Delivering care for people with dementia – why data matters

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Key messages

- With an ageing population, there are more people living longer with a major condition in England. Among these, dementia accounts for the greatest burden of illness. The impact of dementia on people living with the condition and their family and friends is profound and life-changing.
- Data is vital for understanding the scale and nature of demand, planning care, ensuring equitable access to, and outcomes from existing care, and measuring the impact of new treatments and services.
- Despite a range of available data on dementia across health and social care, the quality and consistency of that data lead to an incomplete and fragmented picture of care.
- There are important opportunities for improving dementia care – through the Casey Commission on adult social care reform, the development of modern service frameworks and moves towards population-based strategic commissioning.
- Addressing the data requirements for delivering effective health and social care, including data infrastructure, is key to ensuring that these future actions result in meaningful change for people living with dementia, their families and carers.

About this project
The Alzheimer's Society funded the work for this project. The King's Fund independently developed, researched and wrote this output. All views are the authors' own.

Introduction

Having good data is core to managing the health of the population. It provides an understanding of:

- the scale and needs of the population so that services and support can be planned
- the use of services
- the impact services have on the outcomes and quality of life of the people receiving care.

It is also important for measuring the impact and implementation of any changes in treatment and care.

The projected number of people living with a major condition in England is set to increase to around one in five by 2040, with four-fifths of that rise due to the increase in the number of older people. Among the health conditions that account for the greatest burden of illness in England, dementia ranks highest in terms of its impact on the health care system and individual life expectancy. Among people aged 65 and over, dementia prevalence (the total number of people in the population with dementia) grows significantly, with rates of up to 22% among people aged 85 and over. By 2040, the number of people living with dementia is expected to grow to 1.9% of the population – this represents a 40% increase. With the right data, decision-makers have the potential to not only manage this demand but identify opportunities to reduce demand and its societal impact.

In 2025, The King's Fund undertook a scoping study of the available data on dementia care for the Alzheimer's Society. We identified a wide range of data, generated from:

- the management of health and care systems,
- the inclusion of dementia as a demographic characteristic in other datasets
- legal processes that people are subject to
- the output of academic studies.

There are more types of data available to understand the care of people with dementia than for most other long-term conditions. Yet with information captured through a series of snapshots in time and from different services, our understanding of the lives of people living with dementia, the support they receive and their experience of it is more recognisable as a patchwork of incomplete insights than a meaningful picture of care.

Using the available data and focusing on the care journeys of people living with dementia and their carers, we identified a series of points where data is key to optimising the support people receive. In this long read we set out each one,

exploring the strengths and limitations of current data and considering what this means in light of policy ambitions for health and care.

The importance of diagnosis

> *When I got my diagnosis, it was such a relief. The question mark hanging over me was taken away.*
>
> (Person living with dementia)
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> *The family made the decision to seek the diagnosis. Mum faced it quite openly and knew there was no cure. We needed to know. We also knew a diagnosis, if early enough, might be helped by medication to slow it down… It's good to be reminded of how positive the diagnosis can be. It is easy to be negative and forget the helpful things that have come of it.*
>
> (Carer of a person with dementia)

Understanding the number of people living with dementia is vital for planning support effectively. Early diagnosis provides opportunities to maximise quality of life and is increasingly important in an evolving landscape of new diagnostics and treatments. For most people, the first contact they will have with the health and care system in relation to dementia care and support is their general practitioner (GP). GP surgeries collect data on the number of people with a recorded diagnosis of dementia.

Between 2015 and 2025, the government set targets for the diagnosis rate for people with dementia, based on the estimated rate of dementia in the local population aged 65 and over. While this has driven an overall increase in the number of people who receive a diagnosis of dementia, it comes with limitations. The estimated rate of dementia was established as part of the Cognitive Function and Ageing Study, which was conducted between 1989 and 1994 and repeated between 2008 and 2011. A comparison between the two studies found that the incidence rates of dementia (the number of new cases of dementia in the population in a defined period of time) remained stable. However, while the data accounts for age and sex, it does not account for other demographic factors that have been associated with increased prevalence. For example, ethnicity and deprivation put some people at high risk of diseases that cause dementia.

As a result, national targets may lead to incomplete estimates of prevalence at regional and local levels. This compromises our understanding of how effective areas are at identifying and diagnosing people with symptoms of dementia, and the ability to mediate inequalities in people's access to, and experience of, dementia care.

