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

Rachael Frost
Department of Primary Care and Population Health, University College London, London, UK and
University College London, London, UK

Kate Walters and Jane Wilcock
University College London, London, UK

Louise Robinson
Newcastle University, Newcastle upon Tyne, UK

Karen Harrison Dening
Dementia UK, London, UK

Martin Knapp
LSE, London, UK

Louise Allan
University of Exeter, Exeter, UK, and

Greta Rait
University College London, London, UK

Abstract

Purpose – Post-diagnostic dementia care is often fragmented in the United Kingdom, with great variation in provision. Recent policies suggest moving towards better community-based care for dementia; however, little is known 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/methodology/approach – A mixed-methods e-survey (open Nov 2018–Mar 2019) of dementia commissioners in England recruited through mailing lists of relevant organisations was conducted. The authors 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.

Keywords Voluntary and community sector, Integrated health and social care, Long-term conditions, Local government, Health and social care, Integrated care

Paper type Research paper

Background

Approximately 43.8m people live with dementia globally (GBD 2016 Dementia Collaborators, 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 *et al.*, 2016), which may include information, community support services, treatments, physical healthcare, comorbidity management and behavioural and psychological symptom management (Prince *et al.*, 2016). This support is estimated to cost US$818bn globally (Prince *et al.*, 2015). In the United Kingdom, 815,827 are living with dementia (Prince *et al.*, 2014), and this number is increasing, with costs in England estimated to be £24.2bn (Wittenberg *et al.*, 2019). However, nearly half of people with dementia in the United Kingdom feel they are getting insufficient post-diagnostic support (Kane and 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 healthcare (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 of good quality, there are no current national data on what post-diagnostic support is commissioned across a range of services (Kane and Terry, 2015). Previous surveys focus mainly on single services, for example, memory assessment services (Chrysanthanki *et al.*, 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 (such as information services, social activities) commissioned 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 (Kinnaird, 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 well-being and support, cognitive function and independence, activity and social connection, psychological well-being, 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 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:

(1) 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 (two reminders)

(2) NHS Clinical Commissioners newsletter (one reminder)

(3) Alzheimer's Society Network of local commissioners (one reminder)

(4) Dementia Action Alliance newsletter

(5) Public Health England National Mental Health, Dementia and Neurology Intelligence Network

(6) Existing regional commissioning contacts known to the research team

Communications were staggered over three 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 RF and grouped under the same topic, which were discussed/agreed with wider team members (GR, KW and JW) 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.
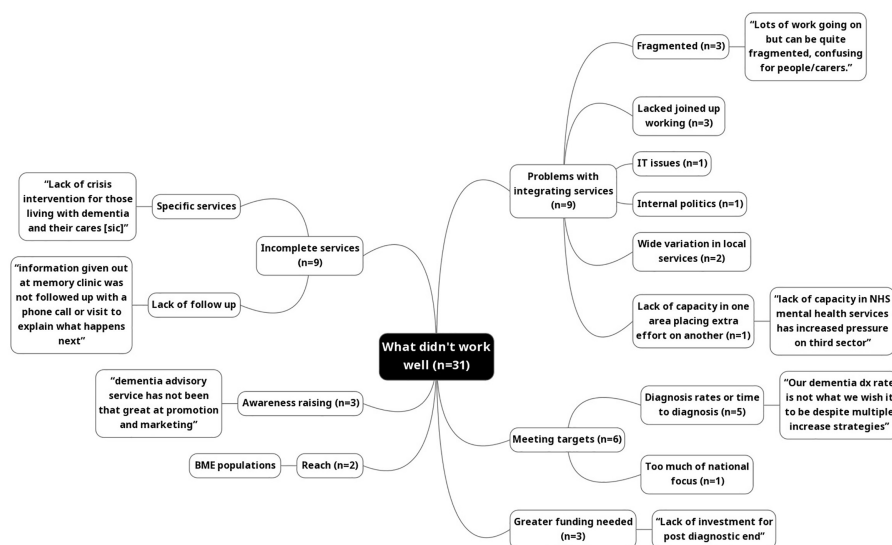
Results
The survey was open for responses between 30th November 2018 and 15th March 2019. There were 154 clicks and 52 complete responses, covering 50/195 CCGs and 26/336 LAs (including ten county councils, nine borough councils, three city councils, three metropolitan district councils and one combined 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 LA. About 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 1.3m), the median number of people with dementia reported across CCGs ($n = 23$, some jointly commissioned across multiple CCGs) was 4,359 (range 1,000–16,000) and across LAs ($n = 14$, some jointly commissioning across multiple areas) was 3,375 (range 1,136–14,000).

