
# Mapping post-diagnostic dementia care in England: an e-survey

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# Mapping post-diagnostic dementia care in England: an e-survey

**Abstract**

Purpose: Post-diagnostic dementia care is often fragmented in the UK, with great variation in provision. Recent policies suggest moving towards better community-based care for dementia, however we know little on how this care is delivered. This study aimed to map the post-diagnostic dementia support provided in England a decade after the introduction of a National Dementia Strategy.

Design: A mixed-methods e-survey (open Nov 2018-Mar 2019) of dementia commissioners in England, recruited through mailing lists of relevant organisations. We descriptively summarised quantitative data and carried out thematic analysis of open-ended survey responses.

Findings: 52 completed responses were received, which covered 82 commissioning bodies, with representation from each region in England. Respondents reported great variation in the types of services provided. Information, caregiver assessments and dementia navigation were commonly reported and usually delivered by the voluntary sector or local authorities. Integrated pathways of care were seen as important to avoid overlap or gaps in service coverage. Despite an increasingly diverse population, few areas reported providing dementia health services specifically for BME populations. Over half of providers planned to change services further within five years.

Practical implications: There is a need for greater availability of and consistency in services in post-diagnostic dementia care across England.

Originality/value: Post-diagnostic dementia care remains fragmented and provided by a wide range of providers in England.

## Background

Approximately 43.8 million people live with dementia globally (Nichols et al., 2019). Dementia is a syndrome which progressively impairs a person's ability to carry out everyday activities, along with cognitive and behavioural symptoms. Post-diagnostic support for dementia can be defined as all services provided in the period following diagnosis, through declining function and increasing care needs, until end of life (Prince, Comas-Herrera, Knapp, Guerchet, & Karagiannidou, 2016), which may include information, community support services, treatments, physical health care, comorbidity management and behavioural and psychological symptom management (Prince et al., 2016). This support is estimated to cost US$ 818billion globally (Prince et al., 2015). In the UK, 815,827 are living with dementia (Prince et al., 2014) and this number is increasing, with costs in England estimated to be £24.2 billion (Wittenberg et al., 2019). However, nearly half of people with dementia in the UK feel they are getting insufficient post-diagnostic support (Kane & Terry, 2015).

In the period after diagnosis, international policy advocates multi-sector collaboration (World Health Organization, 2017). Specific post-diagnostic services recommended by National Institute for Health and Care Excellence (NICE) (2018) dementia guidelines include a named health/social care professional responsible for care coordination, cognitive stimulation therapy, psychosocial and environmental interventions to reduce stress and carer psychoeducation and skills training (NICE, 2018). However, UK post-diagnostic care typically involves multiple sectors, including primary care (first contact services accessible to all (World Health Organisation, 2019)), secondary health care (services accessed through emergency or through referrals from primary care), social care (e.g. care homes, home care, home adaptations), the voluntary sector and unpaid care. Each sector typically has differing funding structures, capacity and priorities. Since 2013, most English health services are commissioned by Clinical Commissioning Groups (CCGs), statutory clinician-led bodies legally required to commission local hospital and community NHS services (National Audit Office, 2018). Social care is commissioned by local authorities (LAs), who may have different council tiers (e.g. county councils, borough councils) (Local Government Association, 2019). Additionally, some voluntary sector services are commissioned by CCGs or LAs, others may be non-commissioned community volunteer groups and residential care service may be

privately provided. This complexity can lead to service fragmentation, duplication or a 'postcode lottery' (highly variable service provision between different localities).

There is a strong move towards greater integration between sectors, particularly between healthcare and voluntary services, to provide better community-based support (NHS England, 2019). However, the current level of integration achieved by dementia services is unclear. Whilst dementia diagnosis (NHS, 2017) and care plan review data (Public Health England, 2019) are good quality, there are no current national data on what post-diagnostic support is commissioned across a range of services (Kane & Terry, 2015). Previous surveys focus mainly on single services, e.g. memory assessment services (Chrysanthanki, Fernandes, Smith, & Black, 2017), dementia navigators (Ipsos Mori, 2016); or have comprehensively mapped services, but within a limited area (Robens et al., 2015).

This study aimed to map what post-diagnostic dementia support is being commissioned in England, specifically: types of services commissioned, sectors delivering these, collaboration between services, successes, challenges, and planned changes. This provides initial data to study trends in what services are being provided and by whom, whether there are gaps in services provided and to what extent services are integrated.

## Design and methods

A mixed-methods electronic survey (Supplementary File 1) of health and social care commissioners was carried out, using Opinio software. Post-diagnostic support was defined within the survey as "any service(s) related to supporting people with dementia at any stage after diagnosis (but not assessment and diagnostic services) across England". Questions asked about NHS, social care and community services commissioned (such as information services, social activities) and who these were provided by; whether they were jointly commissioned; patient involvement in design and oversight; targets and evaluation work carried out; and planned changes over the next five years. A mix of matrices, yes/no, categorical and open question types were used.

The survey was developed based on the research aims, previous similar surveys (Ipsos Mori, 2016) and a framework of categories of post-diagnostic care developed by the larger research programme team from the 8 pillars Model (Alzheimer Scotland, 2012), Memory

Assessment Service National Survey (Chrysanthanki et al., 2017) and Memory Services National Accreditation Programme standards 2018 (Royal College of Psychiatrists, 2016). The framework categorised services provided into information and advice, carer wellbeing and support, cognitive function and independence, activity and social connection, psychological wellbeing, safe and supportive living (community-based schemes or support services for people with dementia e.g. equipment, dementia friendly libraries), care coordination and dementia-specific physical health services.

The initial design had input from a locality commissioner, was reviewed by a CCG dementia commissioner and was presented to a local dementia commissioners' network meeting. This led to addition of questions regarding how services collaborate, removal of some open questions and use of matrix-style questions regarding service provision. After refinement by the internal team, it was reviewed by the wider research programme management board and the Alzheimer's Society policy team. Feedback was incorporated into the survey. The final questionnaire was user-tested by two independent researchers to ensure survey functionality.

