *	3	2	2	7
Mamhidir (2012)	a) Truly representative of the average in the target population. * (all subjects or random sampling)	b) Not justified.	b) The response rate is unsatisfactory, or the comparability between respondents and non-respondents is unsatisfactory.	b) Non-validated measurement tool, but the tool is available or described.*	d) The study does not control for main or other factor	d) No description.	a) The statistical test used to analyse the data is clearly described and appropriate, and the measurement of the association is presented, including confidence intervals and the probability level (p value). *	2	0	0	2
Nakashima (2017)	a) Truly representative of the average in the target population. * (all subjects or random sampling)	b) Not justified.	a) Comparability between respondents and non-respondents characteristics is established, and the response rate is satisfactory. *	a) Validated measurement tool. **	c) The study controls for the most important factor and additional factors **	b) Record linkage. *	a) The statistical test used to analyse the data is clearly described and appropriate, and the measurement of the association is presented, including confidence intervals and the probability level (p value). *	4	2	2	8
Stephens (2012)	b) Somewhat representative of the average in the target population. * (nonrandom sampling)	b) Not justified.	b) The response rate is unsatisfactory, or the comparability between respondents and non-respondents is unsatisfactory.	a) Validated measurement tool. **	c) The study controls for the most important factor and additional factors **	b) Record linkage. *	a) The statistical test used to analyse the data is clearly described and appropriate, and the measurement of the association is presented, including confidence intervals and the probability level (p value). *	3	2	2	7
Di Giulio (2019)	c) Selected group of users.	b) Not justified.	b) The response rate is unsatisfactory, or the comparability between respondents and non-respondents is unsatisfactory.	a) Validated measurement tool. **	b) The study control for any additional factor *	a) Independent blind assessment. *	a) The statistical test used to analyse the data is clearly described and appropriate, and the measurement of the association is presented, including confidence intervals and the probability level (p value). *	2	1	2	5
Volicer (2003)	c) Selected group of users.	b) Not justified.	b) The response rate is unsatisfactory, or the comparability between respondents and non-respondents is unsatisfactory.	b) Non-validated measurement tool, but the tool is available or described.*	d) The study does not control for main or other factor	c) Self report.	a) The statistical test used to analyse the data is clearly described and appropriate, and the measurement of the association is presented, including confidence intervals and the probability level (p value). *	1	0	1	2

Table S13: Risk of Bias (ROB 2)

First author (date)	**Design**	**Randomisation process**	**Deviations from the intended interventions**	**Missing outcomes**	**Measurement of the outcome**	**Selection of reported results**	**Overall bias**
Agar (2017)	Clustered RCT	Some concerns	Low risk of bias	Low risk of bias	Low risk of bias	Some concerns	Some concerns

Table S14: Risk of Bias in Non-Randomised Studies of Interventions (ROBINS-I)

First author (date)	**Bias due to confounding**	**Bias in selection of participants into the study**	**Bias in classification of interventions**	**Bias due to deviations from intended interventions**	**Bias due to missing data**	**Bias in measurement of outcomes**	**Bias in selection of the reported result**	**Overall bias**
Hullick (2016)	Moderate	Low	Low	No information	No information	Low	Low	Moderate risk of bias

A7 – Tables S15-17: High, moderate, and low strength evidence for individual-related, illness-related, and environmental factors

Table S15: High, moderate, and low strength evidence for individual factors

Factors	Reference	Measure of effect* (and variance if available)	Quality score	Direction of effect	Consistency†
High strength evidence					
Ethnicity (Ethnic minority groups; ref = White)	Feng$^{(NH)}$	2.161 p<0.05	High (9)	↑	100% (4/4)
	Feng$^{(Com)}$	1.378	High (9)		
	Sleeman	1.07 (0.95, 1.19) p=0.255‡	High (9)		
	LaMantia	1.13 (1.03, 1.24) p=0.0104§	High (8)		
Socioeconomic position (highest level of income, ref lowest; or most affluent, ref most deprived)	Feng$^{(NH)}$	0.786	High (9)	↓	100% (4/4)
	Feng$^{(Com)}$	0.985	High (9)		
	Sleeman	0.79 (0.69, 0.91) p=0.001‡	High (9)		
	Mondor	0.93 (0.87, 1.00) p=0.035§ (rev)	High (9)		
Moderate strength evidence					
Gender (Women)	Amador	0.661 (0.385-1.135) p=0.133	High (9)	↓	57% (4/7)
	Feng$^{(NH)}$	0.546 p<0.05	High (9)		
	Sleeman	0.86 (0.80, 0.91) p<0.001‡ (rev)	High (9)		
	Rosenwax	0.86 (0.81, 0.86) p<0.001§ (rev)	High (7)		
	Feng$^{(Com)}$	1.436 p<0.01	High (9)	↑	43% (3/7)
	Mondor	1.06 (1.01 – 1.11) p=0.011§	High (9)		
	LaMantia	1.05 (0.95, 1.15) p=0.3610§	High (9)		
Low strength evidence					
Age (with each year of age; or oldest age group)	Feng$^{(NH)}$	0.465	High (9)	↓	42.87% (3/7)
	LaMantia	0.98 (0.98, 0.99), p<0.0001§	High (8)		
	Rosenwax	0.71 (0.55, 0.89) p=0.003§	High (7)		
	Amador	1.067 (0.997, 1.142) p=0.060	High (9)	↑	28.58% (2/7)
	Feng$^{(Com)}$	1.456	High (9)		
	Mondor	1.00 (1.00–1.00) p=0.453§	High (9)	↔	28.58% (2/7)
	Sleeman	1.00 (0.99, 1.00) p=0.208‡	High (9)		
Education, <12yrs education (ref = >12yrs education)	Feng$^{(NH)}$	1.277	High (9)	↑	
	Feng$^{(Com)}$	0.881	High (9)	↓	
Insurance status (ref = Medicare only)					
Dual eligibility	Feng$^{(NH)}$	1.035	High (9)	↑	
	Feng$^{(Com)}$	1.209	High (9)		
Supplemental cover	Feng$^{(NH)}$	1.608	High (9)	↑	
	Feng$^{(Com)}$	0.920	High (9)	↓	

*Adjusted odds ratio unless otherwise specified. †Proportion of moderate-high quality studies pointing in same direction / total moderate-high studies measuring same factor. ‡Incident rate ratio. §sub-/Hazard ratio. (rev) = Direction reversed for consistency. (NH) = Nursing Home residents. (Com) = Community residents.

Table S16: High, moderate, and low strength evidence for clinical factors

Factors	Reference	Measure of effect* (and variance if available)	Quality score	Direction of effect	Consistency†
High strength evidence					
Previous hospital transfers (increasing number; or highest number)	Mondor$^{(Hosp)}$	1.04 (0.98, 1.11) p=0.203§	High (9)	↑	100% (4/4)
	Mondor$^{(ED)}$	1.94 (1.85, 2.04) p<0.001§	High (9)		
	LaMantia$^{(Hosp)}$	1.29 (1.24, 1.35), p<0.0001§	High (8)		
	Rosenwax$^{(ED)}$	1.12 (1.07, 1.16) p<0.001§	High (7)		
Comorbidities (with increasing number; or highest number)	Amador	1.207 (0.879 – 1.655) p=0.245	High (9)	↑	80% (4/5)
	Feng$^{(NH)}$	1.336	High (9)		
	Mondor	1.63 (1.51 – 1.77) p<0.001§	High (9)		
	LaMantia	1.12 (1.09, 1.15), p<0.0001§	High (8)		
	Mamhidir	*0.96 (0.43, 2.16), p=0.93‖*	*Low (2)*		
	Feng$^{(Com)}$	0.891	High (9)	↓	20% (1/5)
	Feng$^{(NH)}$	1.037	High (9)	↑	100% (3/3)
	Feng$^{(Com)}$	1.167	High (9)		

Neuropsychiatric symptoms (depressive / psychiatric)	Sleeman	1.12 (1.01, 1.24) p=0.030‡	High (9)	
	Mamhidir	*0.62 (0.27, 1.40) p = 0.248‖*	*Low (2)*	↓
Low strength evidence				
Comorbidities (specific)				
Heart problems /HF	Feng$^{(NH)}$	1.331	High (9)	↑
	Feng$^{(Com)}$	1.193	High (9)	
	Mamhidir	*1.52 (0.84, 2.75), p = 0.167‖*	*Low (2)*	
Cancer	Feng$^{(NH)}$	1.256	High (9)	↑
	Rosenwax	1.66 (1.49, 1.83), p<0.001§	High (7)	
	Feng$^{(Com)}$	0.767	High (9)	↓
Lung disease/COPD	Feng$^{(NH)}$	0.576	High (9)	↓
	Feng$^{(Com)}$	1.410	High (9)	↑
	Rosenwax	1.51 (1.33, 1.71) p<0.001§	High (7)	
Diabetes	Feng$^{(NH)}$	0.897	High (9)	↓
	Feng$^{(Com)}$	1.449	High (9)	↑
Stroke	Feng$^{(NH)}$	0.603	High (9)	↓
	Feng$^{(Com)}$	1.190	High (9)	↑
Arthritis	Feng$^{(NH)}$	0.533	High (9)	↓
	Feng$^{(Com)}$	1.258	High (9)	↑
Poor self-rated health	Feng$^{(NH)}$	1.192	High (9)	↑
	Feng$^{(Com)}$	0.907	High (9)	↓
Hypertension	Rosenwax	2.63 (2.00, 3.45) p<0.001§	High (7)	↑
Peptic ulcer disease	Rosenwax	1.62 (1.36, 1.92) p<0.001§	High (7)	↑
ADL limitations (number or mean ADL score)	Feng$^{(NH)}$	0.841 p<0.05	High (9)	↓
	Feng$^{(Com)}$	0.953	High (9)	
	Mamhidir	*ED = 10.96±5.3, No ED = 9.56±5.1*	*Low (2)*	↑
CI severity (with poorer CI score; or mean CI score)	Sleeman	0.99 (0.99, 1.00) p=0.021$^{(rev)}$ ‡	High (9)	↓
	LaMantia	1.05 (0.87, 1.27) p=0.6165§	High (8)	↑
	Mamhidir	*ED = 4.45±1.3, No ED = 4.27±1.2*	*Low (2)*	↔
Dementia subtype (vascular, ref=AD; or not specified)	Sleeman	1.16 (1.07, 1.26) p<0.001‡	High (9)	↑
	Rosenwax	1.08 (0.98, 1.19) p=0.105§	High (7)	
	McCormick	Alzheimer's = 0.5, Other dementia = 0.4**	High (8)	↔
Undiagnosed dementia (ref=formal diagnosis)	de Souto Barreto	1.22 (0.95, 1.57) p=0.11	High (7)	↑
Pain (ref = no pain)	Hunt	0.87 (0.64, 1.17)‡	High (9)	↓
	Mamhidir	*0.61 (0.29, 1.25) p = 0.18‖*	*Low (2)*	
Unmet pain need	Hunt	1.46 (1.07, 1.99), p<0.05‡	High (9)	↑
DNHO (no DNHO)	Nakashima	1.20 (0.9, 1.59) p= 0.21	High (8)	↑
DNR (no DNR)	LaMantia	0.91 (0.82, 1.00), p=0.0488§	High (8)	↓
Disease severity				
MDS-HIS score	Mondor	2.36 (2.13–2.62) p<0.001§	High (9)	↑
CHESS (ref=no instability)				
Low	Mondor	0.93 (0.88–0.98) p=0.011§	High (9)	↓
Moderate	Mondor	0.89 (0.83–0.96) p=0.003§	High (9)	↓
High-very high	Mondor	0.82 (0.73–0.92) p=0.001§	High (9)	↓
Medications				
Analgesia	*Mamhidir*	*0.75 (0.41, 1.38) p=0.35‖*	*Low (2)*	↓
Neuroleptics	*Mamhidir*	*0.81 (0.39, 1.66) p=0.57‖*	*Low (2)*	↓
Sedatives	*Mamhidir*	*0.58 (0.29, 1.18) p=0.13‖*	*Low (2)*	↓
Antidepressants	*Mamhidir*	*0.91 (0.49, 1.68) p=0.76‖*	*Low (2)*	↓
Hypnotics	*Mamhidir*	*0.81 (0.39, 1.66) p=0.57‖*	*Low (2)*	↓
Diuretics	*Mamhidir*	*1.03 (0.57, 1.86) p=0.92‖*	*Low (2)*	↑
Mean no. in past week	*Mamhidir*	*ED = 5.49±2.6, No ED = 6.81±9.8*	*Low (2)*	↓
BMI < 22	*Mamhidir*	*0.65 (0.35, 1.21) p = 0.17‖*	*Low (2)*	↓
Pressure ulcers	*Mamhidir*	*0.76 (0.21, 2.76) p = 0.67‖*	*Low (2)*	↓

*Adjusted odds ratio unless otherwise specified. †Proportion of moderate-high quality studies pointing in same direction / total moderate-high studies measuring same factor. ‡Incident rate ratio. §sub-/Hazard ratio. ‖Unadjusted odds ratio. **Mean ED visits. (rev) = Direction reversed for consistency. (NH) = Nursing Home residents. (Com) = Community residents. (ED) = Previous Emergency Department attendance. (Hosp) = Previous hospitalisation. CI = Cognitive Impairment. COPD = Chronic Obstructive Pulmonary Disease. ADL = Activities of Daily Living. AD = Alzheimer's Disease. DNHO = Do Not Hospitalise Order. DNR = Do Not Resuscitate. MDS-HSI = Minimum Data Set Health Status Index (higher score = greater independence). CHESS = Changes in Health and End-stage disease Signs and Symptoms (clinical instability). BMI = Body Mass Index.

Table S17: High, moderate, and low strength evidence for environmental factors

Factors	Reference	Measure of effect[*] (and variance if available)	Quality score	Direction of effect	Consistency[†]
High strength evidence					
Residential facility (dementia specialist unit; or care home; ref=own home)	Wiener	0.714 (0.564, 0.905) p<0.01	High (8)	↓	100% (4/4)
	Stephens 2012	0.72 (0.67–0.76) p<0.0001	High (7)		
	Stephens 2014	0.78 (0.75, 0.82) p<0.001[‡]	High (9)		
	Sleeman	0.81 (0.75, 0.87) p<0.001[‡]	High (9)		
Rurality (rural / remote; ref=urban)	Rosenwax	1.30 (1.07, 1.57) p=0.008[§]	High (7)	↑	75% (3/4)
	Feng(Com)	1.567 p<0.001(rev)	High (9)		
	Mondor	1.18 (1.12-1.25) p<0.001[§]	High (9)		
	Feng(NH)	0.987(rev)	High (9)	↓	25% (1/4)
Marital status (unmarried / widowed[‡‡]/ unpartnered; ref = married)	Feng(Com)	0.861	High (9)	↓	75% (3/4)
	Mondor	0.95 (0.90, 0.99) p=0.021[§]	High (9)		
	Rosenwax	0.90 (0.83, 1.0) p=0.001(rev) [§]	High (7)		
	Feng(NH)	1.332	High (9)	↑	25% (1/4)
Moderate strength evidence					
Palliative care input	Miller(NH)	Early PCC: -11.9% (-20.7%, -3.1%)[††]	High (7)	↓	100% (3/3)
	Rosenwax(Com)	PCC: 0.149 (0.104, 0.212) (rev) [§]	High (7)		
	Agar(NH)	FCC: 0.95 (0.29,3.12) p=0.934[‖]	Some concerns		
Low strength evidence					
Length of residence (number of years)	LaMantia	1.02 (0.97, 1.08), p=0.4642[§]	High (8)	↑	
	Amador	0.965 (0.735, 1.266) p=0.796	High (9)	↓	
Route into residence (ref = own home)	Amador	Relative's home: 0.092 (0.017-0.493) p=0.005	High (9)	↓	
	Amador	Hospital: 0.556 (0.136-2.283) p=0.416	High (9)	↓	
	Amador	Other care home: 0.284 (0.063-1.277) p=0.101	High (9)	↓	
	Amador	Sheltered / warden controlled: 1.055 (0.349-3.186) p=0.925	High (9)	↑	
Clustered domestic model	Dyer	0.27 (0.14 – 0.53), p<0.001[‡]	High (7)	↓	
Months since last contact with MH professional	Sleeman	0.99 (0.98, 0.99) p<.001[‡]	High (9)	↓	
Staff training	Di Guilo	0.22 (0.05, 1.04) p= 0.057[‖]	Medium (5)	↓	
No. of GP contacts	Amador	1.170 (1.012, 1.351), p=0.034	High (9)	↑	
No. of DN contacts	Amador	1.003 (0.926, 1.086), p=0.943	High (9)	↑	
Low continuity of care (ref = high>moderate)	Mondor	1.03 (0.99, 1.07), p=0.159[§]	High (9)	↑	
Pre-/post-ACE service	Hullick	1.17, p=0.56	Medium (5)	↑	
Home care (ref=NH)	Mitchell	1.17 (0.81, 1.68) p=0.387[‖]	High (9)	↑	
Discussions about: *Resuscitation*	Volicer	Discussed =0.83 ±1.59, Not discussed = 1.39 ±1.94, p<0.1[**]	Medium (5)	↓	
ITU	Volicer	Discussed = 1.65 ±2.54, Not discussed = 0.95 ±1.49, p<0.1[**]	Medium (5)	↑	
Ventilation	Volicer	Discussed = 1.52 ±2.29, Not discussed = 0.87 ± 1.41, p<0.05[**]	Medium (5)	↑	
Hospital transfer	Volicer	Discussed = 1.43 ±2.39, Not discussed = 0.93 ±1.36[**]	Medium (5)	↑	
Tube feeding	Volicer	Discussed = 1.13 ±2.14, Not discussed = 1.07 ±1.48[**]	Medium (5)	↑	
IV therapy	Volicer	Discussed = 1.17 ±2.17, Not discussed = 1.05 ±1.45[**]	Medium (5)	↑	
Antibiotics	Volicer	Discussed = 1.11 ±2.09, Not discussed = 1.08 ±1.43[**]	Medium (5)	↑	

[*] Adjusted odds ratio unless otherwise specified. [†] Proportion of moderate-high quality studies pointing in same direction / total moderate-high studies measuring same factor. [‡] Incident rate ratio. [§] sub-/Hazard ratio. [‖] Unadjusted odds ratio. **mean and standard deviations. [††] Individual Rate Difference. [‡‡] most prevalent unmarried category; never married (0.87; 0.78,0.96; p=0.005) and divorced (0.93; 0.86,1.02; p=0.121). (rev) = Direction reversed for consistency. (NH) = Nursing Home; (Com) = Community residents. GP = General Practitioner. DN = District Nurse. ACE = Aged Care Emergency service. MH = Mental Health. PCC = Palliative Care consultations. FCC = Family case conferencing.

A8 – Tables S18-20: Sensitivity analysis of high and moderate strength evidence for individual-related, illness-related, and environmental factors

Table S18: Sensitivity analysis of high and moderate strength evidence for individual factors

Factors	Reference	Measure of effect[*] (and variance if available)	Quality score	Direction of effect	Consistency[†]
Low strength evidence					
Ethnicity (Ethnic minority groups; ref = White)	Feng(NH)	2.161 p<0.05	High (9)	↑	50% (2/4)
	LaMantia	1.13 (1.03, 1.24), p=0.0104[§]	High (8)		
	Sleeman	1.07 (0.95, 1.19) p=0.255[‡]	High (9)	No effect	
	Feng(Com)	1.378	High (9)		
Socioeconomic deprivation (highest level of income, ref lowest; or lowest level of deprivation, ref highest)	Mondor	0.93 (0.87, 1.00) p=0.035(rev) [§]	High (9)	↓	50% (2/4)
	Sleeman	0.79 (0.69, 0.91) p=0.001[‡]	High (9)		
	Feng(Com)	0.985	High (9)	No effect	
	Feng(NH)	0.786	High (9)		
Gender (Women)	Feng(NH)	0.546 p<0.05	High (9)	↓	43% (3/7)
	Sleeman	0.86 (0.80, 0.91) p<0.001(rev) [‡]	High (9)		
	Rosenwax	0.86 (0.81, 0.86) p<0.001(rev) [§]	High (9)		
	Feng(Com)	1.436 p<0.01	High (7)	↑	29% (2/7)
	Mondor	1.06 (1.01 – 1.11) p=0.011[§]	High (9)		
	LaMantia	1.05 (0.95, 1.15) p=0.3610[§]	High (9)	No effect	
	Amador	0.661 (0.385-1.135) p=0.133	High (9)		
Age (with each year of age; or oldest age group)	LaMantia	0.98 (0.98, 0.99), p<0.0001[§]	High (8)	↓	29% (2/7)
	Rosenwax	0.71 (0.55, 0.89) p=0.003[§]	High (7)		
	Feng(NH)	0.465	High (9)	No effect	
	Feng(Com)	1.456	High (9)		
	Amador	1.067 (0.997, 1.142) p=0.060	High (9)		
	Mondor	1.00 (1.00–1.00) p=0.453[§]	High (9)		
	Sleeman	1.00 (0.99, 1.00) p=0.208[‡]	High (9)		

[*] Adjusted odds ratio unless otherwise specified. [†] Proportion of moderate-high quality studies pointing in same direction / total moderate-high studies measuring same factor. [‡] Incident rate ratio. [§] sub-/Hazard ratio. (rev) = Direction reversed for consistency. (NH) = Nursing Home residents. (Com) = Community residents.

Table S19: Sensitivity analysis of high and moderate strength evidence for clinical factors

Factors	**Reference**	**Measure of effect[*] (and variance if available)**	**Quality score**	**Direction of effect**	**Consistency[†]**
High strength evidence					
Previous hospital transfers (increasing number; or highest number)	LaMantia	1.29 (1.24, 1.35), p<0.0001[§]	High (8)	↑	75% (3/4)
	Mondor$^{(ED)}$	1.94 (1.85, 2.04) p<0.001[§]	High (9)		
	Rosenwax$^{(ED)}$	1.12 (1.07, 1.16) p<0.001[§]	High (7)		
	Mondor$^{(Hosp)}$	1.04 (0.98, 1.11) p=0.203[§]	High (9)	No effect	
Low strength evidence					
Comorbidities (with increasing number; or highest number)	Mondor	1.63 (1.51 – 1.77) p<0.001[§]	High (9)	↑	33% (2/6)
	LaMantia	1.12 (1.09, 1.15), p<0.0001[§]	High (8)		
	Mamhidir	*0.96 (0.43, 2.16), p=0.93[‖]*	*Low (2)*	No effect	
	Amador	1.207 (0.879 – 1.655) p=0.245	High (9)		
	Feng$^{(NH)}$	1.336	High (9)		
	Feng$^{(Com)}$	0.891	High (9)		
Neuropsychiatric symptoms (depressive / psychiatric)	Sleeman	1.12 (1.01, 1.24) p=0.030[‡]	High (9)	↑	33% (1/3)
	Feng$^{(NH)}$	1.037	High (9)	No effect	
	Feng$^{(Com)}$	1.167	High (9)		
	Mamhidir	*0.62 (0.27, 1.40) p = 0.248[‖]*	*Low (2)*		

[*] Adjusted odds ratio unless otherwise specified. [†] Proportion of moderate-high quality studies pointing in same direction / total moderate-high studies measuring same factor. [‡] Incident rate ratio. [§] sub-/Hazard ratio. [‖] Unadjusted odds ratio. (rev) = Direction reversed for consistency. (NH) = Nursing Home residents. (Com) = Community residents. (ED) = Previous Emergency Department attendance. (Hosp) = Previous hospitalisation. CI = Cognitive Impairment.

Table S20: Sensitivity analysis of high and moderate strength evidence for environmental factors

Factors	**Reference**	**Measure of effect[*] (and variance if available)**	**Quality score**	**Direction of effect**	**Consistency[†]**
High strength evidence					
Rurality (rural / remote; ref=urban)	Rosenwax	1.30 (1.07, 1.57) p=0.008[§]	High (7)	↑	75% (3/4)
	Feng$^{(Com)}$	1.567 p<0.001$^{(rev)}$	High (9)		
	Mondor	1.18 (1.12-1.25) p<0.001[§]	High (9)		
	Feng$^{(NH)}$	0.987$^{(rev)}$	High (9)	No effect	
Residential facility (dementia specialist unit; or care home; ref = own home)	Wiener	0.714 (0.564, 0.905) p<0.01	High (8)	↓	100% (4/4)
	Stephens 2012	0.72 (0.67–0.76) p<0.0001	High (7)		
	Sleeman	0.81 (0.75, 0.87) p<.001[‡]	High (9)		
	Stephens 2014	0.78 (0.75–0.82) p<0.001[‡]	High (9)		
Low strength evidence					
Marital status (unmarried / widowed[††]/ unpartnered; ref = married)	Mondor	0.95 (0.90, 0.99) p=0.021[§]	High (9)	↓	50% (2/4)
	Rosenwax	0.90 (0.83, 1.0) p=0.001$^{(rev)}$ [§]	High (7)		
	Feng$^{(Com)}$	0.861	High (9)	No effect	
	Feng$^{(NH)}$	1.332	High (9)		
Palliative care input	Miller$^{(NH)}$	Early PCC: -11.9% (-20.7%, -3.1%)[**]	High (7)	No effect	
	Rosenwax$^{(Com)}$	PCC: 0.14 (0.10, 0.21) $^{(rev)}$ [§]	High (7)		
	Agar$^{(NH)}$	FCC: 0.95 (0.29,3.12) p=0.934[‖]	Some concerns		

[*] Adjusted odds ratio unless otherwise specified. [†] Proportion of moderate-high quality studies pointing in same direction / total moderate-high studies measuring same factor. [‡] Incident rate ratio. [§] sub-/Hazard ratio. [‖] Unadjusted odds ratio. [**] Individual Rate Difference. [††] most prevalent unmarried category; never married (0.87; 0.78,0.96; p=0.005) and divorced (0.93; 0.86,1.02; p=0.121). (rev) = Direction reversed for consistency. (NH) = Nursing Home residents. (Com) = Community residents.

Appendix B: Community engagement

B1: Co-produced diagram of the quality end-of-life for people with dementia needing the emergency department

Figure B1: Issues considered to be influential to quality end-of-life for people with dementia who attend the emergency department

B2: Expert panel impact log

YOU SAID, WE DID: How your contributions have influenced the project

YOU SAID:

A&E staff must respectfully review people with dementia without assumptions.

WE DID:

- The report from the interview study discussed the feedback from people with dementia about how the experience within A&E could be improved. This included clear signage and quiet zones, improved communication from staff that is respectfully sensitive to the needs of individuals with dementia, reduced time to assessment, consideration of community-based investigations to avoid admission where possible and being accompanied by a family caregiver or familiar other. The report stated that fundamentally, people with dementia should be taken as individuals and treated without assumption.
- Study findings will be shared with the Alzheimer’s Society and the Royal College of Emergency Medicine when published.

YOU SAID:

Advocacy is vital to ensure people with dementia receive quality care.

WE DID:

- The report from the interview study discussed how people with dementia and family caregivers are sometimes not heard by staff. The report advocated the value of advocates to help mitigate this. The report suggested there may be a role for Admiral Nurses to fulfil this advocacy role, based on previous literature.
- Study findings will be shared with the Dementia UK when published.
- The thesis includes potential solutions for further research – one of these solutions is the availability of advocates for people with dementia and family caregivers.

YOU SAID:

People from minority ethnic backgrounds have no voice in the health and social care system, where language barriers and bias can influence care.

WE DID:

- We discussed this issue in the big data paper, highlighting an urgent need for resources to support end-of-life care discussions with people from South Asian communities and provision of accessible, culturally sensitive end-of-life dementia care.
- These details will be shared with the Alzheimer’s Society and Race Equality Foundation and promoted on social media once the big data paper is published.
- In the interview study paper, we discussed how people from minoritised ethnic groups are underserved by healthcare, experience barriers to accessing community support, and are more likely to use the ED, particularly towards the end of life. We advocated that research must specifically engage with people from minoritised ethnic groups to enable meaningful representation in research, as their unique experiences will be essential to future service planning.

- The discussion chapter of the thesis will cover the differences found in end-of-life A&E attendances between different ethnic groups.

YOU SAID:

The public must be educated to better understand dementia and why it needs to be a priority.

WE DID:

- The report from the interview study discussed how dementia is a source of disadvantage in the system, that it is not prioritised and is therefore treated differently in the health and social care system. The report concluded that until there is parity of esteem between dementia and other conditions, people with dementia will continue to experience barriers to accessing community services and will be more likely to attend A&E towards the end of life.
- Study findings will be shared with the Alzheimer's Society when published.

YOU SAID:

Stigma related to dementia remains strong and persistent.

WE DID:

- The interview study focused on stigma and emphasised that without due parity of esteem between dementia and other conditions, people with continue to be disadvantaged within the health and social care system.
- The conceptual model of ED attendance among people with dementia towards the end of life includes the impact of societal stigma and how current campaigns (e.g., Dementia Friendly) have potential to be counterproductive.
- Findings will be shared with the Alzheimer's Society.

YOU SAID:

General feedback from first two meetings, including points on advocacy, stigma and improving the A&E experience.

WE DID

- Incorporated into interview study which has been written up and submitted for consideration of publication.
- Paper includes personal acknowledgement to you all for your contributions.
- Thesis will include personal acknowledgement to you all for your contributions.

YOU SAID:

Advised change of language for model of predisposing, reinforcing, and enabling factors – avoid 'enabling' / 'disabling'; suggested change to 'empowered' / 'not empowered'

WE DID

- Incorporated into the conceptual model of ED attendance among people with dementia approaching the end of life.
- Incorporated into the discussion of thesis findings and implications for policy, practice, and future research

B3: Expert panel meeting notes

The following pages include anonymised minutes taken from public representative meetings for what had been branded the ‘EDDEL project’ for the purpose of public representative involvement (EDDEL: Emergency Department attendance among people with Dementia approaching the End of Life). There were four project meetings (three scheduled meetings plus one repeat for representatives who could not attend the third meeting).

EDDEL Project: Meeting one notes (anonymised)

Tuesday 02 August, 10.00am-11.00am

Key discussion points	
Allowing people with dementia to be accompanied into hospital	
	Relatives can update clinical staff on important information such as allergy status, which person with dementia may have forgotten to detail to staff – own experience led to allergic reaction to dressing, which could have been avoided.
	Relatives can assist in communicating with clinicians, especially for people from South Asian and other ethnic minority backgrounds, where there are language differences. Communication is a significant barrier for people from ethnic minority backgrounds.
	Relatives can help to keep people with dementia calm to help avoid unnecessary medication for agitation, which can have detrimental consequences and mask underlying problem (i.e., antipsychotics for agitation, causing catatonia, resulting in admission to dementia unit).
	People with dementia are often prevented to have someone with them, whereas (younger) people who have more visible / physical difficulties are allowed to have someone with them – dementia not taken seriously.
Environment	
	Crowded and noisy; bus stop in corridor does not make the environment ‘dementia friendly’.
	Overstimulation in ED can be particularly distressing with some types of dementia.
Stigma and limited understanding of dementia	
	While an inpatient, had to physically support a patient with dementia to drink water, as staff had simply left it on table and instructed them to drink it.
	It is a combination of stigma and lack of understanding among staff, a lack of training. There is lot of focus on preventing dementia, but we need to recognise the stigma. There is lack of understanding of what dementia is – people still assume it is just about memory loss, but it is so much more than that.
	In receipt of life-long post-diagnostic support due to type of dementia, so clinicians are learning from each consultation.
	Have started giving talks to first- and second-year university students, as part of their mandatory training. Students have fed back that they learnt more about dementia in one hour than what they read in textbooks. This should be integrated more.
	Need to be mindful that when in ED, there are different pathways for different categories of patients. Dementia can lead to other things such as dehydration. There needs to be training to help clinicians to identify needs. ED largely staffed by junior doctors, who do not always get enough training in dementia, so a lot more needs to be done.
Limited clinical knowledge among people responsible for care	
	Used to work in a care home; notes are very basic. Person designated to look after someone is usually a personal carer, so no clinical expertise. Often there is one registered nurse for the entire home. If there is a problem, they call the ambulance, and the resident is passed onto the paramedics; staff are no longer concerned because the resident is someone else’s responsibility. Staff will not physically check to see how much the resident is deteriorating. Post-covid, residents can wait up to 14-17hours.