Dementia health services
Memory services (stand-alone 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

| | | Commissioning body | | | |
		CCG	LA	Unclear	Total
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 1.
CCGs and LAs represented in the survey by region

Mind map titled "What didn't work well (n=31)" with the following branches:

- Incomplete services (n=9)
  - Specific services — "Lack of crisis intervention for those living with dementia and their cares [sic]"
  - Lack of follow up — "information given out at memory clinic was not followed up with a phone call or visit to explain what happens next"
- Awareness raising (n=3) — "dementia advisory service has not been that great at promotion and marketing"
- Reach (n=2) — BME populations
- Problems with integrating services (n=9)
  - Fragmented (n=3) — "Lots of work going on but can be quite fragmented, confusing for people/carers."
  - Lacked joined up working (n=3)
  - IT issues (n=1)
  - Internal politics (n=1)
  - Wide variation in local services (n=2)
  - Lack of capacity in one area placing extra effort on another (n=1) — "lack of capacity in NHS mental health services has increased pressure on third sector"
- Meeting targets (n=6)
  - Diagnosis rates or time to diagnosis (n=5) — "Our dementia dx rate is not what we wish it to be despite multiple increase strategies"
  - Too much of national focus (n=1)
- Greater funding needed (n=3) — "Lack of investment for post diagnostic end"

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.

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 regard 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 regard 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.

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 LA 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

	CCG	LA	Unclear	*N* providers (median (range)) (mean (SD))	Most commonly provided by (%)*
Care coordination					
Care plan reviews	39/50	21/26	5/6	1 (0–5) 1.38 (1.25)	Primary care (46%)
Case manager (providing ongoing support)	33/50	18/26	4/6	1 (0–5) 1.41 (1.49)	Local authority (46%)
Medication reviews	39/50	20/26	5/6	1 (0–4) 1.26 (0.89)	Primary care (63%)
Crisis intervention/management	36/50	17/26	5/6	1 (0–6) 1.30 (1.45)	Secondary care (60%)
Advance care planning including lasting power of attorney	37/50	20/26	4/6	2 (0–4) 1.71 (2.37)	Voluntary sector (51%)
Cognitive interventions					
Cognitive stimulation therapy	35/50	16/26	3/6	1 (0–3) 0.79 (0.68)	Secondary care (55%)
Cognitive rehabilitation	18/50	8/26	2/6	0 (0–2) 0.39 (0.58)	Secondary care (30%)
Occupational therapy	35/50	17/26	4/6	1 (0–3) 1.09 (0.97)	Secondary care (61%)
Assistive technology	38/50	23/26	5/6	1 (0–6) 1.35 (1.22)	Local authority (68%)
Psychological support specific to dementia					
Life story work	19/50	11/26	4/6	0 (0–5) 0.80 (1.15)	Voluntary sector (32%)
One-page profiles	18/50	10/26	3/6	0 (0–6) 0.91 (1.48)	Voluntary sector (29%)
Reminiscence/reality orientation	24/50	15/26	5/6	1 (0–4) 0.95 (1.06)	Voluntary sector (43%)
Animal-assisted therapy	15/50	11/26	3/6	0 (0–3) 0.50 (0.79)	Voluntary sector (23%)
Psychological health review	18/50	10/26	4/6	0 (0–3) 0.49 (0.71)	Secondary care (24%)
Individual counselling/ psychotherapy	24/50	13/26	5/6	1 (0–4) 0.89 (1.10)	Secondary care (38%)
Group psychotherapy	15/50	11/26	4/6	0 (0–3) 0.50 (0.79)	Secondary care (27%)
Couples/family/systemic therapy	17/50	10/26	3/6	0 (0–3) 0.68 (1.09)	Secondary care (24%)
Behavioural interventions	29/50	14/26	4/6	1 (0–3) 0.83 (0.84)	Secondary care (37%)
Challenging behaviour team	18/50	12/26	4/6	0 (0–2) 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) 1.06 (0.93)	Primary care (61%)
Mobility/falls services	31/50	15/26	4/6	1 (0.5) 1.12 (1.40)	Secondary care (38%)
Exercise classes	28/50	15/26	4/6	1 (0–5) 1.30 (1.59)	Voluntary sector (35%)
Nutrition	29/50	14/26	4/6	1 (0–4) 0.96 (1.15)	Secondary care (37%)

