

# BMJ Open Commissioning care for people with dementia at the end of life: a mixed-methods study

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## ABSTRACT

**Objectives:** To understand how end-of-life (EoL) care for people with dementia is currently commissioned (ie, contracted) and organised, with a view to informing the development of commissioning guidance for good-quality community-based EoL care in dementia.

**Design:** Mixed-methods study; narrative review and qualitative interviews.

**Setting:** 8 National Health Service (NHS) clinical commissioning groups (CCGs) and five adult services across England.

**Methods:** Narrative review of evidence; 20 semistructured interviews (telephone and face-to-face) with professionals involved in commissioning EoL care for people with dementia.

**Main outcome measures:** Summary of the existing evidence base for commissioning, commissioners' approaches to the commissioning process for EoL care for people with dementia in England.

**Results:** In the context of commissioning EoL for people with dementia, the literature review generated three key themes: (1) importance of joint commissioning; (2) lack of clarity for the process and (3) factors influencing commissioning. In exploring health professionals' perceptions of the commissioning process, 'uncertainty' was elicited as an overarching theme across the CCGs interviewed. Organisation of the process, lack of expertise, issues surrounding integration and the art of specification were considered important factors that contribute to the uncertainty surrounding the commissioning process.

**Conclusions:** The current evidence base for commissioning EoL care is limited with considerable uncertainty as how clinical commissioners in England undertake the process to ensure future services are evidence-based.

## INTRODUCTION

As populations rapidly age, policy is increasingly focused on improving the quality of end-of-life (EoL) care for older people and those living with non-cancer-related long-term illness.<sup>1,2</sup> For people with dementia and

## Strengths and limitations of this study

- The use of a multimethod approach (narrative review, qualitative interviews) allowed for triangulation of our findings.
- The study highlights that information on commissioning specifically for health and social care in England is limited; this is mirrored in commissioners' accounts.
- Our sample comprised participants who responded to our requests for an interview and so may have over-represented those wanting to critique the commissioning process.
- The review presented is a narrative review; the manuscripts were not subject to a quality-assessment process.
- Generalisability of findings might be affected by the small number of published studies, their heterogeneity in methodologies and small sample sizes.

their families, the organisation and provision of care, towards and at the EoL, continues to be challenging, (Amador S, Sampson E, Goodman C, *et al*. Quality indicators for palliative care: How useful are they for the assessment of end of life care in dementia? JAGS Under review) (Amador S, Goodman C, Robinson L, *et al*. UK end of life care services in dementia, initiatives and sustainability: results of a national online survey. *BMJ Supportive and Palliative Care* Revisions submitted)<sup>3–5</sup> with very few dying at home and around a third dying in acute hospitals.<sup>6</sup> The costs of dementia care, especially in the last year of life, are also considerable.<sup>7</sup> With an ageing population potentially rapidly increasing such costs,<sup>7</sup> it is crucial to explore more cost-effective, integrated models of care.<sup>8</sup>

In 2011, the commissioning of healthcare services in England has involved clinicians via newly formed clinical commissioning groups (CCGs) led by general practitioners (GPs). According to Mannion,<sup>9</sup> in an English context commissioning is:

... the process by which the health needs of a population are assessed and responsibility is taken for ensuring that appropriate services are available which meet these needs. GP commissioning in the English NHS dates back to the 1991 internal market reforms that introduced a mandatory separation of purchaser and provider functions.

(Mannion, 2011: 8)

CCGs are organisationally separate structures to those providing care, with responsibility for a significant proportion of the healthcare.<sup>10</sup> To date, guidance to assist commissioners in organising better quality EoL care for people with dementia has been limited.<sup>11 12</sup> This is in contrast to independently developed evidence-based guidance available to healthcare providers.<sup>13 14</sup> In England, the cost of care provision for people with dementia is met through a (varying) combination of an individual's capital, local authority (LA) budgets and healthcare budgets. Despite the introduction of a national dementia strategy in 2009, EoL care in dementia remains a neglected area with policy focused on earlier diagnosis and living well with dementia.<sup>15 16</sup> There is an urgent need to develop evidence-based guidance for commissioners responsible for organising and co-ordinating care towards and at the EoL for those with dementia in order to improve quality of services.<sup>17</sup>

The aim of this study was to gain an understanding of existing approaches to commissioning good-quality community-based EoL care for people dying with and from dementia in England. Our specific research questions included:

- ▶ How is commissioning for EoL care for people with dementia currently undertaken?
- ▶ What are the main factors that influence the decision-making of commissioners when commissioning EoL care for community-dwelling populations?
- ▶ What are the specific issues that arise when commissioning for EoL care for people dying with or from dementia?