## Recruitment

The target audience was people with responsibility for commissioning dementia services in either CCGs or local authorities (LAs) in England. At the time of the survey, there were 195 CCGs (National Audit Office, 2018), 26 county councils, 192 district, borough or city councils, 56 unitary councils, 36 London boroughs and 26 metropolitan boroughs (Local Government Association, 2019). All of these typically fall within one of seven distinct regions of England (South East, South West, North East, London, North West, Yorkshire and the Humber, East of England, East Midlands and West Midlands). Existing channels of communication to commissioners were used to distribute the survey, including:

- NHS England mailing list contacts, including GP bulletin, National Dementia Clinical Network, CCG Bulletin, Health Education England Clinical Commissioning Learning Network, CHAIN newsletter, Local Government Association bulletin (2 reminders)
- NHS Clinical Commissioners newsletter (1 reminder)
- Alzheimer's Society Network of local commissioners (1 reminder)
- Dementia Action Alliance newsletter

- Public Health England National Mental Health, Dementia & Neurology Intelligence Network
- Existing regional commissioning contacts known to the research team

Communications were staggered over 3 months, with reminders sent through mailing list channels. Existing regional contacts were only used to approach commissioners in under-represented regions. The survey was approved by UCL research ethics committee (reference 14097/001).

## Data analysis

Quantitative data were analysed in SPSS version 24. Responses with no data beyond date, title and/or area only were deleted. Duplicate entries from the same CCG or LA were manually combined into single entries, with conflicting responses assumed to indicate the service was being provided. Responses covering multiple CCGs and LAs (e.g. through joint-commissioning) were duplicated accordingly to reflect full coverage of areas. Descriptive statistics were calculated (means and standard deviations or medians and interquartile ranges) and used tables and graphs to display data. No statistical comparisons (e.g. by region) were undertaken due to lack of power. Qualitative data were analysed in Microsoft Excel using basic content analysis (Weber, 1990) to descriptively summarise the broad types of responses given. Phrases within open-ended responses for each question were inductively coded by XX and grouped under the same topic, which were discussed/agreed with wider team members (YY, ZZ and WW) and quantified using frequency of responses within that code. Typically, respondents provided only brief open-ended responses, precluding a more in-depth approach to analysis.

## Results

The survey was open for responses between 30th November 2018 and 15th March 2019. There were 154 clicks and 52 complete responses, covering 50/195 CCGs and 26/336 local authorities (including 10 County councils, nine Borough councils, three city councils, three metropolitan district councils and one combined authorities). It should be noted that only county or unitary councils have responsibility for social care (n=152 in England). In six areas

it was unclear whether the body referred to was a CCG or local authority (LA). 27/51 (53%) respondents reported joint-commissioning with other CCGs, voluntary sector or LAs. There was a spread of responses across the eight regions of England (Table 1), with the greatest response in East of England (23%). One CCG and LA joint-commissioning partnership was divided across two regions (East Midlands and North West) and one did not report their area. Excluding one large Foundation Trust (which reported covering 1.3million), the median number of people with dementia reported across CCGs (n=23, some jointly-commissioned across multiple CCGs) was 4359 (range 1000 to 16,000) and across LAs (n=14, some jointly commissioning across multiple areas) was 3,375 (range 1,136 to 14,000).

[Table 1 about here]

### *Dementia health services*

Memory services (standalone or in older people's community mental health teams) were most commonly reported across both CCGs and LAs (Figure 1). Only 26 reported integrated care services. Some specialist services (care home in-reach teams and young onset services) were frequently reported, but others (black and minority ethnic (BAME)-specific services, learning disability and dementia services) were much less common. Primary care-led services were reported by 29 respondents.

[Figure 1 about here]

From a range of other specific services, commissioners were asked to select services commissioned in their area and who provided them: primary care, secondary care, voluntary sector, local authority, non-commissioned (e.g. community groups) or private (respondents could select more than one option). With regards to health services (Table 2), most CCGs and LAs reported delivering all listed care coordination services, such as medication reviews, care planning, case management and crisis intervention. Although most were delivered by a single provider (although this varied), advance care planning was commonly delivered by two different service providers. Primary care was most likely to deliver care plan reviews, medication reviews and physical health reviews. Cognitive interventions, apart from cognitive rehabilitation, were also frequently commissioned and mainly provided by secondary care. Psychological support was less commonly commissioned, but was usually provided by the voluntary sector or secondary care. With

regards to physical health services, physical health reviews, end of life care and mobility services were prevalent, but dementia-specific vision, hearing and foot services were much rarer. Most physical health services were provided by secondary care.

[Table 2 about here]

### *Dementia community support services*

Community support services for people with dementia and carers are reported in Table 3. Information and advice services, particularly post-diagnostic counselling, dementia navigators and memory cafes, were provided in the vast majority of areas, and typically by the voluntary sector. Carer support services were also widespread, particularly local authority carer assessments and voluntary sector carer groups. The vast majority of commissioning bodies reported that activities and social support were provided in their area, usually by the voluntary sector, although centres were often reported to have multiple providers. Safe and supportive living services (services in the community designed to support the inclusion and independence of people with dementia) were less frequently commissioned, apart from care homes, and were most often provided by local authorities. Dementia friends (an Alzheimer's Society initiative where people or community groups learn more about dementia to increase awareness and understanding of the syndrome) were common and typically had at least two providers per area.

[Table 3 about here]

### *Collaboration, design and oversight*

Commissioners reported high levels of collaboration across services, including signposting or referrals (67/82); joint delivery of services, initiatives or events (57/82); staff from one service attending meetings or providing support for another service (57/82); and/or a local dementia services network (53/82).

When asked who was involved in service design, respondents reported commonly including carers (49/82), followed by people with dementia (45/82) and dementia charities (41/82). Only five respondents selected *none of these* (and another 12 did not know). Fewer, but still a substantial number, reported involvement in oversight or evaluation, but this was primarily carers (43/82), people with dementia (36/82) and charities (33/82). Thirteen

selected none and five did not know. Further details on the type or extent of involvement were not collected.

### *Targets*

Thirty-six respondents out of 52 (which covered multiple CCGs and LAs) reported a wide range of targets (Box 1). Targets were more frequently related to how services operated, with only 22/36 reporting targets relating to outcomes for the person with dementia or their carer. Access targets (n=23), particularly regarding waiting times, were most common, with 19 reporting targets relating to processes of care and support.