Table 2.
Health services
provided in each area

(*continued*)

	CCG	LA	Unclear	N providers (median (range)) (mean (SD))	Most commonly provided by (%)*
Dental care	24/50	11/26	4/6	0 (0–3) 0.70 (0.90)	Secondary care (27%)
Vision	21/50	11/26	4/6	0 (0–4) 0.76 (1.08)	Private (27%)
Hearing	22/50	11/26	4/6	0 (0–4) 0.78 (1.10)	Secondary care (24%) Private (24%)
Foot care	21/50	11/26	4/6	0 (0–4) 0.80 (1.16)	Secondary care (32%)
Specialist hospital liaison/support	28/50	13/26	3/6	1 (0–3) 0.71 (0.79)	Secondary care (48%)
End-of-life care	33/50	15/26	4/6	1 (0–6) 1.65 (1.89)	Secondary care (51%)

Note(s): *Out of 82, although respondents could select more than one option

Table 2.

homes, and were most often provided by LAs. 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.

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). About 13 selected none and five did not know. Further details on the type or extent of involvement were not collected.

Targets
About 36 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.

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 carer 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

	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) 1.30 (1.17)	Voluntary sector (61%)
Online carer resources	33/50	22/26	5/6	1 (0–5) 1.46 (1.42)	Voluntary sector (63%)
Respite	34/50	20/26	5/6	1 (0–3) 1.09 (0.92)	Local authority (51%)
Activities and social support					
Dementia peer support groups	39/50	23/26	5/6	1 (0–6) 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) 1.61 (1.07)	Voluntary sector (80%)
Day centres	41/50	23/26	5/6	1.5 (0–4) 1.61 (1.14)	Local authority (56%) Voluntary sector (56%)
Involvement/user groups	32/50	18/26	4/6	1 (0–4) 1.18 (1.12)	Voluntary sector (50%)
Creative arts therapies, e.g. music, art groups	40/50	23/26	4/6	1 (0–4) 1.43 (1.07)	Voluntary sector (65%)
Safe and supportive living					
Dementia-friendly libraries	26/50	17/26	3/6	1 (0–3) 0.76 (0.82)	Local authority (50%)
Dementia-friendly leisure centres	18/50	11/26	4/6	0 (0–4) 0.65 (0.95)	Local authority (33%)

Table 3.
Community dementia support services commissioned

(*continued*)

	CCG	LA	Unclear	N providers (median (range))	Most commonly provided by (%)*
Adaptations/equipment	29/50	20/26	5/6	1 (0–4) 1.09 (1.15)	Local authority (63%)
Supported independent living	26/50	19/26	4/6	1 (0–4) 1.23 (1.35)	Local authority (57%)
Care homes without nursing	34/50	22/26	5/6	1 (0–3) 1.26 (1.02)	Local authority (56%)
Care homes with nursing	33/50	21/26	5/6	1 (0–4) 1.27 (1.14)	Local authority (54%)
Hospices	26/50	18/26	4/6	1 (0–4) 0.88 (0.93)	Voluntary sector (27%)
Dementia friends	40/50	22/26	5/6	2 (0–6) 2.34 (2.09)	Voluntary sector (61%)

Note(s): *Out of 82, although respondents could select more than one option

Table 3.

Box 1. Targets reported by respondents

(1) Access (n = 23)
  - Waiting times (n = 13)
  - Reach (n = 5)
  - Awareness of services (n = 3)
  - Access for under-represented groups (n = 2)
(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)
  - Well-being (n = 2)
  - Appropriate care (n = 1)
  - Crisis prevention (n = 1)
(3) Dementia care and support processes (n = 19)
  - Care planning (n = 4)
  - Specific service contacts, for example, 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)
(4) Presence of a specific service (n = 8)
  - Care navigator or dementia support worker (n = 3)
  - Welfare and legal services (n = 2)
  - Physical healthcare (n = 1)
  - Psychologist (n = 1)
  - Information, advice and guidance (n = 1)
(5) Workforce outcomes (n = 3), for example, greater training in dementia
(6) Diagnosis (n = 11), including rates and time to diagnosis
(7) Inclusion (n = 9), such as reduced social isolation
(8) Alignment with national guidance (n = 2)
(9) Other (all n = 1), including memory service accreditation, financial confidence and pathway redesign

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).