	Carer came in to assist friend and accidentally gave overdose of antipsychotic medication. Friend was taken into hospital but died in hospital. Could have been avoided.
Systemic pressures	
	It should not matter if service is understaffed, or under-resourced, because they are sending out a message that the service is there for people, but it is not.
	It is about basic care – you are entitled to basic care and dignity, whether they service is understaffed or not.
	Cannot blame care workers because they are run off their feet, massively understaffed and are underpaid, so those who want to care cannot afford to care most of the time. There are some great staff, but reality comes down to resources. Empathetic staff cannot afford to work.
Lack of continuity	
	Have different doctors each time and do not have a CPN anymore – CPNs are now only available for people in crisis but they should be available to offer continuity of care and avoid getting to crisis point.
Poor communication and integration between services	
	All comes back to communication. Needs to start with place-based integrated community care; there is no communication with GPs, hospitals, or care homes.
	National database does not hold data in a central database – there is no sharing of important information.
	In Scotland, meant to have partnership between local authority, care and health service, but health service will not share medical record even if relevant and local authority will not share care record. Currently plans for National Care Service, which is due to be fully implemented by 2025 – calls for greater integration of hospital, community, and primary care services, but dubious how successful a roll-out across the country will be, since it is not working well at the local level.
	No communication from hospital to care home. Can call for an update of what has happened, and care home staff say they do not know because the hospital has not informed them.
	Care home staff explain that data protection stops them from being able to find out what happened to resident in ED, but obviously this is incorrect.
Services working to the rule	
	Experience of going to ED is frightening from care homes (without nursing), as staff send people to the ED alone. Huge difference between nursing and residential homes. For care homes without nursing staff, transferring someone to the ED comes down to administrative systems –is it just because this is what the rulebook says for that care home? What is in place to record what happened to lead the person into the ED? Who is the designated person looking after that person? Where are the notes for that person? They are difficult to get hold of.
	In London, the default is to send an ambulance, so some people who urgently need an ambulance are not getting help quick enough because paramedics must respond to all calls.
Tick boxes	
	Dementia friendly status is a joke – it is a tick-box exercise.

	A lot of it is a tick-box exercise and staff do not have a clue. Odd members of staff who are brilliant, but it is few and far between.
Being dismissed	
	Even if can accompany relative with dementia into hospital, the voice of relative with dementia and own voice are dismissed by staff – concerns are not listened to. At the end of life, had Power of Attorney but this was totally disregarded, which made it very difficult because it felt as though relative's wishes were ignored.
	Friend with dementia who is at end-of-life; family went through care plan and wishes as have Power of Attorney, but family are now being ignored. What the point is in making the plan if Power of Attorney is totally dismissed as insignificant?
	Hospital staff can be dismissive of patients with dementia – was in pain but ignored; informed staff of dietary requirements, which were completely ignored.
Fear of litigation	
	Clinicians are worried about litigation. It is in the back of the minds of all clinicians; is this patient going to sue me? This fear is stronger than knowledge and the oath they have taken – clinicians fall short in this respect.
	This is particularly the case for psychiatrists
Monitoring of service delivery	
	Do not get sense of detail because a lot of monitoring of services is based on measurement statistics and processing throughputs, so there is no clinician perspective, just data analysts' perspectives.

EDDEL Project: Meeting two notes (anonymised)

Monday 10 October, 1.00pm-2.00pm

Key discussion points	
Key issues around stigmatisation and systemic change	
	Aware that dementia comes last in order of priority within the NHS, at pre-diagnosis and post-diagnosis. Does the costing for dementia differ to the costing for other conditions? People affected by dementia do not have political leverage. We need to have clear plan and to capture the statistics and economic evaluations for a campaign to gain traction. Politicians will not look unless there are statistics. We need to look at expenditure.
	Most of the cost of treatment is outsourced. If NHS paid for the care, it would bankrupt the NHS overnight, which is why people pay for their own care. Do not feel it is necessarily the politicians who are responsible, as they do what the public allows them to do. We need public education so people understand how much dementia costs and that anyone can be diagnosed. Need to raise a lot more money, but the public need to understand the importance of dementia.
	The stigma around dementia is prevalent but uncommon in other conditions like cancer. Once one person says something, others agree, and the stigma continues. Findings are reflective of what the real-world is.
	There is an association in society between dementia and the downhill side of life. Politics reflects society, where there is a strong element of investing in the youth and looking down upon or not bothering with older adults. Agree we need to raise awareness of people of dementia and the marginalisation they experience. We must raise awareness because people need to value something personally before they will take notice of it.
	Need to break down the stigma so whenever a person with dementia does go to emergency department, they are treated with the same respect as everyone else – that no assumptions are made about what they want or need and instead to find out what support is needed. Also, not to presume everyone with dementia is the same, and not to presume that one person with dementia will be the same the next day or even later in the day.
Key issues around barriers to access	
	Still hear a lot of the same problems all the time. Wonder how we cannot get this right when we all know what the problems are. Daily stories in newspapers focusing reducing risk and the prevalence, etc., but services are still disjointed, and it is infuriating that we are no further forward.
	There are significant barriers in place for people from ethnic minority backgrounds, who cannot converse in English. They have no voice. There is a definite absence of advocacy for people.
	Barriers are in every service, language, and socioeconomic, etc., and dementia. There should be a system in the emergency department to facilitate history taking and care.
Key issues around end-of-life and advanced care planning	
	End-of-life care planning can be discussed with GP, where the plan is to remain at home and receive palliative care rather that attend the emergency department. If this is not adhered to, services can be sued.
	End-of-life care planning seems as though it would make things a lot better. End-of-life seems very matter of fact among staff, and as though not everything that could be done is done – wonder if this is the culture within the system.

	If a care package is in place, it may make the process more humane. Would give a greater sense of control for family and assurance for the person with dementia that there is someone advocating for you.
	People living in the community have had advanced care plans, but these have not always been followed as expected.
Key issues around safeguarding and advocacy	
	Lots of press coverage about younger people locked in institutions. Families not knowing where to get help when they suspect institutional abuse is problematic. Staff should be accountable. Unclear if there is a protocol of care, an agreement / charter / care memorandum agreed between institution and family, but family sometimes do not know how to register concerns.
	Adult Safeguarding team could be an option to intervene, but not everyone will know this unless they have worked in the system. The Covid-19 enquiry has just started looking at DNAR (Do-Not-Attempt-Resuscitation) forms that were given out against people’s wishes. People have said it was a form of genocide because they were getting rid of older people, deliberately.
	Sometimes even with points of contact, there may be concerns that questioning the quality of care will put a loved one at risk from staff. People with money do not necessarily have that worry in the back of their minds. There is the option to call the safeguarding team, but they are not there at the point of concern to help with situation. Need to have an advocate on site. In the emergency department, there should be an advocate for family and dementia, so if there are any concerns, the advocate can intervene objectively.
	People should not feel afraid to approach staff in case they are judged – a fear of neglect because of questioning the quality of care is a sign of corruption. We should live in a society where older people are equal to younger. Agree it is genocide to remove older people because they are ‘too costly’. Society should not give up on people just because they have dementia.
	Carers have been banned from entering care homes because they have complained or questioned care. Will change if get David’s Law, as this will automatically guarantee carers access to the care home.
	Most important thing to get right is advocacy.
	Agree that most important thing is advocacy
	Need a team dedicated to assessing the needs of people with dementia. There should be a dedicated person, so people with dementia can stay calm without any need to panic. Staff should have sympathy for people with dementia, not pointing fingers at them. The care provided under the pressures of the system is not the value of human life.
	We need a clear action plan, with detailed milestones for any campaign to be successful. We need an incremental approach. It is not an easy task, especially as there are so many competing priorities. Unless the campaign is at the political level, dementia will not compete with other priorities.

EDDEL Project: Meeting three notes (anonymised)

Monday 19 December, 2.00pm-3.00pm

Key points from discussions	
Feedback from model	
	Appreciate the link between theory and practical application in the model. It needs to be brought to the attention of policymakers; therefore, the model needs a financial element to make it more useful and relevant to policymakers. It is useful to consider that there is no contract between individuals and the state as to what can be expected – people contribute diligently but there is no agreement about what care they will receive when they need it.
	The graphic model does not show any factorial correlation; would be useful to include percentages. Cannot ignore the good things about the NHS and the social care system – we need to strike a balance. There is still a taboo around dementia and a lot of people in the age bracket of 40-50yrs have early symptoms of dementia but do not follow this up because they can be scared and assume that an assessment will not bring about any benefit. We need more awareness and education around dementia, so people are not afraid to come forward. We do not need to think about all the biases because, in general, the whole population needs it. We need more awareness so not to overlook younger people with early symptoms.
	Involved in several projects, but the EDDEL project is diverse because it includes people from a range of backgrounds, which is positive. It makes the project richer because we can learn first-hand from people who understand the barriers that others in the community can face. People from different backgrounds are not well represented in research. Agree that there needs to be greater awareness so people do not feel that they cannot ask for help.
	Other conditions take a lot of attention of policymakers. If policymakers are looking at areas of support to service the needs of the people, we need to hit policymakers with figures to demonstrate just how much dementia affects the population and the associated costs.
Sharing findings	
	Newspapers, magazines, and television advertisements
	Radio programmes in vernaculars – in trying to reach people, we cannot leave out a specific ethnic community, so we need to ask who are the beneficiaries and how can we build in-roads to make sure people of these different communities are reached and are aware.
Language used in the model	
	XX and XX have recently shared their experience for a local radio programme, presented in their first language, so it may be possible that other methods of sharing the results (i.e., in a magazine) could be translated to achieve broader reach.

	‘Enabling and disabling’ are very technical terms; some people may not understand the meaning behind them. We need to ensure we use language that people can immediately connect with. Academics use buzz words and terminologies, but it can be helpful to have words in a form that is normally understood to bridge the academic and normal level. This also helps with acceptance.
	Making things accessible is important. Culture can breakdown with differences in language. When translating something, it is not about translating words and more about translating meaning. Congratulations to XX and XX for their work on presenting information in their own language, because people who do not speak English as their first language will miss so much of the richness of information if it is only presented in English.
	Regarding the terms ‘enabled/disabled’ – some argue that we should not use these types of words because they are loaded, and people can be sensitive to them. Also, many ‘D’ words tend to be negative. We are encouraged to say ‘uniquely abled’ rather then enabled or disabled to avoid creating a divide. If want to include all people, we need to use words that do not cause division.

EDDEL Project: Meeting three notes (anonymised)

Thursday 22 December, 10.00am-11.00am

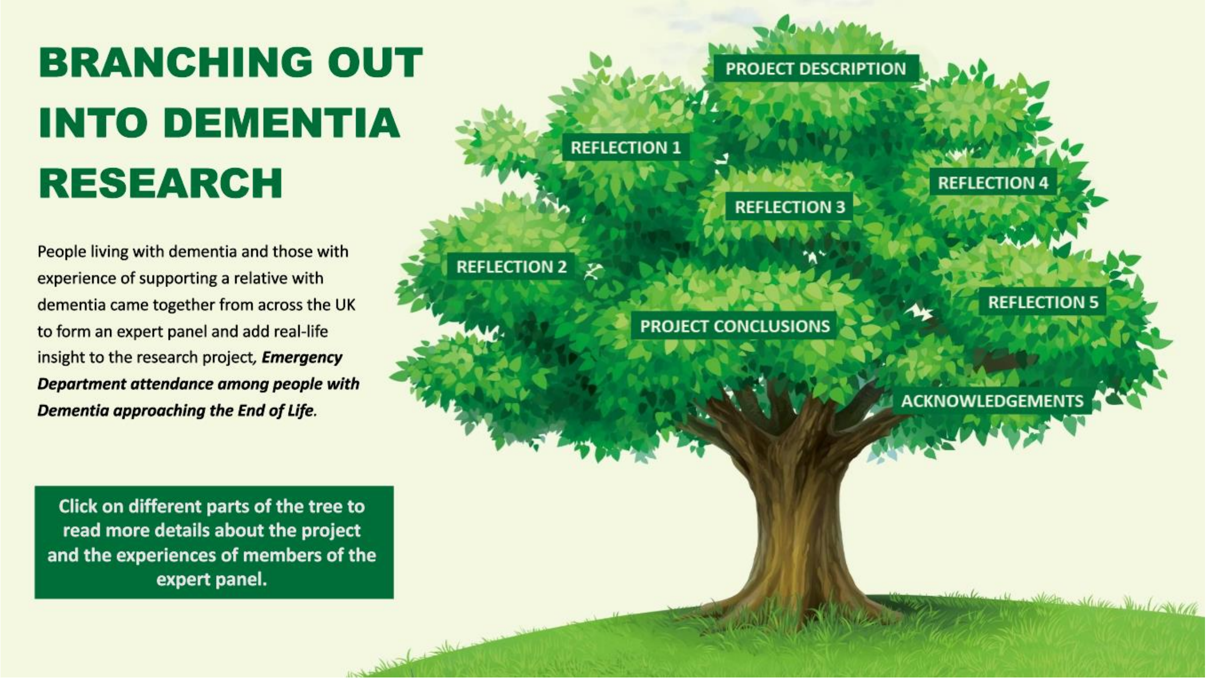
(second meeting for those who could not attend first meeting)

Key discussion points	
Dementia subtype	
	Questionable how often dementia subtype is recorded – this is as important as the rest of the characteristics.
	Dementia tends to be noted as the last in a list of underlying causes of death, but it is often the dementia that drives many of the issues. Questions if the outcomes of death certificates are influenced by the wider system.
Limited access to community services	
	Agree that people go to A&E simply because they cannot get to see their GP, or because the GP redirects people to A&E anyway – possibly to discharge responsibility because they do not have time to provide comprehensive assessment needed, despite this being a fundamental requirement of care.
	There is no community support from the GP, despite being the first point of call for people. They step out of it completely. Possibly a reflection of the wider healthcare system. Read recently that there are calls to return to more community-based care. Although GPs have merged with other services in the community, they cannot accommodate the need at that level – especially for people with dementia, where there is no support, despite there being high proportions of people with dementia who are living on their own. They rely on NHS 111, so it is not surprising that many end up in A&E.
	Charity organisations, such as Alzheimer's Society and other organisations that are affiliated to dementia, are in an ideal position to give support to people in the community but it is all dependent on funding and often services can suddenly close because the funding has been dropped.
Continuity of care	
	Continuity of care is also lacking. Although GPs must provide annual dementia reviews, these do not happen. However, these reviews would pick up on the signs of deterioration or ill-health. Currently working on a dementia strategy to be released in April 2023, which will call for holistic annual review. Good relationships with GPs when they are human and honest, and responsive to needs.
	Questionable if there is continuity of care in nursing homes because turnover of staff is so high. There is often no nurse who is always on duty when they should be. Management of nursing homes cannot state if everything is recorded. They are reliant on a team of support workers who often lack training.
Care homes and social care in general	
	Often training in nursing homes comprise mandatory basics (i.e., manual handling, fire safety, etc.), there is no routine dementia training. Where there is training, this is online and very basic covering only Alzheimer's disease and one other subtype. There is also an issue of timing for staff, as some relatives have had to attend the homes simply to feed their relative because staff do not have time.
	There are significant differences in standards, processes, and protocols between privately-run and local authority nursing homes. The former have more flexibility in their approach.

	Questionable how people can be protected and how safeguarding concerns can be investigated with different standards of care across care homes. Query if care home staff feel able to raise concerns themselves.
	Currently advising government on the need for anonymous whistleblowing and advocacy.
	The community have a different perspective of what it is like in social care. There are promotional videos showing care homes with lots of facilities but there is no time for residents to use the facilities. There needs to be more one-to-one support for people in care homes, as well as more responsive staff. Staff make assumptions that family members will be able to go to hospital with relatives, but assumptions should not be made. Questionable if we are asking too much of staff/services, but there are conflicting messages about taking responsibility for own lives when that is not always possible, and support is needed.
	Alzheimer’s Scotland are working on a project, Better Lives in Care Homes, but often find with some projects that those who are heard most are those who can shout loudest and who tend to be people with earlier stages of dementia, therefore those with more advanced stages and their caregivers who are drained do not have the capability to voice their needs, concerns, and preferences.
	The public do not appreciate the need to spend money on social care. There needs to be more public education, a reality check for the people. Even though there are news items about social care because it is only on the news, it is ‘newsworthy’ and therefore not perceived as being a normal daily occurrence. Often A&E get the blame when it is more do to with social care.
	Social care depends on empathy and people cannot be trained in empathy.
Regional variation	
	Observed in a recent report by Alzheimer’s Scotland that there are services in Scotland offering advice and guidance that are not available in Wales.
	There is a lot of variation around the country regarding post-diagnostic support. In Scotland, there is one-year post-diagnostic support but if this is declined initially, the option for support is moved. There are efforts to ensure that this is not limited to time of diagnosis but when the support is wanted by the person with dementia.
Model terminology	
	Do not like the word, ‘disabling’, as it has historical connotations of stigma.
	Maybe best to avoid using the word ‘enabling’ as well because this infers someone is disabled if not enabled.
	Suggest using ‘empowered’ and ‘not empowered’.
Dissemination of research findings	
	Keeps a list of relevant research to use in different projects – happy to receive summary of big data study and copy of policy brief.
	Helpful to identify the relevant community groups and policymakers who may be more receptive to the research findings.

B4: Public representatives' reflections (poster)

The following images are screenshots from an interactive digital poster that was developed with public representatives to detail their experiences of taking part in the expert panel.

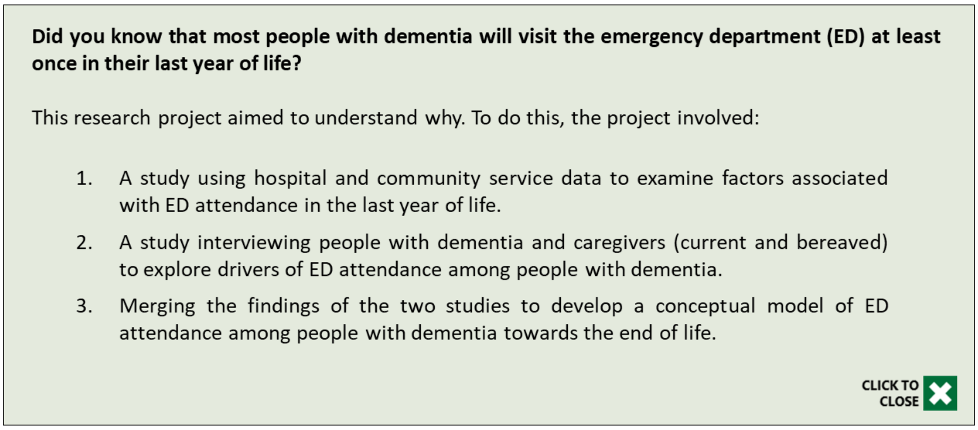


BRANCHING OUT INTO DEMENTIA RESEARCH

People living with dementia and those with experience of supporting a relative with dementia came together from across the UK to form an expert panel and add real-life insight to the research project, ***Emergency Department attendance among people with Dementia approaching the End of Life.***

Click on different parts of the tree to read more details about the project and the experiences of members of the expert panel.

Project description:

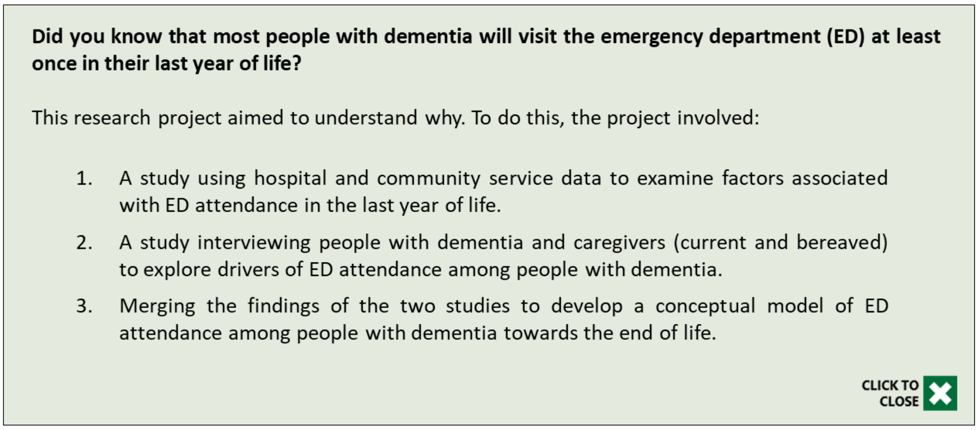


Did you know that most people with dementia will visit the emergency department (ED) at least once in their last year of life?

This research project aimed to understand why. To do this, the project involved:

1. A study using hospital and community service data to examine factors associated with ED attendance in the last year of life.
2. A study interviewing people with dementia and caregivers (current and bereaved) to explore drivers of ED attendance among people with dementia.
3. Merging the findings of the two studies to develop a conceptual model of ED attendance among people with dementia towards the end of life.

Project description:



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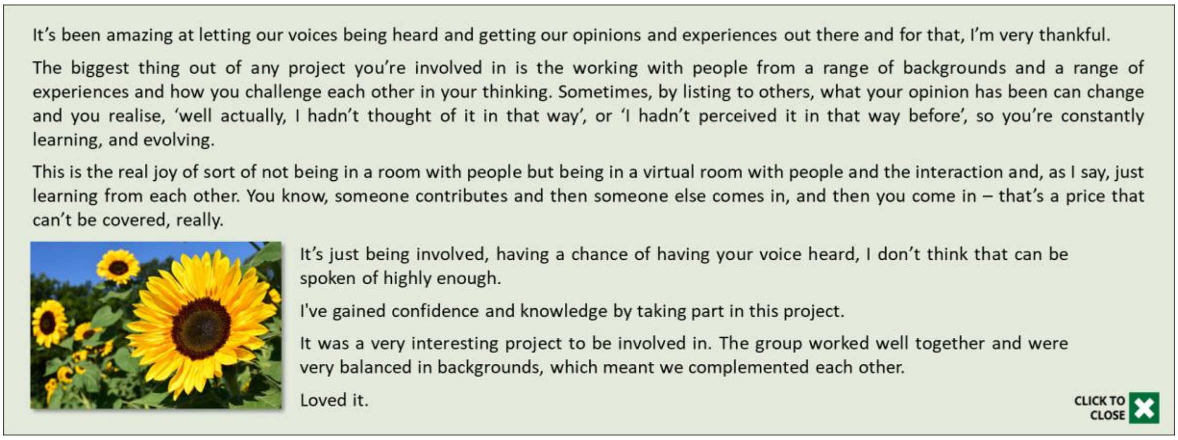
Reflection 1:



It's been amazing at letting our voices being heard and getting our opinions and experiences out there and for that, I'm very thankful.

The biggest thing out of any project you're involved in is the working with people from a range of backgrounds and a range of experiences and how you challenge each other in your thinking. Sometimes, by listing to others, what your opinion has been can change and you realise, 'well actually, I hadn't thought of it in that way', or 'I hadn't perceived it in that way before', so you're constantly learning, and evolving.

This is the real joy of sort of not being in a room with people but being in a virtual room with people and the interaction and, as I say, just learning from each other. You know, someone contributes and then someone else comes in, and then you come in – that's a price that can't be covered, really.

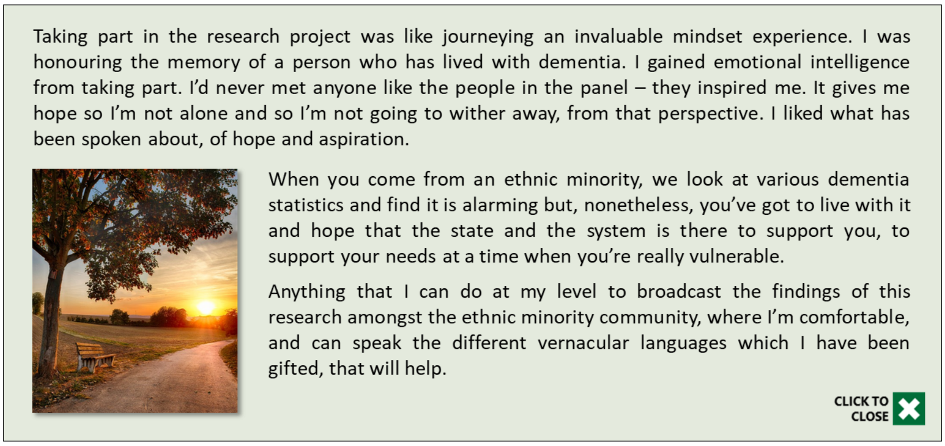
It's just being involved, having a chance of having your voice heard, I don't think that can be spoken of highly enough.

I've gained confidence and knowledge by taking part in this project.

It was a very interesting project to be involved in. The group worked well together and were very balanced in backgrounds, which meant we complemented each other.

Loved it.

Reflection 2:



Taking part in the research project was like journeying an invaluable mindset experience. I was honouring the memory of a person who has lived with dementia. I gained emotional intelligence from taking part. I'd never met anyone like the people in the panel – they inspired me. It gives me hope so I'm not alone and so I'm not going to wither away, from that perspective. I liked what has been spoken about, of hope and aspiration.

When you come from an ethnic minority, we look at various dementia statistics and find it is alarming but, nonetheless, you've got to live with it and hope that the state and the system is there to support you, to support your needs at a time when you're really vulnerable.

Anything that I can do at my level to broadcast the findings of this research amongst the ethnic minority community, where I'm comfortable, and can speak the different vernacular languages which I have been gifted, that will help.

Reflection 3:

We were a small group of diverse people coming together driven by the factor we had in common. Our lives had been affected by dementia. There were those living with the illness and those who had cared for their loved ones with dementia. We talked about how our individual experiences were shaped by varying personal, social, economic and regional circumstances. Remarkably very quickly the outstanding element at the top of our talks were our strong feelings about how people with dementia are supported while experiencing visits to ED during the latter stages of their lives. These strong emotions of the injustice, helplessness and inequality witnessed drove us to engage with the research project to send out the message that change is long overdue.

The picture accompanying my reflection is one my husband took at a time when his dementia was at a point when he needed help using his camera. Soon after he stopped using it. As such is it poignant, the image represents him as a strong large character, sturdy like this tree's trunk, expansive reflecting his varied life experiences. This tree, in winter, has lost its greenery, as Terry lost his spark. Both are at rest. Yet the branches continue to reach out to the light and warmth brought by the sun and its greenery will return. I hope that together we have contributed positively to the research project, reaching out to those who 'create and set the rules', to listen to us saying there is something seriously wrong and it needs fixing. We want to send a message that will bear fruit. Lesley's study has given us the opportunity to send this message. The findings of her study leading to the design of a model of attendance among people with dementia approaching end of life encapsulates the discussions and conclusion of our meetings perfectly.

At a personal level taking part has allowed me to take a step back from my mixed emotions and think about events from a collective perspective and in some ways it helps with my grieving process.

"A seed hidden in the heart of an apple is an orchard invisible."

— Welsh proverb

CLICK TO CLOSE ☒

Reflection 4:

I have the phrase, and I use it constantly: **Catnip to the brain** – it is like a drug to me; the more I have, the more I want. My mental faculties are working way better than they should be because of all the work I do. In a way, I'm doing it for a selfish reason because it's keeping me going, if you like.

The way I like to do things is to use songs to express how I feel, so I have picked lines out of songs that reflect my experiences on the research project:

Shout it from the rooftops -- *Sister Shout*

The times they are a changing -- *Bob Dylan*

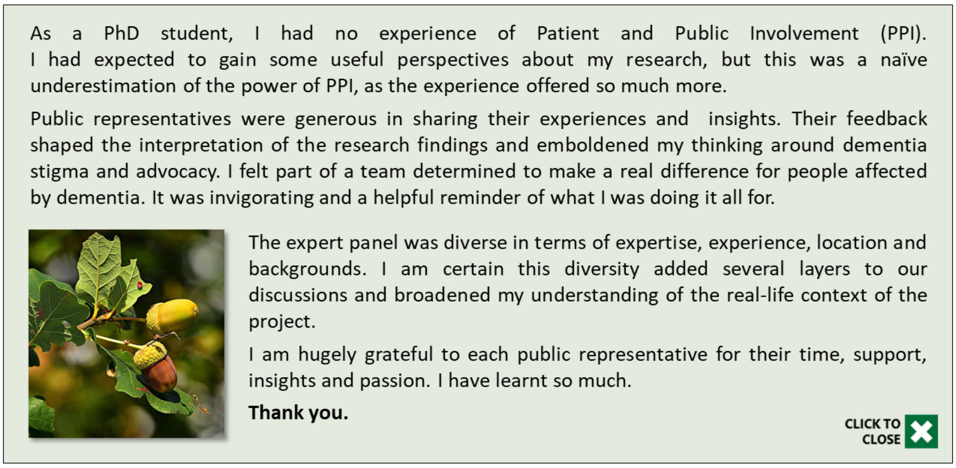
Speaking words of wisdom -- *The Beatles*

United we stand -- *Aesop*

We will rock you -- *Queen*

CLICK TO CLOSE ☒

Reflection 5:



As a PhD student, I had no experience of Patient and Public Involvement (PPI). I had expected to gain some useful perspectives about my research, but this was a naïve underestimation of the power of PPI, as the experience offered so much more.

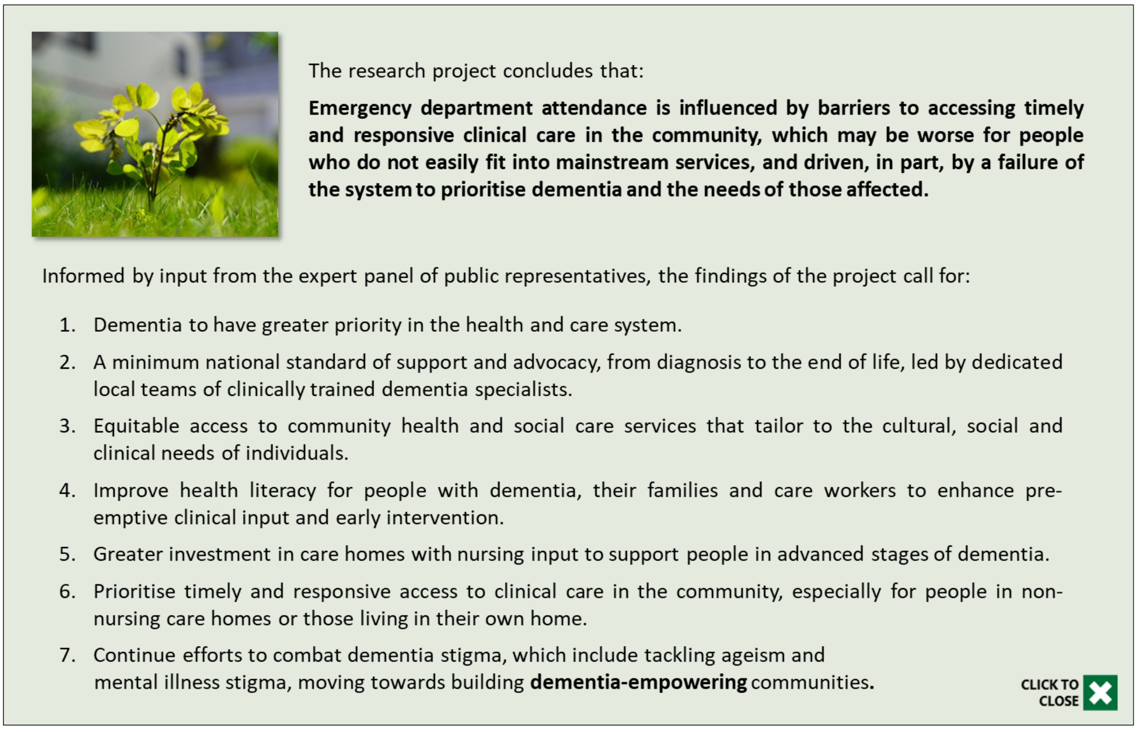
Public representatives were generous in sharing their experiences and insights. Their feedback shaped the interpretation of the research findings and emboldened my thinking around dementia stigma and advocacy. I felt part of a team determined to make a real difference for people affected by dementia. It was invigorating and a helpful reminder of what I was doing it all for.

The expert panel was diverse in terms of expertise, experience, location and backgrounds. I am certain this diversity added several layers to our discussions and broadened my understanding of the real-life context of the project.

I am hugely grateful to each public representative for their time, support, insights and passion. I have learnt so much.

Thank you.

Project conclusions:



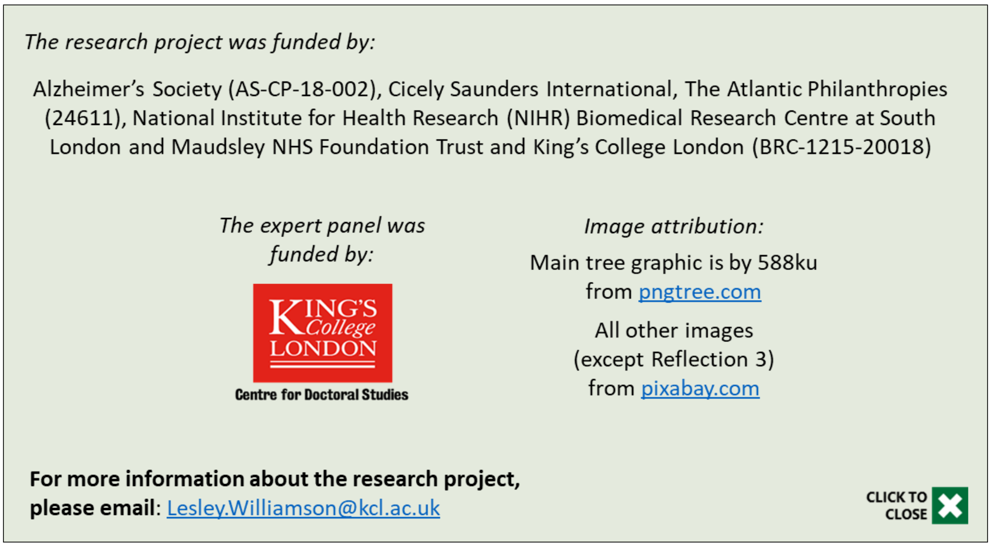
The research project concludes that:

Emergency department attendance is influenced by barriers to accessing timely and responsive clinical care in the community, which may be worse for people who do not easily fit into mainstream services, and driven, in part, by a failure of the system to prioritise dementia and the needs of those affected.