**Box 1. Targets reported by respondents**

- Access (n=23)
  - Waiting times (n=13)
  - Reach (n=5)
  - Awareness of services (n=3)
  - Access for underrepresented groups (n=2)
- Service outcomes for people with dementia and caregivers (n=22)
  - Feeling informed and equipped (n=4)
  - Carer confidence and resilience (n=3)
  - Independence (n=3)
  - Satisfaction (n=3)
  - Reduced acute services use (n=2)
  - Wellbeing (n=2)
  - Appropriate care (n=1)
  - Crisis prevention (n=1)
- Dementia care and support processes (n=19)
  - Care planning (n=4)
  - Specific service contacts e.g. helplines (n=4)
  - Collaboration and communication (n=3)
  - GP dementia lead (n=2)
  - Advance care planning (n=1)
  - Crisis plans (n=1)
  - Attending meetings (n=1)
  - Post-diagnostic care access (n=1)
  - Reviews (n=1)
- Presence of a specific service (n=8)
  - Care navigator or dementia support worker (n=3)
  - Welfare and legal services (n=2)
  - Physical health care (n=1)
  - Psychologist (n=1)
  - Information, advice and guidance (n=1)
- Workforce outcomes (n=3) e.g. greater training in dementia
- Diagnosis (n=11), including rates and time to diagnosis
- Inclusion (n=9), such as reduced social isolation
- Alignment with national guidance (n=2)

Most respondents reported all (15/33) or most (14/33) targets being met: 4/33 were unsure or a new service. Targets around access, following guidelines, inclusion, outcomes and some aspects of process such as communication, intensive support and GP leads were often reported as met. Types of targets least likely to be met were diagnosis rates (4/22), waiting times (2/22), presence of a psychologist, having sufficient volunteers in a carers service and calls to helplines (all 1/22).

### *Evaluation*

Only 36 commissioning bodies (44%, including 22 CCGs, 11 LAs and 3 unclear) reported carrying out evaluations. A small number carried out reviews, whilst 12 provided a contact for further details, 24 had not evaluated their service and 22 did not respond to this question.

When asked what worked well, responses from 37 commissioners centred on three themes: integration of services, good quality services and providing community-based support (see Figure 2). Mirroring this, there were six main areas identified in 31 responses that did not work well: integration problems, absent/incomplete services, problems meeting targets or with sufficient funding, a need to raise awareness and reach to minority populations (Figure 3).

[Figures 2 and 3 about here]

Forty-six out of eighty-two commissioning bodies (29/50 CCGs, 14/26 LAs and 2/6 unclear) planned to change their dementia services in the next five years. These included (n=29 responses) reviewing service pathways for gaps (n=7), re-procurement of same services (n=4), large pathway changes (n=4), increased primary care involvement (n=2), better fitting with local plan (n=2) and other (n=5). Changes were due to established need (n=16), contracts ending (n=5), better local service alignment (n=4), better policy alignment (n=4), cost savings (n=2), providing new services (n=2), good practice (n=2) and to increase dementia awareness (n=1).

## Discussion

This e-survey of commissioners from 82 commissioning bodies (50/195 CCGs, 26/336 LAs, 6 unclear) provides a snapshot of post-diagnostic dementia care in England. Specialist memory services, standalone or in a community mental health team, were the most commonly commissioned health services. Respondents reported great variation in services provided, and who provided them. The voluntary sector and local authorities played a large role in providing information, caregiver support and services to aid living well in the community. Some commissioning areas reported multiple providers delivering the same service, whilst services were rarely consistently delivered by the same provider across areas. Most areas reported some involvement from people with dementia and carers in

commissioning and oversight. Commissioners identified a need for integrated pathways of care to avoid overlap or gaps in service coverage. Targets were frequently reported to be met (although this is likely to suffer from response bias). Over half of providers planned to change services within the next five years.

The results show some consistency with recent national and international policies and evidence-based national clinical guidelines, such as good provision of cognitive stimulation therapy, dementia adviser services and a focus on providing community support (NHS England, 2019; NICE, 2018; World Health Organization, 2017). Community services are seen as popular and closer to the communities they serve, but they are also under pressure to accommodate increasing demand and build capacity within constrained funding (Chadborn, Craig, Sands, Schneider, & Gladman, 2019). Similar community dementia support services, e.g. dementia advisers, information and advice services, social activities, dementia navigation, carer support services (Ipsos Mori, 2016) and memory cafes (Robens et al., 2015) have been reported in previous surveys, suggesting the findings are likely to be fairly accurate.

However, this survey found low rates of programme evaluation, which may be due to the difficulty of providing measurable outcomes within the short-term nature of voluntary sector commissioning (Chadborn et al., 2019). The good levels of involvement of people with dementia and carers in service commissioning and evaluation represents a positive step, although data on the depth and nature of this were not collected. Challenges in equity of access were reported by some commissioners in this survey, with few targeting dementia health services towards BAME groups. This risks services being inappropriate for some population subgroups and/or perpetuating inequalities in access.

This survey confirms the common impression that dementia service provision is highly variable and inconsistent across areas. Although this could represent local tailoring, it makes cross-locality comparisons of service standards challenging. This is likely complicated by the lack of clear recommendations on post-diagnostic service providers – for example whilst best practice standards exist for memory services (Royal College of Psychiatrists, 2016), implementation guidance suggests roles such as dementia advisors and case managers can come from any sector (NHS, 2017). This survey found service provider duplication in some areas, which could perhaps be better integrated or streamlined. Health and social care

integration has been a commissioning aim and strategy over the last decade (Gleave, Wong, Porteus, & Harding, 2010), but little progress appears to have been made in this area for dementia. Only 26 survey respondents reported integrated health care services, although all respondents reported some dementia service collaboration. Professionals such as case managers, who can improve integration, were provided in two-thirds of areas but can vary widely in caseload, remit and availability. A key factor can be supporting interprofessional communication though electronic systems (Robertshaw & Cross, 2019).

This survey had representation from all regions, mapped a wide range of services and underwent extensive piloting. National-level data on this topic were previously lacking, and few other methods would be able to capture the variety of services from multiple providers across a broad range of areas. There are limitations. Despite efforts to recruit through multiple channels, responses were low, limiting survey generalisability and precluding cross-regional comparisons. A response rate denominator could not be calculated due to the overlap of potential respondents between recruitment methods. Other surveys have achieved coverage of 141 CCGs and LAs (Ipsos Mori, 2016). It is likely that responders had greater interest in and provision of dementia services than non-responders. Given the low provision of some services in that those who did respond, this raises the question of how comprehensive services are in non-responding areas. It is also important to note that services are rarely identical and the details of contacts, remit, uptake and coverage are likely to vary widely. One London Memory Service audit found that only 0-50% of services referred people to cognitive stimulation therapy and 13-68% to a dementia navigator (London Clinical Networks, 2016). A more concise survey with more detailed descriptions of service content and function may have improved consistency. Respondents may not have direct control over service quality and consistency and may not be fully aware of all local services, particularly non-commissioned or privately provided services. Finally, in order to balance survey brevity and comprehensiveness, only a limited depth of data could be collected on some topics.