About 46 out of 82 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, stand-alone 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 LAs 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 et al., 2019). Similar community dementia support services, for example, 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 represent 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 sub-groups 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
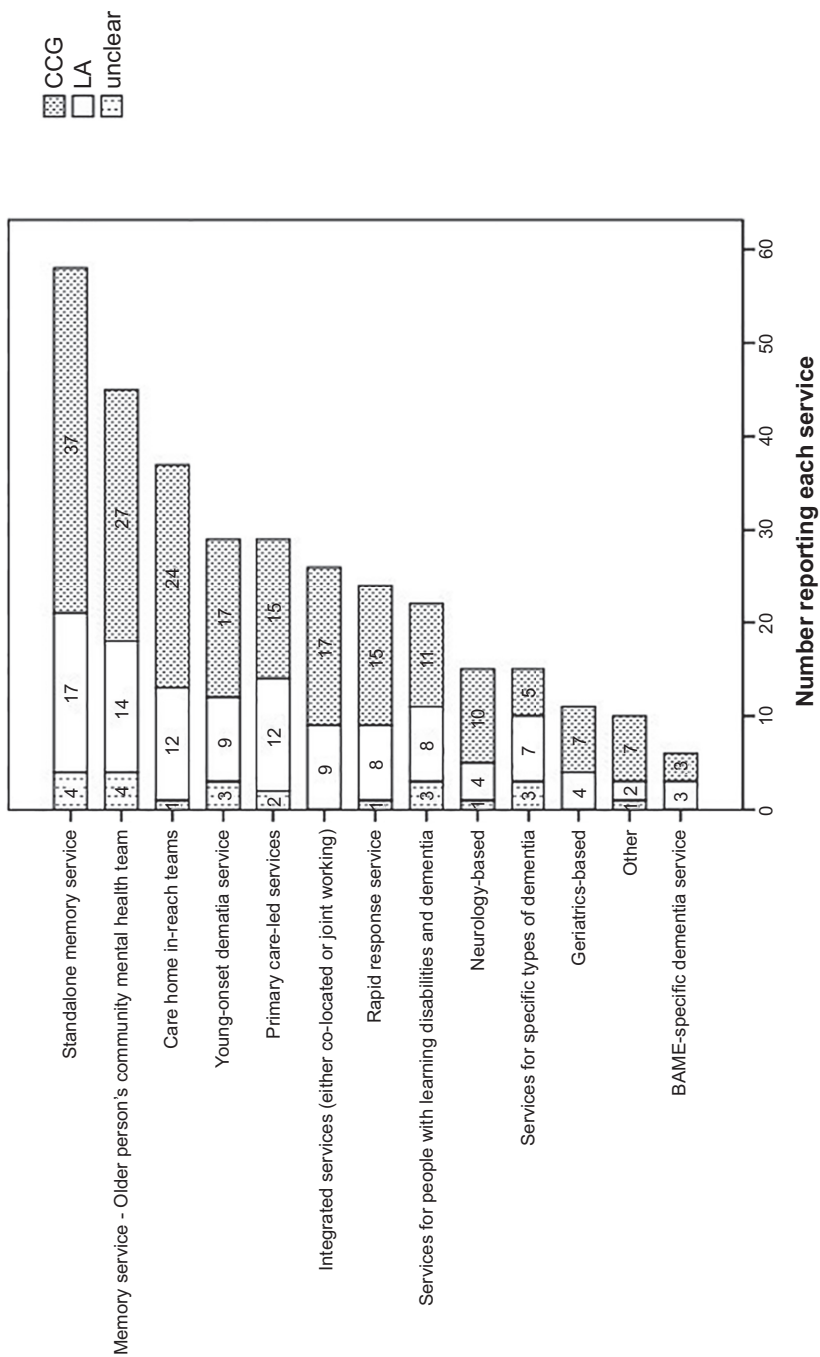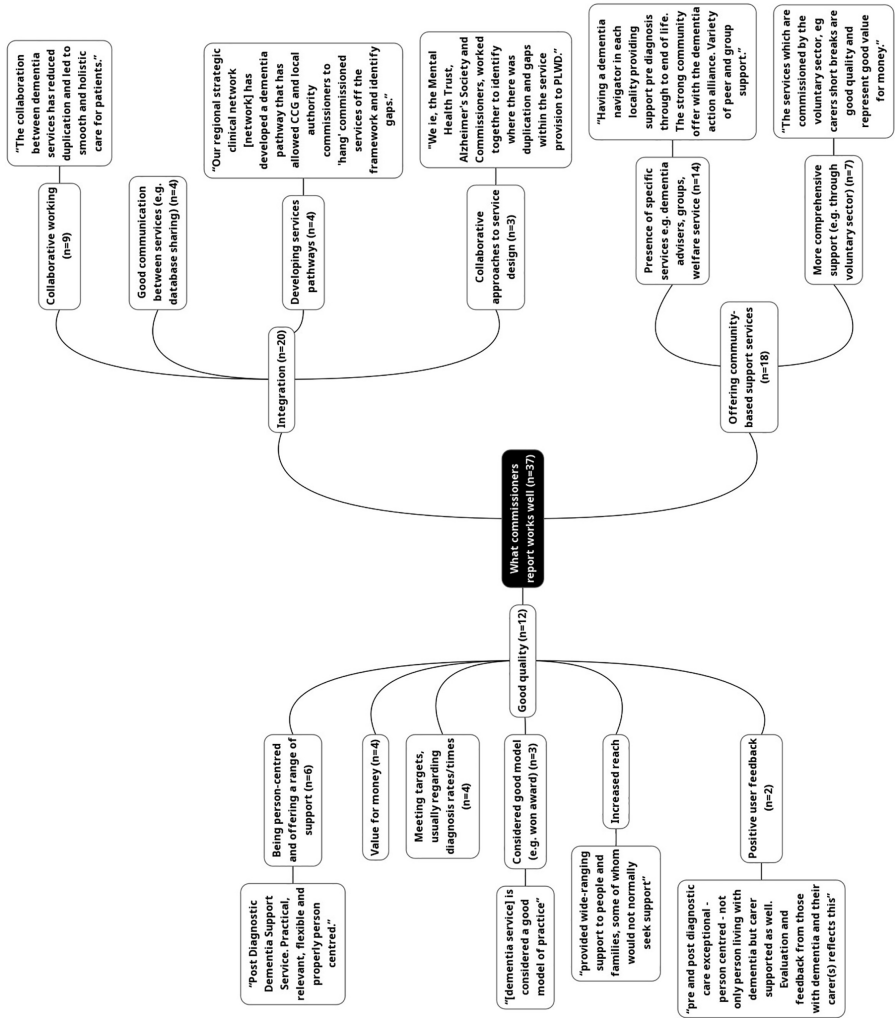
Figure 3.
Commissioners'
reports of what is not
working well in their
services

