

BMJ Open

Care commissioning and the use of guidance: the case of end of life care and dementia

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2016-013554
Article Type:	Research
Date Submitted by the Author:	21-Jul-2016
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Primary Subject Heading:	Health services research
Secondary Subject Heading:	Palliative care, Medical management
Keywords:	Adult palliative care < PALLIATIVE CARE, Clinical governance < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Dementia < NEUROLOGY, Change management < HEALTH SERVICES ADMINISTRATION & MANAGEMENT

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Criteria for inclusion: Types of studies*

Participants: Professionals who commission end of life and/or dementia services, from across social and health care. Service providers may also participate in these studies.

Interventions: *Any /local authority/clinical commissioning group involved in commissioning services for a health care environment.* Outcome measures were not used as inclusion/exclusion criteria.

Search strategy: A web-based search for national policy and guidance documents, based on the following search topics: End of life care and dementia; End of life care; Dementia. Reference chaining from documents referenced in policy and guidance documents.

English language academic literature papers (descriptive, discursive, and empirical) published 2012-2015 inclusive, which detail factors and process influencing the process of commissioning services for health and social care, in-keeping with commissioning reforms following the Health & Social Care Act 2012; in particular the establishment of clinical commissioning groups.

Local policy documents, such as dementia strategy for a local authority area, identified by service commissioners interviewed as part of the study or identified through web-based searches using search terms relevant to the locality. Online-based searches of Web of Knowledge (including MEDLINE); Scopus; Oxford Journals; The Kings Fund.

An iterative snowball technique was employed, manually identifying further documents from the bibliographic entries of the ones already retrieved; in addition, abstracts and posters from conferences were included in the search

Search terms: commissioning; commissioning health social care; commissioning dementia; commissioning end of life. Reference chaining from included literature.

Documents were included, if their titles suggested that they detailed commissioner's experiences of the commissioning process AND/OR service provider's experiences of the commissioning process AND/OR factors which enable or inhibit the commissioning process AND/OR compare commissioning arrangements. Other studies were considered eligible if they offered a relevant and rigorous analysis of the commissioning process for end of life and/or dementia care. Searches yielded a total number of 45 papers and their relevance for the study was ascertained through reading the abstract. Returns are displayed in the table below.

**only studies published in the English language were considered and were restricted to those published 2012 and later.*

Additional supplementary data: Box 1 Inclusion criteria and search strategy

Question	Pubmed	Web of Science	Scopus	Proquest*	Proquest Social Sciences Premium Collection only	Ovid (all)	JSTOR	NHS Evidence	AMED	BNI	CINAHL	EMBASE	Health Business Elite	HMIC	PsychINFO	Medline
commission* AND care AND dementia AND (palliati* OR "end of life" OR terminal)	6	8	13	548	534	1210	509	1417	0	2	2	11	0	7	2	3
commission* AND care AND dementia	84	81	116	2685	2458	5390	1931	3042	0	29	38	68	22	68	45	44
commission* AND care AND (palliati* OR "end of life" OR terminal)	325	364	363	9836	5859	11156	12187	4254	36	36	95	236	55	129	48	148

*including 'British Periodicals (1691-1939)', 'Periodicals Archive Online' and 'Proquest Social Sciences Premium Collection'

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Additional supplementary data: Table 2; Policy Documentation