This survey provides evidence to confirm~~s~~ the impression that dementia services vary widely across locality in terms of availability, provider type and comprehensiveness. Whilst some community services (such as activity groups, carer assessment, dementia advisors, memory cafes) have relatively consistent coverage across areas, psychological support services for

people with dementia and their carers were less frequently provided and require investment. Further development of integrated service pathways is needed to avoid service duplication or gaps, with consistent evaluation and standards to ensure services are delivering good quality care, and support for minority groups. Many respondents reported intended changes, so the landscape of post-diagnostic dementia care is likely to shift further in the near future. Repeating this survey in a number of years may offer an opportunity to track if and how this landscape has changed, whilst ~~.~~ in-depth case studies of what is commissioned in a small number of localities would complement the results of this survey.

## Conclusion

Post-diagnostic dementia care in England represents a fragmented landscape with multiple sectors delivering many services. There are challenges around developing integrated pathways and providing support for minority groups, particularly in light of regular service changes. Better cross-sectoral service integration would improve coordination, increase consistency and reduce duplication.

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**Table 1 CCGs and LAs represented in the survey by region**

| | | Commissioning body | | | Total |
|---|---|---|---|---|---|
| | | CCG | LA | unclear | |
| Region | North East and Cumbria | 1 (2%) | 3 (12%) | 1 (17%) | 5 (6%) |
| | North West | 3 (6%) | 1 (4%) | 1 (17%) | 5 (6%) |
| | Yorkshire and the Humber | 6 (12%) | 3 (12%) | 0 | 9 (11%) |
| | West Midlands | 4 (8%) | 2 (8%) | 0 | 6 (7%) |
| | East Midlands | 7 (14%) | 3 (12%) | 0 | 10 (12%) |
| | East of England | 12 (24%) | 6 (23%) | 1 (17%) | 19 (23%) |
| | London | 3 (6%) | 4 (15%) | 1 (17%) | 8 (10%) |
| | South East | 9 (18%) | 2 (8%) | 1 (17%) | 12 (15%) |
| | South West | 4 (8%) | 1 (4%) | 0 | 5 (6%) |
| | Cross-region | 1 (2%) | 1 (4%) | 0 | 2 (2%) |
| | Missing | - | - | 1 (17%) | 1 (1%) |
| Total | | 50 | 26 | 6 | 82 |

**Table 2. Health services provided in each area**

| | CCG | LA | UNCLEAR | N PROVIDERS (MEDIAN (RANGE)) | MOST COMMONLY PROVIDED BY (%)* |
|---|---|---|---|---|---|
| **CARE COORDINATION** | | | | | |
| Care plan reviews | 39/50 | 21/26 | 5/6 | 1 (0-5)<br>1.38 (1.25) | Primary care (46%) |
| Case manager (providing ongoing support) | 33/50 | 18/26 | 4/6 | 1 (0-5)<br>1.41 (1.49) | Local authority (46%) |
| Medication reviews | 39/50 | 20/26 | 5/6 | 1 (0-4)<br>1.26 (0.89) | Primary care (63%) |
| Crisis intervention / management | 36/50 | 17/26 | 5/6 | 1 (0-6)<br>1.30 (1.45) | Secondary care (60%) |
| Advance care planning including lasting power of attorney | 37/50 | 20/26 | 4/6 | 2 (0-4)<br>1.71 (2.37) | Voluntary sector (51%) |
| **COGNITIVE INTERVENTIONS** | | | | | |
| Cognitive stimulation therapy | 35/50 | 16/26 | 3/6 | 1 (0-3)<br>0.79 (0.68) | Secondary care (55%) |
| Cognitive rehabilitation | 18/50 | 8/26 | 2/6 | 0 (0-2)<br>0.39 (0.58) | Secondary care (30%) |
| Occupational therapy | 35/50 | 17/26 | 4/6 | 1 (0-3)<br>1.09 (0.97) | Secondary care (61%) |
| Assistive technology | 38/50 | 23/26 | 5/6 | 1 (0-6)<br>1.35 (1.22) | Local authority (68%) |
| **PSYCHOLOGICAL SUPPORT SPECIFIC TO DEMENTIA** | | | | | |
| Life story work | 19/50 | 11/26 | 4/6 | 0 (0-5)<br>0.80 (1.15) | Voluntary sector (32%) |
| One page profiles | 18/50 | 10/26 | 3/6 | 0 (0-6)<br>0.91 (1.48) | Voluntary sector (29%) |
| Reminiscence/ reality orientation | 24/50 | 15/26 | 5/6 | 1 (0-4)<br>0.95 (1.06) | Voluntary sector (43%) |
| Animal assisted therapy | 15/50 | 11/26 | 3/6 | 0 (0-3)<br>0.50 (0.79) | Voluntary sector (23%) |

| | | | | | |
|---|---|---|---|---|---|
| Psychological health review | 18/50 | 10/26 | 4/6 | 0 (0-3)<br>0.49 (0.71) | Secondary care (24%) |
| Individual counselling/ psychotherapy | 24/50 | 13/26 | 5/6 | 1 (0-4)<br>0.89 (1.10) | Secondary care (38%) |
| Group psychotherapy | 15/50 | 11/26 | 4/6 | 0 (0-3)<br>0.50 (0.79) | Secondary care (27%) |
| Couples/family/ systemic therapy | 17/50 | 10/26 | 3/6 | 0 (0-3)<br>0.68 (1.09) | Secondary care (24%) |
| Behavioural interventions | 29/50 | 14/26 | 4/6 | 1 (0-3)<br>0.83 (0.84) | Secondary care (37%) |
| Challenging behaviour team | 18/50 | 12/26 | 4/6 | 0 (0-2)<br>0.48 (0.61) | Secondary care (35%) |
| **PHYSICAL HEALTH SERVICES SPECIFIC TO DEMENTIA** | | | | | |
| Physical health reviews | 34/50 | 18/26 | 5/6 | 1 (0-4)<br>1.06 (0.93) | Primary care (61%) |
| Mobility/falls services | 31/50 | 15/26 | 4/6 | 1 (0.5)<br>1.12 (1.40) | Secondary care (38%) |
| Exercise classes | 28/50 | 15/26 | 4/6 | 1 (0-5)<br>1.30 (1.59) | Voluntary sector (35%) |
| Nutrition | 29/50 | 14/26 | 4/6 | 1 (0-4)<br>0.96 (1.15) | Secondary care (37%) |
| Dental care | 24/50 | 11/26 | 4/6 | 0 (0-3)<br>0.70 (0.90) | Secondary care (27%) |
| Vision | 21/50 | 11/26 | 4/6 | 0 (0-4)<br>0.76 (1.08) | Private (27%) |
| Hearing | 22/50 | 11/26 | 4/6 | 0 (0-4)<br>0.78 (1.10) | Secondary care (24%)<br>Private (24%) |
| Foot care | 21/50 | 11/26 | 4/6 | 0 (0-4)<br>0.80 (1.16) | Secondary care (32%) |
| Specialist hospital liaison/support | 28/50 | 13/26 | 3/6 | 1 (0-3)<br>0.71 (0.79) | Secondary care (48%) |
| End of life care | 33/50 | 15/26 | 4/6 | 1 (0-6)<br>1.65 (1.89) | Secondary care (51%) |