Informed by input from the expert panel of public representatives, the findings of the project call for:

1. Dementia to have greater priority in the health and care system.
2. A minimum national standard of support and advocacy, from diagnosis to the end of life, led by dedicated local teams of clinically trained dementia specialists.
3. Equitable access to community health and social care services that tailor to the cultural, social and clinical needs of individuals.
4. Improve health literacy for people with dementia, their families and care workers to enhance pre-emptive clinical input and early intervention.
5. Greater investment in care homes with nursing input to support people in advanced stages of dementia.
6. Prioritise timely and responsive access to clinical care in the community, especially for people in non-nursing care homes or those living in their own home.
7. Continue efforts to combat dementia stigma, which include tackling ageism and mental illness stigma, moving towards building **dementia-empowering** communities.

Acknowledgements:



The research project was funded by:

Alzheimer’s Society (AS-CP-18-002), Cicely Saunders International, The Atlantic Philanthropies (24611), National Institute for Health Research (NIHR) Biomedical Research Centre at South London and Maudsley NHS Foundation Trust and King’s College London (BRC-1215-20018)

The expert panel was funded by:

KING'S College LONDON

Centre for Doctoral Studies

Image attribution:

Main tree graphic is by 588ku from pngtree.com

All other images (except Reflection 3) from pixabay.com

For more information about the research project, please email: Lesley.Williamson@kcl.ac.uk

B5: Expert panel evaluation report and blog

Public engagement small grant scheme – Final report (March 2023)

Project lead

Name:	Lesley Williamson
Job title:	PhD Clinical Training Fellow
Dept/Faculty:	Cicely Saunders Institute – Florence Nightingale Faculty of Nursing, Midwifery and Palliative Care
Email:	Lesley.Williamson@kcl.ac.uk

Project details

Project title:
Keeping it real: bringing dementia research into the real-world using an expert panel of people affected by dementia
Short summary of activity:

Aim: To create a guiding coalition of people affected by dementia to ensure study findings are interpreted in context, and that recommendations are grounded in the realities of living with dementia and engaging with care services

Objectives:
1) Facilitate public members' contributions to interpreting project findings. This will be achieved by providing a safe environment for public members on the panel to share experiences and insights relevant to study findings. This objective will directly benefit public members on the panel, and indirectly benefit wider public affected by dementia by increasing the application and thus potential impact of the research.

2) Provide opportunity for public members to identify and prioritise objectives for change. This will be achieved by inviting public members on the panel to discuss what is important to them, what needs to change and how. This objective will directly benefit public members on the panel, and indirectly benefit wider public affected by dementia by increasing the application and thus potential impact of the research.

3) Promote the project and increase its potential impact. This will be achieved by developing a dissemination strategy of accessible outputs with public members on the panel, including dissemination at a stakeholder engagement event for the wider public and policymakers. This objective will directly benefit public members on the panel and broader public audiences by educating attendees about dementia, informing attendees of research findings, and demonstrating how people affected by dementia can make valuable contributions to research.

Summary:
The panel of public members were established in June/July and met four times: 02 August 2022, 10 August 2022, 19 December 2022, and 30 January 2023. In the first three meetings, findings from three studies were presented and discussed. An impact log (you said, we did) was maintained and shared with public representatives in the third meeting. In the final meeting, representatives reflected on their involvement in the project and agreed to create a poster to summarise their experiences for dissemination.

Estimated number of people engaged during the project:

There were six members of the panel. Meeting attendance ranged from four to five members.

Any other outputs from the project

Any blogposts, documents, project reports may be appended or weblinks provided

Interactive poster and blog

Reflecting on the project

Summary of evaluation data

Objective 1: Facilitate public members' contributions to interpreting project study findings
Public representatives had direct influence on the interpretation of project findings (*see* attached impact log). Their feedback and interpretation altered the write-up of a publication, which included formal acknowledgement of their contributions. Their feedback also influenced the final theoretical model of the project, focusing on empowering rather than enabling people with dementia.

Objective 2: Provide opportunity for public members to identify and prioritise objectives for change
Public representatives identified priorities for change, which included improvements to the emergency department environment; improvements in access to clinical care in the community, especially in care homes; the need for advocates for people with dementia and their family caregivers; and a greater focus on advance care planning and on empowering people with dementia These have been incorporated into the thesis and plans for future research.

Objective 3: Promote the project and increase its potential impact
Public representatives provided useful suggestions to promote the project study and increase its impact potential, including translation of study findings into different languages for wider accessibility. One public representative has several contacts including the World Health Organisation and has offered to share among his contacts the study findings as and when they have been published.

THREE successes of the project:

1. Public representatives shaped the development of the project and individual studies, resulting in their formal acknowledgement in a paper currently under peer review.
2. Public representatives fed back their enjoyment and personal benefits of taking part in the study.
3. Members of the project expert panel have joined the Cicely Saunders Institute Patient and Public Involvement Forum.

THREE key learning points:

1. Securing dates for meetings often meant back and forth emails and several Doodle Polls. In future, a simple initial email asking for dates and times that public representatives cannot attend would help to guide the Doodle Poll.
2. The findings of the studies generated such rich discussion, one hour was simply too short to cover everything. In future, meetings would be extended to 2hrs with a scheduled 15mins break.
3. It was fed back after the first meeting that opening the Zoom call 30mins before the official start time of the meeting would be useful for people to informally chat if they wished. This was done in subsequent meetings and seemed to work well. In future, this will be a standard.

Ways in which learning has been shared beyond the project team

The interactive poster and short news item will be shared with the Centre for Doctoral Studies, Dementia Researcher and Cicely Saunders Institute for consideration of inclusion on their websites. It will also be shared with the charities from which public representatives were recruited: Alzheimer’s Society and Dementia Engagement and Empowerment Project.

A reflective piece to share with other junior researchers has been written and will be published as a blog (*see* below).

Blog

Keeping it real: Bringing dementia research into the real-world using an expert panel of people affected by dementia.

***Lesley Williamson** is a PhD Clinical Training Fellow at Cicely Saunders Institute of Palliative Care, Policy and Rehabilitation, King’s College London. Lesley.Williamson@kcl.ac.uk*

Did you know that most people with dementia will attend the emergency department in the last year of life?

Understanding why people with dementia attend the ED towards the end of life was the focus of my PhD thesis (Emergency department attendance among people with dementia approaching the end of life).

Involving an expert panel of public representatives

While I sought public involvement for the development of study protocols and piloting interview topic guides, I also established an expert panel of public representatives with the financial support of the Public Engagement Small Grants fund from the King’s Centre for Doctoral Studies.

The expert panel comprised people with dementia and those with experience of supporting a relative with dementia. Details of how the expert panel was established and how it functioned are summarised in Box 1.

BOX 1: How the expert panel was established and how it functioned

How the panel was established:

- Adverts were emailed to the charities, Alzheimer’s Society Research Network and the Dementia Engagement Empowerment Project (DEEP), who circulated them to their members.
- After sharing project details and role descriptions with interested individuals, and discussing expectations and preferences with each, the first three people with dementia and the first three people with experience of supporting someone with dementia were recruited.

How the panel functioned:

- Three online meetings were scheduled between August and December 2022 to coincide the project milestones.
- Each meeting took place on Zoom and lasted one hour. The specific timing of meetings was determined via Doodle Poll, at public representatives’ requests.
- Public representatives were sent a one-page written summary of study findings, presentation slides and a meeting agenda at least one week in advance of the meeting.
- The Zoom room was open 30mins before the meeting started to allow members to catch up and thus optimise time within the meetings to focus on the project.
- Meetings included a brief presentation, and a discussion about the meanings and implications of the study findings.
- Public representatives were reimbursed for their time, contributions, and internet usage in accordance with National Institute of Health and Care Research guidelines.
- The third meeting included review of how the expert panel had influenced the project.

The aim of the expert panel was to establish a guiding coalition of people affected by dementia to ensure study findings were interpreted in context, and that recommendations were grounded in the realities of living with dementia and engaging with care services.

Impact of the expert panel

Involvement of public representatives had direct impact on my interpretations and reporting of individual studies and the development of recommendations for future improvement. I maintained a log of this impact by using the ‘You Said, We Did’ structure and specifically talked to each section of the log during the third meeting to thank public representatives but also to ensure they knew just how much an impact their contributions had had already. Box 2 gives some examples of impact from this log.

In addition to the impact log, public representatives were invited to complete a brief online anonymous survey which asked them to prioritise research findings as targets for change which informed the discussion of my thesis. I also used it as an opportunity to gain more quantitative feedback on the expert panel experience.

BOX 2: Impact log – examples of ‘you said, we did’

You said:	*Advocacy is vital to ensure people with dementia receive quality care.*
We did:	Interview study participants expressed that they did not feel heard by staff and described fighting for help. The report included discussion of the role of advocacy in mitigating this.
You said:	*People from minority ethnic backgrounds have no voice in the health and social care system, where language barriers and bias can influence care.*
We did:	The big data study showed more ED visits associated with South Asian ethnicity. The report discussed the need for resources to support end-of-life care discussions in accessible, culturally sensitive ways. The report for the interview study included discussion about how people from minoritised ethnic groups are underserved by healthcare and called for more research to specifically engage with people from minoritised ethnic groups.
You said:	*ED staff must respectfully review people with dementia without assumptions.*
We did:	Interview study participants described their experiences of being within the ED. The report specifically stated that fundamentally, people with dementia should be taken as individuals and treated without assumption.
You said:	*Avoid using terms like enabling or disabling as these have stigmatising connotations; use empowering and not empowering instead.*
We did:	The conceptual model was refined to include empowering rather than enabling. This was incorporated into project recommendations to work towards creating dementia-empowering communities.

Reflections and lessons learned

Engaging with an expert panel was such an enjoyable experience and it genuinely enhanced the quality of my research and subsequent recommendations. It also spurred me on when I was deep in data cleaning or lost in peer review comments. There were some practical challenges in setting up the panel, from securing the funding to organising and facilitating online meetings. With the help of the public representatives, I learnt as I went along. I have shared some practical tips here for anyone with minimal experience wanting to set up something similar:

1) **Clarify roles and expectations:** I provided each public representative a document that outlined the project, role description, reimbursement details, support structures and contact details of the researcher. This was useful to direct initial conversations, agree roles and expectations, discuss any supportive requirements and preferences to optimise meaningful involvement.
2) **Prioritise diversity:** The expert panel was diverse in age, gender, ethnicity, location, experience, and expertise. This afforded a great richness of discussions and helped to contextualise the research findings.
3) **Take an assets-based approach:** Each member of the expert panel brought something unique to the project, whether this was their personal insights, ideas, or wide-reaching connections. Recognising and working with the assets we each brought to the table was a solid foundation for teamwork.

4) **Be accessible:** I invited public representatives to contact me at any time if they had any queries or concerns about the project. I also emailed them individually after each meeting to share the meeting notes but also to check-in with each representative. This was especially important after discussions during the meeting that may have been emotionally sensitive. This post-meeting contact also facilitated continuous improvement of the expert panel.
5) **Practise reciprocal feedback:** Public representatives provided valuable feedback to enhance the research quality and relevance. It is essential to ensure they are aware of the contributions that they have made. I ensured I updated public representatives of any impacts during the meetings and dedicated a section of the final meeting to share the impact log.

Be mindful:

1) **Duration of meetings:** One hour per meeting was too short for us – having longer meetings with a scheduled break would have permitted greater depth of discussion.
2) **Doodle Polls:** We used Doodle Polls to identify meeting dates, but I realised it is essential to narrow down to just a few options to ensure poll completion is not cognitively burdensome.
3) **Survey feedback:** Using an anonymous survey yielded interesting insights, but the response rate was limited. In hindsight, I would first consider if the same information could be obtained using different evaluation methods and/or supplemented.

Reflections from public representatives

All public representatives were invited to provide informal feedback on the progress of each meeting, in addition to the survey. Although only half of the expert panel responded to the survey, responses were positive, indicating strong agreement of having opportunity to contribute to discussions, enjoyed taking part, felt the meetings ran well, and felt supported to take part in the project. Free text responses included:

> *"Felt very much part of the panel."*
>
> *"I was pleased to have been part. It was an excellent opportunity to contribute to an issue that is of importance to people with dementia. The topic requires serious attention with a view to taking remedial action as it appears to be a neglected area in dementia care."*

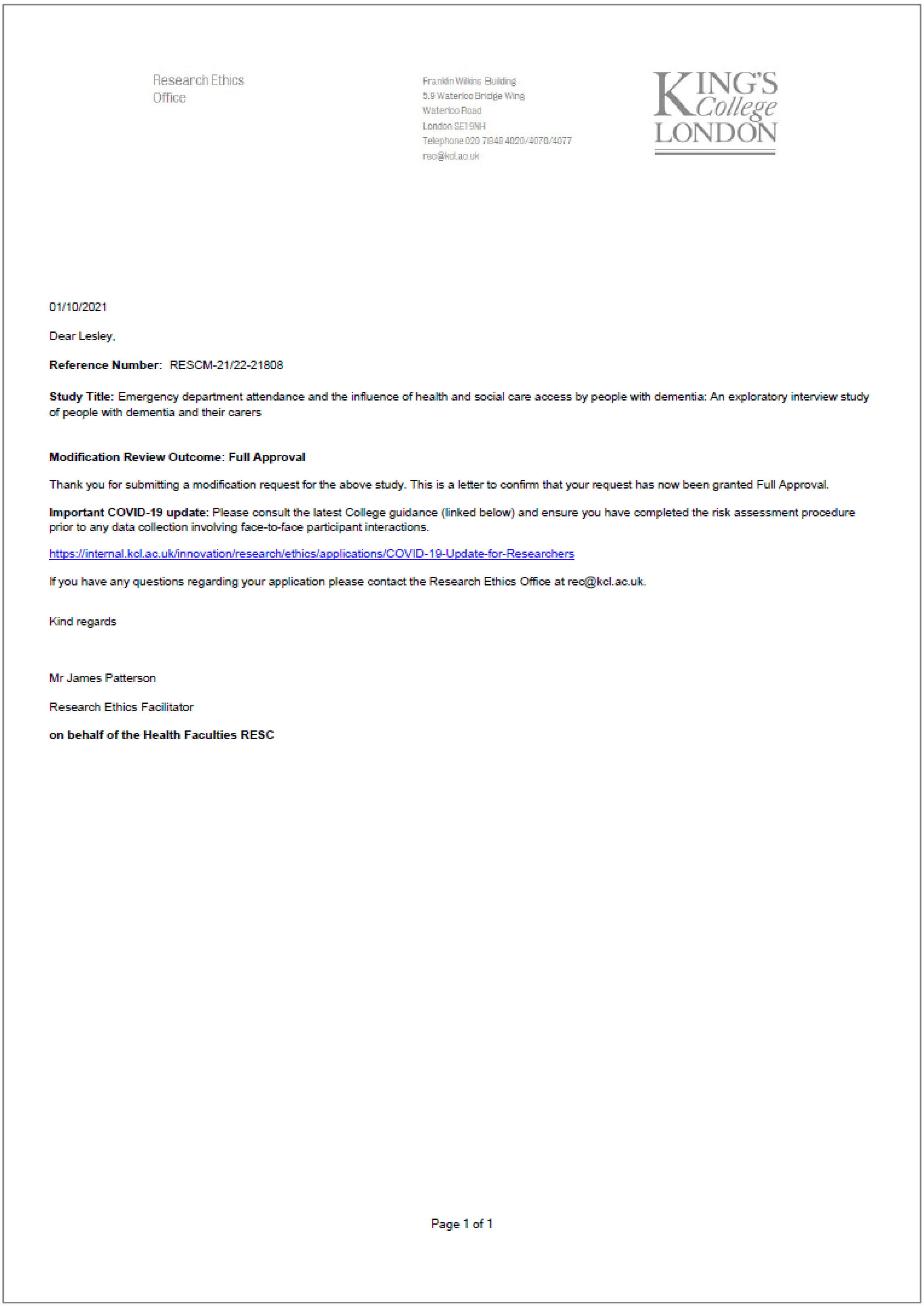
Four public representatives also attended a fourth meeting (with reimbursement) to discuss their experiences of being involved in the project. They were given flexibility to develop their own ideas to develop a reflective piece that could be shared with wider audiences. The public representatives decided to document their reflections in a poster and invited me to include my reflections as well.

You can look at the digital interactive poster here.

Please email Lesley.Williamson@kcl.ac.uk if you would like to see the printable version and/or receive more information about the project.

Appendix C: Supplementary material from the social assessment

C1: Research Ethics Committee approval letter



Research Ethics
Office

Franklin Wilkins Building
5.9 Waterloo Bridge Wing
Waterloo Road
London SE1 9NH
Telephone 020 7848 4020/4070/4077
rec@kcl.ac.uk

01/10/2021

Dear Lesley,

Reference Number: RESCM-21/22-21808

Study Title: Emergency department attendance and the influence of health and social care access by people with dementia: An exploratory interview study of people with dementia and their carers

Modification Review Outcome: Full Approval

Thank you for submitting a modification request for the above study. This is a letter to confirm that your request has now been granted Full Approval.

Important COVID-19 update: Please consult the latest College guidance (linked below) and ensure you have completed the risk assessment procedure prior to any data collection involving face-to-face participant interactions.

https://internal.kcl.ac.uk/innovation/research/ethics/applications/COVID-19-Update-for-Researchers

If you have any questions regarding your application please contact the Research Ethics Office at rec@kcl.ac.uk.

Kind regards

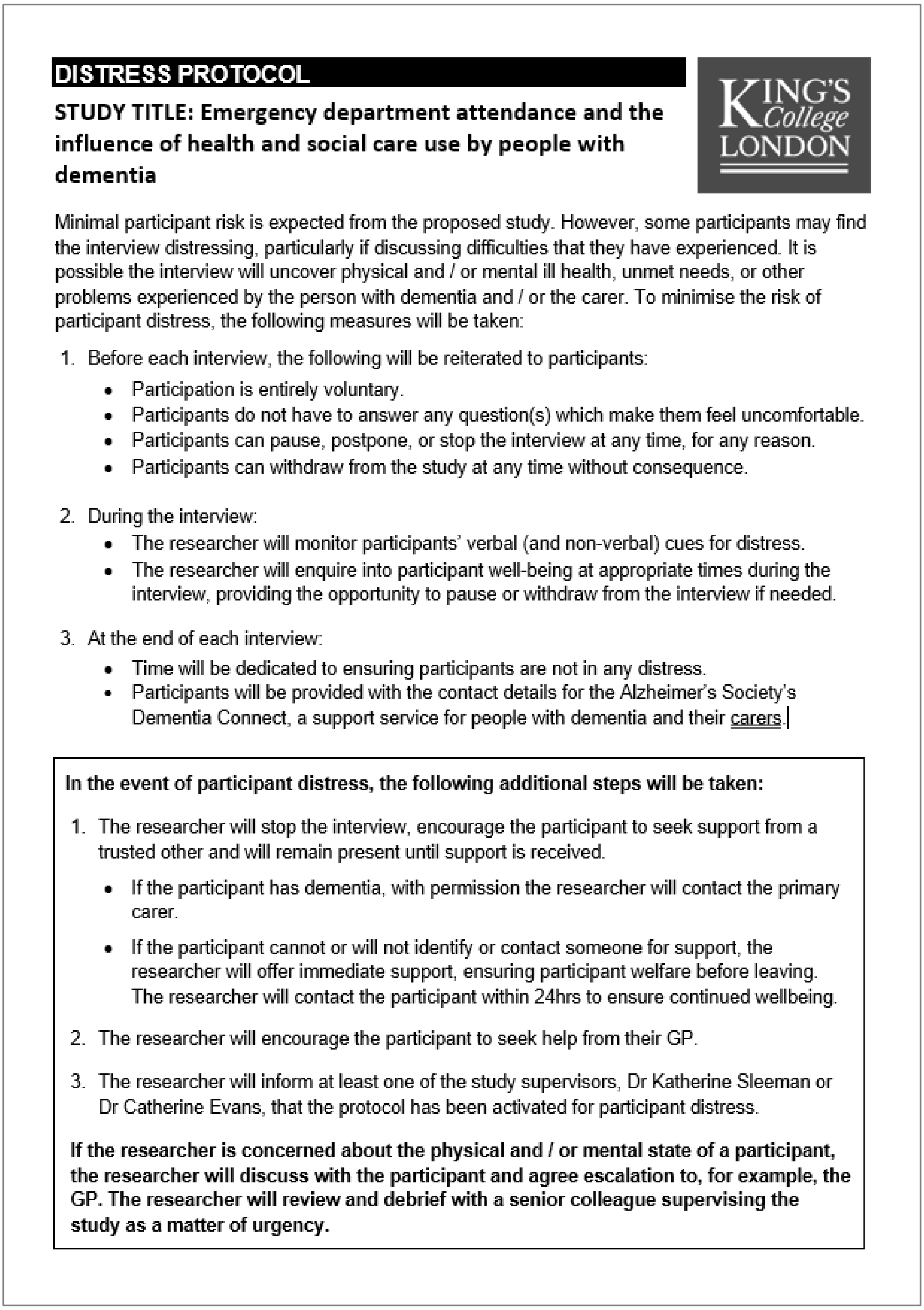
Mr James Patterson

Research Ethics Facilitator

on behalf of the Health Faculties RESC

Page 1 of 1

C2: Distress Protocol



DISTRESS PROTOCOL

STUDY TITLE: Emergency department attendance and the influence of health and social care use by people with dementia

Minimal participant risk is expected from the proposed study. However, some participants may find the interview distressing, particularly if discussing difficulties that they have experienced. It is possible the interview will uncover physical and / or mental ill health, unmet needs, or other problems experienced by the person with dementia and / or the carer. To minimise the risk of participant distress, the following measures will be taken:

1. Before each interview, the following will be reiterated to participants:
   - Participation is entirely voluntary.
   - Participants do not have to answer any question(s) which make them feel uncomfortable.
   - Participants can pause, postpone, or stop the interview at any time, for any reason.
   - Participants can withdraw from the study at any time without consequence.

2. During the interview:
   - The researcher will monitor participants' verbal (and non-verbal) cues for distress.
   - The researcher will enquire into participant well-being at appropriate times during the interview, providing the opportunity to pause or withdraw from the interview if needed.

3. At the end of each interview:
   - Time will be dedicated to ensuring participants are not in any distress.
   - Participants will be provided with the contact details for the Alzheimer's Society's Dementia Connect, a support service for people with dementia and their carers.

In the event of participant distress, the following additional steps will be taken:

1. The researcher will stop the interview, encourage the participant to seek support from a trusted other and will remain present until support is received.
   - If the participant has dementia, with permission the researcher will contact the primary carer.
   - If the participant cannot or will not identify or contact someone for support, the researcher will offer immediate support, ensuring participant welfare before leaving. The researcher will contact the participant within 24hrs to ensure continued wellbeing.
2. The researcher will encourage the participant to seek help from their GP.
3. The researcher will inform at least one of the study supervisors, Dr Katherine Sleeman or Dr Catherine Evans, that the protocol has been activated for participant distress.

If the researcher is concerned about the physical and / or mental state of a participant, the researcher will discuss with the participant and agree escalation to, for example, the GP. The researcher will review and debrief with a senior colleague supervising the study as a matter of urgency.

C3: COREQ-32 checklist

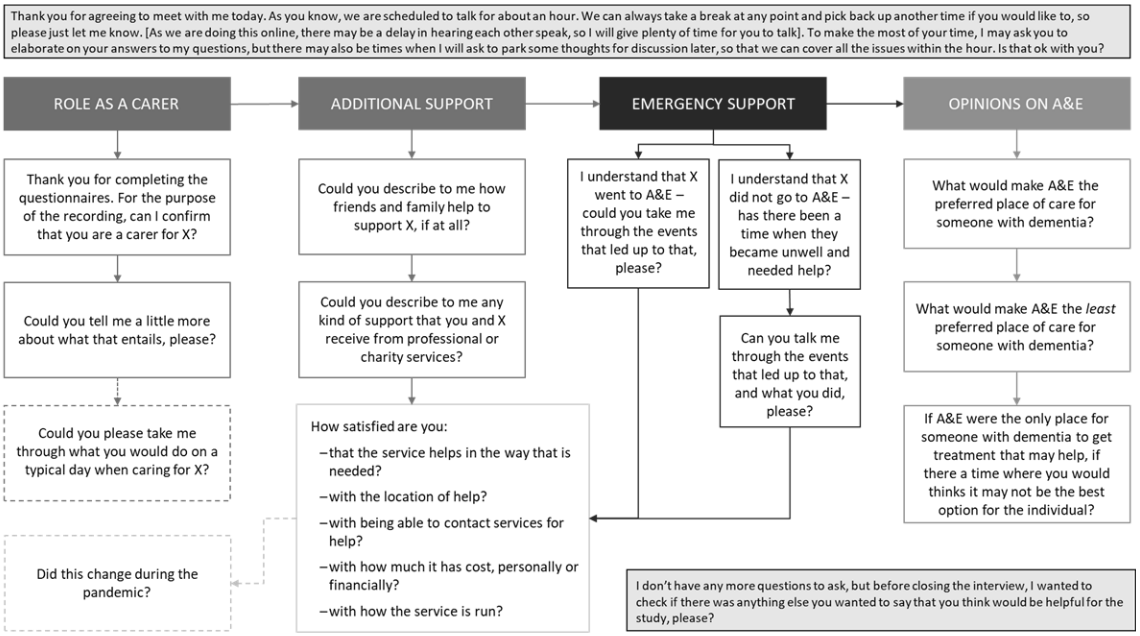
No. Item	Guide questions/description	Reported on pg.#
Domain 1: Research team and reflexivity		
Personal Characteristics		
1. Inter viewer/facilitator	Which author/s conducted the interview or focus group?	5
2. Credentials	What were the researcher's credentials? E.g., PhD, MD	6
3. Occupation	What was their occupation at the time of the study?	6
4. Gender	Was the researcher male or female?	6
5. Experience and training	What experience or training did the researcher have?	6
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement?	5
7. Participant knowledge of the interviewer	What did the participants know about the researcher? E.g., personal goals, reasons for doing the research	NA
8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? E.g., Bias, assumptions, reasons, and interests in the research topic	NA
Domain 2: study design		
Theoretical framework		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	3
Participant selection		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	4
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	4
12. Sample size	How many participants were in the study?	6
13. Non-participation	How many people refused to participate or dropped out? Reasons?	6
Setting		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	5
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	5
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	4
Data collection		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	5
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	7
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	5
20. Field notes	Were field notes made during and/or after the interview or focus group?	5
21. Duration	What was the duration of the interviews or focus group?	7
22. Data saturation	Was data saturation discussed?	NA
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	NA
Domain 3: analysis and findings		
Data analysis		
24. Number of data coders	How many data coders coded the data?	6
25. Description of the coding tree	Did authors provide a description of the coding tree?	NA
26. Derivation of themes	Were themes identified in advance or derived from the data?	6
27. Software	What software, if applicable, was used to manage the data?	6
28. Participant checking	Did participants provide feedback on the findings?	NA
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? E.g., participant number	19-21 (Tables 2-4; S6)
30. Data and findings consistent	Was there consistency between the data presented and the findings?	7-11
31. Clarity of major themes	Were major themes clearly presented in the findings?	7-11
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	NA

C4: Participant recruitment charities and registers

Organisation	Description	Website address
Alzheimer's Society Research Network	Charity network of 357 volunteers living with dementia and current and former caregivers	https://www.alzheimers.org.uk/research/get-involved/our-research-network-volunteers
Dementia Engagement and Empowerment Project	Charity network of 80 rights-based groups of people living with dementia	https://www.dementiavoices.org.uk/
Dementia Carers Count	Charity of registered members comprising current and former caregivers	https://dementiacarers.org.uk/
National Institute for Health and Care Research (NIHR) Join Dementia Research	National register of over 55,000 individuals of people affected by dementia.	https://www.joindementiaresearch.nihr.ac.uk/

C5: Interview Guides

Family caregiver



Thank you for agreeing to meet with me today. As you know, we are scheduled to talk for about an hour. We can always take a break at any point and pick back up another time if you would like to, so please just let me know. [As we are doing this online, there may be a delay in hearing each other speak, so I will give plenty of time for you to talk]. To make the most of your time, I may ask you to elaborate on your answers to my questions, but there may also be times when I will ask to park some thoughts for discussion later, so that we can cover all the issues within the hour. Is that ok with you?

ROLE AS A CARER

Thank you for completing the questionnaires. For the purpose of the recording, can I confirm that you are a carer for X?

Could you tell me a little more about what that entails, please?

Could you please take me through what you would do on a typical day when caring for X?

Did this change during the pandemic?

ADDITIONAL SUPPORT

Could you describe to me how friends and family help to support X, if at all?

Could you describe to me any kind of support that you and X receive from professional or charity services?

How satisfied are you:

- that the service helps in the way that is needed?
- with the location of help?
- with being able to contact services for help?
- with how much it has cost, personally or financially?
- with how the service is run?

EMERGENCY SUPPORT

I understand that X went to A&E – could you take me through the events that led up to that, please?

I understand that X did not go to A&E – has there been a time when they became unwell and needed help?

Can you talk me through the events that led up to that, and what you did, please?

OPINIONS ON A&E

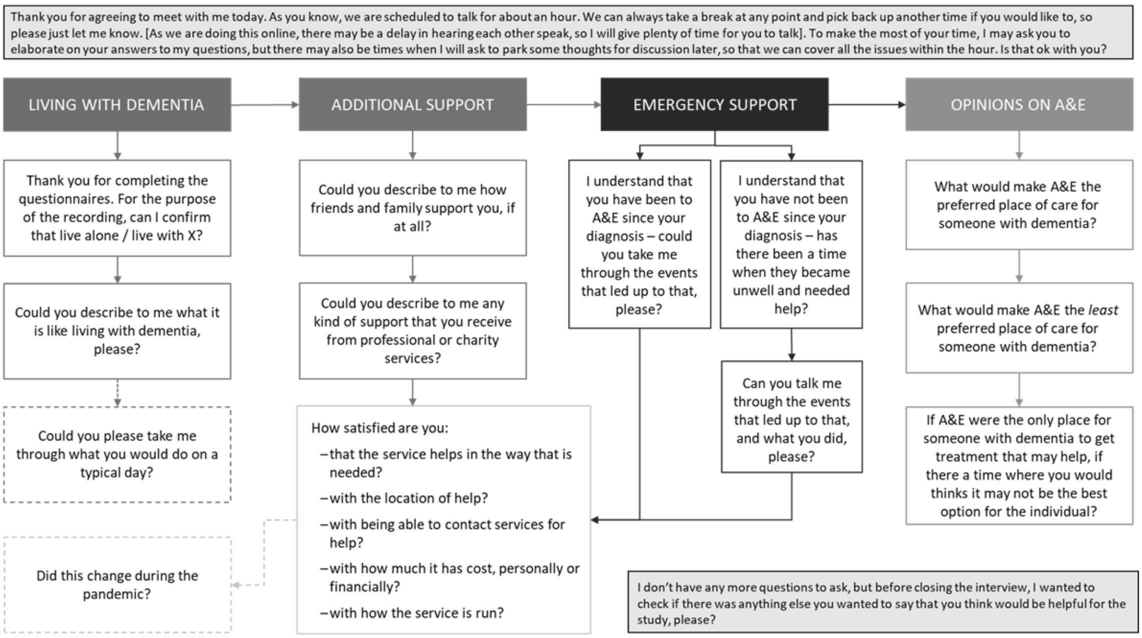
What would make A&E the preferred place of care for someone with dementia?

What would make A&E the *least* preferred place of care for someone with dementia?

If A&E were the only place for someone with dementia to get treatment that may help, if there a time where you would thinks it may not be the best option for the individual?

I don't have any more questions to ask, but before closing the interview, I wanted to check if there was anything else you wanted to say that you think would be helpful for the study, please?

Person with dementia



Thank you for agreeing to meet with me today. As you know, we are scheduled to talk for about an hour. We can always take a break at any point and pick back up another time if you would like to, so please just let me know. [As we are doing this online, there may be a delay in hearing each other speak, so I will give plenty of time for you to talk]. To make the most of your time, I may ask you to elaborate on your answers to my questions, but there may also be times when I will ask to park some thoughts for discussion later, so that we can cover all the issues within the hour. Is that ok with you?

LIVING WITH DEMENTIA

Thank you for completing the questionnaires. For the purpose of the recording, can I confirm that live alone / live with X?

Could you describe to me what it is like living with dementia, please?

Could you please take me through what you would do on a typical day?