	Name of document	Key aim / purpose
Guidance Documents	<i>End of Life Care for People with dementia: Commissioning Guide; Implementing NICE Guidance</i> (National Institute for Health and Clinical Excellence, 2010)	EoL care and dementia care commissioning; sets out key issues from start (planning from point of diagnosis, integrated care, supporting carers) specifying EoL care service components.
	<i>Guide to commissioners on End of Life Care for Adults</i> (National Institute for Health and Clinical Excellence, 2011)	EoL care commissioning; addresses how to identify people at EoL where death will occur within 12 months (identification/assessment; holistic support; access to services; care in the last days of life; care after death; workforce)
	Commissioning Guidance for Specialist Palliative Care: Helping to deliver commissioning objectives (Association for Palliative Medicine of GB and Ireland; Consultant Nurse in Palliative Care Reference Group; Marie Curie Cancer Care; National Council for Palliative Care; Palliative Care section of the Royal Society of Medicine, 2012)	EoL care commissioning; focus on specialist palliative care by multi-professional teams in advanced cancers; end stage organ failures; neurodegenerative diseases; advanced dementia/Alzheimer's, allocation set locally.
	<i>RCGP Commissioning Guidance in End of Life Care</i> (Royal College of General Practitioners, 2013)	EoL care commissioning; 6 steps; Quality accountability report, Right person, Right care, Right place, Right time, Every time. Targets all people approaching EoL including their carers/families
	Guidance for commissioners of dementia services; Joint Commissioning Panel for Mental Health, Feb 2013	Dementia care commissioning; sets out 6 key principles underpinning dementia commissioning (seamless services; services commissioned on basis of need and should be age-sensitive; different services needed at different times; mainstream health and social care services should be dementia friendly; care should be delivered in partnership; care should be personalised)
	Support for commissioning dementia care; National Institute for Health and Clinical Excellence, April 2013	Dementia care commissioning; promotes an integrated whole-systems approach with focus on improving early diagnosis, living well with dementia and supporting carers. Gives measurable outcomes.
	<i>Positive Partnerships Palliative Care for Adults with Severe Mental Health Problems</i> (National Council for	EoL care and dementia care; to promote both physical and psychosocial wellbeing using a palliative care approach. Key principles (focus on QoL i.e, good symptom

	Hospice and Specialist Palliative Care Services and Scottish Partnership Agency for Palliative and Cancer Care, 2000)	control; whole person approach i.e, persons past life experience/current situation; care of both the person with the life threatening disease and those that matter to them; respect for patient autonomy and choice (e.g. place of care, treatment options); emphasis on open and sensitive communication which extends to patients, informal carers and professional colleagues).
	<i>Care towards the end of life for people with dementia: An online resource guide</i> (NHS End of Life Care Programme Improving End of Life Care, 2010)	EoL care and dementia care; aimed at professionals working in health and social care in EoLC for pwd. 6 steps (Discussions as EoL approaches, assessment, care planning & review, co-ordination of care, delivery of high quality services in different settings, care in the last days of life, care after death)
	<i>My life until the end, Dying well with Dementia</i> (Alzheimer's Society, 2012)	EoL care and dementia care; reports 7 key issues surrounding EoL care from the perspective of pwd and their carers (public awareness, Care planning and Proxy decision making, Dignity, Pain, Withholding and withdrawing treatment, Emotional and Spiritual concerns, Place of care and death)
	One Chance To Get It Right: Improving people's experience of care in the last few days and hours of life; Leadership Alliance for the Care of Dying People (LACDP), June 2014	EoL care; focuses on achieving five Priorities for Care to make the dying person the focus of care in the last few days and hours of life. Emphasises care should be individualised/reflect the needs and preferences of the dying person and those who are important to them.
	The Prime Minister's Challenge on dementia: annual report of progress; Department of Health, May 2013	Dementia; to improve QoL for pwd, their families/carers. Need individualised, joined up care. Proposed changes -(timely diagnosis; better quality care; reduce stigma by increasing understanding and awareness across society; build national capacity and capability in dementia research)
	Dementia Quality Standard; National Institute for Health and Clinical Excellence, June 2010	Dementia; set out "aspirational but achievable markers of high quality cost effective care" covers care provided by health and social care for pwd in hospital, community, home-based, residential and specialist settings.
	Clinical Commissioning Groups Supporting improvement in General Practice?: The Kings Fund, Nuffield Trust, 2013	Dementia; examines perceived impact of CCG's using 6 case study sites over 3 years (2012-2015). 3 main areas of focus (nature of relationships being built inside CCG's, role of CCG in supporting quality improvement in general practice, structures and processes used)
	Commissioning for Quality and Innovation (CQUIN) 2013/14 Guidance; NHS Commissioning Board, Feb 2013	Commissioning; to secure improvements in quality of services and better outcomes for patients, alongside strong financial management. Goals for 2013/14 (friends and family test, NHS safety thermometer, improving dementia care, venous thromboembolism – funding to be split evenly among the 4 goals)