*out of 82, although respondents could select more than one option

**Table 3. Community dementia support services commissioned**

| | CCG | LA | UNCLEAR | N providers (median (range)) | MOST COMMONLY PROVIDED BY (%)* |
|---|---|---|---|---|---|
| **INFORMATION AND ADVICE SERVICES** | | | | | |
| Post-diagnostic counselling | 41/50 | 19/26 | 6/6 | 1 (0-4) 1.22 (0.89) | Voluntary sector (48%) |
| Dementia adviser/navigator | 46/50 | 25/26 | 6/6 | 1 (0-3) 1.29 (0.76) | Voluntary sector (66%) |
| Memory/dementia cafes | 45/50 | 23/26 | 5/6 | 1 (0-6) 1.35 (0.94) | Voluntary sector (70%) |
| Drop-ins | 31/50 | 19/26 | 4/6 | 1 (0-4) 1.09 (0.98) | Voluntary sector (57%) |
| Telephone lines | 38/50 | 23/26 | 4/6 | 1 (0-5) 1.11 (0.96) | Voluntary sector (62%) |
| Online resources | 39/50 | 23/26 | 6/6 | 1 (0-6) 1.44 (1.21) | Voluntary sector (60%) |
| Advocacy | 38/50 | 23/26 | 4/6 | 1 (0-4) 1.07 (0.75) | Voluntary sector (59%) |
| Welfare benefits or legal advice | 41/50 | 23/26 | 6/6 | 1 (0-5) 1.34 (0.83) | Voluntary sector (68%) |
| Information on transitions (e.g. Moving to a care home) | 33/50 | 18/26 | 6/6 | 1 (0-5) 1.01 (0.95) | Local authority (38%) |
| **CARER SUPPORT** | | | | | |
| Carer assessment | 48/50 | 25/26 | 5/6 | 1 (0-4) 1.40 (0.70) | Local authority (72%) |
| Post-diagnostic carer courses | 39/50 | 21/26 | 4/6 | 1 (0-3) 1.10 (0.80) | Voluntary sector (54%) |
| Carer groups | 41/50 | 24/26 | 5/6 | 1 (0-5) 1.46 (0.98) | Voluntary sector (79%) |
| Carer counselling/ psychotherapy | 31/50 | 21/26 | 5/6 | 1 (0-5) 0.98 (0.87) | Voluntary sector (34%) |

| | | | | | |
|---|---|---|---|---|---|
| Telephone helplines (advice / support) | 38/50 | 22/26 | 3/6 | 1 (0-5)<br>1.30 (1.17) | Voluntary sector (61%) |
| Online carer resources | 33/50 | 22/26 | 5/6 | 1 (0-5)<br>1.46 (1.42) | Voluntary sector (63%) |
| Respite | 34/50 | 20/26 | 5/6 | 1 (0-3)<br>1.09 (0.92) | Local authority (51%) |
| **ACTIVITIES AND SOCIAL SUPPORT** | | | | | |
| Dementia peer support groups | 39/50 | 23/26 | 5/6 | 1 (0-6)<br>1.42 (1.11) | Voluntary sector (74%) |
| Dementia activity groups (e.g. Singing, tea dances, lunch clubs) | 44/50 | 25/26 | 5/6 | 1 (0-5)<br>1.61 (1.07) | Voluntary sector (80%) |
| Day centres | 41/50 | 23/26 | 5/6 | 1.5 (0-4)<br>1.61 (1.14) | Local authority (56%)<br>Voluntary sector (56%) |
| Involvement/user groups | 32/50 | 18/26 | 4/6 | 1 (0-4)<br>1.18 (1.12) | Voluntary sector (50%) |
| Creative arts therapies e.g. Music, art groups | 40/50 | 23/26 | 4/6 | 1 (0-4)<br>1.43 (1.07) | Voluntary sector (65%) |
| **SAFE AND SUPPORTIVE LIVING** | | | | | |
| Dementia friendly libraries | 26/50 | 17/26 | 3/6 | 1 (0-3)<br>0.76 (0.82) | Local authority (50%) |
| Dementia friendly leisure centres | 18/50 | 11/26 | 4/6 | 0 (0-4)<br>0.65 (0.95) | Local authority (33%) |
| Adaptations / equipment | 29/50 | 20/26 | 5/6 | 1 (0-4)<br>1.09 (1.15) | Local authority (63%) |
| Supported independent living | 26/50 | 19/26 | 4/6 | 1 (0-4)<br>1.23 (1.35) | Local authority (57%) |
| Care homes without nursing | 34/50 | 22/26 | 5/6 | 1 (0-3)<br>1.26 (1.02) | Local authority (56%) |
| Care homes with nursing | 33/50 | 21/26 | 5/6 | 1 (0-4)<br>1.27 (1.14) | Local authority (54%) |

| | | | | | |
|---|---|---|---|---|---|
| Hospices | 26/50 | 18/26 | 4/6 | 1 (0-4)<br>0.88 (0.93) | Voluntary sector<br>(27%) |
| Dementia friends | 40/50 | 22/26 | 5/6 | 2 (0-6)<br>2.34 (2.09) | Voluntary sector<br>(61%) |