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 that 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 *et al.*, 2010), but little progress appears to have been made in this area for dementia. Only 26 survey respondents reported integrated healthcare 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 through electronic systems (Robertshaw and 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 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 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.

References

Chadborn, N., Craig, C., Sands, G., Schneider, J. and Gladman, J. (2019), "Improving community support for older people's needs through commissioning third sector services: a qualitative study", *Journal of Health Services Research and Policy*, Vol. 24 No. 2, pp. 116-123, doi: 10.1177/1355819619829774.

Chrysanthanki, T., Fernandes, B., Smith, S. and Black, N. (2017), "Can memory assessment services (MAS) in England be categorised? A national survey", *Journal of Public Health*, Vol. 39 No. 4, pp. 828-840.

Gleave, R., Wong, I., Porteus, J. and Harding, E. (2010), "What is "More Integration" between health and social care? Results of a survey of primary care trusts and Directors of adult social care in England", *Journal of Integrated Care*, Vol. 18 No. 5, pp. 29-44, doi: 10.5042/jic.2010.0558.

Kane, M. and Terry, G. (2015), "Dementia 2015: aiming higher to transform lives", *Alzheimer's Society, Leading the Fight Against Dementia*, available at: https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/dementia_201_aiming_higher_to_transform_lives.pdf.