We address these questions through the analysis of two principal data sources: the findings of a narrative review of current evidence and policy, and semistructured interviews with service commissioners. In the discussion, we integrate these findings and suggest a number of considerations which should be used to inform guidance of practical use to commissioners in the area of EoL and dementia. We also draw attention to the impact the ongoing organisation of commissioning has had—and will have—in this area of care.

## METHODS

This study is part of a 5-year programme grant, Supporting Excellence in End of life care in Dementia (SEED), aimed at improving the quality of community-based EoL care for people with dementia.

A mixed-methods approach was used incorporating:

1. A narrative literature review, to identify current policy and published literature which would outline in theory what constituted good practice in this area;
2. Qualitative data collection, via in-depth one-to-one interviews with commissioners, to explore their perceptions of the priorities for EoL care for people dying with or from dementia and the barriers and enablers to commissioning EoL services for this population.

### Narrative review

Details of the search strategy and study selection criteria are given in online supplementary box 1 available as supplementary data. The first search was undertaken in January, 2014, with an updated search in January, 2016. The search was enhanced through reference chaining to identify further documents as the literature was reviewed. Only studies reported in English were considered for inclusion. Abstracts were scrutinised by independent reviewers (NB and ZG) and when agreement was achieved, the retrieved articles were screened according to the inclusion criteria (see online supplementary box 1). Disagreements were resolved through discussion with a third reviewer (RPL). In total, 45 full-text papers were reviewed, 42 of which met the inclusion criteria.

### Qualitative one-to-one interviews

Semistructured interviews, either by telephone or face-to-face, were undertaken between October 2014 and January 2016; participants had lead responsibility for the commissioning of relevant services (table 1, below). Interviewees responded to regional and national calls for participation and direct emails to LAs and CCGs, resulting in 20 offers of participation (14 CCGs). The initial interview schedule was developed from our literature search. The content of the schedules was adapted progressively as we carried out the interviews and included the following: how EoL care for dementia is commissioned; whether existing national or local guidance is used; preferred structures; criteria for effectiveness and factors which influence, either positively or negatively, the commissioning process (see online supplementary box 2 in supplementary data for topic guide). We aimed to identify participants who had experience of commissioning from a range of community-based providers. All interviews were recorded and transcribed verbatim, and checked and anonymised by the researcher prior to analysis. The transcripts were analysed using a thematic approach.<sup>18</sup>

### Ethical approval

National Health Service (NHS) Assurance for interviews with commissioners was granted by North East and Cumbria, West Midlands and Wessex Clinical Research Networks (Ref 162985).

**Table 1** Study participants

Participant	Organisation type and region
CR01	Adult services, Northeast England
CR02	Adult services, South of England
CR03	CCG/adult services, North of England
CR04	Adult services, North of England
CR05	CCG, South of England
CR06	Adult services, South of England
CR07	CCG, South of England
CR08	CCG, South of England
CR09	CCG, Northeast England
CR10	CCG, Midlands
CR11	CCG, Northeast England
CR12	Adult services, Northeast England
CR13	Adult services, Northeast England
CR14	CCG, Midlands
CR15	CCG, Midlands
CR16	CCG, Northeast England
CR17	CCG, Northeast England
CR18	CCG, Southwest England
CR19	CCG, Northeast England
CR20	CCG, Northeast England

CCG, clinical commissioning group.