*out of 82, although respondents could select more than one option

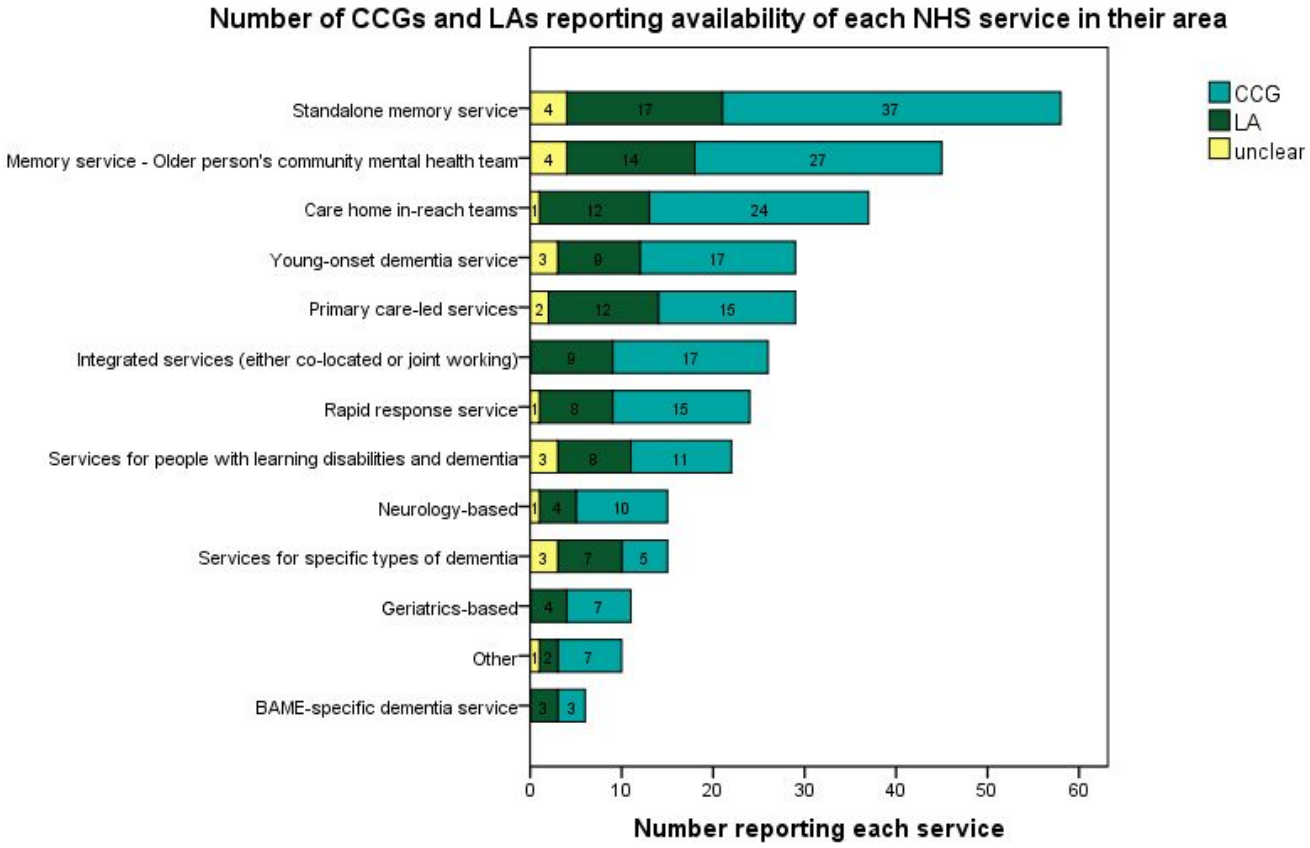


**Figure 1 CCGs and LAs reporting availability of each type of NHS service in their area**

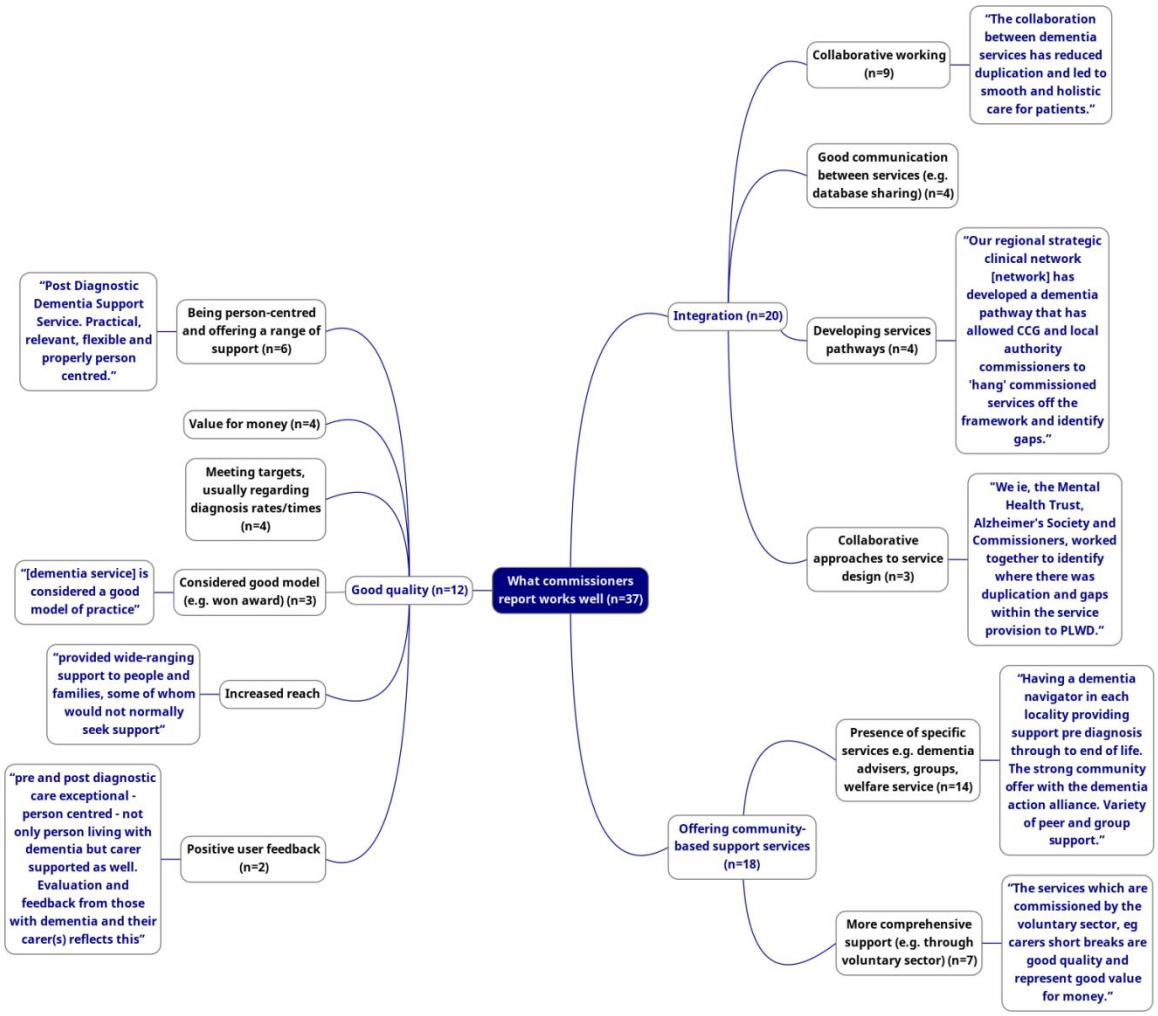


**Figure 2. Commissioners' responses as to what worked well in their services**

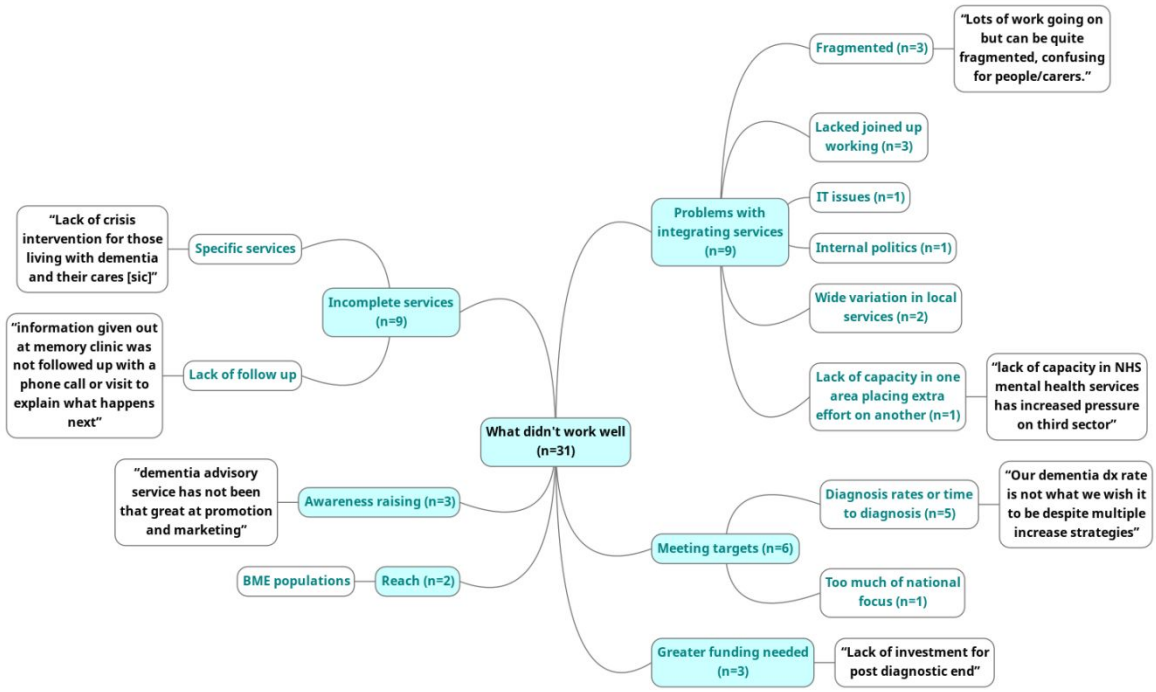


**Figure 3. Commissioners' reports of what is not working well**

# Mapping dementia care after diagnosis in England: an e-survey

Thank you for your interest in this survey, which is being carried out by University College London. It is funded by the Alzheimer's Society.

Post-diagnostic dementia services across the UK are highly varied in how they are delivered. It is not clear which service models may offer the most effective and sustainable care for persons with dementia and their carers. We are surveying people who commission any service(s) related to **supporting people with dementia at any stage after diagnosis** (but not assessment and diagnostic services) across England.

We want to understand how these services are being delivered, who by, how this fits with current policy and what is working well in practice.

This survey is part of a larger project, PriDem (please see website here) led by Newcastle University, which is exploring the best way to deliver effective and sustainable primary care-led models of care after a dementia diagnosis. However we are interested in all types of care provided after diagnosis in this survey.

The survey should take approximately 10-15min. You can save it and return to complete it later if necessary. The survey has been reviewed by UCL Ethics Committee (ref 14097/001). If you would like to read further information about the survey and how your data will be used, please click here. You can also contact the Research Associate, Dr Rachael Frost, on rachael.frost@ucl.ac.uk or 0207 830 2881.

Otherwise, if you are happy to take part in this survey, please click the Start button below.

Thank you for completing this survey. Please complete as many questions as it is possible for you to answer. If you do not have the information to hand to answer a question, please leave it blank. Please note we are interested in **all services you provide as part of care after diagnosis** for a person with dementia and/or their carer(s), but **we are not interested in assessment and diagnostic services**.