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	The Mandate: a mandate from the government to the NHS Commissioning Board: April 2013 to March 2015; Department of Health, Nov 2013	Commissioning; to make partnership working a success. Sets out 5 main areas to improve (corresponds to NHS Outcomes Framework); preventing people from dying prematurely; enhancing quality of life for people with long-term conditions; helping people recover from episodes of ill health or injury; ensuring people experience better care; providing safe care.
Strategy Documents		
	End of Life Care Strategy – Fourth Annual Report; How people die remains in the memory of those who live on; (Department of Health, 2012)	EoL care; Responsibility for EOLC and EOLC Strategy moves from DH to NHS Commissioning Board from April 2013. National End of Life Care Intelligence Network (NEoLCIN) set up to address the lack of routine data, information and intelligence on EOLC. Hospitals should follow the 6 steps in EoLC (Advance Care Planning, Electronic Palliative Care Co-ordination Systems, the AMBER Care Bundle, the Rapid Discharge Home to Die Pathway, the Liverpool Care Pathway)
	The End of Life Care strategy: New Ambitions; The National Council for Palliative Care, Nov 2013	EoL care; identifies challenges in EoL care with emphasis on locally commissioning personalised care, data and intelligence, conversations surrounding death/dying.
	End of Life Care Strategy: Promoting high quality care for all adults at the end of life. (Department of Health, 2008)	EoL care; outlines recommendations for good EoL care (good death indicators, high quality EoL care available to all – hospital/home, stepped care pathway approach, staff knowledge and skills, Gold Standards Framework)
	Living well with dementia: A National Dementia Strategy Putting People First (Department of Health, Feb, 2009)	Dementia; to make significant improvements to dementia services across 3 key areas; improved awareness; earlier diagnosis and intervention; higher quality of care. Identifies 17 key objectives.

Additional supplementary data: Table 1; Factors influencing the commissioning process in EoL, dementia care: Overview of papers

Author(s)	Title	Year	Citation	Study Country & Date	Research Objectives	Participants	Methods	Main Findings & Conclusions	Study Limitations
Anderson, David N	Commissioning dementia services	2013	<i>The Psychiatrist</i> , 37(7), p.246	n/a – not a study, but opinion / column	n/a – not a study, but opinion / column	n/a – not a study, but opinion / column	n/a – not a study, but opinion / column	<ul style="list-style-type: none"> * not necessary that whole system is commissioned from one single provider * it is crucial that the whole system has to be commissioned and commissioners need to see the whole system and bind the parts together * new commissioning system creates opportunity to think more imaginatively, something that is needed to meet the dementia challenge 	One single opinion referencing only three publications
Cartmell, Nick	Dementia: commissioning for quality	2012	<i>British Journal of General Practice</i> , 62(595), pp. 64-5	n/a – not a study, but editorial	n/a – not a study, but editorial	n/a – not a study, but editorial	n/a – not a study, but editorial	<ul style="list-style-type: none"> * dementia services currently suffer from 'therapeutic nihilism' and a 'care vacuum' * both can be addressed through locally designed and proactive community service → this is an opportunity for commissioners to improve dementia services * robust quantitative evidence is required to evaluate such new services – in order to obtain such data, services must be commissioned for a longer time period than the current 1-2 year pilot studies 	n/a
Cass, Elaine	Safeguarding: commissioning care homes	2012	<i>The Journal of Adult Protection</i> , 14(5), pp. 244-7	UK		n/a – not a study, but review	Review of two SCIE resources	<ul style="list-style-type: none"> * commissioners can improve quality of residential services through better partnership working with communities, service users, carers and local voluntary organisations & better use of intelligence from a variety of sources to reduce risk to people in residential care * commissioners need to ensure that local market offers quality & choice, as people do not want to accept poor quality services only because there is nothing else available * commissioners need to ensure that care home staff are properly trained and supported, as they are key to quality & safeguarding → frontline staff should feed into monitoring process, so commissioners can learn from their experience and 	Recommendations made based on review of only two resources Lack of empirical data