Understanding needs across health and social care

> *My daughter and I both need[ed] significant hospital stays last year for different reasons. When I came out, my daughter couldn't physically do as much as before. So we got professional carers*.
>
> (Person living with dementia)
>
> *Her [Mum] moving into a care home has been a really positive experience, and it just shows that it can be the right thing to do… When she was at home, dealing with her personal care was a challenge. Now, she has got some of her independence back. She showers herself and even allows the hairdresser to do her hair.*
>
> (Carer of a person with dementia)

The support that people living with dementia need is often provided by both health and social care services. After diagnosis, people continue to have a relationship with their GP and may receive assessments and treatments from an NHS trust service such as a memory clinic. Over time, they may additionally require support in the home, or in some cases they may need to move to a residential care setting for specialised support.

The ability to deliver person-centred care is dependent on having a holistic understanding of their needs. Within NHS services, the routine capturing of dementia diagnoses starts to build a picture of the interactions people with dementia have with health services, the processes they are subject to (such as care planning) and the treatments they receive.

In contrast, access to social care is defined by a need for support related to activities of daily living and personal care, and eligibility is means tested. People whose main reason for requesting support relates to their memory and cognition, and who are eligible for care, are captured in the data. However, recording needs related to memory and cognition where it is not the primary reason for care is not mandatory. Furthermore, data collected on the delivery and funding of social care only captures the setting in which the care is delivered, whether that is a residential setting or in the community, rather than the type of care they receive in those settings. As a result, social care data provides only a limited understanding of the number of people living with dementia and their carers who have social care needs. There is also a gap in knowledge about the type of care they need, and about the needs of people who do not meet the eligibility criteria for local authority funded support.

Navigating the dementia care pathway

> *It needs a smooth transition from medical to social departments, with no time gap; allowing for uninterrupted information to be passed between different areas, and the family, to stop the added stress and worry to those affected by this devastating condition. By contrast, my experience of being told I had cancer was far better. Here the doctor, when he told me about it, had a (Macmillan) nurse immediately on hand to answer both medical queries and provide information on what support was available. The gap between social and medical services was intertwined and not two autonomous areas, enabling any stress and worry to be kept to a minimum.*
>
> (Person living with dementia)

People living with dementia may require different services and support at different stages of their journey. The dementia care pathway represents a structured approach to ensure that people receive timely and appropriate care at each stage. In 2025, the government launched guidance and a toolkit on requirements that are key to the development and delivery of an effective dementia care pathway. A core foundation for the pathway is the maintenance of a dementia register, providing a route for data sharing and increasing the visibility of a person's needs when presenting to different health settings. However, changes to the Quality and Outcomes Framework in 2025 mean that although GPs are still required to maintain a register, rates of diagnosis will no longer be incentivised in primary care, risking de-prioritisation of early diagnosis.

The toolkit also recognises that achieving a seamless pathway across organisational boundaries is contingent on collaborative working and establishing processes so that different organisations can share and view patient-level data. But current data on the delivery of health and care services for people with dementia exists primarily within the context of individual organisations or services. Furthermore, routine data on key areas of performance are largely absent, including data on:

- waiting times to assessment and diagnosis
- interventions that people receive beyond medication
- care and treatment outcomes.

The National Audit of Dementia provides a good example of the insight data can generate within the context of individual services, while also recognising the potential benefit of capturing information across patient pathways to better understand how the context and configuration of services affect outcomes.

People's experiences of care

> *Towards the end of 2018, I realised I needed to consider professional care. The main decision criteria for me were consistency of care and a person-centric approach… It was important that any care home recognised my wife's age and interests. Above all, I wanted an environment that was the antithesis of the depressing care homes I visited as a child when seeing ageing relatives*.
>
> (Carer of a person with dementia)

Feedback from patients and carers is key to improving services and care. There is a surprising amount of data on the experiences that people living with dementia and their carers have of care. This is largely due to dementia being captured as a demographic characteristic in several national NHS surveys. This provides insight into those experiences, and how they compare to the experiences of people without dementia or with other long-term conditions. Despite this, the number of people with dementia is relatively small and the data is likely to exclude those with significant cognitive impairment – providing an indicative understanding of the experiences of people with dementia, rather than being representative. A key limitation of these surveys is that they do not differentiate between the services that people receive, making it difficult to identify opportunities for improvement. This is particularly relevant in relation to services that are key to the dementia care pathway, such as memory clinics. The extent to which such services collect this data is unclear, although an audit of general hospitals in England and Wales found that just under half reported regularly collecting feedback from people living with dementia.