**Q1: What is your job title or role in relation to dementia commissioning?**

**Q2: Which Clinical Commissioning Group, Local Authority and locality are you based in?**

# Dementia services in your area

**Q3: Approximately how many people with dementia are there in your area?**

**Q4: Are your dementia services jointly commissioned?**

○ Yes ○ No ○ Don't know

If so, with whom?

**Q5: Which of the following NHS dementia service(s) are you aware of in your local area?**

- ☐ Primary care-led
- ☐ Memory service: standalone
- ☐ Memory service: older person's community health team
- ☐ Integrated services (either co-located or joint working)
- ☐ Geriatrics-based
- ☐ Neurology-based
- ☐ Rapid response service
- ☐ Young-onset dementia service
- ☐ BAME-specific dementia service
- ☐ Care home in-reach teams
- ☐ Services for specific types of dementia
- ☐ Services for people with learning disabilities and dementia
- ☐ Other

If you have chosen "other", please specify:

**Q6: Which of the following dementia information and advice services are provided in your area? Please specify who provides the service (leave the row blank if the service is not being provided in your area or you are unsure).**

| | NHS - Primary care | NHS - Secondary care | Local authority | Third sector | Non-commissioned (e.g. community initiatives) | Private |
|---|---|---|---|---|---|---|
| Post diagnostic counselling | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Dementia adviser/navigator | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Memory/dementia cafes | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Drop-ins | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Telephone lines | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Online resources | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Advocacy | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Welfare benefits or legal advice | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Information on transitions (e.g. moving to a care home) | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