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6	Checkland, Kath et al.	Accountable to whom, for what? An exploration of the early development of Clinical Commissioning Groups in the English NHS	2013	<i>BMJ Open</i> , 3(12), e003769 doi:10.1136/bmjopen-2013-003769	UK, September 2011-June 2012	Explore how CCGs interpret their accountability relationships & how the new system is developing in practice	91 (GPs, managers, governing body members in 8 developing CCGs)	<ul style="list-style-type: none"> * Examination of CCG constitutional documents * 96 Semi-structured interviews in 8 CCGs * Observation in meetings in 8 CCGs (439h) * National web-based survey (only marginally relevant for this article) 	<ul style="list-style-type: none"> * CCGs subject to managerial, sanction-backed accountability to NHS England (NHSE) through annual assessments – however, those involved with setting up CCGs did not appreciate either extent of this managerial and fiscal accountability nor its potential impact (e.g. loss of ability to function as autonomous statutory body & loss of income * CCGs externally accountable to the public and some other newly founded organisations (e.g. economic regulator [Monitor], Health and Wellbeing Boards, Local Medical Committees, etc.) – greater awareness amongst CCGs about this type of accountability * CCGs internally accountable to their members through a two-way process → CCG at centre of complex web of accountability relationships which are more complex than for their predecessor organisations, as CCGs accountable to a much wider range of organisations and bodies of people (although external & internal accountabilities are much weaker than accountability to NHSE) → practical implications (i.e. whether more complex accountability translates into being more responsive or more easily held to account) remains to be seen * one problem: key guidance documents for CCGs provide neither advice on mechanics on accountability relationships nor on how conflicts between them might be resolved 	Study carried out in the development stage of CCGs – follow up required to study how accountability relationships develop over time & to listen to CCGs regarding their experience with such relationships
7	Checkland, Kath et al.	Primary care-led commissioning: applying lessons from the past to the early development of clinical commissioning	2013	<i>British Journal of General Practice</i> , 63(614), pp. e611-9	UK, September 2011-June 2012	* Evaluate Pathfinder Programme (= programme for aspiring CCGs to find out best way to organise themselves)	91 mainly medical staff, but also lay members (5), practice managers (3) & LA representative	<ul style="list-style-type: none"> * Systematic review of evidence relating to clinically-led commissioning * 8 case studies supplemented by descriptive 	<ul style="list-style-type: none"> * on paper, CCGs have got more autonomy than their predecessors in that they are statutory bodies and carry full budgetary responsibility * guidance re CCG structures and governance was non-prescriptive → emerging structures & governance arrangements very diverse with 	Study only a snapshot of development of CCGs at an early stage
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	groups in England				* relate findings from case studies to what is known from previous research about clinical commissioning	(1) from 8 CCGs	information from web surveys * observation of 146 meetings (439h) with governing bodies, GP members, HWBs, locality meetings	inconsistencies regarding size of governing body, membership & names used for subcommittees → decision made to identify groups by their functions rather than their names (although the distribution of functions in a site was often more fluid than the typology suggests) * 'grassroot engagement' is regarded as important, but 'engagement' can mean different things to different groups * contrary to previous commissioning organisations, membership in CCGs is compulsory for GPs, which may have a negative impact on their engagement in the long term * what it means to be a member of a CCG has yet to be fully understood and it is possible that the trend to form larger organisations may adversely affect engagement * CCGs may find it difficult to move beyond commissioning focused on the immediate needs of patients owing to the ongoing uncertainty about the role of public health in the new system * one area where GPs could make an impact is in engagement with providers around service development and contracting	
Checkland, Kath et al.	Understanding the work done by NHS commissioning managers	2013	<i>Journal of Health Organization and Management</i> , 27(2), pp. 149-170	UK, April 2009-September 2010	Explore micro-processes of daily work by which commissioning managers enact sensemaking in their organisations	41 managers & GPs from 4 PCTs	* qualitative case study approach (shadowing managers, meetings [93 hours] observations [60 hours], interviews [41]) * analysis with Atlas.ti	* findings expand understanding of sense-making in organisations and have practical implications for managers of CCGs * shake-up of organisation of NHS provides opportunities for proactive managers to embrace new practices * spatial separation of managers from those setting the direction of commissioning may be problematic * artefacts (such as minutes) will assume greater importance, as discussions will be less informal	* potential researcher bias owing to purposive sampling
Checkland, Kath et al.	'Animateurs' and animation: what	2012	<i>Journal of Health Service Research &</i>	UK, April 2009-September 2010	Examine managerial	41 managers & GPs from 4	* qualitative case study approach	* in addition to the skills of a good generic manager, commissioning managers will	* potential researcher bias owing to purposive sampling