Did this change during the pandemic?

ADDITIONAL SUPPORT

Could you describe to me how friends and family support you, if at all?

Could you describe to me any kind of support that you receive from professional or charity services?

How satisfied are you:

- that the service helps in the way that is needed?
- with the location of help?
- with being able to contact services for help?
- with how much it has cost, personally or financially?
- with how the service is run?

EMERGENCY SUPPORT

I understand that you have been to A&E since your diagnosis – could you take me through the events that led up to that, please?

I understand that you have not been to A&E since your diagnosis – has there been a time when they became unwell and needed help?

Can you talk me through the events that led up to that, and what you did, please?

OPINIONS ON A&E

What would make A&E the preferred place of care for someone with dementia?

What would make A&E the *least* preferred place of care for someone with dementia?

If A&E were the only place for someone with dementia to get treatment that may help, if there a time where you would thinks it may not be the best option for the individual?

I don't have any more questions to ask, but before closing the interview, I wanted to check if there was anything else you wanted to say that you think would be helpful for the study, please?

C6: Demographic questionnaire (for people with dementia, for example)

1. How old are you?	☐ 50-59
	☐ 60-69
	☐ 70-79
	☐ 80-89
	☐ 90+

2. What is your gender?	☐ Male
	☐ Female
	☐ Other:
	☐ Prefer not to say

3. How would you describe your ethnicity?	☐ Asian / Asian British
	☐ Black / African / Caribbean / Black British
	☐ Mixed / multiple ethnic groups
	☐ White
	☐ Other:
	☐ Don’t know

4. What is your marital status?	☐ Married / civil partnership
	☐ Never married
	☐ Divorced / separated
	☐ Widowed
	☐ Other:

5. Do you know what type of dementia you have?	☐ Alzheimer’s disease
	☐ Vascular dementia
	☐ Mixed
	☐ Other:
	☐ Don’t know

6. Do you have, or have you ever had any of these conditions? (Please tick all that apply)	☐ Heart condition (e.g. heart failure, heart attack)
	☐ Breathing condition (e.g. asthma, COPD)
	☐ Past stroke (or mini stroke, also known as TIA)
	☐ High blood pressure
	☐ Diabetes (high sugars)
	☐ Joint problems (e.g. arthritis)
	☐ Depression
	☐ Other(s):
	☐ Don’t know

7. Which of the following descriptions comes closest to how you feel about your household’s income nowadays?	☐ Living comfortably on present income
	☐ Coping on present income
	☐ Difficult on present income

	☐ Very difficult on present income
	☐ Don’t know
	☐ Prefer not to say

8. Who do you live with?	☐ Live with your spouse/partner
	☐ Live with your children
	☐ Live with your spouse/ partner **AND** children
	☐ Live with residents of care home
	☐ Live alone
	☐ Other: Lodger

9. Do your family or friends support you with your care? (If so, please tick all that apply)	☐ No support from family or friends
	☐ Support from spouse / partner
	☐ Support from children
	☐ Support from sibling
	☐ Support from friend
	☐ Support from other:

10. Roughly how far away is the nearest Accident & Emergency (A&E) department?	☐ Less than 5 miles away from home
	☐ More than 5 miles away from home
	☐ Don’t know

11. Roughly how many times have you been to A&E since you were diagnosed with dementia? *(or in the last 5 years if you were diagnosed more than 5 years ago)*	☐ No A&E visits
	☐ 1 visit
	☐ 2 visits
	☐ 3 or more visits

12. Roughly when was the last time you visited A&E?	☐ Within the last year (during the pandemic)
	☐ 2 years ago (before the pandemic)
	☐ 3 or more years ago
	☐ Not applicable

C7: Safeguarding questionnaire (for people with dementia, for example)

The contact details you provide here will **only** be used to maintain welfare and safety if, for example, you become distressed, unwell or a welfare concern arises during the research study.

Your personal details will **not** be used as part of the research study and will be kept separately from your interview responses.

Your first name and surname	
Your home postcode	
Your telephone number	
Name of primary carer / next of kin	
Contact number of primary carer / next of kin	
Name of your GP surgery	

If you become distressed or unwell during the study or if there are any raised concerns for the welfare of any individual, the researcher will inform you of their intention to report the concern and your details to any of the following people, where appropriate:

Project supervisors

Your primary carer / next of kin

Your GP

Local Authority Safeguarding Team

C8: Additional data extracts per theme

S6.1: Theme 1 – Navigating a ‘push’ system

ID	Quote
PWD9	I mean, I think if people have got attention at times, if they've got somebody to talk to or somebody to, even some games or something like that keeps them occupied and keeps them away from knowing that they've got that or forgetting that they've got that and just don't dwell on it, I think is the main thing.
CC1	“…one of the biggest things for me with my dad with his Alzheimer's is that it took a while to kind of, it was so important to bring a routine and a schedule into their day. And my mum wasn't really up to orchestrating that physically with her own fragility… So it took a while after my dad’s diagnosis really to get the right conditions and the right set of medications that enabled me to get a schedule into their day. And so that was part of the reason why I took six months off, was to start that as well to kind of embed it… So all of those things that have brought schedule into their day has enabled both of them to get a decent sleep which I think is a fairly restful night which I think has also contributed to the fact that my dad's decline hasn't been too rapid. I think all of these factors the better you care to someone the better they can live and keep going and have some reason to keep going and keep motivated. And I think it has an effect in the general way as well.”
PWD10	“Yeah, most of the time you know. And if it is anything that I'm going through that I'm not happy or I don't understand or whatever I call her [daughter]. Either she explain, or come here and then explain it to me and things like that… Thankfully she doesn't really live that far it is just a walking distance so it's not that bad.”
PWD6	“At the moment, I wouldn't have a clue who to contact if I need help. Well, there isn't anybody, but you know that -- it's having that point of contact, knowing that they're there if you need help. It might be just as a signpost. It might be just for advice. Support isn't needed continually, it's needed as and when to just prevent a crisis from happening.”
BC2	“Again, I was just incredibly ignorant. I knew nothing about dementia, nothing about old – I thought maybe this is just what old people are like… But then I was watching, one of my favourite tv programmes, an American programme and one of the characters’ old mothers came to stay with them and went funny every day at 5pm and one of the other characters said, ‘oh, she must have Alzheimer’s because that’s called sundowning’ and suddenly everything fell into place. Isn’t it terrible that I got my info from an American TV programme?!”
CC2	“If I was to tell you – because I did actually map it out – there's probably 16 agencies I'm currently dealing with my mum. From the police to the fire service, to the memory clinics, to the adult team, the psychiatric team, the emergency team, the doctor… And then trying to get hold of them, is even worse. Because you end up invariably talking to a call centre somewhere. So you ring, you'll ring, for example, the emergency team, you'll get a call centre, which I think is based in [city] who will then refer you to the person you need, which can take, however long. Same with the doctor surgery, Yep we'll get the doctor to call you back. Same with technology… Somebody came out, and then I've got the text -- and then I get a call back from tech… the -- technology enabled care team who are going to put the actual gadgets in. And I'm like, Okay so where does that fit into the grand scheme of things, because I was talking to the fire service. So, there's so many referral on points it gets incredibly confusing who does what when etcetera.”
CC7	“But that really would be a big improvement if they could make that bit more joined up. I mean, I'm not even sure now if I was phoning the right people some of the time to try and move things on because there was the council social care phone number and there was also the hospital social care for a number. To start with I was phoning the council because I didn't even know there was a separate department at the hospital, and they do work for the council, they're part of the same organisation, but they come separate. So that's an area where more joined up working would be helpful.”
BC1	“And at the time, if I talked to the medical people about ‘what else is there out here that can support [husband]’s other needs, his emotional needs, his social needs, they’d sort of look at me and say ‘ooh, I don’t really know’. I knew far more than they did. And quite often the consultant used to sit there and say ‘well that’s really useful, I didn’t know we did that, oooh’ [laughs]. I think everyone was aware of that and I certainly took part in a number of conferences across the county where I was speaking along exactly these lines and I was pushing at an open door.”
CC6	“And she said, ‘The nurse flagged it at the last visit, she's put on the system’. So, I said, ‘Are you telling me that she contacted the GP?’ So, she said, ‘No, she's just, she's put the photos on if the GP wants to see it’. So, I said, ‘Yeah, but has she notified the GP?’ And she said, ‘No, they're just there if he wants to see them’. So, I said, ‘Well, how is the GP supposed to know?’ I get my little communication book out, I go back to Wednesday, it says ‘no concerns’…”
CC8	“First of all, he's not really able, and he hasn't been able to tell the doctors for the last three to five years, how he's feeling. And then second, when they tell him their verdict on what needs to be done or what they think is wrong, [he’s] not able to tell us because we get, like I say, we get 10 different versions of events and then nobody else speaks to us about what was actually said… I think the confidentiality act should go out the window for somebody with dementia… It's quite dangerous practice, so I think when somebody is diagnosed with dementia, Alzheimer's there should be an automatic new person or people who they then name, that the person with dementia nominates, and they can speak with medical staff, and medical staff can converse with them.”
CC5	“Well, that data protection issue, becoming a registered person, you know that I can’t go into the surgery and people believe me when I say I’m somebody’s son and I want to take an interest in their – I need to take an interest in their care because of their mental state and they don’t believe you, and you have to go through this form filling procedure. As I say, once we got onto it, it was alright, but had mum progressed a bit further and not been in a position to fill that form in, then where would we have been now, you see? You would need somebody to say, ‘Ok, well that’s the system, but the practicalities of today’s situation means I’m going to ignore it’, you see, ‘and I'm going to give you full access’. But there aren’t many people who have the courage to throw the rule book out of the window when it’s really necessary.”

BC16	“My daughter, who works in [region 1], seemed to think at the time, she didn’t know for sure, but she seemed to think that there seemed to be more money available in [region 2] than what there was in [region 1] because I was getting things that I didn’t have to pay for and some of it was like the stuff that she wore for incontinence, but in [region 1] they were limited in supply and I think some of it was free but, so.”
BC13	“you find out there’s certain things, you know, you’re brother-in-law is looking after someone on the other end of the country, their looking after their parents and then you get diagnosed and you think you can ring up and go ‘oh, you know, you can help me’, but half the things that may be someone in I don’t know, [region 1], are getting won’t exist or have different names down in [region 2]. It’s that, it’s just so difficult of actually understanding the landscape out there.”
CC3	“Eventually I went on the Alzheimer's Society website and I got a number for a local dementia cafe and they were having a bit of an open morning and it was a care home in the [region]… I went on my own and I got talking to a lady that was in there with her mum, and it was her that told me about some of the things that were available locally that we could go to with my dad. She'd already been part way down that journey, but for her to get part way down that journey she would have been in touch with lots of services at certain points, but that information isn't so freely available.”
BC9	“because things change all the time, don’t they? It's not a static thing, it’s quite, you know, it moves around; at different times, mum needed different things, and you know, and I needed different things in a way too, so I stopped the agency nights because they were quite expensive anyway, and employed my daughter for some more hours in the day… So you know, if I hadn’t have my daughter as a former a nurse with me, I’d have been, well, I'd have been swooshing around in a what, I don’t know [laughs] not know what I was doing at all! So no, I didn’t find the health service helpful really.”
BC7	“I got so angry and frustrated, you know, well, we can’t assess her unless she comes here and I said well, she has dementia I can’t get her there, she won’t come. It took months for me to eventually persuade them to send somebody here. So, from that point of view, yes, the mental health trust was just... supposed to know about dementia and she’s got to come here, she’s got to come to us.”
BC8	“getting him up and washing him was taking longer, and then they report back to their head office, or whatever, you know, to their office, and then they put him at the end of the run, sort of thing. So, he was being put to bed at half past six, er, in pads, and then they were coming to wake him up at eleven o’clock. I said that that is too long, you know, to have somebody in pads, for all that length, so I changed care provider yeah, because the council used a couple of companies, and to be honest, they weren’t much better either, because they, erm, they couldn’t get him out of the wheelchair, one day, and they wanted him to stay in the wheelchair overnight, and I wasn’t happy about that.”
CC8	“I have to take him to all his appointments because there is a bus service, it's very good, it's not very accessible. And it's not at the right times for appointments, for the hospital appointments to fit around the bus service. Whenever he's got a hospital appointment, a doctor's appointment, picking up prescriptions… it's running backwards, forwards, taking him to get prescriptions, and hospital appointments and so on… And then they come out of the hospital appointment and they're hanging about in town again, waiting for the next bus home, so you have to take the whole day.
BC12	“I didn’t know, I didn’t know. And that makes me feel so bad [upset]. Erm, because things just sort of escalated from that point, erm, if I’d known better, then that might not have happened. Erm, I could have dealt with that, that he was frightened, rather than seeing it as something else, you know? But I just didn’t read, I just didn’t read it, so er, yeah, so if there were people around who were clinically skilled in dementia but also understanding of what was going on for individuals, that would help. But I appreciate there just isn’t enough people anywhere, for anything, and that’s a problem.”
CC3	“I just can't believe we know what we know medically in our world, and we have all these challenges. But when it comes down to somebody that hasn't the ability to communicate effectively, it's the biggest barrier of all, because people really have to knuckle down and use all that training and knowledge and it's like being a detective with no clues. You've got to figure out where you need to go and next, but you can't do that unless you're with that person. And that person is not always able to walk through the door of a general practice. Well, is your dad bed bound well no, he's not but that doesn't mean to say I can get him in the car. Getting him in the car will be an easier conversation than having to keep phoning you up and virtually begging you to come and see him, which I thought it was your job. You're a GP.”
CC10	“Like filling in the personal independence payment. We were turned down once for that, weren't we? And then I wrote 9,000 words in support of it, and we actually got it. It was like my masters. It was dreadful.”
CC7	And maybe I just know how to play the system. There is a saying that middle class people do much better out of the NHS than working class people. Those are inverted commas or whatever. I know how to work the system… [friend] only got a pay-as-you-go phone. So, he phoned his GP and there will be a long palaver about being careful about Covid. And then they'll say you’re number 7 or 8, in the queue. And you wait for ages. But sometimes they'll say there's more than 20 people in the queue. Please phone back later. So, then he spent all this money and got nothing… I can play the system, I'm quite intelligent and stuff. I've got a suitable phone, but he's got a pay as you go mobile, and he's just not quite patient and bright enough to work through the 111 system.”

BC=Bereaved caregiver CC=Current caregiver; PWD=Person with dementia.

S6.2: Theme 2 – ED as the ‘last resort’

ID	Quote
PWD2	“But they're [ED patients] all very loud. And they sounded like the sort of people that if anybody complained, then they would probably, potentially sort of… yeah, I didn’t feel, I didn’t feel safe”
CC9	“But no, like sitting there for that length of time with a dementia patient who's asking you every five minutes, Why am I here? What are we doing here? Can we go home now? You know, this is, What have I done. You know, what have I done? I say, Look, you've at the big bruise on your arm mummy. You've hurt your arm and you've broken your ankle. I must have told her that, I don't know, hours and hours and hours passed like it was, to me it was cruel.”
PWD8	“It's the not knowing. For me, because of dementia, I have to know exactly what's going on at all times. If there's a gap, my anxiety gets the better with me because I don't know what's happening… And when I was left in that room for what seemed like hours and I think I went out a couple of times to find the nurse to tell me what's going on, ‘Just go back in the room, we'll be there when we can’. Well, that never comes... But just being put in that room and the door closed, that's even worse. You know, it's like being a in a little prison and not knowing what's happening.”
CC3	“…if you're taking my dad away and be able to offer something that's going to either keep him more comfortable or make the situation better: Fine. But when you say to us we can't come with you because of COVID, he's going to be in the hospital. I mean, we're talking about a hospital that lost his entire belongings. Lost him on a bloody trolley. It's just like if you're going to take responsibility, do it well or don't do it at all because there is nothing worse for those families knowing our dad died somewhere in your hospital that no one was around him that he knew.”
PWD1	“I will not go in again unless I'm unconscious. There is no way on this Earth I would do it. My family knows that, and I was so distressed by the time I came out. I'd been shielding from the very beginning because of my respiratory thing. Shielding is a nightmare anyway, because you lose things because you're not being with people, but we were being so careful. And then they put you in the fire because they don't do things the right way. So, you know, I've made it clear I wouldn't… but you try and stay safe in your bubble and follow the rules and it almost feels like A&E could kill you. That's how it feels… so you know, things do go wrong, you're so anxious by the time you leave, it was just it to try not to go there.”
PWD6	“as soon as they know I live alone, it can take me months to get out again. You know, because they want things in place to make sure I can be risk-free at home and all the rest of it, instead of just allowing me home like anyone else.”
BC14	“they are under huge pressure with huge numbers of people, and a combination of people with dementia not understanding what’s going on and feeling extremely stressed because they’re in pain or because they’re in A&E and the A&E, the hospital service in general being highly pressurised with a huge number of different needs, it just doesn’t, it could never fit together.”
BC3	“she got up one morning and her breathing was really difficult, so I thought I’d try – the hospice had rang occasionally for a while quite regularly and I hadn’t heard from them for a while – anyway, I rang them and I said because they had doctors and I said, I explained what was happening and she was not helpful, she said dial 111. So, I didn’t get anywhere there. Rang them and anyway the upshoot was that it would be two hours before an ambulance would come at minimum, or something like that, it was really cold weather, it was the end of March and I think it snowed, so, but she was looking really like she was really struggling, so I thought, we can’t wait for this ambulance, so I got an appointment with this local, with the GP practice at the local hospital and, but it wasn’t, it was another hour’s wait and she was getting really bad so I thought I’d take her down there. So, I took her down there and jumped the queue pretty much and said look you know, look at her, she’s not breathing, I'm really worried. This doctor didn’t know, he put a mask, a breathing mask on her, which when the paramedics, he then called the paramedics and when they arrived, they said that the breathing mask was the wrong size and wasn’t doing anything and they took her into hospital.”
BC12	“so, I phoned them, as I said, ‘he’s not supposed to be in hospital – he’s in palliative care, the agreement was that he would die at home’, erm, if that was what was to happen. ‘But he’s only gone in for tests’, you know [laughs], still thinking that [sighs].”
CC2	“I mean, A&E, not the place to be, if you can at all avoid it. But I don't know what -- because I know in the past, there'd be other walk-in centres that you could -- there was one in [city] there was one near where my mum lived. I don't know what happened to those they must've all shut. Yeah. Some of the walk-in centres. So, it is only A&E.”
BC3	“I suppose, you know, if you’re caring for someone at home, you don’t have the expertise that they’ve got and it’s no good ringing 111 I think, you go through so many hoops and you don’t really get anywhere, and she ends up being taken to A&E anyway. I phoned 111 throughout the pandemic, I don’t know what it’s meant to be but to me, and it certainly didn’t help with mum when I tried to ring, so I don’t know what other options you’ve got really, if you’ve, if you can’t get someone out and you haven’t got the expertise, there’s no other option but to take them, is there? In them circumstances.”
BC14	“I think their protocol was probably necessary because they hadn’t got the support – I don’t know, may be because they hadn’t got the support from the GP practices locally, so if you haven’t got, you can’t call on them and know that they are going to give you the support you need to solve the situation, you need to take the, perhaps the GP practices would say, you know, ‘we’re not dealing with it, call A&E’. It’s probably unfair to load it all on the care home, I don't know how the structures work before that bit.”
CC2	“Because at one point, and I don't know who said it to us, I can't remember who said. It might have been one of the emergency team – effectively said, ‘If’, along the lines of, ‘if this continues we're going to have to –' what effective they were saying, ‘we'll probably have to section her a 136 and take her into hospital. Take her into A&E and then she's in hospital’ and I'm like, ‘Well wait a minute, ring us’. And that's when I went back to the police and said, ‘Okay you've rang once, you've not got an answer, so you're ringing the emergency team and the emergency teams going to take my mother into A&E, no… The control rooms or call centres, whatever each [Police] force refers to them, they will have protocols… Okay, what you do? What's your policy saying? Yeah and I bet they just, send them off to A&E.”

CC6	“So, we're getting home from work, and none of us have heard back from the paramedic going out. So, I go around to check on Grandad, and she's left us a note saying, ‘Everything seems fine, but I booked an ambulance to come and pick him up at six o'clock tonight and take him to the hospital, and we'll just check him over’. So, I rang the doctor, said, ‘You're not taking him to, you know, why do you think we got him up off the floor ourselves? Why do you think we asked you to come and do this? You're not taking him to hospital, cancel the ambulance’. They cancelled it and they said, you know, ‘We strongly advise him to go to the hospital’. And I said, ‘Can you tell me why? Give me a reason. I said I'm absolutely fine -- If you're saying to me he needs to go to the hospital and this is why, and this is what they'll do, then that's fine. I'm not taking to hospital if there's no reason for it’. And this was before pandemic, so I wasn't worried about COVID at the time, I don't want him in the hospital. And that's quite regular, that they will just be like, ‘Basically, we don't know what to do, we'll send him to hospital’, and it's for the daftest things… You know, and it's constant. And the first suggestion's when you raise something is hospital and then you have to be like, ‘No’. And then you have to justify why you don't want them to go. Like, ‘You justify to me why you want them to go’.
BC1	“…it was all done via the care home who contacted the doctor who said ‘Look’, you know, ‘we are now thinking of end-of-life care plan and as part of that end-of-life care plan, let’s have an agreement that unless it’s absolutely necessary, [husband] stays in the care home and he will be cared for and nursed in the care home’, which is what happened. And so there were two of three other – and in fact, at that point, when he had a couple of incidents, they managed to get the emergency care team out to him to come to the care home to provide, in one case he had to have some particular injection and they said provided this emergency team response team come out and do this, then he won’t need to go into A&E… But that was only, as I said to you, probably only in the last couple of months may be.”
BC10	“Erm, yeah, she just eventually hadn’t got up at all. She knew I was there, somebody was there, but that was it and then the final night, I got a call to say that she wouldn’t last the night. The doctor had been in they didn’t think it would be worth going to A&E because they couldn’t do anymore that the doctor who was there was doing. So, I was up there on Saturday, and she died like that night.”
BC14	“they were professionals that know a lot more about healthcare than I do – I know nothing about it, I can’t make those sort of decisions because I’m not a healthcare professional. So those you do know you hope are making the right decisions. It’s a guilt trip the whole way, isn’t it? You know, if it comes back to ok well, it’s you’re responsibility, you’re the daughter, and you make the wrong call – you know, you didn’t take her to A&E because she had a broken hip, and you know, everything you do gets laid back on you, that’s life.”
CC6	I think it does add weight, you know, when you say to them, you know, Grandad does have a Respect form in place and it's not his wishes to go to hospital, I think that's an easy way to have the conversation. It's less, it's less on you trying to justify and more like actually, I've got this document in place. And if they do read it, you know, then they will just magically come up with something else you can do instead of hospital. You know, considering hospital's supposed to be the last case scenario, it's amazing how many other scenarios, they come up with after you've said, you don't want to go to hospital.
BC2	“I’m not a nurse, my mother wants her body to go to science, I don’t want pressure sores, and you know, I’d like a visit, I need your [District Nurses] support. I’m an unpaid carer, for goodness’ sake! But after the first week, every day when they’d leave, they had been instructed to say you know, do we have to come back tomorrow basically. And I would say, well, yes please. And after they’d go, you know, I used to weep a lot because it just – why? Why?! When I’ve, you know, done so much, why at the end did they not want to come and give support and make sure my mother was alright. So that was an enormous disappointment.”
BC5	“So, he knew it was me without actually recognising me. And so, we were still able to have those really personal, intimate moments, which I wouldn’t have been able to have if I hadn’t have had all of these services and stuff at the end to support that… It helped me emotionally, which then helped to actually deal with that end process, to actually start to step away and accept that this is, you know, that this is going to happen. Yeah. I don’t think I’d have probably, I don’t think the services would have been as supportive if I’d managed to get some in the community without going into hospital first, I don’t think it would have been as supportive to be honest, because there wouldn’t have been so much of it. I think it would just because we’d just come out of hospital, knowing that this is a palliative route, that it’s going to be finite and that they then bombarded us with all these services you know, so there was hospice at home, the district nurses on hand if I needed them, 24/7 you know, there was no way I was going to access that sort of service if I was still in the community because they wouldn’t have put that in place for us.”

BC=Bereaved caregiver CC=Current caregiver; PWD=Person with dementia.

S6.3: Theme 3 – Taking dementia ‘seriously’

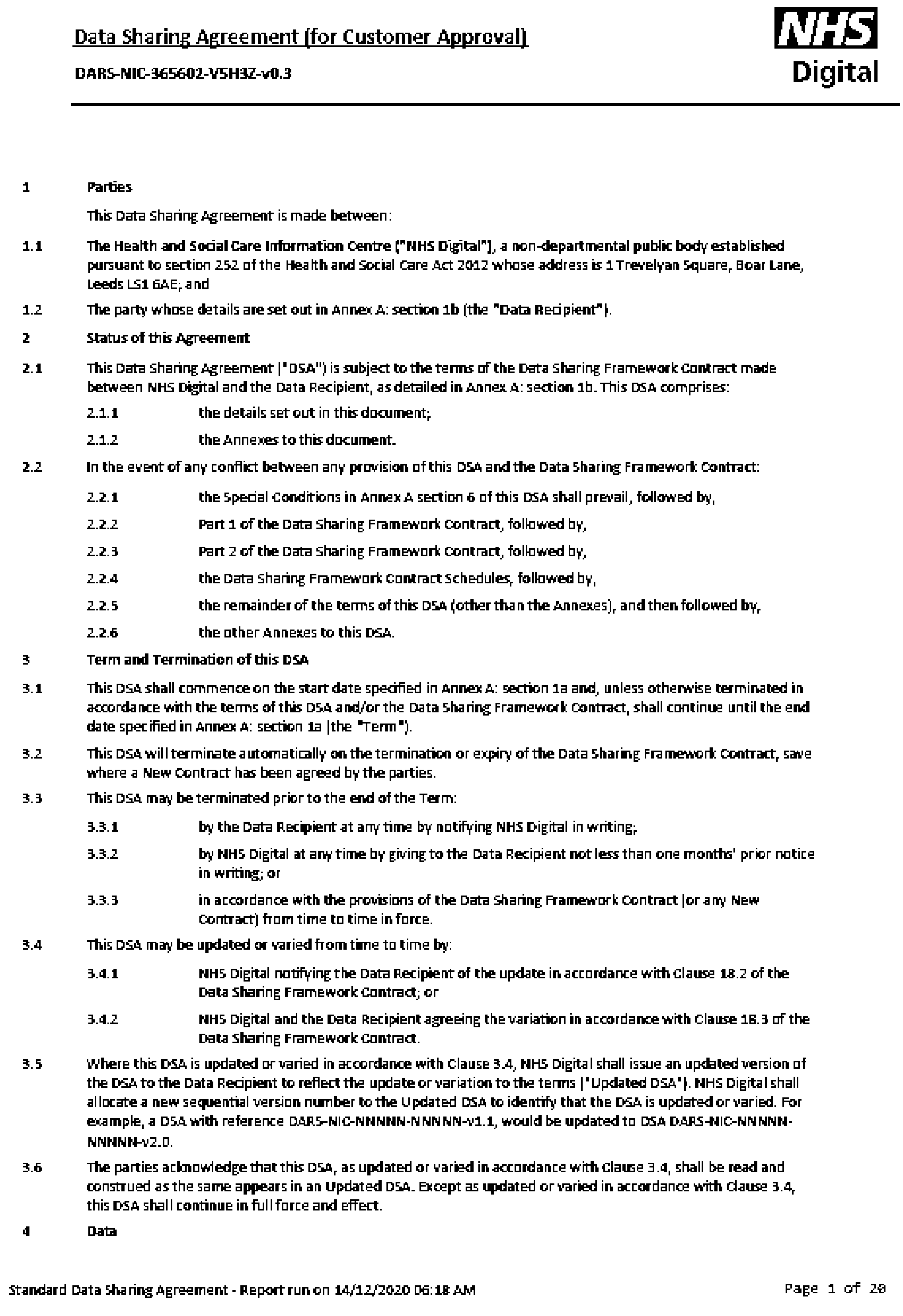
ID	Quote
PWD5	“Once they had, once they did all their things to confirm you have dementia, they said ‘We'll now discharge you to your GP’. But the GP, nobody bothers with you then… from the GP side, you've got dementia, you've got dementia. There's nothing I could do about it. So, I'll treat [name] down the road for ingrowing toenails… When you do have the questions, there's nobody to answer them even though they can answer them maybe. But it's nice to put the question. I really would like to know how long am I going to be like this? I know I don't know. I do well, I guess. It's awful. I hate the bloody disease. Sorry.”
BC12	“He was living with advanced dementia; I have a feeling people were just writing him off… I think that’s an attitude that’s there as well, that, [sighs], you don’t get that if somebody is fighting cancer, do you know what I mean? Erm, but you are getting it because you’re old and you’ve got dementia, well, what is there for you? And it’s as if people have no understanding about quality of life for people living with dementia, and you add that to the fact that they’ll see staff under huge pressures at the front, then you know, the front line, then [sighs], they probably got far more time for people that are going to have a better chance of a better life because they can intervene and can do something for them.”
PWD4	“And then the other thing I think is of interest, and I think is wrong, is that after I received my, it was in 2020 I received my diagnosis of dementia with [inaudible], and after I received my diagnosis I was discharged from the neurologist. So, the only medical health professional I'm under now is the Parkinson's nurse. And I've experienced that you get really good support and help with Parkinson's, but there's nothing for the dementia... And I think that's because Parkinson's comes under medical care and dementia comes under social care.”
CC5	“the medical side of things was psychiatry, and it doesn’t seem to fit with me in psychiatry somehow, it seems to be, you know, something more medical or somewhere in between the two perhaps, so that’s, yeah. It seems to be either psychiatry which is, just involved with the initial making that diagnosis and then back over to the GP care, which seems to be more health, you know, day-to-day, well, not it’s not actually, there’s a gap there I feel”
BC10	“But again, but when you ask the GP for help for those kinds of things, even though the GP was quite good, he’s pointing me back to the psychiatrist all the time, he’s saying ‘It’s a mental thing. It’s not a medical thing, it’s a mental thing’. So, you’re caught between the two of them and the psychiatrist said, ‘Oh well, did the doctor give you a diet sheet?’ and all this, I said ‘A diet sheet? She won’t’ eat anything, let alone a diet sheet.’ So, you’re back and forwards.”
CC6	“And it's spotting those little differences in their behaviour, get the antibiotic quick enough and you never escalate to the point where you're at crisis point and you have to go to hospital. The difficulty is that sometimes you get to the point, maybe you're not even at crisis point, but you bring your doctor and you say, you know, my person's falling, and they say, Yeah, they've got dementia, what do you want us to do? Which is very common.”
CC3	“I honest, I have to speak the God's honest truth at this point in this journey with my dad, I honestly think he's over 80 and he's got all those secondary complications with his health. I actually think he is a financial and a medical risk, and I think they give him a wide berth. That's what I genuinely feel. I've had two weeks of conversations to get the GP to come and visit my dad yesterday. I had eight phone call conversations expressing why I want you to come and see my dad. If this was another illness. If I was saying, ‘Look, my dad's passing blood’, you'd be there.”
CC10	“I'm talking to a psychologist tomorrow. [Name of participant]'s been involved in various pieces of research. There's a legal team that we can access if we need to. There's all sorts of things that are all neurological hospital.”
CC5	“…but in mum’s situation, as soon as she said she wasn’t going to have anything to do with medication, they dropped her. Completely. The memory clinic. They said ‘well, if you change your mind, you can always get back in touch with us.’ They didn’t say, oh we’ll review in six months’ time, or we’ll pop in and see you in six months, see how you’re getting on, there’s nothing. They said you can get back in touch with us via the GP if you want to. Hopeless!”
BC12	“if I’d had that sort of person, because whereas I could talk to [hospice], they were not the experts in dementia – if I could talk to an Admiral Nurse, they’re nurses, they will know a lot about people’s health, etc. But they also know a lot about dementia, and I think that’s the sort of expertise that we need locally to you know – I could have phoned them, and said I’m not happy about him and that might then prevent people from going to A&E. Erm, yeah, yeah. Particularly if they can then utilise the right people to go in and provide what’s necessary.”
CC1	“But, you know, I found that period particularly stressful because I was seeing my dad sort of almost self-harming really, that's what I'd draw a comparisons to. And I was being bounced between GPs and trying to go back to the memory service. And even though, even that the memory service nurse didn't seem to be getting it when I was talking to her. Even she wasn't getting it. And the only person that kind of stepped in and really helped me during that time with the Admiral Nurse because I have been kind of being battered about between the two health care professionals but not getting anywhere.”
PWD4	“And I certainly don't think there's enough support for caregivers out there. For people living with dementia, definitely not. So yes, Admiral Nurses, I think they are wonderful. We need many more of them. And they specialise in dementia. And they get us.”
BC12	“we haven’t got Admiral Nurses here, in [area], there are no Admiral Nurses, we know how much it’s going to cost, and we’re looking at if we can work with people like [charity] and so forth, we can raise funds to be able to have Admiral Nurses locally because that I see is, they’re experts in that field, we need that, and that would be very supportive to people. Now, it’s not going to be coming from the NHS, that’s for sure. It’s not a high priority for them, they’ve got to be spending money in other ways. The local authority won’t be bringing in any, you know, they haven’t got any money either. Erm, and nor, nor the right skills.”
PWD4	“I'm sorry, but to me dementia is damage to your brain, and it's a life limiting, terminal diagnosis. But it's not treated, you're not treated like that because -- I get nothing for my dementia. If I have any changes and I've noticed a few changes, I don't have a consultant I can get in touch with or I don't have an annual review or anything like that which I know, I am supposed to have an annual review about my dementia and medication. So yeah. And you know, somebody who has cancer, they, there's a clear pathway to go on. Same with my Parkinson's disease. But with dementia, there's nothing at all.”