**Q7: Which of the following carer wellbeing and support services are provided in your area? Please specify who provides the service (leave the row blank if the service is not being provided or you are unsure).**

| | NHS - Primary care | NHS - Secondary care | Local authority | Third sector | Non-commissioned | Private |
|---|---|---|---|---|---|---|
| Carer assessment | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Post-diagnostic carer courses | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Carer groups | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Carer counselling/psychotherapy | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Telephone helplines (advice / support) | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Online carer resources | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Respite | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

**Q8: Which services to maintain cognitive function and independence in dementia are provided in your area? Please specify who provides the service (leave the row blank if the service is not provided or you are unsure).**

| | NHS - Primary care | NHS - Secondary care | Local authority | Third sector | Non-commissioned (e.g. community initiatives) | Private |
|---|---|---|---|---|---|---|
| Cognitive stimulation therapy | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Cognitive rehabilitation | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Occupational therapy | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Assistive technology | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

**Q9: Which services for activity and social connection for people with dementia are provided in your area? Please specify who by (leave the row blank if the service is not provided or you are unsure).**

| | NHS - Primary care | NHS - Secondary care | Local authority | Third sector | Non-commissioned (e.g. community initiatives) | Private |
|---|---|---|---|---|---|---|
| Dementia peer support groups | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Dementia activity groups (e.g. singing, tea dances, lunch clubs) | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Day centres | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Involvement/user groups | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Creative arts therapies e.g. music, art groups | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

**Q10: Which services to support the psychological wellbeing of people with dementia are provided in your area? Please specify who provides the service (leave the row blank if the service is not provided or you are unsure).**

| | NHS - Primary care | NHS - Secondary care | Local authority | Third sector | Non-commissioned (e.g. community initiatives) | Private |
|---|---|---|---|---|---|---|
| Life story work | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| One page profiles | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Reminiscence/reality orientation | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Animal assisted therapy | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Psychological health review | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

| | | | | | | |
|---|---|---|---|---|---|---|
| Individual counselling/psychotherapy | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Group psychotherapy | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Couples/family/systemic therapy | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Behavioural interventions | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

**Q11: Which services to give people with dementia a safe and supportive living environment are provided in your area? Please specify who provides the service (leave the row blank if the service is not provided or you are unsure).**

| | NHS - Primary care | NHS - Secondary care | Local authority | Third sector | Non-commissioned (e.g. community initiatives) | Private |
|---|---|---|---|---|---|---|
| Dementia friendly libraries | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Dementia friendly leisure centres | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Adaptations / equipment | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Supported independent living | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Care homes without nursing | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Care homes with nursing | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Hospices | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Dementia friends | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Challenging behaviour team | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

**Q12: Which services are provided locally to help coordinate the care of people with dementia? Please specify who provides the service (leave the row blank if the service is not provided or you are unsure).**

| | NHS - Primary care | NHS - Secondary care | Local authority | Third sector | Non-commissioned (e.g. community initiatives) | Private |
|---|---|---|---|---|---|---|
| Care plan reviews | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Case manager (providing ongoing support) | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

| | | | | | | |
|---|---|---|---|---|---|---|
| Medication reviews | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Crisis intervention / management | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Advance care planning including Lasting Power of Attorney | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

**Q13: Which dementia-specific physical health services are provided in your area? Please specify who provides the service (leave the line blank if the service is not provided or you are unsure).**

| | NHS - Primary care | NHS - Secondary care | Local authority | Third sector | Non-commissioned (e.g. community initiatives) | Private |
|---|---|---|---|---|---|---|
| Physical health reviews | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Mobility/falls services | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Exercise classes | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Nutrition | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Dental care | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Vision | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Hearing | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Foot care | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Specialist hospital liaison/support | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| End of life care | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| | | ☐ | ☐ | ☐ | ☐ | ☐ |

## Working with other services

**Q14: How closely does the service(s) you commission collaborate with other dementia services being delivered in your area?**

- ☐ Signposting/referrals between services
- ☐ Staff from one service occasionally attend meetings or provide support for another service
- ☐ Joint delivery of some services, initiatives or events
- ☐ Local network of dementia services

- [ ] We do not collaborate
- [ ] Other

If you have chosen "other", please specify:

# Involvement of people with dementia and carers

**Q15: Who was involved in designing or choosing the services you commission?**

- ☐ People with dementia
- ☐ Carers
- ☐ Dementia charity
- ☐ None of the above
- ☐ Don't know
- ☐ Other

If you have chosen "other", please specify:

**Q16: Who is involved in oversight or evaluation of the services you commission?**

- ☐ People with dementia
- ☐ Carers
- ☐ Dementia charity
- ☐ None of the above
- ☐ Don't know
- ☐ Other

If you have chosen "other", please specify:

# Targets

**Q17: What are the key targets or performance indicators for the service(s) you commission?**

**Q18: Which of these have been met in the last year?**

**Q19: Which of these have not been met in the last year?**

# Evaluation

**Q20: Have you carried out any work to evaluate the dementia service(s) you commission?**

◯ Yes ◯ No

If yes, please provide a link to a report if available or your email address if you are happy for us to contact you for further information

**Q21: What, in your opinion, has worked well in the dementia service(s) you commission and why?**

**Q22: What, in your opinion, has not worked well in the dementia service(s) you commission and why?**

**Q23: In an ideal world, how would you change the dementia service(s) you currently commission?**

**Q24: What is the approximate total budget for dementia services in your area/locality per annum?**

◯ Unsure ◯ Do not want to disclose ◯ £

If you have chosen "other", please specify:

# Future service plans

**Q25: Do you plan to change any of your dementia service(s) in the next five years?**

◯ Yes ◯ No

If yes, how?

**Q26: What is the reason for this change?**

# Further contact

**Q27: Would you be interested in being contacted about potentially taking part in further research undertaken as part of this project (e.g. an interview)?If so, your name, email address and job title will be shared with our research team at Newcastle University**

◯ Yes ◯ No

**Q28: Are you happy for us to contact you regarding further queries about your service (e.g. to locate service audits or evaluations) if necessary?**

◯ Yes ◯ No

**Q29: Would you like us to contact you with the results of this survey?**

◯ Yes ◯ No

**Q30: If yes to any of the above, please provide your name and email address below. We will only use your details to contact you about the things you agreed to.**