## RESULTS

### Narrative review

#### Commissioning: review of policy, guidance and strategies

We identified 19 documents relevant to the commissioning of: (1) EoL care in dementia; (2) dementia care in general and (3) EoL care in general (available in see online supplementary data as table 1; Policy Documentation). There appeared to be a gap in the guidance and strategies for EoL care specifically for people with dementia, despite a policy consensus that the quality of care for people with dementia needed to be improved. Recent documents emphasised: individualised care; working collaboratively in partnership; skill development of the workforce at all levels and better understanding and knowledge of the dying trajectory in dementia. There was agreement across the documents that quality improvement should be linked to measurable outcomes and that commissioners must take measurability into account when commissioning services. However, the emphasis was on encouraging a flexible approach to commissioning care in different situations and geographical localities. There were no definitive rules or frameworks for the commissioning processes and the practicalities of how improvements could be achieved remained unclear and open to interpretation.

#### Commissioning: review of academic literature

The existing evidence from the academic literature explored commissioning on a general level, with less focus on the decision-making process for condition-specific commissioning; there was little evidence specific to EoL care. Three core themes were identified: (1) the importance of joint commissioning; (2) a lack of clarity

in the commissioning process and (3) facilitators and barriers to commissioning. The review of the included papers (n=42) is summarised in the supplementary data (see online supplementary table S2; Factors influencing the commissioning process: Overview of papers).

#### Commissioners and service providers favour a joint commissioning approach

The favouring of 'joined-up' services (ie, the integration of social and healthcare services) and delivery by multi-disciplinary teams is advocated as more likely to deliver better services, including to those care homes.<sup>19–21</sup> At the local level, a joint commissioning approach is thought to deliver better outcomes for less money;<sup>22</sup> however, we did not find any evidence to support this in the literature. Co-ordinated care by multidisciplinary teams and inter-agency working alongside government guidance are seen as crucial elements of delivery in dementia care, where the need is greater than the provision of one service.<sup>21</sup> Commissioners are assigned a key role in building relationships and focusing on common values and a shared purpose.<sup>23</sup> A joined-up approach is also favoured at the monitoring stage, where frontline staff are encouraged to feed back on the process, so commissioners can learn from their experience and knowledge.<sup>19</sup>

#### Lack of clarity about the nature of commissioning and who should play what role

In the ideal commissioning scenario, commissioners examined the complete care system with the aim of 'binding the component parts together',<sup>24</sup> a system with one governance structure, one budget and one integrated health and social care team.<sup>25</sup> Our review illustrates, however, that the reality of commissioning is distinctly different. Some commissioners are unclear about the exact nature of their role "I'm not sure, I haven't had a job description and I'm not really sure what my terms are".<sup>26</sup> Checkland and colleagues<sup>27</sup> trace this problem to the foundation of the CCGs, when national guidance regarding CCG structures and governance was non-prescriptive. As a result, local CCG structures and governance arrangements are very diverse with inconsistencies regarding size of governing body, membership and names used for subcommittees. 'Engagement' can mean different things to different groups, and although membership of a CCG is now compulsory for GP practices, it has yet to be fully understood what this membership means and how active engagement might be affected by the trend to form larger organisations.<sup>27</sup>

#### Facilitators and barriers influencing commissioning

In contrast, commissioners described how the implementation of specific local enhanced services (LES), additionally remunerated initiatives over and above core services, was facilitated by coherent evidence-based guidance to support staff and enable decision-making. A national framework (Competency Framework) was a useful tool used by some CCGs to help them make

complex resource allocation decisions;<sup>28–29</sup> such an approach was considered ‘best practice’. This is a process where two or more CCGs work together to commission the same service for which they are jointly responsible; this allows a sharing of risk and transfer of skills and support. It also suggested that CCGs should seek and act on the views of the practice population, to facilitate a more efficient system of continual resource acquisition.<sup>30</sup> The value of supportive interprofessional working was also emphasised, with a patient-centred ethos, resulting ideally in a joined-up approach to commissioning,<sup>31</sup> for example, nursing input is considered vital to the success of any healthcare commissioning approach.<sup>32</sup> The involvement of external providers was also felt to improve the quality of commissioning. In a mixed case study, Wye *et al*<sup>33</sup> describe the success of commissioning contracts being due to collaboration with external parties for their analytical, clinical and managerial expertise.