BC5	“So even before he went into hospital and I said I was trying to keep him at home, and I’d spoken to the doctor to see could we get some palliative care for him, he sort of poo-pooed it and brushed it off and said, ‘Oh you know, the dementia nurse will be in’ and whatever, and so we didn’t have access to stuff.”
PWD6	“And that's when the doctor said, ‘Well on paper you don't need an operation because you've got dementia, you don't need -- what do you need a left hand for?’ [Pauses]. So it was that. Seeing the dementia not the person. It was so wrong it was unbelievable.”
PWD4	“So they put a butterfly to say that you have dementia. Now there's a flaw with the Butterfly scheme because it doesn't say at what stage of dementia you are. And I came out of recovery and I was taken to the ward and this nurse came up to me and she was, Talking. To. Me. Like. This. And I said, Why are you speaking to me strangely? And she said, Because you've got dementia. I said, Yes but I got early onset dementia. So I think the Butterfly scheme is a good initiative, but they need something extra to sort of say what stage of dementia you're at.”
PWD1	“I get lost in the hospital now. I can come out of a room after going in, and I don't know which way to go. I go to the ladies, and I don't know where the exit is. So, it’s things like having the words on the door, so you know where to go and things like that rather than -- the thing I don't understand, I was on one ward, and there was nothing really to sort of -- and then they've got a bus stop. And that was for dementia patients. I didn't understand that.”
BC12	“one doctor who came in, you know, in full PPE outfit, she came a couple of times, always convinced that he had a urine infection, and was insistent that I went and got a sample from him [laughs] and that, which was quite bizarre, and difficult! And, and, and that was it, ’oh he hasn’t got a urine infection, oh he must be alright’, you know, sort of and off she went. That was it. Erm, very strange. But weren’t listening to what I was saying about his coughing and not taking it any further than that, so I think there’s definitely something that says to me, we need to have more people around who actually know about dementia because it’s an increasing problem in this country with our age and demographics, etcetera, so we need more, more of that.”
BC14	“That people at the sharp end that people really do want to do, do care, and want to do a good job. They often fail but it’s not because they don’t intend to do a good job it’s just because there isn’t the staff, support, money, etc. for them to do it properly. People are still basically good.”
CC1	“I think it's a big ask, isn't it, to ask every GP to recognise, perhaps, that kind of thing. Because I suppose, most GP training, I think when you train as a GP, everything is probably around, there is there is a cause for this that's like, a physical cause for it, not perhaps something that's going on in the brain. And I mean, that's about a general practitioner, isn't it? That you're not expert in any particular field at that point, are you? When you're doing that job. You do have to have a very broad view of things. And maybe it's too much of an ask to add that onto a GP burden for them to also now become an expert in dementia and dementia behaviours and things, but I think with the projected rates of dementia that I'm reading about all the time, it's got to be a big part of their caseload, is people walking through the door, either concerning diagnosis or symptoms.”
BC1	“People with dementia get sent to A&E for issues that somebody of their age or old without dementia wouldn’t got to A&E for, because the dementia itself is a complicating factor and it makes whatever physical ailment they have worse, it makes it much more difficult to deal with, the dementia itself makes it more difficult to deal with the physical problem and I think a lot of it comes down to the people who are supporting that person, caring for them, not knowing how to deal with the two things together.”
PWD7	“…because dementia is becoming more of a thing now that people are recognising, a little bit more, then maybe they will put a little bit more into the training about things because. if you can put things in place for a disabled person or a person with a condition then you’ll help everybody. It's, it’s like clearing the ramp before you clear the steps. Because if you clear the ramp everyone can walk up the ramp, only the able bodied people can climb the steps. It’s one of those type of things.”
CC4	“so, I think there’s a stigma there, especially with people from my dad’s generation there’s that, you know, they’re ashamed a little bit or embarrassed a little bit, and you know… I mean he’s had lots of medical input and lots of operations and things over the years… so he’s used to nurses and people going in and out of the house, but I think to him that’s medical, whereas it’s more, I think he puts what’s with my mum, it’s more you know, more mental health issues, so he’s got a different compartment, so I suppose that’s a challenge for him…”
BC2	“…we were told not to come back; they didn’t like my mother’s language and the volunteers shouldn’t have to hear that and that she didn’t fit in and please don’t come back. So, I very much got the impression that with someone like my mother, it was like Mr Rochester’s wife in Jane Eyre, that they just had to be hidden away. And that wasn’t very nice, you know, my mother had always been very interested in people…”
PWD7	“you can say to somebody, well I have a diagnosis of Alzheimer's, well it is a ‘no, no, no, you sound perfectly fine to me’; ‘Oh, that happens to me, I do that all the time’. It’s a bit like gaslighting in a sense that they don’t take something seriously and that makes me just shut up, clam up and then I don’t talk about it as it is. I won’t say it’s insulting, but it is not given the seriousness that I think that the disease should have.”
PWD5	“What happened there was we used to go to the Dementia Cafe… But they wouldn't talk about dementia. They wouldn't -- well the last time I went, they said right, ‘Does anybody want to say something?’ I said, ‘Yes, could we amongst the people with dementia, can we discuss the dementia?’ Well, the partners, ‘Oh, no, no’. And I thought, well, what we here for? …I understand they can't give you a definite answer to your questions. But the fact that you're allowed to ask the question is a big thing.”
PWD8	“So half the group that I belong to would never tell anybody they've got dementia at all. As far as they're concerned, people don't need to know, and they get embarrassed by it because especially some of the men get embarrassed more than women do. In the early days I used to tell people, I used to be quite open about my dementia. Over the years, I realised that actually, that could be a bad thing because people do treat you differently if you tell them you have dementia. I don't think they want to, but they judgments are there. Whatever you do or what you say, it's human nature. So these days I'm careful about who I tell. If I feel like it's beneficial to me because of a bad day I might say something to somebody. But most times I go through life trying not to tell people unless I have to, because people do treat you differently unfortunately.”

BC=Bereaved caregiver CC=Current caregiver; PWD=Person with dementia.

Appendix D: Supplementary material for the epidemiological assessment

D1: NHS Digital and King’s College London Data Sharing Agreement



Data Sharing Agreement (for Customer Approval)

DARS-NIC-365602-V5H3Z-v0.3

NHS Digital

1 Parties

This Data Sharing Agreement is made between:

1.1 The Health and Social Care Information Centre ("NHS Digital"), a non-departmental public body established pursuant to section 252 of the Health and Social Care Act 2012 whose address is 1 Trevelyan Square, Boar Lane, Leeds LS1 6AE; and

1.2 The party whose details are set out in Annex A: section 1b (the "Data Recipient").

2 Status of this Agreement

2.1 This Data Sharing Agreement ("DSA") is subject to the terms of the Data Sharing Framework Contract made between NHS Digital and the Data Recipient, as detailed in Annex A: section 1b. This DSA comprises:

- 2.1.1 the details set out in this document;
- 2.1.2 the Annexes to this document.

2.2 In the event of any conflict between any provision of this DSA and the Data Sharing Framework Contract:

- 2.2.1 the Special Conditions in Annex A section 6 of this DSA shall prevail, followed by,
- 2.2.2 Part 1 of the Data Sharing Framework Contract, followed by,
- 2.2.3 Part 2 of the Data Sharing Framework Contract, followed by,
- 2.2.4 the Data Sharing Framework Contract Schedules, followed by,
- 2.2.5 the remainder of the terms of this DSA (other than the Annexes), and then followed by,
- 2.2.6 the other Annexes to this DSA.

3 Term and Termination of this DSA

3.1 This DSA shall commence on the start date specified in Annex A: section 1a and, unless otherwise terminated in accordance with the terms of this DSA and/or the Data Sharing Framework Contract, shall continue until the end date specified in Annex A: section 1a (the "Term").

3.2 This DSA will terminate automatically on the termination or expiry of the Data Sharing Framework Contract, save where a New Contract has been agreed by the parties.

3.3 This DSA may be terminated prior to the end of the Term:

- 3.3.1 by the Data Recipient at any time by notifying NHS Digital in writing;
- 3.3.2 by NHS Digital at any time by giving to the Data Recipient not less than one months' prior notice in writing; or
- 3.3.3 in accordance with the provisions of the Data Sharing Framework Contract (or any New Contract) from time to time in force.

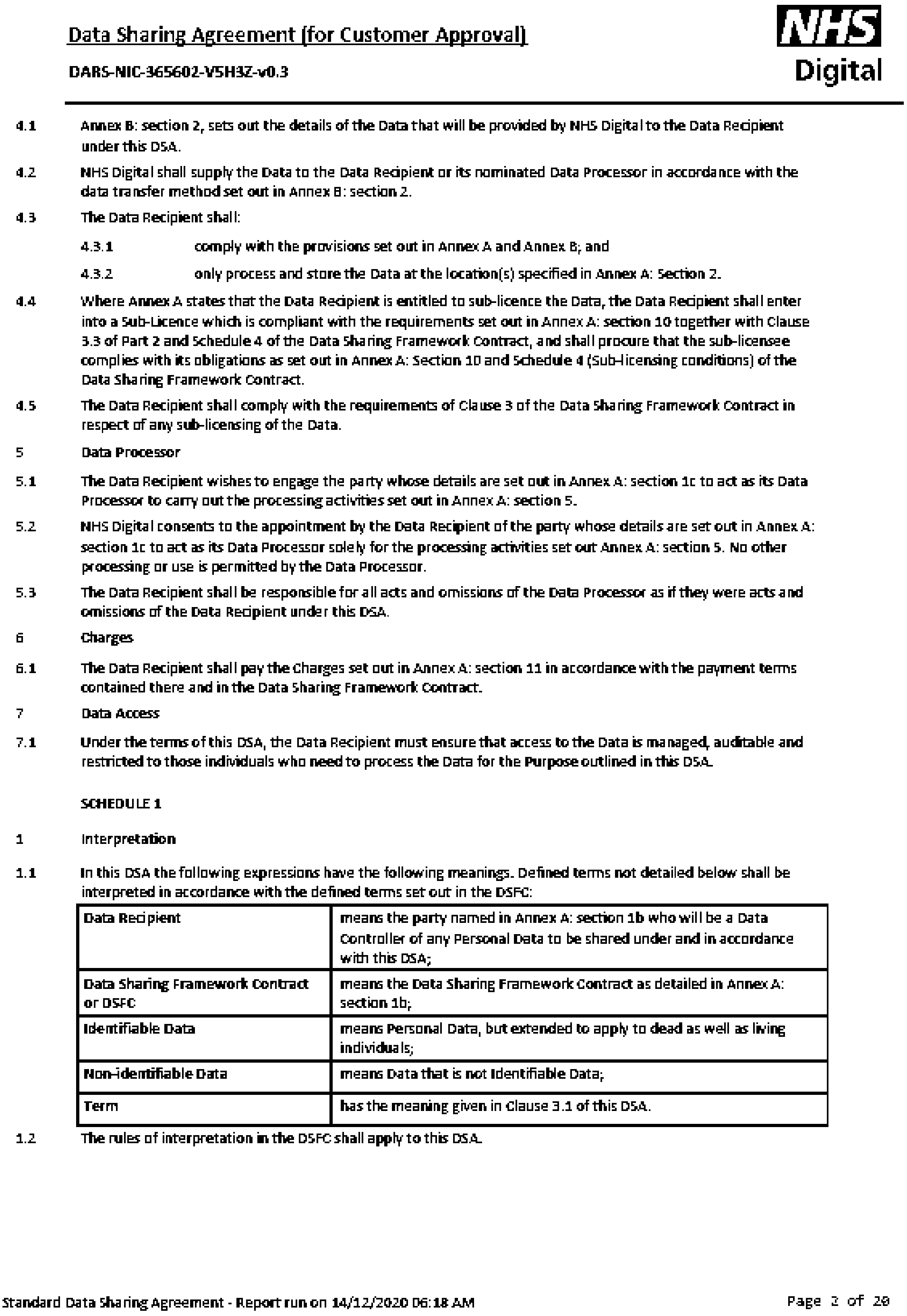
3.4 This DSA may be updated or varied from time to time by:

- 3.4.1 NHS Digital notifying the Data Recipient of the update in accordance with Clause 18.2 of the Data Sharing Framework Contract; or
- 3.4.2 NHS Digital and the Data Recipient agreeing the variation in accordance with Clause 18.3 of the Data Sharing Framework Contract.

3.5 Where this DSA is updated or varied in accordance with Clause 3.4, NHS Digital shall issue an updated version of the DSA to the Data Recipient to reflect the update or variation to the terms ("Updated DSA"). NHS Digital shall allocate a new sequential version number to the Updated DSA to identify that the DSA is updated or varied. For example, a DSA with reference DARS-NIC-NNNNN-NNNNN-v1.1, would be updated to DSA DARS-NIC-NNNNN-NNNNN-v2.0.

3.6 The parties acknowledge that this DSA, as updated or varied in accordance with Clause 3.4, shall be read and construed as the same appears in an Updated DSA. Except as updated or varied in accordance with Clause 3.4, this DSA shall continue in full force and effect.

4 Data



4.1 Annex B: section 2, sets out the details of the Data that will be provided by NHS Digital to the Data Recipient under this DSA.

4.2 NHS Digital shall supply the Data to the Data Recipient or its nominated Data Processor in accordance with the data transfer method set out in Annex B: section 2.

4.3 The Data Recipient shall:

- 4.3.1 comply with the provisions set out in Annex A and Annex B; and
- 4.3.2 only process and store the Data at the location(s) specified in Annex A: Section 2.

4.4 Where Annex A states that the Data Recipient is entitled to sub-licence the Data, the Data Recipient shall enter into a Sub-Licence which is compliant with the requirements set out in Annex A: section 10 together with Clause 3.3 of Part 2 and Schedule 4 of the Data Sharing Framework Contract, and shall procure that the sub-licensee complies with its obligations as set out in Annex A: Section 10 and Schedule 4 (Sub-licensing conditions) of the Data Sharing Framework Contract.

4.5 The Data Recipient shall comply with the requirements of Clause 3 of the Data Sharing Framework Contract in respect of any sub-licensing of the Data.

5 **Data Processor**

5.1 The Data Recipient wishes to engage the party whose details are set out in Annex A: section 1c to act as its Data Processor to carry out the processing activities set out in Annex A: section 5.

5.2 NHS Digital consents to the appointment by the Data Recipient of the party whose details are set out in Annex A: section 1c to act as its Data Processor solely for the processing activities set out Annex A: section 5. No other processing or use is permitted by the Data Processor.

5.3 The Data Recipient shall be responsible for all acts and omissions of the Data Processor as if they were acts and omissions of the Data Recipient under this DSA.

6 **Charges**

6.1 The Data Recipient shall pay the Charges set out in Annex A: section 11 in accordance with the payment terms contained there and in the Data Sharing Framework Contract.

7 **Data Access**

7.1 Under the terms of this DSA, the Data Recipient must ensure that access to the Data is managed, auditable and restricted to those individuals who need to process the Data for the Purpose outlined in this DSA.

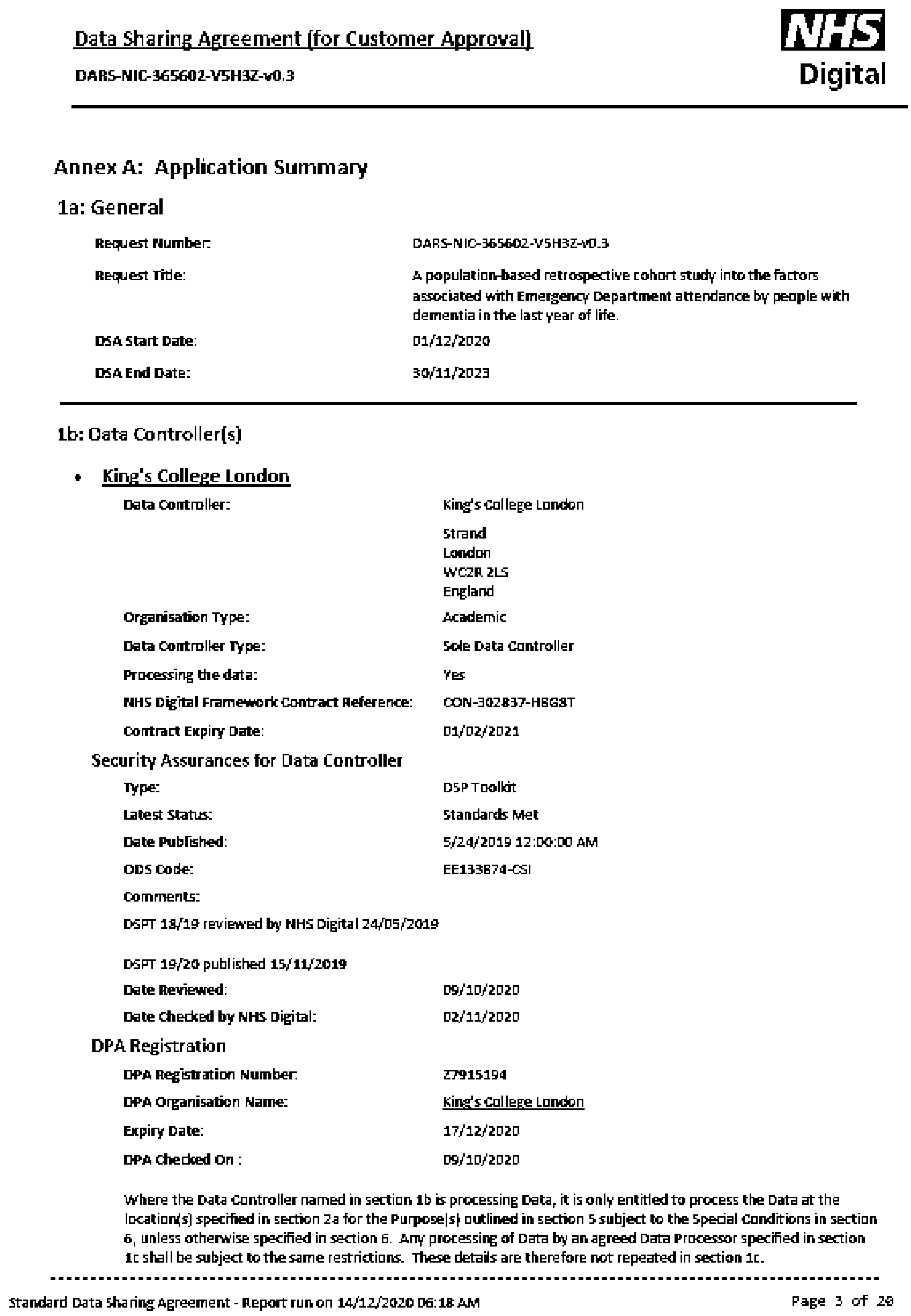
SCHEDULE 1

1 **Interpretation**

1.1 In this DSA the following expressions have the following meanings. Defined terms not detailed below shall be interpreted in accordance with the defined terms set out in the DSFC:

Data Recipient	means the party named in Annex A: section 1b who will be a Data Controller of any Personal Data to be shared under and in accordance with this DSA;
Data Sharing Framework Contract or DSFC	means the Data Sharing Framework Contract as detailed in Annex A: section 1b;
Identifiable Data	means Personal Data, but extended to apply to dead as well as living individuals;
Non-identifiable Data	means Data that is not Identifiable Data;
Term	has the meaning given in Clause 3.1 of this DSA.

1.2 The rules of interpretation in the DSFC shall apply to this DSA.



Data Sharing Agreement (for Customer Approval)

DARS-NIC-365602-V5H3Z-v0.3

Annex A: Application Summary

1a: General

Request Number:	DARS-NIC-365602-V5H3Z-v0.3
Request Title:	A population-based retrospective cohort study into the factors associated with Emergency Department attendance by people with dementia in the last year of life.
DSA Start Date:	01/12/2020
DSA End Date:	30/11/2023

1b: Data Controller(s)

- **King's College London**

Data Controller:	King's College London Strand London WC2R 2LS England
Organisation Type:	Academic
Data Controller Type:	Sole Data Controller
Processing the data:	Yes
NHS Digital Framework Contract Reference:	CON-302837-HBG8T
Contract Expiry Date:	01/02/2021

Security Assurances for Data Controller

Type:	DSP Toolkit
Latest Status:	Standards Met
Date Published:	5/24/2019 12:00:00 AM
ODS Code:	EE133874-CSI

Comments:

DSPT 18/19 reviewed by NHS Digital 24/05/2019

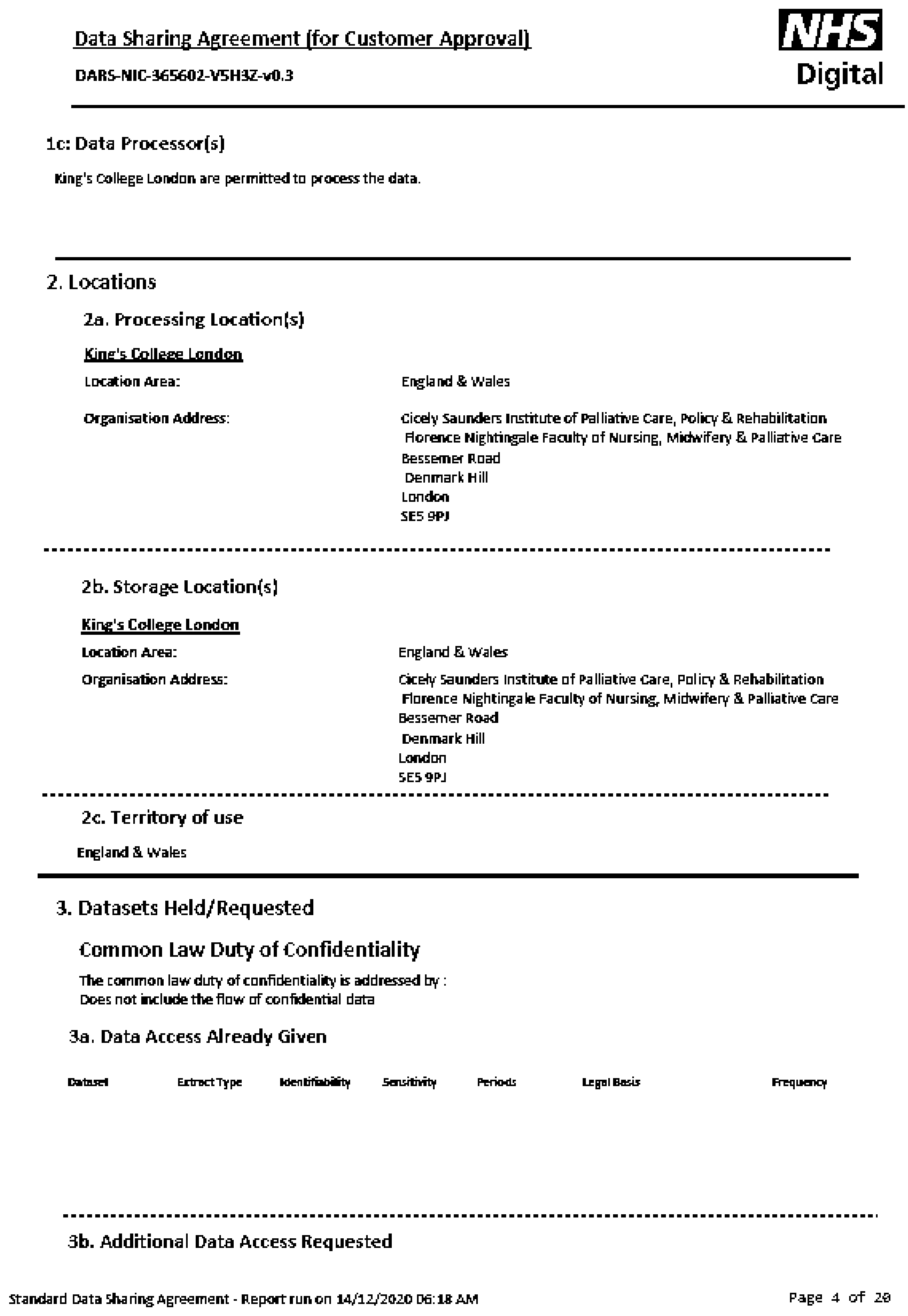
DSPT 19/20 published 15/11/2019

Date Reviewed:	09/10/2020
Date Checked by NHS Digital:	02/11/2020

DPA Registration

DPA Registration Number:	Z7915194
DPA Organisation Name:	King's College London
Expiry Date:	17/12/2020
DPA Checked On :	09/10/2020

Where the Data Controller named in section 1b is processing Data, it is only entitled to process the Data at the location(s) specified in section 2a for the Purpose(s) outlined in section 5 subject to the Special Conditions in section 6, unless otherwise specified in section 6. Any processing of Data by an agreed Data Processor specified in section 1c shall be subject to the same restrictions. These details are therefore not repeated in section 1c.



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NHS Digital

1c: Data Processor(s)

King's College London are permitted to process the data.

2. Locations

2a. Processing Location(s)

King's College London

Location Area:	England & Wales
Organisation Address:	Cicely Saunders Institute of Palliative Care, Policy & Rehabilitation Florence Nightingale Faculty of Nursing, Midwifery & Palliative Care Bessemer Road Denmark Hill London SE5 9PJ

2b. Storage Location(s)

King's College London

Location Area:	England & Wales
Organisation Address:	Cicely Saunders Institute of Palliative Care, Policy & Rehabilitation Florence Nightingale Faculty of Nursing, Midwifery & Palliative Care Bessemer Road Denmark Hill London SE5 9PJ

2c. Territory of use

England & Wales

3. Datasets Held/Requested

Common Law Duty of Confidentiality

The common law duty of confidentiality is addressed by :
Does not include the flow of confidential data

3a. Data Access Already Given

Dataset	Extract Type	Identifiability	Sensitivity	Periods	Legal Basis	Frequency

3b. Additional Data Access Requested

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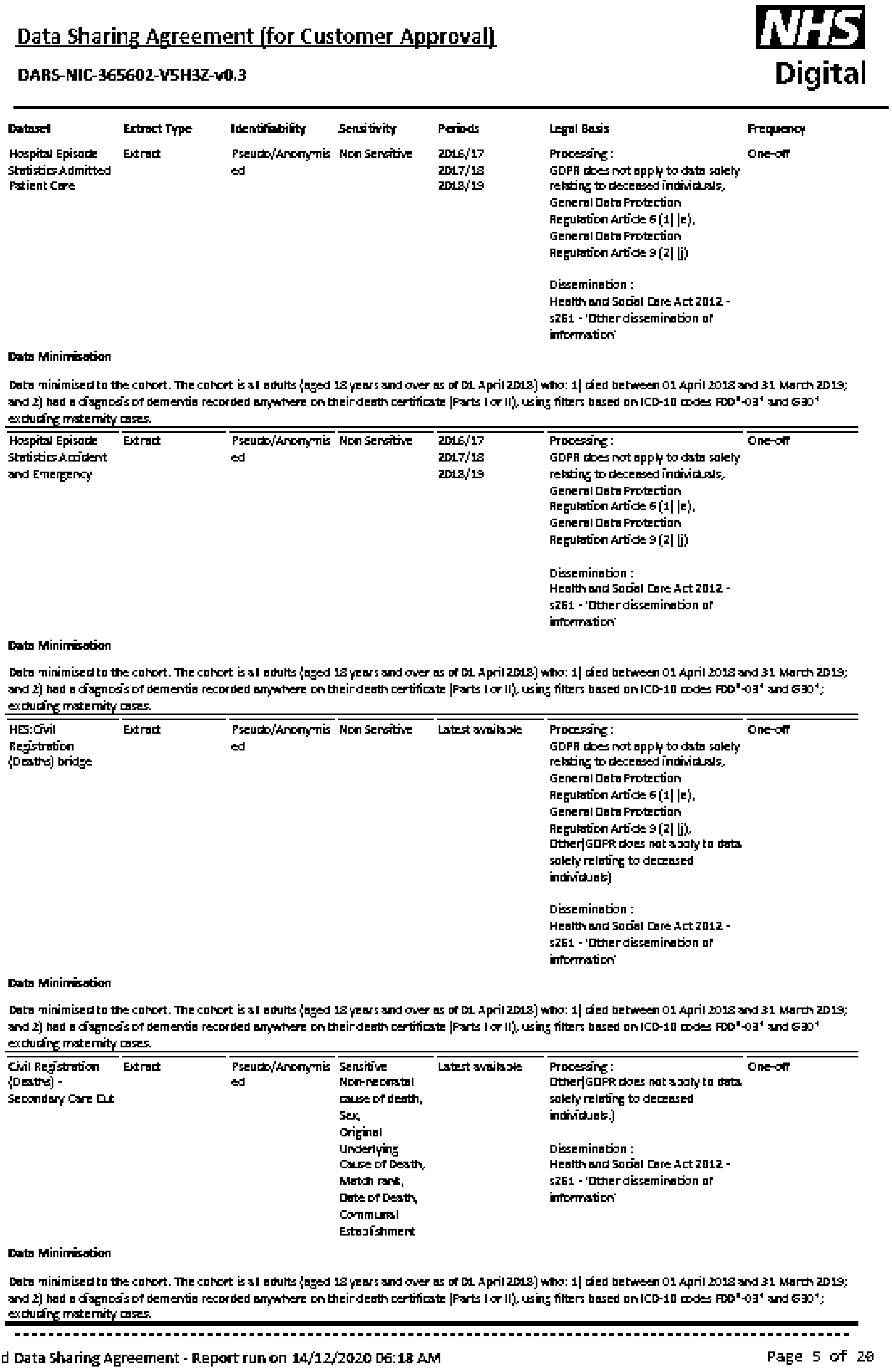

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Dataset	Extract Type	Identifiability	Sensitivity	Periods	Legal Basis	Frequency
Hospital Episode Statistics Admitted Patient Care	Extract	Pseudo/Anonymised	Non Sensitive	2016/17 2017/18 2018/19	Processing : GDPR does not apply to data solely relating to deceased individuals, General Data Protection Regulation Article 6 (1) (e), General Data Protection Regulation Article 9 (2) (j) Dissemination : Health and Social Care Act 2012 - s261 - 'Other dissemination of information'	One-off

Data Minimisation

Data minimised to the cohort. The cohort is all adults (aged 18 years and over as of 01 April 2018) who: 1) died between 01 April 2018 and 31 March 2019; and 2) had a diagnosis of dementia recorded anywhere on their death certificate (Parts I or II), using filters based on ICD-10 codes F00*-03* and G30* excluding maternity cases.

Hospital Episode Statistics Accident and Emergency	Extract	Pseudo/Anonymised	Non Sensitive	2016/17 2017/18 2018/19	Processing : GDPR does not apply to data solely relating to deceased individuals, General Data Protection Regulation Article 6 (1) (e), General Data Protection Regulation Article 9 (2) (j) Dissemination : Health and Social Care Act 2012 - s261 - 'Other dissemination of information'	One-off

Data Minimisation

Data minimised to the cohort. The cohort is all adults (aged 18 years and over as of 01 April 2018) who: 1) died between 01 April 2018 and 31 March 2019; and 2) had a diagnosis of dementia recorded anywhere on their death certificate (Parts I or II), using filters based on ICD-10 codes F00*-03* and G30*; excluding maternity cases.

HES:Civil Registration (Deaths) bridge	Extract	Pseudo/Anonymised	Non Sensitive	Latest available	Processing : GDPR does not apply to data solely relating to deceased individuals, General Data Protection Regulation Article 6 (1) (e), General Data Protection Regulation Article 9 (2) (j), Other(GDPR does not apply to data solely relating to deceased individuals) Dissemination : Health and Social Care Act 2012 - s261 - 'Other dissemination of information'	One-off

Data Minimisation

Data minimised to the cohort. The cohort is all adults (aged 18 years and over as of 01 April 2018) who: 1) died between 01 April 2018 and 31 March 2019; and 2) had a diagnosis of dementia recorded anywhere on their death certificate (Parts I or II), using filters based on ICD-10 codes F00*-03* and G30* excluding maternity cases.

Civil Registration (Deaths) - Secondary Care Cut	Extract	Pseudo/Anonymised	Sensitive Non-neonatal cause of death, Sex, Original Underlying Cause of Death, Match rank, Date of Death, Communal Establishment	Latest available	Processing : Other(GDPR does not apply to data solely relating to deceased individuals.) Dissemination : Health and Social Care Act 2012 - s261 - 'Other dissemination of information'	One-off

Data Minimisation

Data minimised to the cohort. The cohort is all adults (aged 18 years and over as of 01 April 2018) who: 1) died between 01 April 2018 and 31 March 2019; and 2) had a diagnosis of dementia recorded anywhere on their death certificate (Parts I or II), using filters based on ICD-10 codes F00*-03* and G30*; excluding maternity cases.