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	makes a good commissioning manager?		<i>Policy</i> , 17(1), pp. 11-17		behaviour & explore their impact	PCTs	(in-depth interviews) * formal & informal observation (150 hours)	have to work creatively to align objectives and the ensure that everyone works towards overall, mutually defined objectives → CCG managers will require deep & contextualised understanding of NHS – this is particularly important, if managers from outside the NHS are brought in → important that organisational processes do not inhibit managerial behaviour (e.g. hot desking inhibits informal networking, cancellation of meetings has negative impact)	
Clarke, Aileen et al.	Evidence-based commissioning in the English NHS: who uses which sources of evidence? A survey 2010/2011	2013	<i>BMJ Open</i>	England, 2010-2011	Investigate types of evidence used by health care commissioners and whether decisions were influenced by commissioners' experience, personal characteristics or role at work	345 staff employed at NHS band 7 or above in 11 PCTs representative of all PCTs in England	* Cross-sectional survey * Logistic regression analysis with SPSS	* use of evidence varies according to professional background (public health employees & female employees likely to use empirical evidence, more senior employees more likely to use practical evidence) → practical evidence (local intelligence, benchmarking data, expert advice) are as influential on decision making as NICE guidance * about 50% of decisions not based on cost-effectiveness * commissioning is undertaken by people with varying professional backgrounds → important to know how personal characteristics can influence commissioning decisions (important implication for future commissioning)	* PCTs were asked to provide their own lists of relevant participants → potential bias in sampling * no formal assessment of validity and reliability of survey questions * findings may be subject to recall and social desirability bias (self-reported limitation) * study would benefit from corroboration by further research using prospective design to follow decisions through commissioning process (self-reported limitation)
Coleman, Anna et al.	Joining it up? Health and Wellbeing Boards in English Local Governance: evidence from Clinical Commissioning Groups and Shadow Health and Wellbeing Boards	2014	<i>Local Government Studies</i> , 40(4), pp. 560-580	UK, 2011-2	Explore early HWB development	91 mainly medical staff, but also lay members (5), practice managers (3) & LA representative (1) from 8 CCGs	* Case studies * observation of 146 meetings (439h)	* Role definition: little clarity re exact role of Health and Wellbeing Boards (HWBs) * HWBs have no statutory powers → good local relationships required to achieve their goals * development of CCG-HWB relationships affected by many small practical issues, e.g. timing & frequency of meetings, decisions re representations & Chair * HWBs situated at unitary level of local governments → concerns about how far local issues will be reflected in decisions (particularly as CCGs may cover smaller populations than their HWBs)	* used the same case studies as Checkland * study took place at early development stage of CCGs * research focus on CCG perspective

								* uncertainty as to how far political complexity of LAs may disrupt work of HWBs → commitment from all partners are required to make CCG-HWB relationship work in practice	
Craig, Georgina	Outcomes Based Commissioning: The key to unlock better outcomes	2014	<i>The Health Service Journal</i> , 124(6382), pp. 20-1	Lincolnshire, 2012	Explore how Experience Led Commissioning (working with families, communities and frontline teams) can help develop outcomes frameworks and commissioning intentions	Not stated	Not stated	* commissioners play a key role in uniting providers & communities, build relationships, and help everyone to focus on what they have in common * outcomes based commissioning requires providers to get innovative around how services add value for the people who use them * outcomes based commissioners need to unite and align providers behind common values, a shared purpose and vision	* Based on a very small area only * draws on user opinion, etc., but nebulous re methodology used to obtain these data
Davies, ACL	This time it's for real: The Health and Social Care Act 2012	2013	<i>The Modern Law Review</i> , 76(3), pp. 564-588	n/a – not a study, but review of Health and Social Care Act 2012	Providing overview of 'market' elements of Health and Social Care Act 2012 Examining whether reforms introduced under Health and Social Care Act 2012 are compatible with constitutional requirements of accountability or the provision of a public service	n/a – not a study, but review of Health and Social Care Act 2012	n/a – not a study, but review of Health and Social Care Act 2012	* reforms threaten accountability for three reasons (they make Secretary of State for Health's relationship with NHS more complex, they create opaque networks of non-statutory bodies which may influence NHS decision-making & greater emphasis on legal regulation will take some aspects of NHS activity out of control of Department of Health) → reforms will contribute to 'creeping' privatisation of NHS * private involvement in NHS is not new, but Health and Social Care Act 2012 facilitates greater private participation	
Dickinson, Helen et al.	Beyond the Berlin Wall?: Investigating joint commissioning and its various meanings using a Q methodology approach	2014	<i>Public Management Review</i> , 16(6), pp. 830-51	UK, no date	Map out relationships between joint commissioning arrangement, services and outcomes to examine the	5 case study sites	POETO (Partnership Online Evaluation Tool with Q methodology)	* joint commissioning has high degree of salience on local level → regarded as something that can deliver better outcomes for less money * on the other hand, joint commissioning is set up to fail by being seen as a way of being able to deliver too many different things to too many different people	* asked people to describe their job description → results do not reflect the views of any particular professional group * sample drawn on an 'opportunistic' basis → merely reflects viewpoints at a