Commissioners required information to build a cohesive and persuasive case to determine and influence a course of action. They preferred knowledge exchange which is fast and flexible, for example, conversations and patient stories, rather than research papers;<sup>34</sup> ‘working on the ground’ involved the gathering of evidence to determine how local service provision is improving patients’ lives.<sup>25</sup> This experiential knowledge and local evidence played a key role in improving the quality of judgements in decision-making.<sup>28</sup> In handling complex situations, commissioners rarely accessed explicit evidence from research but instead relied on internalised guidelines, or ‘Mindlines’ built on training, experience, interactions, local circumstances and collective views of colleagues on how things should be done.<sup>34</sup> ‘The art of commissioning’ has been described<sup>35</sup> whereby commissioners pragmatically select different types of evidence from a range of sources (ie, best practice guidance, clinicians’ views of services, academic research evidence) to build a case.

Success or failure of LES was largely dependent on GPs’ willingness to participate; this willingness was motivated by existing treatment delivery, hierarchy to support LES implementation and financial incentives.<sup>29</sup> One of the reasons for potential non-participation was increased workload;<sup>36–37</sup> other contributory factors included: convening wide-ranging groups of people; developing and sustaining strategic partnerships and establishing, running and managing formal meetings for service development work.<sup>37</sup> Other reported features impeding commissioning were a lack of shared records and local directories of available services<sup>20</sup> as well as outdated block contracts and tariffs.<sup>38</sup> These aspects were compounded by interorganisational politics between hospitals, commissioners and primary care, which could impact on decision-making.<sup>31</sup> Commissioners’ focus on demand-led services was also reported as a growing area of concern.<sup>38</sup> While there was an acknowledgement that local ‘markets’ need to offer quality and choice of

services for commissioners to consider,<sup>19</sup> there was concern that, under new regulations introduced under the Health and Social Care Act 2012, market forces, rather than local commissioning decisions, would ultimately determine how care is provided. There were fears that this may ultimately lead to privatisation of healthcare in England, place commissioning groups (and GPs) into a difficult position and will ultimately damage the trust between GPs and their patients.<sup>39</sup>

### Interviews with commissioners

We interviewed 20 commissioners from eight CCGs and five LA adult services across England.

Thematic analysis of the interviews with commissioners revealed many commonalities with the key themes from the review and also generated additional four key themes:

1. Organisation of commissioning;
2. Expertise in commissioning;
3. EoL care and dementia: integration issues;
4. ‘Specification’ as an emerging art form.

#### Theme 1: organisation of commissioning

Current commissioning of dementia services in England is centred on early diagnosis and intervention. Commissioners worried that national policy interfered with their local commissioning priorities. Consequently, “primary care is overwhelmed [...] they just tackle what they have to, and unfortunately that’s often centrally and politically driven” [CR05]. Some participants felt there was a distinct lack of clarity regarding ‘accountability’ of the commissioning process and that financial aspects impacted on decisions. Several interviewees pointed out that it was often difficult to identify how much funding has been specifically allocated to dementia care [CR09], due to a pooled budget for mental health and elderly care, “within that pool budget there is nothing for dementia except what is already committed” [CR10]. Such financial pressure and loss of staff (eg, redundancies) had a negative impact on relationships/networks [CR11]. One interviewee explained that “with a pool budget, you have no impetus to do things ... I am a joint commissioner, I don’t actually have a budget” [CR10]. Strategies for improving the current situation therefore focus on working towards a more integrated approach to commissioning social care and healthcare.

#### Theme 2: expertise in commissioning

Commissioners interviewed were fully aware of their responsibilities: “If I’m the commissioner, then it’s my responsibility, my accountability, to choose the correct provider” [CR04]. While adult social care has a long-standing history of commissioning services, CCGs were new to the process and still developing these skills; several felt that training, such as the CCG leadership course, could support this. Such training is important; as commissioning guidance is currently non-standardised and fragmented, interviewees therefore increasingly

resorted to “see[ing] what other people have done elsewhere” [CR01]. Some also stated that it was difficult for commissioners to understand and apply current guidance due to the complexity of information available; “so for a long time we’ve had non-cancer patients on our list and we’ve used it as, as a framework loosely, not as detailed as it’s got to lately” [CR05]. Multiple forms of guidance could appear at the same time with no clear-stated relationship [CR11]. There was also criticism that guidance did not cover everything—“dementia seems to have been outside that box” [CR10].