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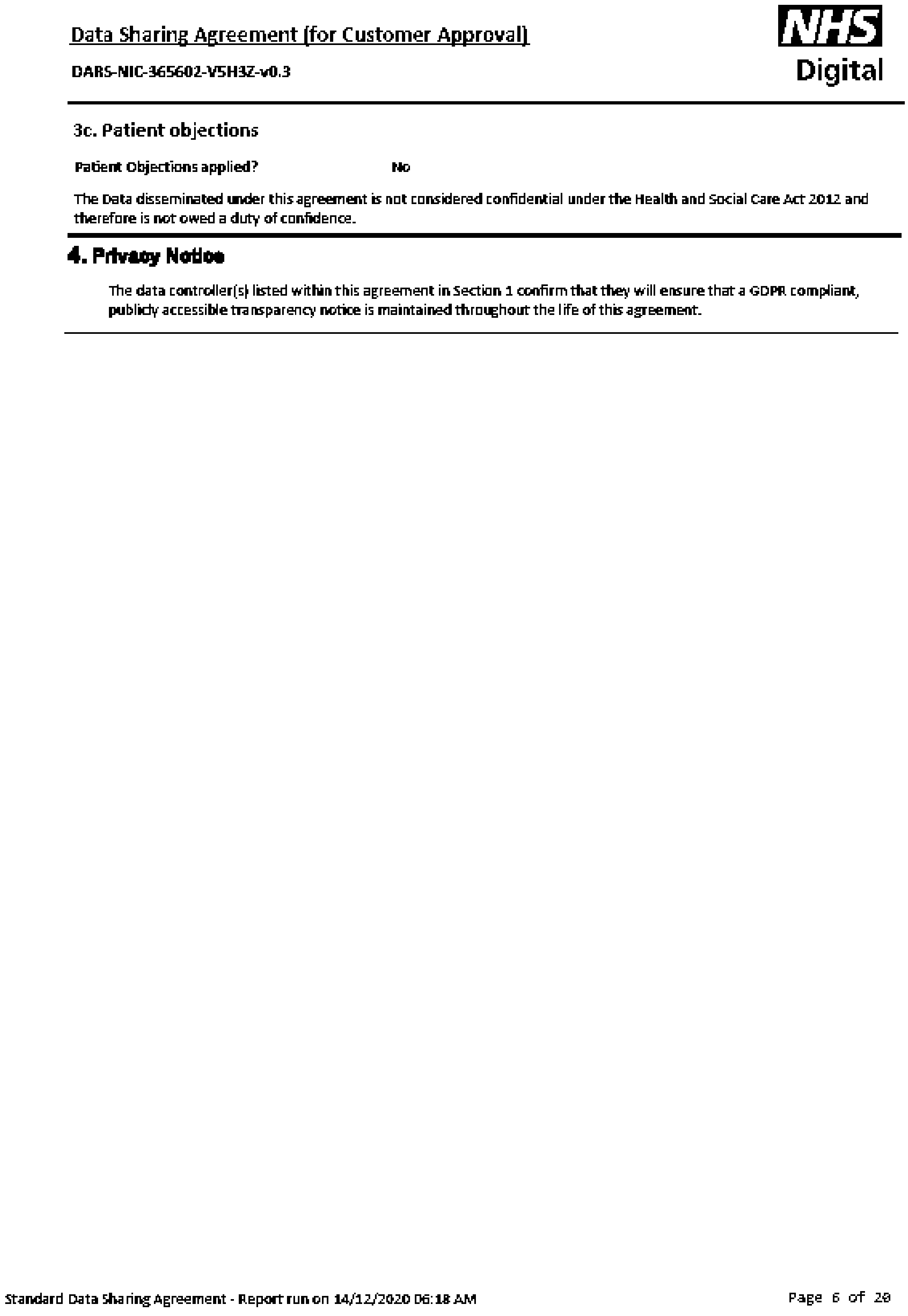

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3c. Patient objections

Patient Objections applied? **No**

The Data disseminated under this agreement is not considered confidential under the Health and Social Care Act 2012 and therefore is not owed a duty of confidence.

4. Privacy Notice

The data controller(s) listed within this agreement in Section 1 confirm that they will ensure that a GDPR compliant, publicly accessible transparency notice is maintained throughout the life of this agreement.

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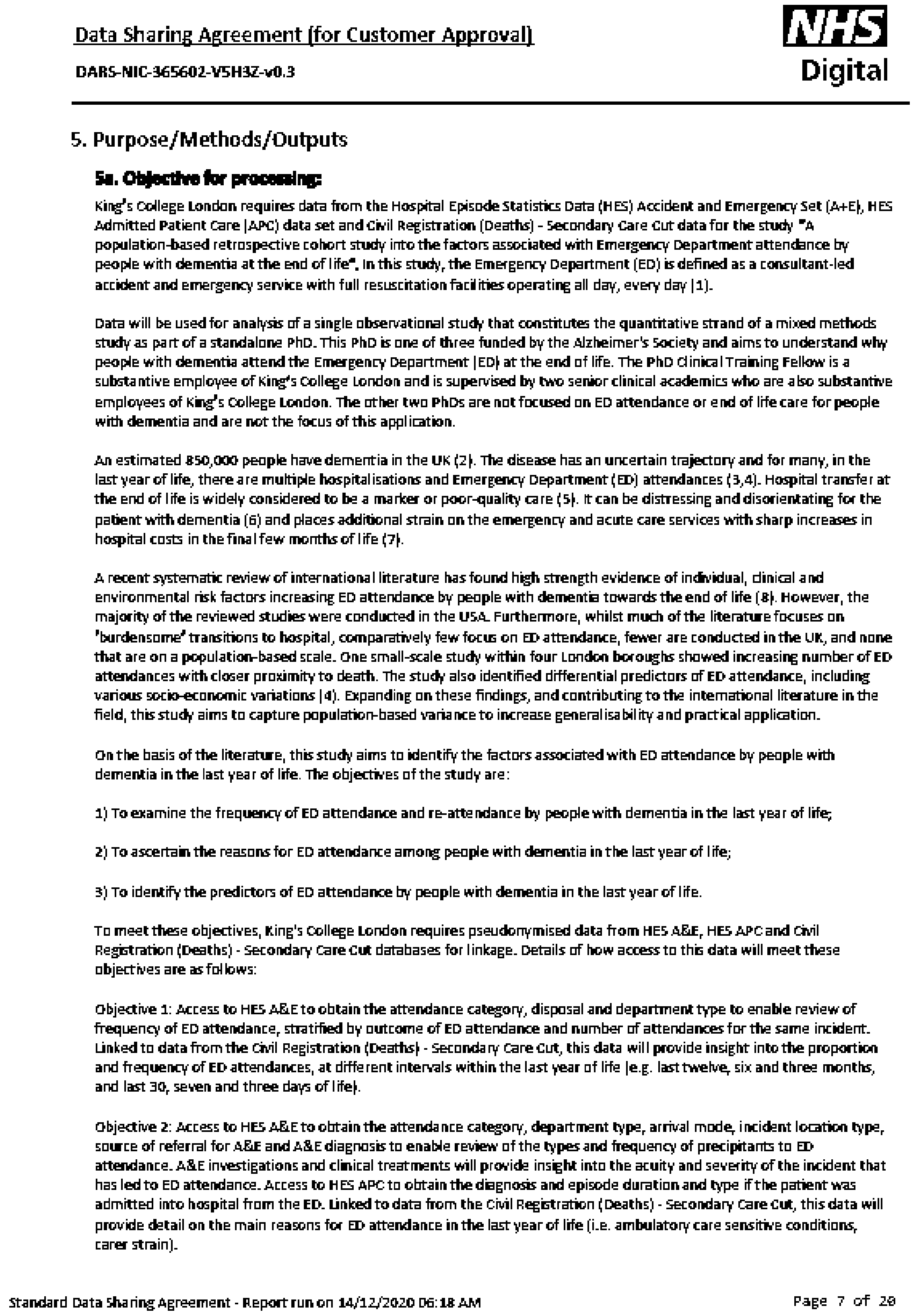

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5. Purpose/Methods/Outputs

5a. Objective for processing:

King's College London requires data from the Hospital Episode Statistics Data (HES) Accident and Emergency Set (A+E), HES Admitted Patient Care (APC) data set and Civil Registration (Deaths) - Secondary Care Cut data for the study "A population-based retrospective cohort study into the factors associated with Emergency Department attendance by people with dementia at the end of life". In this study, the Emergency Department (ED) is defined as a consultant-led accident and emergency service with full resuscitation facilities operating all day, every day (1).

Data will be used for analysis of a single observational study that constitutes the quantitative strand of a mixed methods study as part of a standalone PhD. This PhD is one of three funded by the Alzheimer's Society and aims to understand why people with dementia attend the Emergency Department (ED) at the end of life. The PhD Clinical Training Fellow is a substantive employee of King's College London and is supervised by two senior clinical academics who are also substantive employees of King's College London. The other two PhDs are not focused on ED attendance or end of life care for people with dementia and are not the focus of this application.

An estimated 850,000 people have dementia in the UK (2). The disease has an uncertain trajectory and for many, in the last year of life, there are multiple hospitalisations and Emergency Department (ED) attendances (3,4). Hospital transfer at the end of life is widely considered to be a marker or poor-quality care (5). It can be distressing and disorientating for the patient with dementia (6) and places additional strain on the emergency and acute care services with sharp increases in hospital costs in the final few months of life (7).

A recent systematic review of international literature has found high strength evidence of individual, clinical and environmental risk factors increasing ED attendance by people with dementia towards the end of life (8). However, the majority of the reviewed studies were conducted in the USA. Furthermore, whilst much of the literature focuses on 'burdensome' transitions to hospital, comparatively few focus on ED attendance, fewer are conducted in the UK, and none that are on a population-based scale. One small-scale study within four London boroughs showed increasing number of ED attendances with closer proximity to death. The study also identified differential predictors of ED attendance, including various socio-economic variations (4). Expanding on these findings, and contributing to the international literature in the field, this study aims to capture population-based variance to increase generalisability and practical application.

On the basis of the literature, this study aims to identify the factors associated with ED attendance by people with dementia in the last year of life. The objectives of the study are:

1) To examine the frequency of ED attendance and re-attendance by people with dementia in the last year of life;

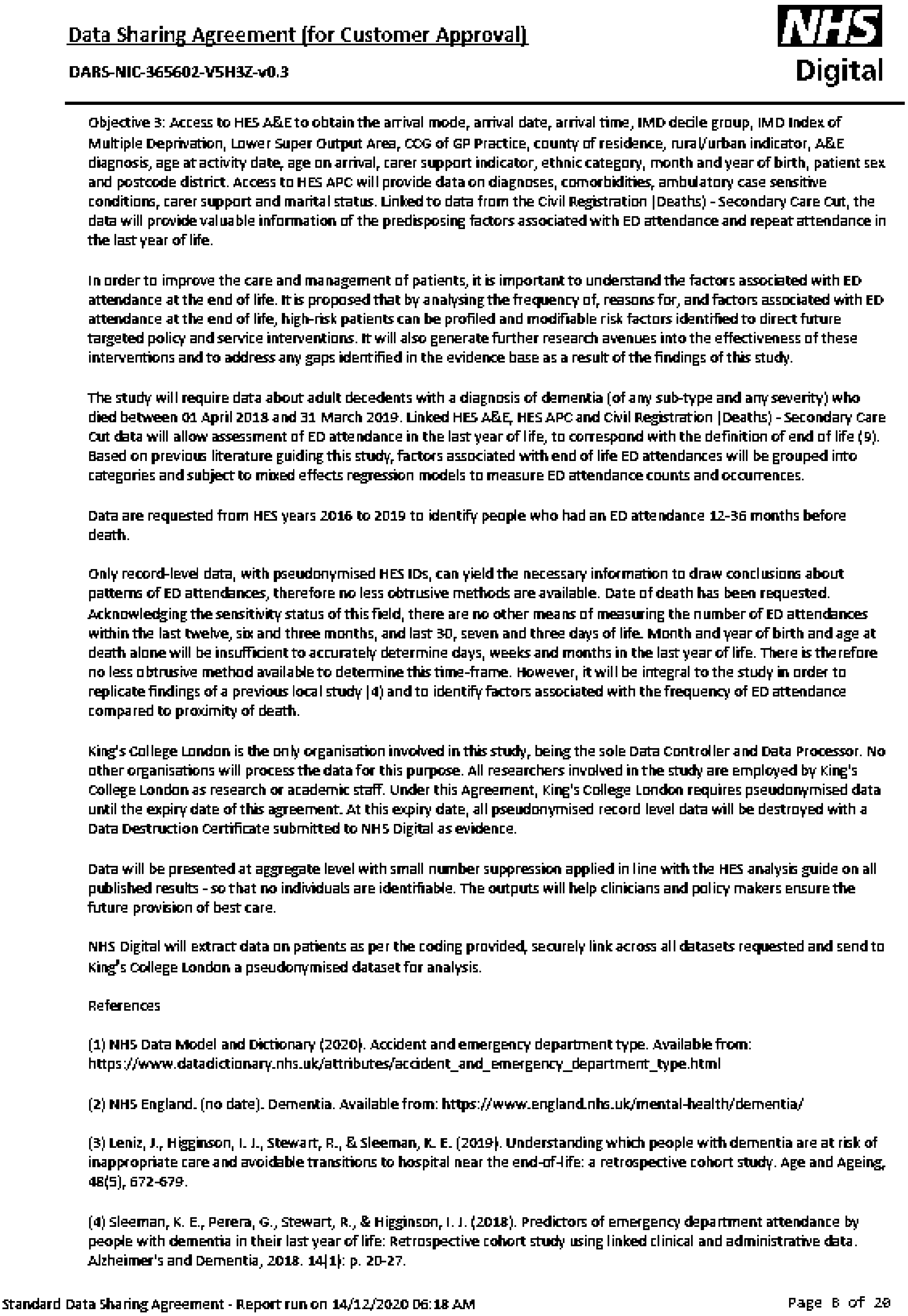
2) To ascertain the reasons for ED attendance among people with dementia in the last year of life;

3) To identify the predictors of ED attendance by people with dementia in the last year of life.

To meet these objectives, King's College London requires pseudonymised data from HES A&E, HES APC and Civil Registration (Deaths) - Secondary Care Cut databases for linkage. Details of how access to this data will meet these objectives are as follows:

Objective 1: Access to HES A&E to obtain the attendance category, disposal and department type to enable review of frequency of ED attendance, stratified by outcome of ED attendance and number of attendances for the same incident. Linked to data from the Civil Registration (Deaths) - Secondary Care Cut, this data will provide insight into the proportion and frequency of ED attendances, at different intervals within the last year of life (e.g. last twelve, six and three months, and last 30, seven and three days of life).

Objective 2: Access to HES A&E to obtain the attendance category, department type, arrival mode, incident location type, source of referral for A&E and A&E diagnosis to enable review of the types and frequency of precipitants to ED attendance. A&E investigations and clinical treatments will provide insight into the acuity and severity of the incident that has led to ED attendance. Access to HES APC to obtain the diagnosis and episode duration and type if the patient was admitted into hospital from the ED. Linked to data from the Civil Registration (Deaths) - Secondary Care Cut, this data will provide detail on the main reasons for ED attendance in the last year of life (i.e. ambulatory care sensitive conditions, carer strain).



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Objective 3: Access to HES A&E to obtain the arrival mode, arrival date, arrival time, IMD decile group, IMD Index of Multiple Deprivation, Lower Super Output Area, CCG of GP Practice, county of residence, rural/urban indicator, A&E diagnosis, age at activity date, age on arrival, carer support indicator, ethnic category, month and year of birth, patient sex and postcode district. Access to HES APC will provide data on diagnoses, comorbidities, ambulatory case sensitive conditions, carer support and marital status. Linked to data from the Civil Registration (Deaths) - Secondary Care Cut, the data will provide valuable information of the predisposing factors associated with ED attendance and repeat attendance in the last year of life.

In order to improve the care and management of patients, it is important to understand the factors associated with ED attendance at the end of life. It is proposed that by analysing the frequency of, reasons for, and factors associated with ED attendance at the end of life, high-risk patients can be profiled and modifiable risk factors identified to direct future targeted policy and service interventions. It will also generate further research avenues into the effectiveness of these interventions and to address any gaps identified in the evidence base as a result of the findings of this study.

The study will require data about adult decedents with a diagnosis of dementia (of any sub-type and any severity) who died between 01 April 2018 and 31 March 2019. Linked HES A&E, HES APC and Civil Registration (Deaths) - Secondary Care Cut data will allow assessment of ED attendance in the last year of life, to correspond with the definition of end of life (9). Based on previous literature guiding this study, factors associated with end of life ED attendances will be grouped into categories and subject to mixed effects regression models to measure ED attendance counts and occurrences.

Data are requested from HES years 2016 to 2019 to identify people who had an ED attendance 12-36 months before death.

Only record-level data, with pseudonymised HES IDs, can yield the necessary information to draw conclusions about patterns of ED attendances, therefore no less obtrusive methods are available. Date of death has been requested. Acknowledging the sensitivity status of this field, there are no other means of measuring the number of ED attendances within the last twelve, six and three months, and last 30, seven and three days of life. Month and year of birth and age at death alone will be insufficient to accurately determine days, weeks and months in the last year of life. There is therefore no less obtrusive method available to determine this time-frame. However, it will be integral to the study in order to replicate findings of a previous local study (4) and to identify factors associated with the frequency of ED attendance compared to proximity of death.

King's College London is the only organisation involved in this study, being the sole Data Controller and Data Processor. No other organisations will process the data for this purpose. All researchers involved in the study are employed by King's College London as research or academic staff. Under this Agreement, King's College London requires pseudonymised data until the expiry date of this agreement. At this expiry date, all pseudonymised record level data will be destroyed with a Data Destruction Certificate submitted to NHS Digital as evidence.

Data will be presented at aggregate level with small number suppression applied in line with the HES analysis guide on all published results - so that no individuals are identifiable. The outputs will help clinicians and policy makers ensure the future provision of best care.

NHS Digital will extract data on patients as per the coding provided, securely link across all datasets requested and send to King's College London a pseudonymised dataset for analysis.

References

(1) NHS Data Model and Dictionary (2020). Accident and emergency department type. Available from: https://www.datadictionary.nhs.uk/attributes/accident_and_emergency_department_type.html

(2) NHS England. (no date). Dementia. Available from: https://www.england.nhs.uk/mental-health/dementia/

(3) Leniz, J., Higginson, I. J., Stewart, R., & Sleeman, K. E. (2019). Understanding which people with dementia are at risk of inappropriate care and avoidable transitions to hospital near the end-of-life: a retrospective cohort study. Age and Ageing, 48(5), 672-679.

(4) Sleeman, K. E., Perera, G., Stewart, R., & Higginson, I. J. (2018). Predictors of emergency department attendance by people with dementia in their last year of life: Retrospective cohort study using linked clinical and administrative data. Alzheimer's and Dementia, 2018. 14(1): p. 20-27.

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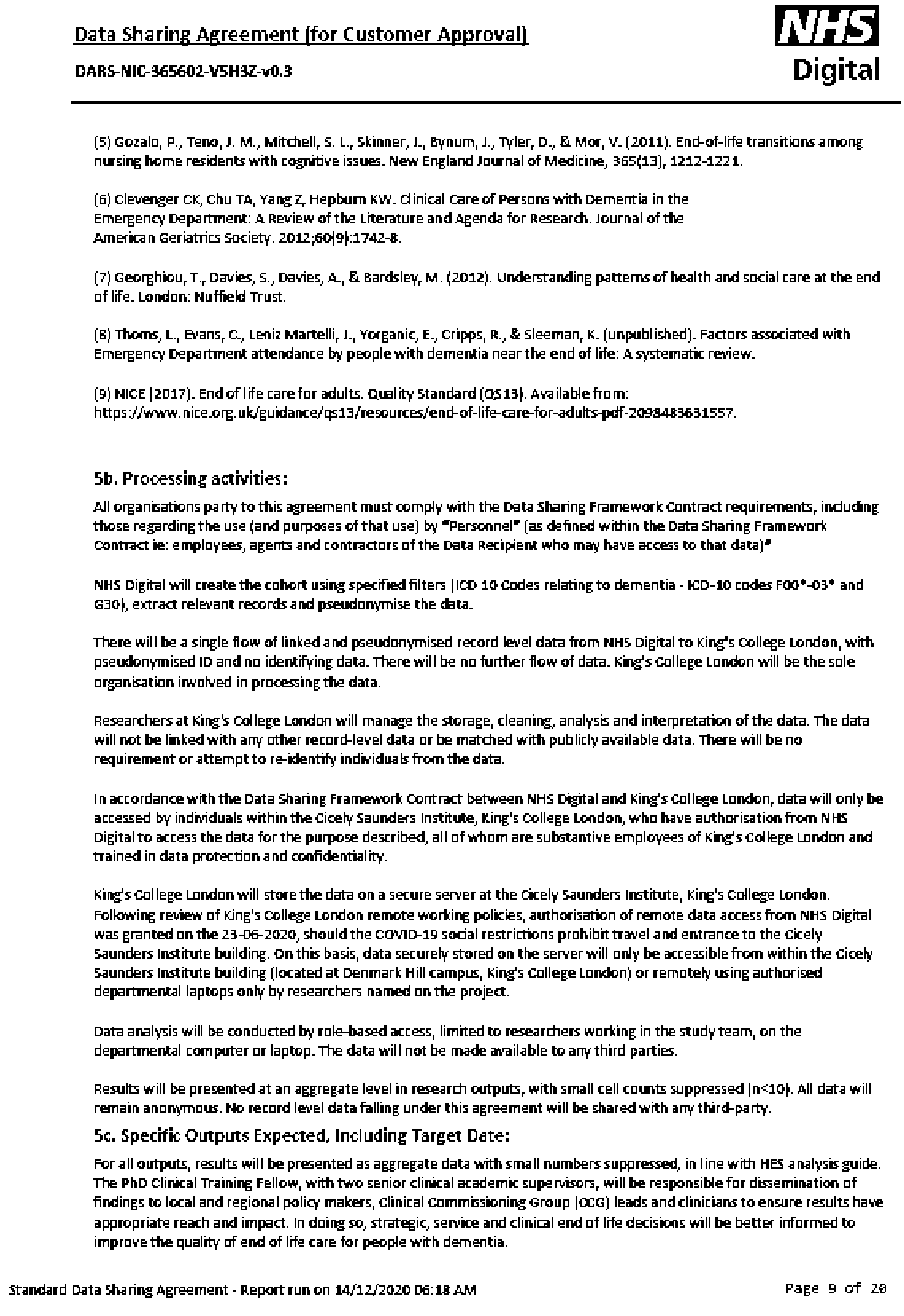


(5) Gozalo, P., Teno, J. M., Mitchell, S. L., Skinner, J., Bynum, J., Tyler, D., & Mor, V. (2011). End-of-life transitions among nursing home residents with cognitive issues. New England Journal of Medicine, 365(13), 1212-1221.

(6) Clevenger CK, Chu TA, Yang Z, Hepburn KW. Clinical Care of Persons with Dementia in the Emergency Department: A Review of the Literature and Agenda for Research. Journal of the American Geriatrics Society. 2012;60(9):1742-8.

(7) Georghiou, T., Davies, S., Davies, A., & Bardsley, M. (2012). Understanding patterns of health and social care at the end of life. London: Nuffield Trust.

(8) Thoms, L., Evans, C., Leniz Martelli, J., Yorganic, E., Cripps, R., & Sleeman, K. (unpublished). Factors associated with Emergency Department attendance by people with dementia near the end of life: A systematic review.

(9) NICE (2017). End of life care for adults. Quality Standard (QS13). Available from: https://www.nice.org.uk/guidance/qs13/resources/end-of-life-care-for-adults-pdf-2098483631557.

5b. Processing activities:

All organisations party to this agreement must comply with the Data Sharing Framework Contract requirements, including those regarding the use (and purposes of that use) by "Personnel" (as defined within the Data Sharing Framework Contract ie: employees, agents and contractors of the Data Recipient who may have access to that data)"

NHS Digital will create the cohort using specified filters (ICD 10 Codes relating to dementia - ICD-10 codes F00*-03* and G30), extract relevant records and pseudonymise the data.

There will be a single flow of linked and pseudonymised record level data from NHS Digital to King's College London, with pseudonymised ID and no identifying data. There will be no further flow of data. King's College London will be the sole organisation involved in processing the data.

Researchers at King's College London will manage the storage, cleaning, analysis and interpretation of the data. The data will not be linked with any other record-level data or be matched with publicly available data. There will be no requirement or attempt to re-identify individuals from the data.

In accordance with the Data Sharing Framework Contract between NHS Digital and King's College London, data will only be accessed by individuals within the Cicely Saunders Institute, King's College London, who have authorisation from NHS Digital to access the data for the purpose described, all of whom are substantive employees of King's College London and trained in data protection and confidentiality.

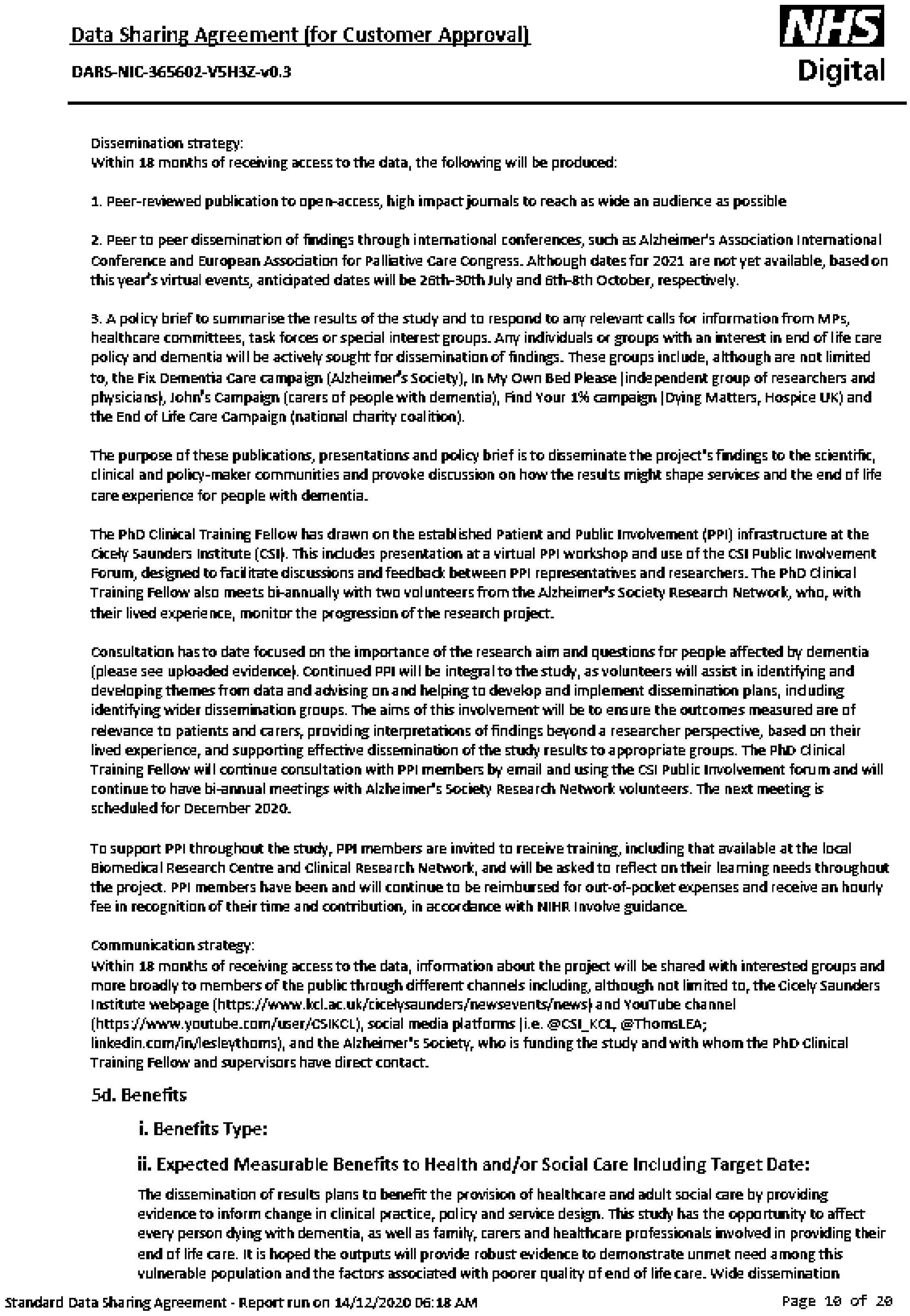
King's College London will store the data on a secure server at the Cicely Saunders Institute, King's College London. Following review of King's College London remote working policies, authorisation of remote data access from NHS Digital was granted on the 23-06-2020, should the COVID-19 social restrictions prohibit travel and entrance to the Cicely Saunders Institute building. On this basis, data securely stored on the server will only be accessible from within the Cicely Saunders Institute building (located at Denmark Hill campus, King's College London) or remotely using authorised departmental laptops only by researchers named on the project.

Data analysis will be conducted by role-based access, limited to researchers working in the study team, on the departmental computer or laptop. The data will not be made available to any third parties.

Results will be presented at an aggregate level in research outputs, with small cell counts suppressed (n<10). All data will remain anonymous. No record level data falling under this agreement will be shared with any third-party.

5c. Specific Outputs Expected, Including Target Date:

For all outputs, results will be presented as aggregate data with small numbers suppressed, in line with HES analysis guide. The PhD Clinical Training Fellow, with two senior clinical academic supervisors, will be responsible for dissemination of findings to local and regional policy makers, Clinical Commissioning Group (CCG) leads and clinicians to ensure results have appropriate reach and impact. In doing so, strategic, service and clinical end of life decisions will be better informed to improve the quality of end of life care for people with dementia.



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Dissemination strategy:
Within 18 months of receiving access to the data, the following will be produced:

1. Peer-reviewed publication to open-access, high impact journals to reach as wide an audience as possible

2. Peer to peer dissemination of findings through international conferences, such as Alzheimer's Association International Conference and European Association for Palliative Care Congress. Although dates for 2021 are not yet available, based on this year's virtual events, anticipated dates will be 26th-30th July and 6th-8th October, respectively.

3. A policy brief to summarise the results of the study and to respond to any relevant calls for information from MPs, healthcare committees, task forces or special interest groups. Any individuals or groups with an interest in end of life care policy and dementia will be actively sought for dissemination of findings. These groups include, although are not limited to, the Fix Dementia Care campaign (Alzheimer's Society), In My Own Bed Please (independent group of researchers and physicians), John's Campaign (carers of people with dementia), Find Your 1% campaign (Dying Matters, Hospice UK) and the End of Life Care Campaign (national charity coalition).

The purpose of these publications, presentations and policy brief is to disseminate the project's findings to the scientific, clinical and policy-maker communities and provoke discussion on how the results might shape services and the end of life care experience for people with dementia.

The PhD Clinical Training Fellow has drawn on the established Patient and Public Involvement (PPI) infrastructure at the Cicely Saunders Institute (CSI). This includes presentation at a virtual PPI workshop and use of the CSI Public Involvement Forum, designed to facilitate discussions and feedback between PPI representatives and researchers. The PhD Clinical Training Fellow also meets bi-annually with two volunteers from the Alzheimer's Society Research Network, who, with their lived experience, monitor the progression of the research project.

Consultation has to date focused on the importance of the research aim and questions for people affected by dementia (please see uploaded evidence). Continued PPI will be integral to the study, as volunteers will assist in identifying and developing themes from data and advising on and helping to develop and implement dissemination plans, including identifying wider dissemination groups. The aims of this involvement will be to ensure the outcomes measured are of relevance to patients and carers, providing interpretations of findings beyond a researcher perspective, based on their lived experience, and supporting effective dissemination of the study results to appropriate groups. The PhD Clinical Training Fellow will continue consultation with PPI members by email and using the CSI Public Involvement forum and will continue to have bi-annual meetings with Alzheimer's Society Research Network volunteers. The next meeting is scheduled for December 2020.

To support PPI throughout the study, PPI members are invited to receive training, including that available at the local Biomedical Research Centre and Clinical Research Network, and will be asked to reflect on their learning needs throughout the project. PPI members have been and will continue to be reimbursed for out-of-pocket expenses and receive an hourly fee in recognition of their time and contribution, in accordance with NIHR Involve guidance.

Communication strategy:
Within 18 months of receiving access to the data, information about the project will be shared with interested groups and more broadly to members of the public through different channels including, although not limited to, the Cicely Saunders Institute webpage (https://www.kcl.ac.uk/cicelysaunders/newsevents/news) and YouTube channel (https://www.youtube.com/user/CSIKCL), social media platforms (i.e. @CSI_KCL, @ThomsLEA; linkedin.com/in/lesleythoms), and the Alzheimer's Society, who is funding the study and with whom the PhD Clinical Training Fellow and supervisors have direct contact.