					degree to which joint commissioning leads to better services & outcomes for service users			* understanding what joint commissioning is differs between people in the same organisation → profound implications for how we think about and conceptualise joint working (p. 847) * potential meanings of joint commissioning go way beyond those found in existing literature	particular time & space * in some localities, respondents' sorts did not contribute to any of the groups identified
Dickinson, Helen et al.	Making sense of joint commissioning: three discourses of prevention, empowerment and efficiency	2013	<i>BMC Health Services Research</i> , 13(Suppl 1), pp. S6-15	UK, no date	Examine type of impacts claimed for joint commissioning within literature	n/a not study, but literature review	Interpretive review	* lack of high quality research evidence on joint commissioning (mostly opinion pieces or voices of those involved in leading such initiatives) * lack of clarity about what joint commissioning is and what it should achieve (i.e. little evidence to link joint commissioning to change in outcomes; no one single definition of joint commissioning; joint commissioning used in a variety of ways across health & social care) * three dominant discourses of joint commissioning: prevention, empowerment & efficiency → tensions may exist between the three in practice	
Dixon, Michael	Clinically led commissioning – joyous liberation or here we go again?	2012	<i>Journal of the Royal Society of Medicine</i> , 105, pp. 217-20	n/a – not a study, but an opinion piece	None stated	n/a – not a study, but an opinion piece	n/a – not a study, but an opinion piece	* future of NHS depends on ability of clinicians to make clinical commissioning work * theory that underpins clinical commissioning represents the NHS's best chance of survival	* one person's opinion * no literature quoted
Dixon, Anna & Ham, Chris	Setting objectives for the NHS Commissioning Board	2012	<i>BMJ</i> , 345:e5893	n/a – not a study, but editorial		n/a – not a study, but editorial	n/a – not a study, but editorial	* NHS Commissioning Board created to separate politicians from management of NHS * Board works under mandate from secretary of state for health * draft mandate setting out objectives and priorities for NHS falls short of what is needed (large number of objectives; vague language in which objectives are expressed; some objectives bear hallmarks of policy leaders) * transactional rather than transformative tone of the mandate is another weakness	* opinion of two people