### Theme 3: EoL care and dementia—integration issues

A common theme was the necessity for a more integrated approach to commissioning, that is, stronger collaborative working between health and social care in order to improve EoL care services for people with dementia. It was proposed by one interviewee that such a step proved successful in Wales [CR13]; “...we have, in Wales, a more integrated approach to car”, however, closer collaboration in England is impeded by structural and organisational barriers. We identified a lack of communication/engagement between clinicians and social services as a core issue. Many interviewees blamed clinicians’ failure to engage with providers and their lack of clinical championship in dementia.

They’ve pulled their clinical engagements staff out because of resources at their end, and it was basically since the introduction of 111. [CR11]

Health funding is uncertain. You haven’t got, you haven’t got strategic clinical champions for dementia in the same way as you’ve got in other areas. [CR10]

Other participants admitted that “we’ve very much left the commissioning around end of life care largely to our health commissioner” [CR02]. The lack of interaction between health and social care was regarded as historically rooted and compounded by geographical and temporal issues. A number of interviewees mentioned that clinicians were under extreme time constraints; “time constraints often make you, or encourage you to kind of cut out parts of the process” [CR04], with agencies frequently involved in the decision-making process often geographically dispersed; rendering face-to-face meetings a difficult task. Furthermore, more collaborative approaches were hampered by historically embedded organisational structures and an unwillingness to “[look] outside the box” as agencies “just keep doing things the way that they’ve done them” [CR09/CR07]. One interviewee pointed out that “it’s just trying to bring two cultures together in terms of local government and NHS, two sets of performance indicators, two sets of financial arrangements, particularly two kinds of organisations or sets of organisations that are under extreme financial pressure” [CR02]. Consequently, people spoke different ‘languages’:

The language of commissioning gets in the way... we kind of talk about integrated care provision in adult social care and we’re talking about integration to mean social care in the NHS, when, whereas colleagues in the NHS may be talking about integrating between acute and primary, or community services. [CR02]

### Theme 4: ‘specification’ as an emerging art form

One interviewee regarded commissioning as a ‘developing process’ [CR07]. Within this process ‘specification’—as a structured description of what the provider requires from a service—was considered to be ‘an emerging art form’:

I would suggest because historically with [community] providers you’ve had a block contract, so they get a certain amount of money for a wide generic range of services, there hasn’t been a great deal of detail into what they should provide under that block contract [...]. So locally we have, with the integrated care teams, been specifying more in detail what we want them to try and achieve. [CR07]

It remained unclear, where the process started. While some began with ‘informal discussions’ [CR07] at the local level, others started at the national level by looking at “what’s happening nationally [...] and then how [...] that feeds down to a local [...] level [...]” [CR12]. Commissioners were fully aware of the importance of contract specifications; “If you don’t put it in the contract, that’s your legal agreement about what should be provided. So if things go wrong, then you have no recourse really on the provide” [CR10]. Commissioners had high expectations of their service providers. Referring to the provision of quality “quality service [...] within the budget constraints” [CR12]. Additional expectations include sufficiently trained staff and an efficient monitoring system. However, a unified system of negotiating and recording these expectations within contracts was lacking. While one interviewee stated that “we have a high expectation that providers that we’re commissioning services from will meet the requirements that we’ve set out in the service specification [...] with robust monitoring of that” [CR06], others claimed that contracts were not specific enough. This might be to do with the type of contracts currently in use (block contracts vs generic/standard contracts) and the high number of agencies involved in the process. As a result, contracts were perceived to be ‘unbelievably complicated’ [CR05].