5d. Benefits

i. Benefits Type:

ii. Expected Measurable Benefits to Health and/or Social Care Including Target Date:

The dissemination of results plans to benefit the provision of healthcare and adult social care by providing evidence to inform change in clinical practice, policy and service design. This study has the opportunity to affect every person dying with dementia, as well as family, carers and healthcare professionals involved in providing their end of life care. It is hoped the outputs will provide robust evidence to demonstrate unmet need among this vulnerable population and the factors associated with poorer quality of end of life care. Wide dissemination

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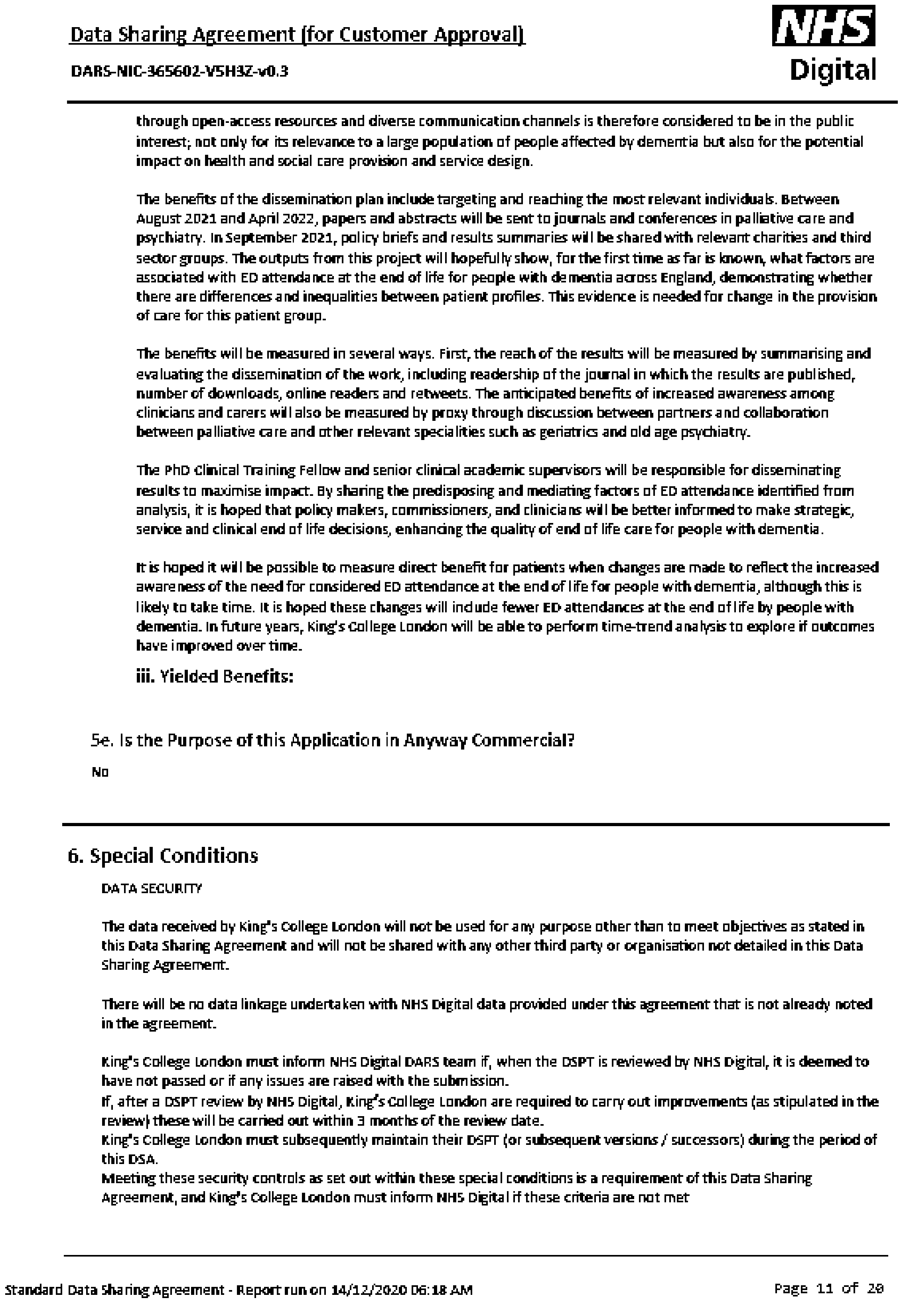

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through open-access resources and diverse communication channels is therefore considered to be in the public interest; not only for its relevance to a large population of people affected by dementia but also for the potential impact on health and social care provision and service design.

The benefits of the dissemination plan include targeting and reaching the most relevant individuals. Between August 2021 and April 2022, papers and abstracts will be sent to journals and conferences in palliative care and psychiatry. In September 2021, policy briefs and results summaries will be shared with relevant charities and third sector groups. The outputs from this project will hopefully show, for the first time as far is known, what factors are associated with ED attendance at the end of life for people with dementia across England, demonstrating whether there are differences and inequalities between patient profiles. This evidence is needed for change in the provision of care for this patient group.

The benefits will be measured in several ways. First, the reach of the results will be measured by summarising and evaluating the dissemination of the work, including readership of the journal in which the results are published, number of downloads, online readers and retweets. The anticipated benefits of increased awareness among clinicians and carers will also be measured by proxy through discussion between partners and collaboration between palliative care and other relevant specialities such as geriatrics and old age psychiatry.

The PhD Clinical Training Fellow and senior clinical academic supervisors will be responsible for disseminating results to maximise impact. By sharing the predisposing and mediating factors of ED attendance identified from analysis, it is hoped that policy makers, commissioners, and clinicians will be better informed to make strategic, service and clinical end of life decisions, enhancing the quality of end of life care for people with dementia.

It is hoped it will be possible to measure direct benefit for patients when changes are made to reflect the increased awareness of the need for considered ED attendance at the end of life for people with dementia, although this is likely to take time. It is hoped these changes will include fewer ED attendances at the end of life by people with dementia. In future years, King's College London will be able to perform time-trend analysis to explore if outcomes have improved over time.

iii. Yielded Benefits:

5e. Is the Purpose of this Application in Anyway Commercial?

No

6. Special Conditions

DATA SECURITY

The data received by King's College London will not be used for any purpose other than to meet objectives as stated in this Data Sharing Agreement and will not be shared with any other third party or organisation not detailed in this Data Sharing Agreement.

There will be no data linkage undertaken with NHS Digital data provided under this agreement that is not already noted in the agreement.

King's College London must inform NHS Digital DARS team if, when the DSPT is reviewed by NHS Digital, it is deemed to have not passed or if any issues are raised with the submission.
If, after a DSPT review by NHS Digital, King's College London are required to carry out improvements (as stipulated in the review) these will be carried out within 3 months of the review date.
King's College London must subsequently maintain their DSPT (or subsequent versions / successors) during the period of this DSA.
Meeting these security controls as set out within these special conditions is a requirement of this Data Sharing Agreement, and King's College London must inform NHS Digital if these criteria are not met

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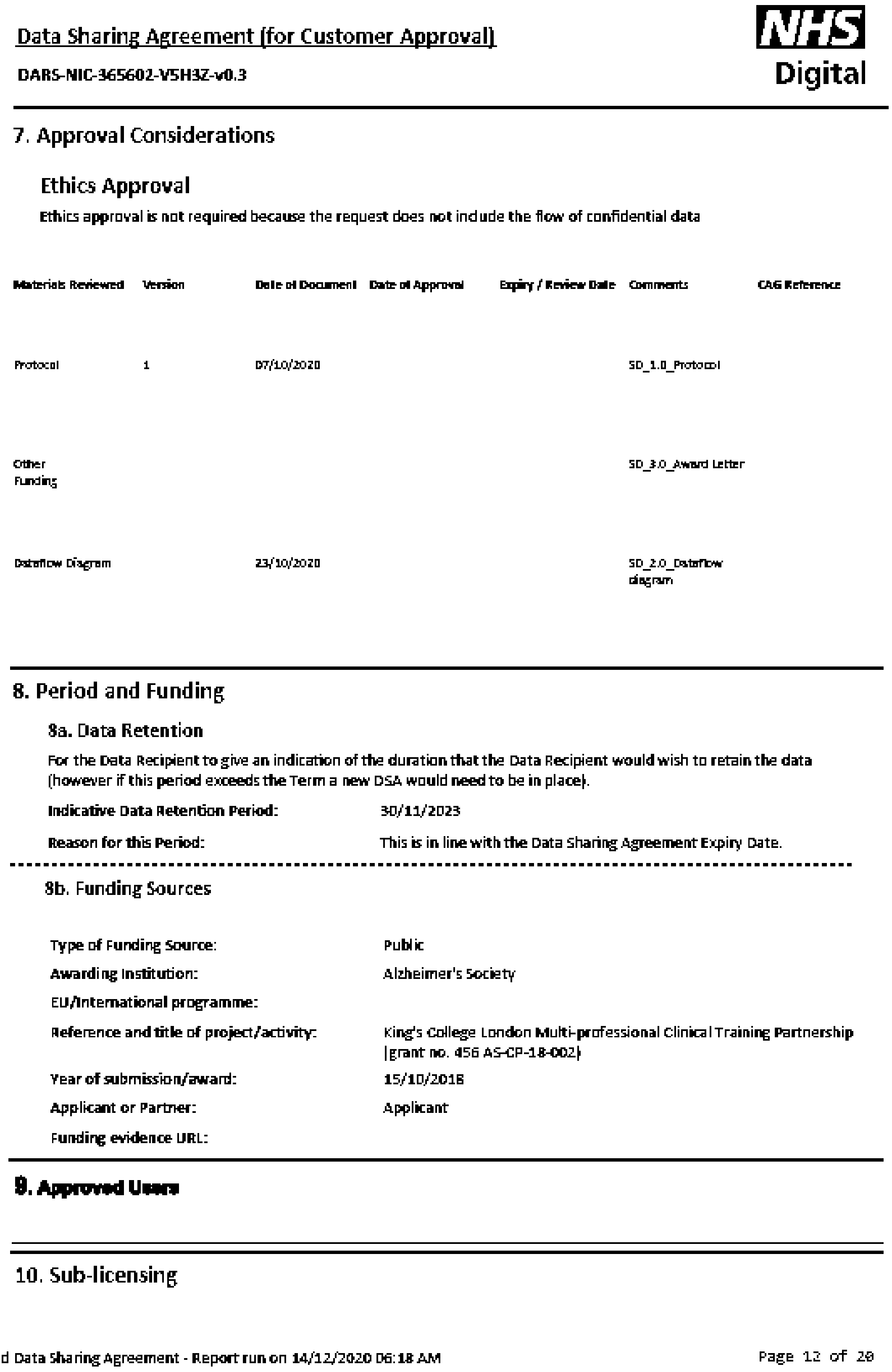


7. Approval Considerations

Ethics Approval

Ethics approval is not required because the request does not include the flow of confidential data

Materials Reviewed	Version	Date of Document	Date of Approval	Expiry / Review Date	Comments	CAG Reference
Protocol	1	07/10/2020			SD_1.0_Protocol	
Other Funding					SD_3.0_Award Letter	
Dataflow Diagram		23/10/2020			SD_2.0_Dataflow diagram	

8. Period and Funding

8a. Data Retention

For the Data Recipient to give an indication of the duration that the Data Recipient would wish to retain the data (however if this period exceeds the Term a new DSA would need to be in place).

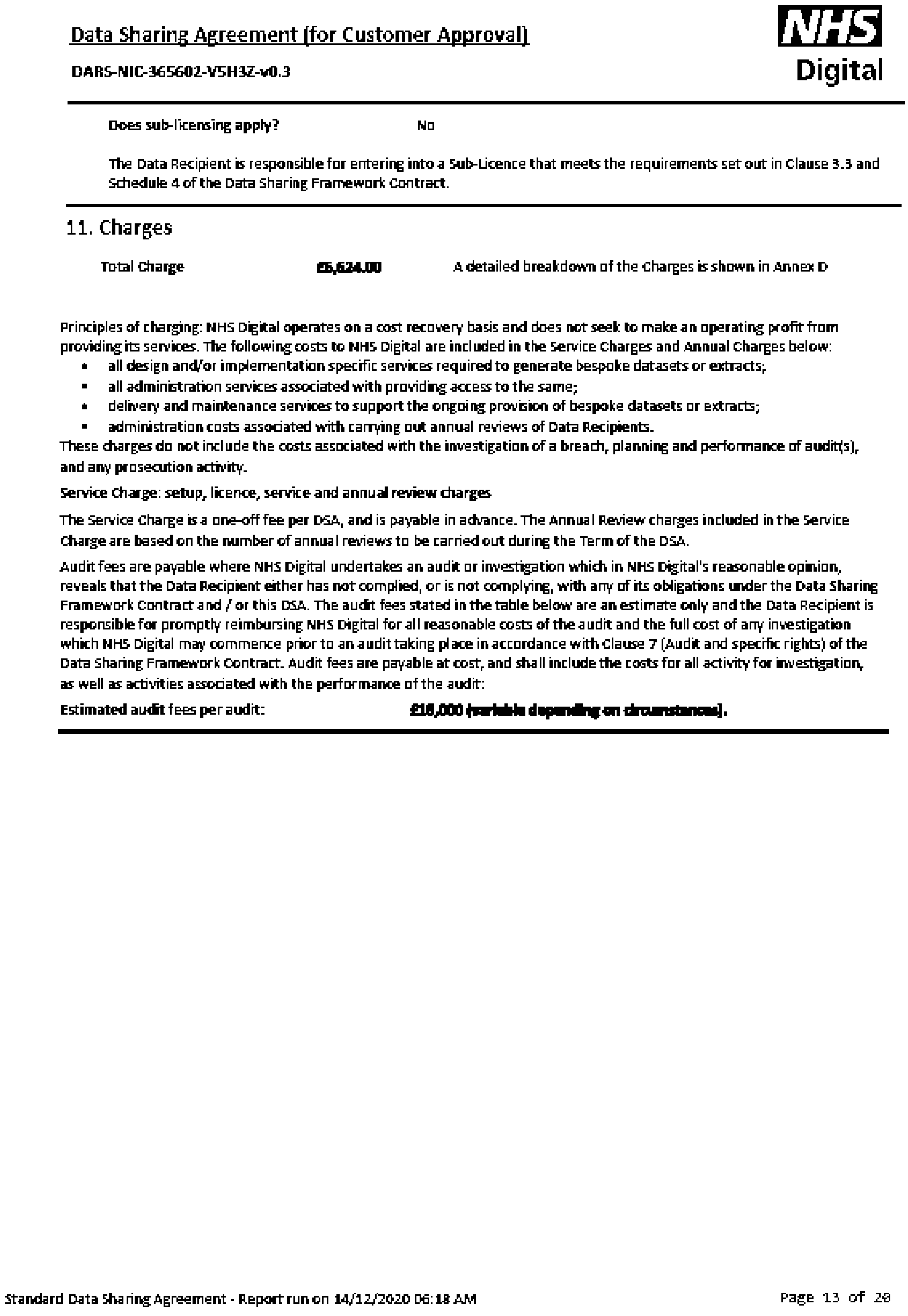
Indicative Data Retention Period:	30/11/2023
Reason for this Period:	This is in line with the Data Sharing Agreement Expiry Date.

8b. Funding Sources

Type of Funding Source:	Public
Awarding Institution:	Alzheimer's Society
EU/International programme:	
Reference and title of project/activity:	King's College London Multi-professional Clinical Training Partnership (grant no. 456 AS-CP-18-002)
Year of submission/award:	15/10/2018
Applicant or Partner:	Applicant
Funding evidence URL:	

9. Approved Users

10. Sub-licensing



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Does sub-licensing apply?	No

The Data Recipient is responsible for entering into a Sub-Licence that meets the requirements set out in Clause 3.3 and Schedule 4 of the Data Sharing Framework Contract.

11. Charges

Total Charge	**£6,624.00**	A detailed breakdown of the Charges is shown in Annex D

Principles of charging: NHS Digital operates on a cost recovery basis and does not seek to make an operating profit from providing its services. The following costs to NHS Digital are included in the Service Charges and Annual Charges below:

- all design and/or implementation specific services required to generate bespoke datasets or extracts;
- all administration services associated with providing access to the same;
- delivery and maintenance services to support the ongoing provision of bespoke datasets or extracts;
- administration costs associated with carrying out annual reviews of Data Recipients.

These charges do not include the costs associated with the investigation of a breach, planning and performance of audit(s), and any prosecution activity.

Service Charge: setup, licence, service and annual review charges

The Service Charge is a one-off fee per DSA, and is payable in advance. The Annual Review charges included in the Service Charge are based on the number of annual reviews to be carried out during the Term of the DSA.

Audit fees are payable where NHS Digital undertakes an audit or investigation which in NHS Digital's reasonable opinion, reveals that the Data Recipient either has not complied, or is not complying, with any of its obligations under the Data Sharing Framework Contract and / or this DSA. The audit fees stated in the table below are an estimate only and the Data Recipient is responsible for promptly reimbursing NHS Digital for all reasonable costs of the audit and the full cost of any investigation which NHS Digital may commence prior to an audit taking place in accordance with Clause 7 (Audit and specific rights) of the Data Sharing Framework Contract. Audit fees are payable at cost, and shall include the costs for all activity for investigation, as well as activities associated with the performance of the audit:

Estimated audit fees per audit:	**£18,000 (variable depending on circumstances).**

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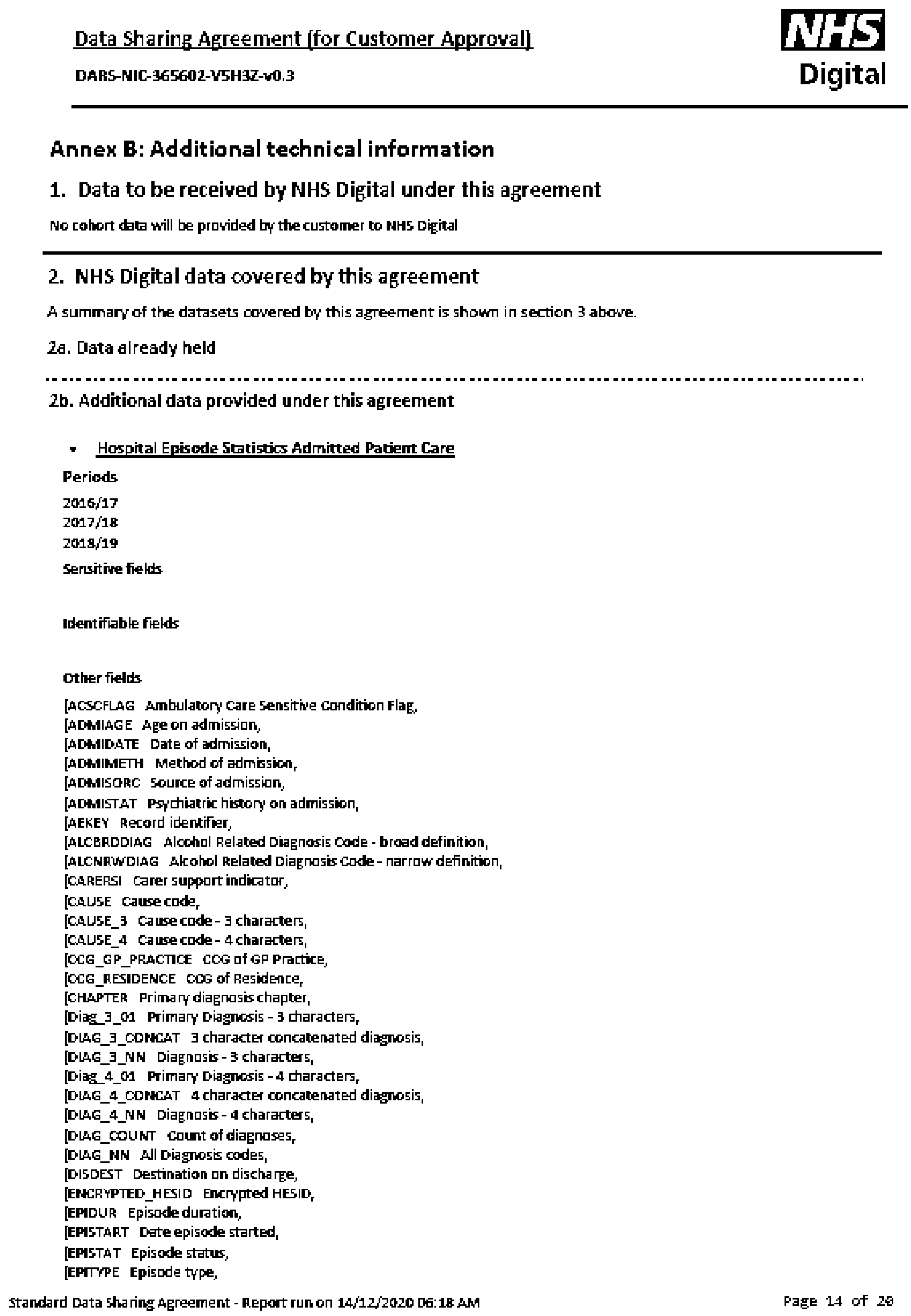

Data Sharing Agreement (for Customer Approval)

DARS-NIC-365602-V5H3Z-v0.3

NHS Digital

Annex B: Additional technical information

1. Data to be received by NHS Digital under this agreement

No cohort data will be provided by the customer to NHS Digital

2. NHS Digital data covered by this agreement

A summary of the datasets covered by this agreement is shown in section 3 above.

2a. Data already held

2b. Additional data provided under this agreement

- Hospital Episode Statistics Admitted Patient Care

Periods

2016/17
2017/18
2018/19

Sensitive fields

Identifiable fields

Other fields

[ACSCFLAG Ambulatory Care Sensitive Condition Flag,
[ADMIAGE Age on admission,
[ADMIDATE Date of admission,
[ADMIMETH Method of admission,
[ADMISORC Source of admission,
[ADMISTAT Psychiatric history on admission,
[AEKEY Record identifier,
[ALCBRDDIAG Alcohol Related Diagnosis Code - broad definition,
[ALCNRWDIAG Alcohol Related Diagnosis Code - narrow definition,
[CARERSI Carer support indicator,
[CAUSE Cause code,
[CAUSE_3 Cause code - 3 characters,
[CAUSE_4 Cause code - 4 characters,
[CCG_GP_PRACTICE CCG of GP Practice,
[CCG_RESIDENCE CCG of Residence,
[CHAPTER Primary diagnosis chapter,
[Diag_3_01 Primary Diagnosis - 3 characters,
[DIAG_3_CONCAT 3 character concatenated diagnosis,
[DIAG_3_NN Diagnosis - 3 characters,
[Diag_4_01 Primary Diagnosis - 4 characters,
[DIAG_4_CONCAT 4 character concatenated diagnosis,
[DIAG_4_NN Diagnosis - 4 characters,
[DIAG_COUNT Count of diagnoses,
[DIAG_NN All Diagnosis codes,
[DISDEST Destination on discharge,
[ENCRYPTED_HESID Encrypted HESID,
[EPIDUR Episode duration,
[EPISTART Date episode started,
[EPISTAT Episode status,
[EPITYPE Episode type,

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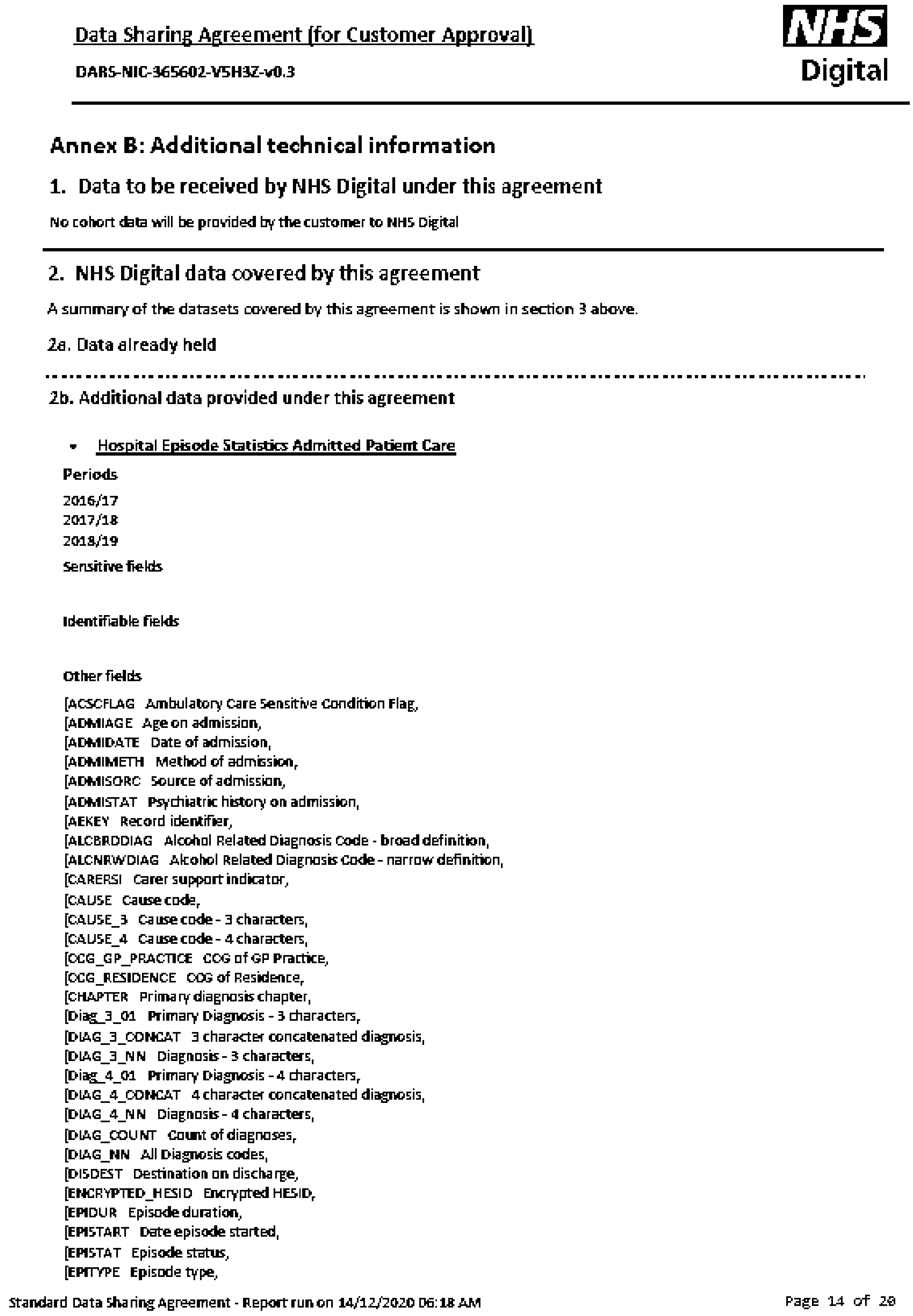

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[CHAPTER Primary diagnosis chapter,
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[DIAG_3_NN Diagnosis - 3 characters,
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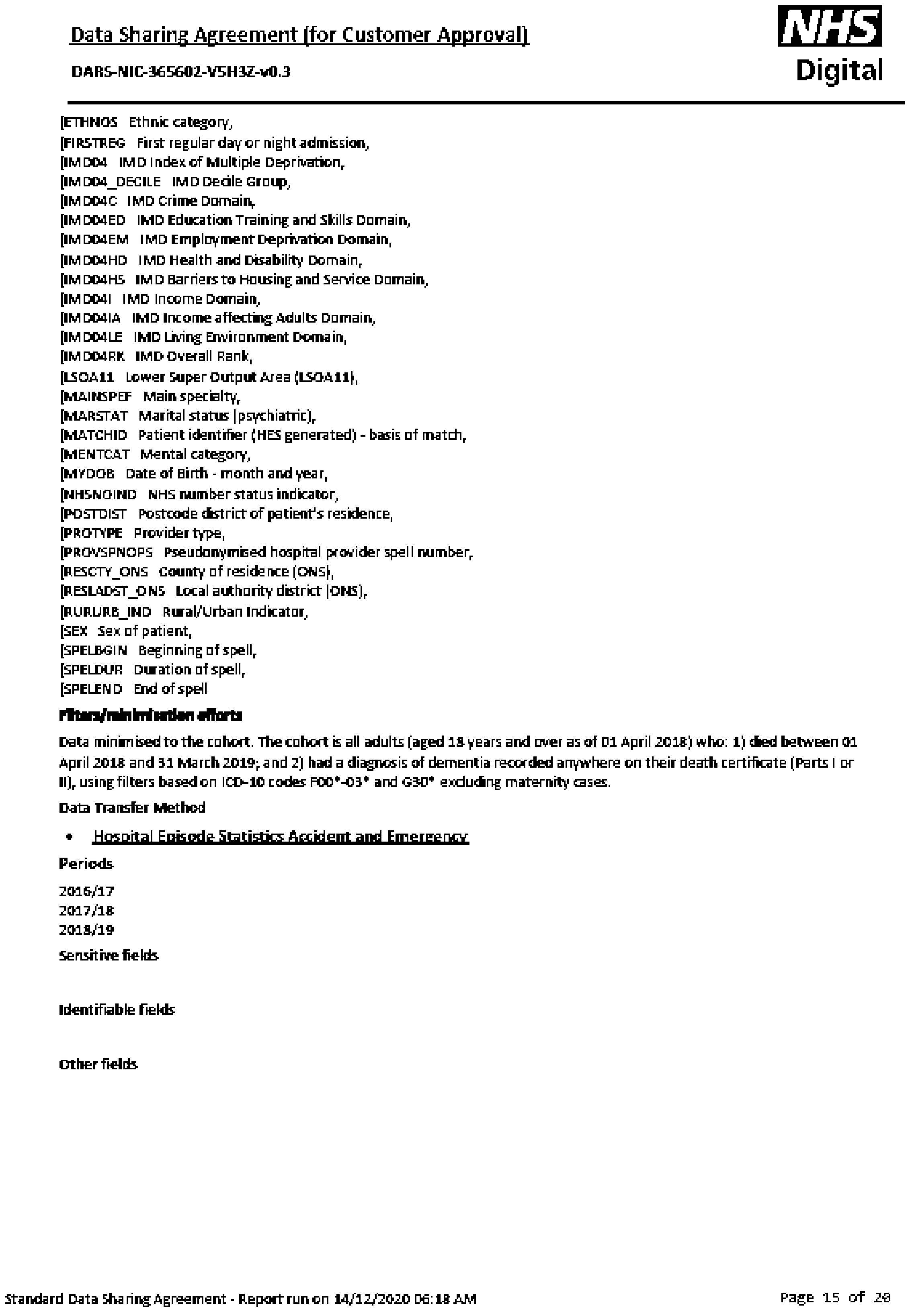
[DIAG_4_CONCAT 4 character concatenated diagnosis,
[DIAG_4_NN Diagnosis - 4 characters,
[DIAG_COUNT Count of diagnoses,
[DIAG_NN All Diagnosis codes,
[DISDEST Destination on discharge,
[ENCRYPTED_HESID Encrypted HESID,
[EPIDUR Episode duration,
[EPISTART Date episode started,
[EPISTAT Episode status,
[EPITYPE Episode type,



[ETHNOS Ethnic category,
[FIRSTREG First regular day or night admission,
[IMD04 IMD Index of Multiple Deprivation,
[IMD04_DECILE IMD Decile Group,
[IMD04C IMD Crime Domain,
[IMD04ED IMD Education Training and Skills Domain,
[IMD04EM IMD Employment Deprivation Domain,
[IMD04HD IMD Health and Disability Domain,
[IMD04HS IMD Barriers to Housing and Service Domain,
[IMD04I IMD Income Domain,
[IMD04IA IMD Income affecting Adults Domain,
[IMD04LE IMD Living Environment Domain,
[IMD04RK IMD Overall Rank,
[LSOA11 Lower Super Output Area (LSOA11),
[MAINSPEF Main specialty,
[MARSTAT Marital status (psychiatric),
[MATCHID Patient identifier (HES generated) - basis of match,
[MENTCAT Mental category,
[MYDOB Date of Birth - month and year,
[NHSNOIND NHS number status indicator,
[POSTDIST Postcode district of patient's residence,
[PROTYPE Provider type,
[PROVSPNOPS Pseudonymised hospital provider spell number,
[RESCTY_ONS County of residence (ONS),
[RESLADST_ONS Local authority district (ONS),
[RURURB_IND Rural/Urban Indicator,
[SEX Sex of patient,
[SPELBGIN Beginning of spell,
[SPELDUR Duration of spell,
[SPELEND End of spell

Filters/minimisation efforts

Data minimised to the cohort. The cohort is all adults (aged 18 years and over as of 01 April 2018) who: 1) died between 01 April 2018 and 31 March 2019; and 2) had a diagnosis of dementia recorded anywhere on their death certificate (Parts I or II), using filters based on ICD-10 codes F00*-03* and G30* excluding maternity cases.