The experience of people living with dementia and their carers is also captured in relation to receipt of social care support. Like NHS data, this data provides a useful understanding of people's satisfaction with social care and the extent to which people report their needs being met. It is also able to track trends over time. However, the data collected on the experiences of people with problems related to memory and cognition is limited to those in receipt of long-term support services that are funded or managed by social services.

Workforce

> *My wife got a call from an Admiral nurse [a specialist dementia nurse], who told us about a support group. That first peer group meeting was very important… It was reassuring to hear people saying how they were feeling. One guy said that he could get quite emotional, and I shouldn't worry about it, if I felt that way too. 'Thank goodness,' I thought, because that's just how I was feeling.*
>
> (Person living with dementia)

Delivering timely and effective care is dependent on having the right workforce with appropriate training. A range of health care professionals are involved in the dementia care pathway, including dementia specialists and diagnostics professionals. Currently there is limited data on the dementia capabilities of the workforce. The NHS workforce dataset captures the numbers of GPs, old age psychiatrists and both clinical and support staff within diagnostics, but the categorisation of other staff is insufficient to identify numbers or roles by service type relevant to the delivery of dementia care. Examples such as the cancer workforce strategy highlight the importance of considering the workforce in relation to each stage of care and the initiatives required to achieve this, although the ambition for a national cancer workforce plan has not survived wider political and strategic changes in the NHS.

Equally important to the specialist workforce, are the levels of training among health and care staff who play a vital role in recognising and responding to the needs of people with dementia. In adult social care, levels of training are captured in national data, although submission of this data is not mandatory and the data may therefore be an under-estimate. Conversely, data on training levels in the NHS is not captured at a national level. Meanwhile at a local level, only 58% of general hospitals in England and Wales were able to report the proportion of staff with tier 2 training – the recommended level for staff who interact with people living with dementia. Gaps in this data compromise approaches to workforce planning and the ability to ensure that the right staff, with the right training, are available to deliver high-quality care and support across the dementia pathway.

Optimising data to support future care

At the heart of the government's 10 Year Health Plan for England is an ambition to better meet the needs of the population through three fundamental shifts in care. Two of these shifts – from hospital to home with the development of a neighbourhood health service and from treatment to prevention – are dependent on adopting a population health approach. This approach is further embedded as part of the NHS operating model for integrated care systems, with linked datasets identified as a key enabler for strategic commissioning.

An example of this in relation to dementia highlights the potential for better understanding the care that people receive and the opportunities for improving it. Yet it equally highlights how poor-quality data and gaps in the data can preclude those ambitions.

The impact of the optimisation of data on existing care is evident, but as important is its impact on future care. Dementia is the leading cause of death in England and Wales. Recent breakthroughs in treatment, such as the licensing of monoclonal antibodies for use in early-stage Alzheimer's disease, however, highlight how early

diagnosis could lead to more treatment options and better outcomes, following the same trajectory as for other long-term conditions such as cancer. Recommendations of the Sudlow Review, which looked at the health data landscape in the UK, provide a template for those changes, including:

- recognising health data as part of critical national infrastructure
- providing leadership and accountability for data
- maximising the utility of data by establishing a single, national, health data access system.

However, the care of people living with dementia is dependent on both NHS and social care. The development of client-level data in social care is one promising development that could facilitate a better understanding of the care pathways and enable data sharing with the NHS. But the disparities between NHS and social care data, and a lack of a national plan for social care, leave a fundamental gap in the picture. The task of setting out that plan lies with the Casey Commission. In the Commission's initial findings, Baroness Casey highlighted a system where families and carers of people living with dementia currently 'bear the brunt' of a failing system, while also recognising that the NHS needs to do more to prioritise progress on the clinical treatment of dementia through the Modern Service Framework for Frailty and Dementia. Addressing data as part of both plans will be vital to supporting implementation and ensuring that actions result in meaningful change for people living with dementia and their families and carers.