## DISCUSSION

A number of key issues were identified from the analyses of the review papers and the qualitative data. While some guidance exists for the commissioning of EoL care for people with dementia, commissioners experience difficulty in finding useful and practical guidance to assist them in their role within a context of budget constraints

and conflicting national priorities for dementia. As a result, commissioners rely on local knowledge and experience rather than evidence-based data. In England, the current organisation of commissioning is suffering from a number of pressing demands, including political pressure, financial constraints and a lack of accountability and guidance. These demands leave commissioners with an overwhelming and complex workload. Our integrated findings suggest a more joined-up approach to commissioning as a solution to these problems, although the detail as to how this is best achieved in practice remains unclear.

In England, the commissioning process is also strongly dependent on individual commissioners' expertise, to see the entire care system and 'bind the component parts together'.<sup>24</sup> Our interviews have revealed that many clinical commissioners are still familiarising themselves with the new healthcare organisational structure. In doing so, they are drawing heavily on guidance, which is often non-standardised, fragmented and difficult to comprehend; such guidance often does not cover areas of care, such as dementia, which are considered to fall 'outside the box'. Stronger collaboration, even to the point of full integration, between health and social care was considered the ideal, but is difficult to achieve, despite the perceived benefits of such an approach for dementia in light of the complexity of the illness. Notwithstanding the evidence base for integrated health and social care is limited especially on cost-effectiveness,<sup>40</sup> although positive examples of international case studies of integrated care for older people with complex needs have been reported.<sup>41</sup> The art of contract specification for a service is a complex issue. Our interviews confirmed findings from the literature review about the importance of collaborating with local teams and drawing on experiences of neighbouring authorities. However, participants commented that many contracts were too generic; a similar problem has been reported for the provision of stroke rehabilitation services.<sup>38</sup> Besides having a legal role, contracts are now essential tools for holding providers to account, shaping the delivery of service and controlling costs. Service commissioners need access to rapid evidence appraisal to help them incorporate scientific data into a process that one of our participants described as the 'art of contract specification'. Compare this need to the current process to update national guidance on dementia care which is estimated to take around 2 years to complete (National Institute for Health and Care Excellence (NICE) 2006).

Varieties of partnership working, differing levels and forms of expertise and uncertainties over responsibility, all characterise the move towards 'decentralisation' of care services. Checkland *et al.*<sup>27</sup> recognise the implications of this as distilled in the formation of CCGs. Combined with existing divisions between health and social care and budget reductions, commissioning for EoL care for people with dementia is fraught with

difficulties. National policy and guidance are not necessarily attuned to the practical day-to-day problems faced by commissioners. However, despite the perceived 'user' need for national commissioning guidance, it is unlikely such documents will be able to overcome all of the structural and procedural challenges detailed above; it could help by:

- ▶ Recognising the challenges explicitly in order for commissioners to feel supported;
- ▶ Prioritising the areas commissioners should focus on based on current evidence, including the specification of contracts and monitoring;
- ▶ Being concise, grounded in existing evidence base and clearly referenced to provide a recognised signpost.

Our ongoing research seeks to develop practical and evidence-based, small-scale guidance 'intervention' to help professionals working in a very difficult area; for political, economic, social and demographic reasons these difficulties look set to increase during the 21st century.

### Strengths and weaknesses

The paper reports the results of the first study to explore the processes involved in commissioning EoL care for people with dementia. Through an evidence synthesis of current policy and qualitative data from commissioners themselves, such a mixed-methods approach allows us to 'test' findings from a narrative review against accounts from commissioners. However, there are a number of limitations. Our sample comprised participants who responded to our requests for an interview and so may have over-represented those wanting to critique the commissioning process. In conducting comprehensive electronic searches for the identification of papers for the review, some studies may have been overlooked because no hand-searches of journals were carried out. Manuscripts included were limited to English language databases and papers published in English only. Restriction on the time period (ie, 2012 and later) for searches may have restricted the scope of findings, and, when interpreting the findings of the papers selected, it is possible that over time terminology could have changed (eg, 'contracting'/'commissioning'). We identified methodological inconsistencies across the studies included in the review; it was often unclear how authors identified participants or determined their sample sizes, which were often small. Further, there was ambiguity in establishing a specific time period for the research. Few studies illuminate the actual commissioning process, instead making comparisons between the old and new systems. Although this narrative review was carried out in a structured and systematic way, this was not a systematic review, as such, the quality of the manuscripts were not assessed for their quality.

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