Data Transfer Method

- Hospital Episode Statistics Accident and Emergency

Periods

2016/17
2017/18
2018/19

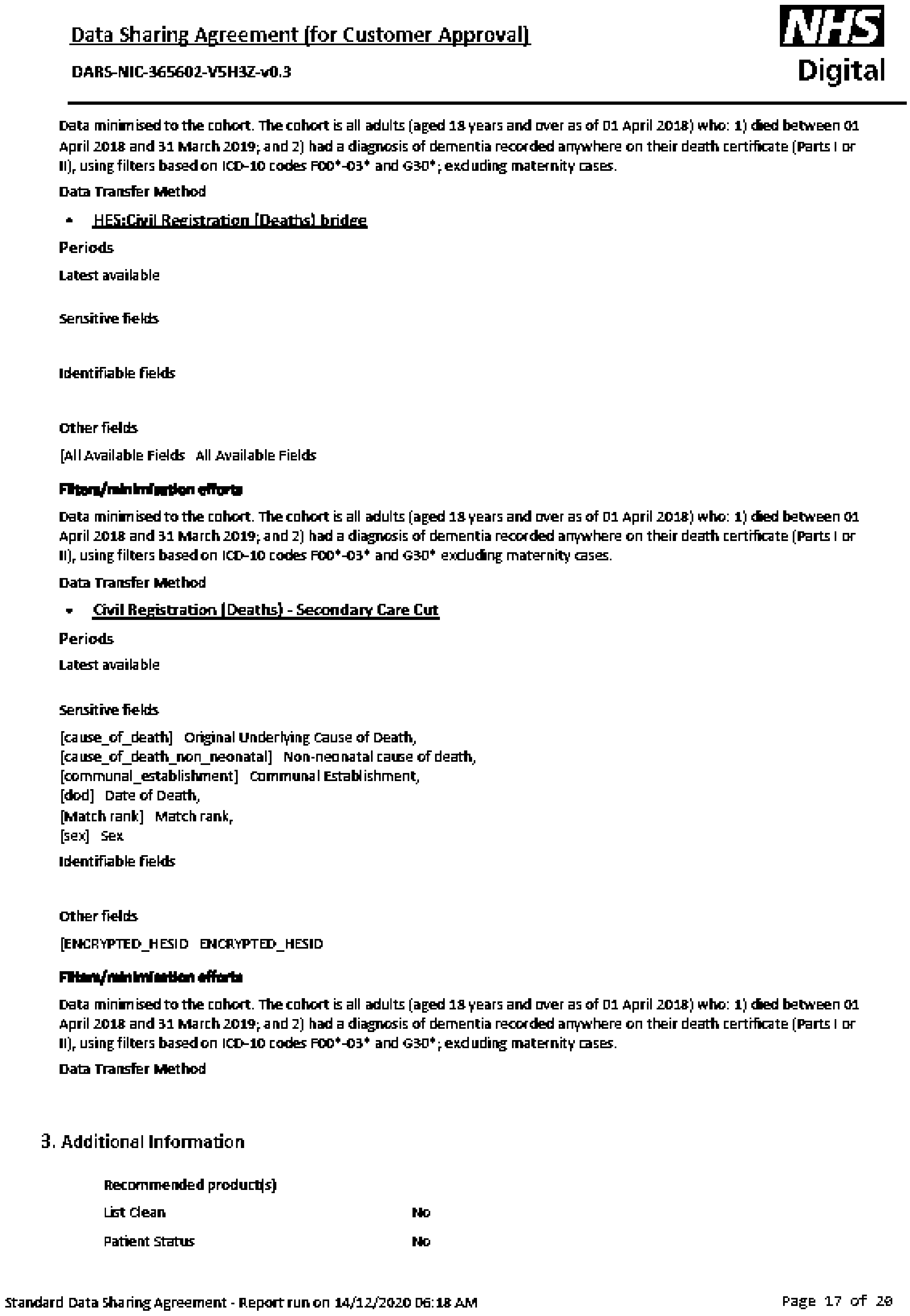
Sensitive fields

Identifiable fields

Other fields

[ACTIVAGE Age at activity date,
[AEARRIVALMODE Arrival mode,
[AEATTEND_EXC_PLANNED Attendances excluding planned,
[AEATTENDCAT Attendance category,
[AEATTENDDISP Attendance disposal,
[AEDEPTTYPE Department type,
[AEINCLOCTYPE Incident location type,
[AEPATGROUP Patient group,
[AEREFSOURCE Source of referral for A&E,
[ARRIVALAGE Age on arrival,
[ARRIVALDATE Arrival date,
[ARRIVALTIME Arrival time,
[CARERSI Carer support indicator,
[CCG_GP_PRACTICE CCG of GP Practice,
[CCG_RESIDENCE CCG of Residence,
[CONCLDUR Duration to conclusion,
[CONCLTIME Conclusion time,
[DEPDUR Duration to departure,
[DEPTIME Departure time,
[DIAG_NN A&E diagnosis,
[DIAG3_NN A&E diagnosis: 3 character,
[ENCRYPTED_HESID Encrypted HESID,
[EPIKEY Record identifier,
[ETHNOS Ethnic category,
[FYEAR Financial Year,
[IMD04 IMD Index of Multiple Deprivation,
[IMD04_DECILE IMD Decile group,
[IMD04C IMD Crime domain,
[IMD04ED IMD Education, skills and training,
[IMD04EM IMD Employment domain,
[IMD04HD IMD Health and disability domain,
[IMD04HS IMD barriers to housing and services,
[IMD04I IMD Income domain,
[IMD04IA IMD Income affecting adults domain,
[IMD04LE IMD Living Environment domain,
[IMD04RK IMD Overall rank,
[INITDUR Duration to assessment,
[INITTIME Initial assessment time,
[INVEST_NN A&E investigation,
[INVEST2_NN A&E Investigation: 2 character,
[LSOA11 Lower Super Output Area,
[MYDOB Date of Birth - month and year,
[NEWNHSNO_CHECK NHS Number valid flag,
[NODIAGS Number of Diagnosis values,
[NOINVESTS Number of Invesitgations,
[NOTREATS Number of Treatments,
[PCFOUND Postcode Found,
[POSTDIST Postcode district,
[RESCTY_ONS County of residence (ONS),
[RESLADST_ONS Local authority district (ONS),
[RURURB_IND Rural/Urban Indicator,
[SEX Sex of patient,
[TREAT_NN A&E treatment,
[TREAT2_NN A&E Treatment: 2 character,
[TRETDUR Duration to treatment,
[TRETTIME Time seen for treatment

Filters/minimisation efforts



Data minimised to the cohort. The cohort is all adults (aged 18 years and over as of 01 April 2018) who: 1) died between 01 April 2018 and 31 March 2019; and 2) had a diagnosis of dementia recorded anywhere on their death certificate (Parts I or II), using filters based on ICD-10 codes F00*-03* and G30*; excluding maternity cases.

Data Transfer Method

- **HES:Civil Registration (Deaths) bridge**

Periods

Latest available

Sensitive fields

Identifiable fields

Other fields

[All Available Fields All Available Fields

Filters/minimisation efforts

Data minimised to the cohort. The cohort is all adults (aged 18 years and over as of 01 April 2018) who: 1) died between 01 April 2018 and 31 March 2019; and 2) had a diagnosis of dementia recorded anywhere on their death certificate (Parts I or II), using filters based on ICD-10 codes F00*-03* and G30* excluding maternity cases.

Data Transfer Method

- **Civil Registration (Deaths) - Secondary Care Cut**

Periods

Latest available

Sensitive fields

[cause_of_death] Original Underlying Cause of Death,
[cause_of_death_non_neonatal] Non-neonatal cause of death,
[communal_establishment] Communal Establishment,
[dod] Date of Death,
[Match rank] Match rank,
[sex] Sex

Identifiable fields

Other fields

[ENCRYPTED_HESID ENCRYPTED_HESID

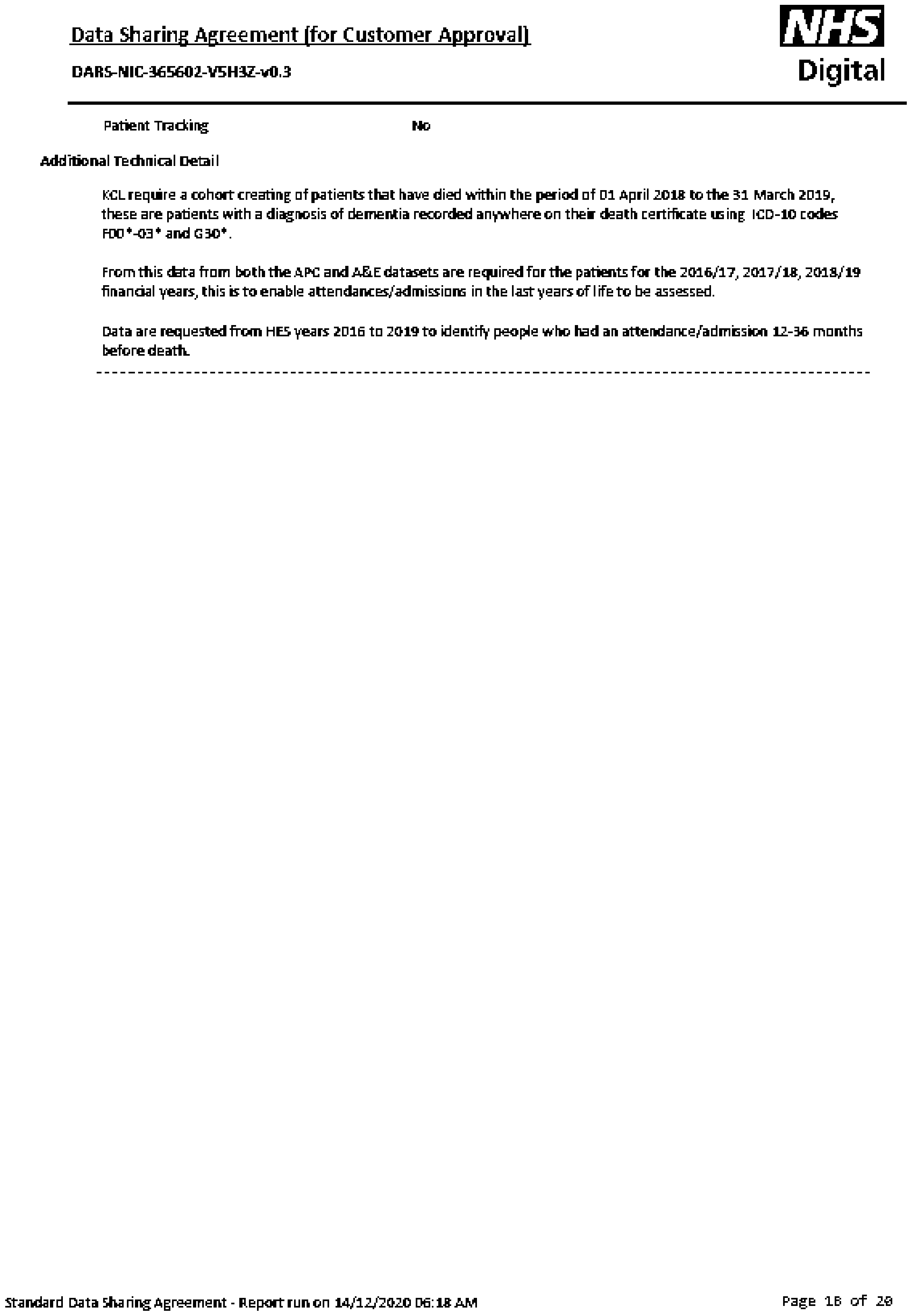
Filters/minimisation efforts

Data minimised to the cohort. The cohort is all adults (aged 18 years and over as of 01 April 2018) who: 1) died between 01 April 2018 and 31 March 2019; and 2) had a diagnosis of dementia recorded anywhere on their death certificate (Parts I or II), using filters based on ICD-10 codes F00*-03* and G30*; excluding maternity cases.

Data Transfer Method

3. Additional Information

Recommended product(s)	
List Clean	No
Patient Status	No



Patient Tracking	**No**

Additional Technical Detail

KCL require a cohort creating of patients that have died within the period of 01 April 2018 to the 31 March 2019, these are patients with a diagnosis of dementia recorded anywhere on their death certificate using ICD-10 codes F00*-03* and G30*.

From this data from both the APC and A&E datasets are required for the patients for the 2016/17, 2017/18, 2018/19 financial years, this is to enable attendances/admissions in the last years of life to be assessed.

Data are requested from HES years 2016 to 2019 to identify people who had an attendance/admission 12-36 months before death.

Data Sharing Agreement (for Customer Approval)

DARS-NIC-365602-V5H3Z-v0.3

NHS Digital

Annex C: Approval Information

Signed for and on behalf of the Information Asset Owner:

Name:	Bethan Thomas
Electronic approval reference:	2E939A7E-FC68-1D28-F04F-E51DCD393636
Organisation Name:	NHS Digital
Role:	Information Analysis Lead Manager
Date/time:	11/12/2020

Signed for and on behalf of NHS Digital:

Name:	Garry Coleman
Electronic approval reference:	51145B44-B133-5B04-1F25-28C6A44A7442
Role:	Business and Operational Delivery Director
Date/time:	14/12/2020

Signed for and on behalf of the Data Controller:

Organisation Name:	
Electronic approval reference:	
Name:	
Position in organisation:	
Date:	

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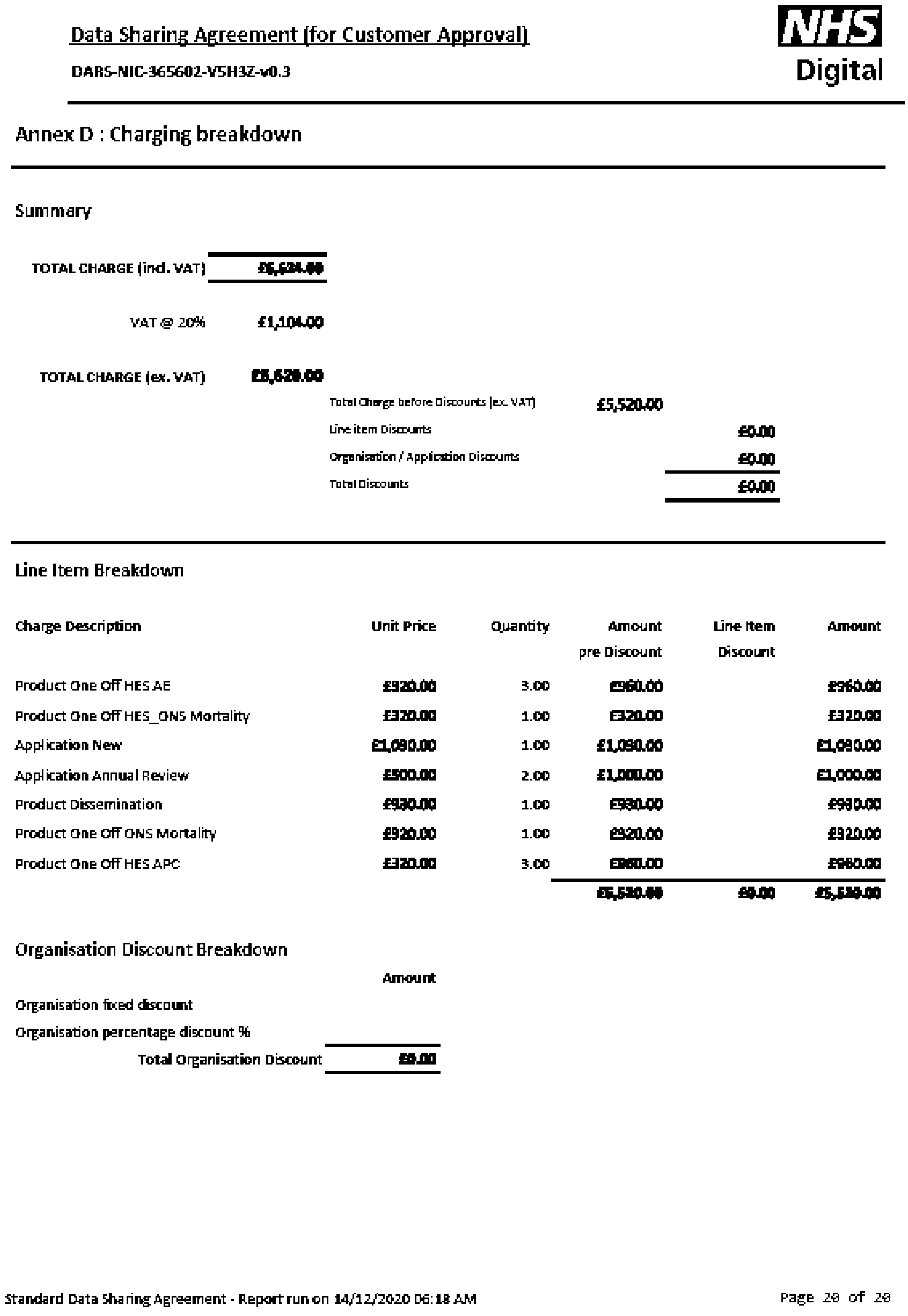

Data Sharing Agreement (for Customer Approval)

DARS-NIC-365602-V5H3Z-v0.3

Annex D : Charging breakdown

Summary

TOTAL CHARGE (incl. VAT)	**£6,624.00**
VAT @ 20%	**£1,104.00**
TOTAL CHARGE (ex. VAT)	**£5,520.00**

Total Charge before Discounts (ex. VAT)	**£5,520.00**	
Line item Discounts		**£0.00**
Organisation / Application Discounts		**£0.00**
Total Discounts		**£0.00**

Line Item Breakdown

Charge Description	**Unit Price**	**Quantity**	**Amount pre Discount**	**Line Item Discount**	**Amount**
Product One Off HES AE	**£320.00**	3.00	**£960.00**		**£960.00**
Product One Off HES_ONS Mortality	**£320.00**	1.00	**£320.00**		**£320.00**
Application New	**£1,080.00**	1.00	**£1,080.00**		**£1,080.00**
Application Annual Review	**£500.00**	2.00	**£1,000.00**		**£1,000.00**
Product Dissemination	**£880.00**	1.00	**£880.00**		**£880.00**
Product One Off ONS Mortality	**£320.00**	1.00	**£320.00**		**£320.00**
Product One Off HES APC	**£320.00**	3.00	**£960.00**		**£960.00**
			£5,520.00	**£0.00**	**£5,520.00**

Organisation Discount Breakdown

	Amount
Organisation fixed discount	
Organisation percentage discount %	
Total Organisation Discount	**£0.00**

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D2 – S1: Service-level factors

Table S1.1: Service-related covariates, data source and linkage

Covariates	**Source**	**Linkage description**
SERVICE WORKFORCE		
Total General Practitioners (FTE)	NHS Digital (A)	GP and Nurse FTEs were not submitted by 60 and 140 GP surgeries, respectively. To manage this missing data, the median number of FTEs in GP surgeries of the LA were imputed to GP surgeries of the same LA with missing values. Practice codes were used to link GP surgery and workforce data from NHS Digital to practice postcodes from data in the 'epraccur' database of GP Practices from NHS Digital (B). Discrepancies in postcodes were manually verified against the March 2019 CQC Care Directory dataset (C). Postcodes were matched to the ONS Postcode Directory to obtain LA area and then matched to the LA Tiers (April 2019) data to limit to upper LA areas. Data for Cornwall and Isles of Scilly were merged for consistency across datasets (assigned Cornwall LA code).
Total Nurses (FTE)		
Total adult social care direct care workers (FTE)	NHS Digital (D)	Adult social care workforce data in 2018/19 provided by NHS Digital on request, mirroring the headcount data available from table 2 of the Personal Social Services: Staff of Social Services Departments 30 September – England, 2019: Data Reference Tables (E). Data referred to the adult social care sector comprising 1.44 million jobs in both the LA and the independent sectors. Jobs working for direct payment recipients and those working in the NHS were not included in the workforce estimates. Data received for Cornwall and the Isles of Scilly as a combined total, therefore LA code for Cornwall was assigned to both and LA code for Isles of Scilly removed. Bournemouth and Poole LAs data were combined to form the LA Bournemouth, Christchurch and Poole (BCP), although Christchurch remained within the Dorset LA.
Total adult social care professionals$^{\$}$ (FTE)		
SERVICE CAPACITY		
Number of beds in nursing homes	CQC (C)	Data were limited to 'care homes', and service type as 'care home service with nursing', which includes care homes with combined nursing and non-nursing service. Postcodes were obtained from each care home and matched to the ONS Postcode Directory to obtain LA area and then matched to the LA Tiers (April 2019) data to limit to upper LA areas. Data for Cornwall and Isles of Scilly were merged for consistency across datasets (assigned Cornwall LA code).
Number of beds in residential homes		Data were limited to 'care homes', and service type as 'care home service without nursing' and blanks were filtered for under service type 'care home service with nursing'. Postcodes were obtained from each residential home and matched to the ONS Postcode Directory to obtain LA area and then matched to the LA Tiers (April 2019) data to limit to upper LA areas. Data for Cornwall and Isles of Scilly were merged for consistency across datasets (assigned Cornwall LA code).
Number of UTCs		Postcodes were obtained from each UTC and matched to the ONS Postcode Directory to obtain LA area and then matched to the LA Tiers (April 2019) data to limit to upper LA areas. Data for Cornwall and Isles of Scilly were merged for consistency across datasets (assigned Cornwall LA code).
Number of type 1 emergency departments	NHS Digital (F)	Postcodes were obtained for each type 1 ED and matched to the ONS Postcode Directory to obtain LA area and then matched to the LA Tiers (April 2019) data to limit to upper LA areas. Data for Cornwall and Isles of Scilly were merged for consistency across datasets (assigned to Cornwall LA code).
SERVICE PROXIMITY		
GP surgeries	NHS Digital (A)	Practice codes were used to link GP surgery and workforce data from NHS Digital to practice postcodes from data in the 'epraccur' database of GP Practices from NHS Digital (B). Discrepancies in postcodes were manually verified against the March 2019 CQC Care Directory dataset (C). Postcodes were matched to the ONS Postcode Directory to obtain latitude and longitude. The distances between each GP surgery and the average latitude and longitude for each postcode district was calculated, limited to the shortest distance.
Type 1 emergency departments	NHS Digital (F)	Postcodes were matched to the ONS Postcode Directory to obtain latitude and longitude. The distances between each type 1 emergency department and the average latitude and longitude for each postcode district was calculated, limited to the shortest distance.
UTCs$^{\#}$	CQC (C)	Those starting after 31 March 2019 were removed (n=11). Postcodes were matched to the ONS Postcode Directory to obtain latitude and longitude. The distances between each UTC and the average latitude and longitude for each postcode district was calculated, limited to the shortest distance.
SERVICE FUNDING		
Net expenditure on adult social care	NHS Digital (G)	Net current expenditure for 2018-2019 was extracted from table 16. Bournemouth and Poole LAs data were combined to form the LA Bournemouth,

		Christchurch and Poole (BCP), although Christchurch remained within the Dorset LA. Data for Cornwall and Isles of Scilly were merged for consistency across datasets (assigned Cornwall LA code).

LA=Local Authority; FTE=Full Time Equivalent based on 37hrs worked per week; [$]Includes Registered Nurses, Occupational Therapists and Social Workers; [#]Includes minor injury units, urgent treatment centres and walk-in centres

All data was merged with adult population data (>65yrs) for each local authority (LA) from ONS estimates of the population for the England (H), from which data per 10,000 population was calculated.

Sources

(A) NHS Digital. General Practice Workforce, Final 31 March 2019, experimental statistics. 2019 [10 April 2022]; Available from: https://digital.nhs.uk/data-and-information/publications/statistical/general-practice-workforce-archive/final-31-march-2019.

(B) Office for National Statistics. GP and GP practice related data. 2022 [10 April 2022]; Available from: https://digital.nhs.uk/services/organisation-data-service/file-downloads/gp-and-gp-practice-related-data

(C) Care Quality Commission. HSCA Active Locations March 2019. 2019 [22 March 2022]; Available from: https://docs.google.com/spreadsheets/d/1-lIz1bPw9lKCdRQDUMEPgPSupxItnow8/edit#gid=311221897

(D) Skills for Care. Ref: NIC-645822-Y3N2Q - Personal Social Services: Staff of Social Services Departments, England 2019; request for WTE data. NHS Digital; 2019.

(E) NHS Digital. Personal Social Services: Staff of Social Services Departments, England 2019. 2019 [22 March 2022]; Available from: https://digital.nhs.uk/data-and-information/publications/statistical/personal-social-services-staff-of-social-services-departments/england-2019/content.

(F) NHS Digital. Addresses of major (type 1) A&E departments in England. 2017 [22 March 2022]; Available from: https://www.whatdotheyknow.com/request/addresses_of_major_type_1_ae_dep_2.

(G) NHS Digital. Adult Social Care Activity and Finance Report, England - 2018-19 [PAS]. 2019 [28 March 2022]; Available from: https://digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-activity-and-finance-report/2018-19.

(H) Office for National Statistics. Estimates of the population for the UK. Mid-2018: 2019 LA boundaries edition of this dataset. 2019 [09 May 2022]; Available from: https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/datasets/populationestimatesforukenglandandwalesscotlandandnorthernireland

D3 –S2: Categorisation of ethnicity codes

HES A&E DATA DICTIONARY “ETHNOS” CODE	ETHNICITY CATEGORY
A = British (White)	White
B = Irish (White)	
C = Any other White background	
D = White and Black Caribbean (Mixed)	Mixed
E = White and Black African (Mixed)	
F = White and Asian (Mixed)	
G = Any other Mixed background	
H = Indian (Asian or Asian British)	South Asian
J = Pakistani (Asian or Asian British)	
K = Bangladeshi (Asian or Asian British)	
L = Any other Asian background	
M = Caribbean (Black or Black British)	Black
N = African (Black or Black British)	
P = Any other Black background	
R = Chinese (other ethnic group)	Other
S = Any other ethnic group	
Z = Not stated	Not stated/unknown
X = Not known (prior to 2013)	
99 = Not known (2013 onwards)	

D4 – S3 Emergency department (ED) visits descriptive data

Table S3.1: Frequency of unplanned type 1 ED attendances

Unplanned visits to type 1 ED (*n*=296,842)	**Frequency (%)**
ED visits in last 36-13 months before death	142,334 (47.9)
ED visits in last 12 months before death	154,508 (52.1)

Table S3.2: Frequency of unplanned type 1 ED attendances in last twelve months of life (*n*=154,508)

	Frequency (%)
1 month before death	36,849 (23.9)
2 months before death	19,749 (12.8)
3 months before death	14,499 (9.4)
4 months before death	12,108 (7.8)
5 months before death	10,722 (6.9)
6 months before death	9,857 (6.4)
7 months before death	9,180 (5.9)
8 months before death	8,773 (5.7)
9 months before death	8,488 (5.5)
10 months before death	8,286 (5.4)
11 months before death	8,057 (5.2)
12 months before death	7,940 (5.1)

Table S3.3: Unplanned type 1 ED attendances in last twelve months of life (*n*=154,508)

		Frequency (%)
Arrival mode	Ambulance	138,418 (89.6)
	Other	13,766 (8.9)
	Unknown	2,324 (1.5)
In/Out of Hours	Out of hours	83,769 (54.2)
	In hours	70,739 (45.8)
Source of referral	Self-referral	63,790 (41.3)
	Same/other healthcare provider	39,548 (25.6)
	Emergency services	24,888 (16.1)
	Unknown	11,650 (7.5)
	GP	7,621 (4.9)
	Other	6,016 (3.9)
	Educational establishment	562 (0.4)
	Social services	291 (0.2)
	Police	124 (0.1)
	General dental practitioner	9 (0.0)
	Work	3 (0.0)
	Community dental service	2 (0.0)
Outcome of visit	Admitted into hospital	89,776 (58.1)
	Discharged without follow-up	36,132 (23.4)
	Unknown	12,1780 (7.9)

	Discharged with GP follow-up	9,556 (6.4)
	Transferred to another provider	2,855 (1.9)
	Outpatient clinic referral	849 (0.6)
	Died in department	840 (0.5)
	Fracture clinic referral	833 (0.5)
	Other healthcare profession referral	559 (0.4)
	Other	456 (0.3)
	Left before receiving treatment	249 (0.2)
	ED clinic referral	171 (0.1)
	Refused treatment	43 (0.0)
Top 10 clinical diagnoses	Diagnosis not classifiable	14,149 (11.6)
	Respiratory conditions (non-asthma)	13,810 (11.6)
	Urological conditions (including cystitis)	13,439 (11.3)
	No abnormality detected	7,810 (6.5)
	Cardiac conditions (non-ischaemic)	6,867 (5.8)
	Septicaemia	6,373 (5.3)
	Closed fracture	6,367 (5.3)
	Cerebrovascular conditions	3,940 (3.3)
	Psychiatric conditions	3,930 (3.3)
	Non-notifiable infectious disease	3,740 (3.1)

D5 – S4 Univariate negative binomial regression

Table S4.1: Univariate negative binomial regression (*n*=74,486)

		Parameter estimates	Lower 95% CI	Upper 95% CI	p-value
		Incident Rate Ratio (IRR)			
FIXED PART: PATIENT LEVEL					
Intercept					
Age (centred)		0.99	0.99	0.99	0.00
Gender (ref: men)	Women	0.81	0.80	0.83	0.00
Ethnicity (ref: white)	Black	1.29	1.22	1.36	0.00
	South Asian	1.31	1.25	1.37	0.00
	Mixed	0.98	0.83	1.17	0.84
	Other	1.11	1.04	1.19	0.00
	Unknown	0.84	0.82	0.86	0.00
Subtype (ref: Alzheimer's disease)	Vascular	1.17	1.15	1.19	0.00
	Dementia in other diseases	1.12	1.06	1.18	0.00
	Unspecified dementia	1.15	1.13	1.17	0.00
Underlying cause of death (ref: dementia)	Chronic respiratory disease	1.40	1.35	1.46	0.00
	Cancer	1.03	1.00	1.06	0.04
	Cardiovascular disease	1.19	1.16	1.22	0.00
	Cerebrovascular disease	1.15	1.11	1.18	0.00
	Chronic neurological disease	1.07	1.03	1.12	0.00
	Other	1.26	1.23	1.29	0.00
Settlement (ref: rural)	Urban	1.18	1.16	1.20	0.00
Socioeconomic position (ref: 1, more deprived)	Quintile 2	0.93	0.92	0.95	0.00
	Quintile 3	0.87	0.85	0.89	0.00
	Quintile 4	0.84	0.83	0.86	0.00
	Quintile 5 (least deprived)	0.81	0.79	0.83	0.00
Region (ref: South East, largest region)	London	1.45	1.41	1.49	0.00
	North West	1.20	1.18	1.23	0.00
	East of England	1.10	1.08	1.13	0.00
	West Midlands	1.23	1.20	1.26	0.00
	South West	0.86	0.83	0.88	0.00
	Yorkshire and the Humber	1.19	1.16	1.22	0.00
	East Midlands	1.19	1.16	1.23	0.00
	North East	1.10	1.06	1.14	0.00
FIXED PART: LOCAL AUTHORITY LEVEL					
GP FTE (ref: 1, lowest quintile)	Quintile 2	1.02	1.01	1.04	0.01
	Quintile 3	1.10	1.08	1.12	0.00
	Quintile 4	1.08	1.06	1.10	0.00
	Quintile 5 (highest)	1.24	1.21	1.26	0.00
ASC Carer FTE (ref: 1, lowest quintile)	Quintile 2	0.95	0.93	0.97	0.00
	Quintile 3	1.04	1.02	1.06	0.00
	Quintile 4	1.12	1.10	1.14	0.00
	Quintile 5 (highest)	1.16	1.13	1.18	0.00
No. of nursing home beds (ref 1: lowest quintile)	Quintile 2	1.05	1.03	1.07	0.00
	Quintile 3	0.99	0.97	1.01	0.29
	Quintile 4	0.92	0.90	0.94	0.00
	Quintile 5 (highest)	0.92	0.90	0.94	0.00
No. of residential home beds (ref 1: lowest quintile)	Quintile 2	0.93	0.90	0.95	0.00
	Quintile 3	0.84	0.82	0.86	0.00
	Quintile 4	0.89	0.87	0.91	0.00
	Quintile 5 (highest)	0.91	0.89	0.93	0.00
No. of EDs (ref 1: lowest quintile)	Quintile 2	1.03	1.01	1.05	0.01
	Quintile 3	1.09	1.07	1.11	0.00
	Quintile 4	1.07	1.05	1.09	0.00
	Quintile 5 (highest)	1.19	1.17	1.22	0.00
No. of UTCs (ref 1: lowest quintile)	Quintile 2	0.97	0.96	0.99	0.01
	Quintile 3	1.07	1.04	1.09	0.00
	Quintile 4	1.13	1.10	1.15	0.00
	Quintile 5 (highest)	1.19	1.16	1.23	0.00