Kinnaird, L. (2012), *Delivering Integrated Dementia Care: The 8 Pillars Model of Community Support*, Alzheimer Scotland, Edinburgh.

Local Government Association (2019), "What is local government?", available at: https://www.local.gov.uk/about/what-local-government (accessed 26 April 2019).

London Clinical Networks (2016), *Understanding Dementia Memory Services across London*, London Clinical Network, London, available at: http://www.londonscn.nhs.uk/wp-content/uploads/2016/06/dem-memory-service-audit-062016.pdf.

Ipsos Mori (2016), *Dementia Advisers Survey: Survey of Provision of Dementia Adviser Services*, Ipsos Mori Social Research Institute, London.

National Audit Office (2018), *A Review of the Role and Costs of Clinical Commissioning Groups*, National Audit Office, London.

NHS (2017), "Implementation guide and resource pack for dementia care", available at: https://www.england.nhs.uk/wp-content/uploads/2018/01/implementation-guide-and-resource-pack-dementia-guide.pdf.

NICE (2018), "Dementia: assessment, management and support for people living with dementia and their carers", doi: 10.1007/978-1-349-95810-8_867.

NHS England (2019), *The NHS Long Term Plan*.

GBD 2016 Dementia Collaborators (2019), "Global, regional, and national burden of Alzheimer's disease and other dementias, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016", *The Lancet Neurology*, Vol. 18 No. 1, pp. 88-106, doi: 10.1016/S1474-4422(18)30403-4.

Prince, M., Knapp, M., Guerchet, M., McCrone, P., Prina, M., Comas-Herrera, A., Wittenberg, R., Adelaja, B., Hu, B., King, D., Rehill, A. and Salimkumar, D. (2014), *Dementia UK: Update*, Alzheimer's Society, London.

Prince, M., Wimo, A., Guerchet, M., Ali, G.C., Wu, Y.T., Prina, M. and Alzheimer's Disease International (2015), *World Alzheimer Report 2015, London, UK*, doi: 10.1111/j.0963-7214.2004.00293.x.

Prince, M., Comas-Herrera, A., Knapp, M., Guerchet, M. and Karagiannidou, M. (2016), *World Alzheimer Report 2016 Improving Healthcare for People Living with Dementia: Coverage, Quality and Costs Now and in the Future*, Alzheimer's Disease International, London.

Public Health England (2019), "Dementia profile", available at: https://fingertips.phe.org.uk/profile-group/mental-health/profile/dementia/data#page/10/gid/1938132897/pat/15/par/E92000001/ati/154/are/E38000056/iid/91215/age/1/sex/4 (accessed 19 August 2019).

Robens, S., Emmens, T., Ross, S., Dickens, C., Cartmell, N., Lang, I. and Wheeler, B. (2015), "Mapping dementia services in the South west final report" November 2015, available at: swp.nihr.ac.uk/uploads/attachments/Projects/20151130%20Mapping%20Dementia%20Services%20in%20the%20South%20West%20FINAL%20copy.pdf.

Robertshaw, D. and Cross, A. (2019), "Roles and responsibilities in integrated care for dementia", *Journal of Integrated Care*, Vol. 27 No. 2, pp. 131-140, doi: 10.1108/JICA-05-2018-0037.

Royal College of Psychiatrists (2016), *Memory Services National Accreditation Programme (MSNAP): Standards for Memory Services*, Royal College of Psychiatrists, London.

Weber, R. (1990), *Basic Content Analysis*, 2nd ed., SAGE Publications, Thousand Oaks.

Wittenberg, R., Knapp, M., Hu, B., Comas-Herrera, A., King, D., Rehill, A., Shi, C., Banerjee, S., Patel, A., Jagger, C. and Kingston, A. (2019), "The costs of dementia in England", *International Journal of Geriatric Psychiatry*, Vol. 34 No. 7, pp. 1095-1103, doi: 10.1002/gps.5113.

World Health Organisation (2019), "Primary health care: main terminology", available at: http://www.euro.who.int/en/health-topics/Health-systems/primary-health-care/main-terminology (accessed 07 February 2019).

World Health Organization (2017), *Global Action Plan on the Public Health Response to Dementia 2017 - 2025*, World Health Organization, Geneva.

Corresponding author
Rachael Frost can be contacted at: rachael.frost@ucl.ac.uk