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6	Ellis, Jonathan	Hospices in the UK are losing out under complex new commissioning and contracting arrangements	2013	<i>International Journal of Palliative Nursing</i> , 19(7), pp. 318-9	UK, no date	Examine how new structures introduced with the 2012 Health and Social Care Act affected hospices	Member Hospices of charity 'Help the Hospices' – number not stated	survey	<ul style="list-style-type: none"> * commissioning & contracting have become more complicated under Health & Social Care Act 2012, saddling many hospices with extra bureaucracy & costs * number of commissioners hospices are dealing with now has increased * many hospices have different arrangements with commissioners including service level agreements, block contracts, spot contracts & NHS contract * Introduction of NHS contract required replacing straightforward service delivery with a more complex contract that is not reflective of the relationship between hospices and the NHS and cannot be adapted locally * high level of data reporting required by NHS contract causes concern → new legislation gives commissioners considerable discretion to adopt alternative commissioning and contracting arrangements with charitable providers, but such examples are scarce, as CCGs are risk averse * frozen or reduced funding is a problem, as are short-term contracts → recommendations to improve the situation include: <ul style="list-style-type: none"> * reducing duplication of commissioning arrangements * adapting NHS contract for commissioning hospice care * more flexibility on behalf of the commissioners * developing a national framework for commissioning hospice care * more long-term contracts 	<ul style="list-style-type: none"> * methodology poorly explained (e.g. what kind of survey, how many participants, etc.) * biased sampling * very descriptive reporting * no references provided
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37	Gandy, Robert et al.	Using care profiles to commission end-of-life services	2012	<i>Primary Health Care Research & Development</i> , 13, pp. 106-119	Liverpool, 2010	Adapting original care profiles structure for commissioning purposes &	43 representatives of clinicians, managers, ambulance	Iterative approach involving 4 half-day workshops each targeted at	<ul style="list-style-type: none"> * service requirements for EoLC are the same, irrespective of disease → care profiles could be widely adopted for commissioning, not only for EoLC services * care profiles useful for commissioning 	Tested in only one geographical area
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					produce series of care profiles that would cover the full EoLC pathway Identifying any other relevant EoLC support required for patients with specific diseases such as dementia	services, care homes, commissioning, community nursing, GPs, hospices, IT, out-of-hours services, patients, carers, personal social services, palliative care teams, therapy professionals	forming a case study	owing to their flexibility and simplicity * care profiles can also be used to inform patients & carers of what services they can expect * recommendations endorsed by PCT → project considered successful	
Gerada, Clare	What should clinical commissioning groups do on 1 April 2013?	2103	<i>BMJ</i> 2013;346:f1977	n/a – not a study, but an opinion piece	n/a – not a study, but an opinion piece	n/a – not a study, but an opinion piece	n/a – not a study, but an opinion piece	* new regulations under HSCA 2012 are not clear & seem to conflict with previously stated intentions of government (i.e. regulation 5 requires that all services are put out to tender unless there is only one single market) * new regulations have been brought in too hastily & without proper democratic consultation * under new regulations market forces will determine how care is provided → step towards privatisation of health care → new regulation puts commissioning groups (and GPs) into a difficult position and will ultimately damage the trust between GPs and their patients	* one person's opinion
Gillen, Sally	In tune with the times	2013	<i>Nursing Standard</i> , 27(52), p.61	n/a – not a study, but an opinion piece	n/a – not a study, but an opinion piece	n/a – not a study, but an opinion piece	n/a – not a study, but an opinion piece	* Health and Social Care Act 2012 has created new opportunities for nurses (CCGs have legal obligation to appoint a nurse to their governing board) * nurses' day-to-day job gives them a good idea of what constitutes service quality	* contains excerpts of interviews with nurses from selected areas → potentially biased
Holloway, Frank	The Health and Social Care Act 2012: what will it mean for mental health services in England?	2012	<i>The Psychiatrist</i> , 36, pp. 401-403	n/a – not a study, but an opinion piece	n/a – not a study, but an opinion piece	n/a – not a study, but an opinion piece	n/a – not a study, but an opinion piece	* article focuses on organisational changes to the NHS introduced by Health and Social Care Act 2012 → new management configuration is rather similar to the previous one * some good relationships between local authorities and health services are	* one person's opinion

								unravelling owing to the reorganisation	
Hudson, Bob	Public and patient engagement in commissioning in the English NHS	2015	<i>Public Management Review</i> , 17(1), pp. 1-16	n/a – not a study	Outlining new possibilities for public and patient engagement (PPE) in the context of the Health and Social Care Act 2012	n/a – not a study	Review of existing literature	<ul style="list-style-type: none"> * PPE has record of low achievement over past half century → can new context of Health and Social Care Act 2012 change this? * Evidence base for effectiveness of PPE in health care is underdeveloped * CCGs have to take into account PPE in decision-making greater conceptual clarity and clearer understandings on purpose of PPE are prerequisites to change 	* lacks empirical data
Colville E; Kennedy C	ACP Conversations in clinical practice	2012	British Journal of Community Nursing, 17(5), 230-234	UK	To establish whether nurses implement new knowledge and strategies into their practice, following educational intervention of ACP	16 nurses (generalist and specialist mix from community and hospital settings)	Qualitative semi-structured individual interviews	<ul style="list-style-type: none"> • Training increased participants' awareness of ACP, validated their knowledge and skills and had positive impact on their practice clinically. • Educational programmes are beneficial and impact clinical care 	<ul style="list-style-type: none"> • Small-scale exploratory study, participants volunteered (may have previously engaged in ACP). • Education only one way to encourage ACP in healthcare (the complex, transactional nature of ACP should be recognised)
Kmietowicz Z	Blue sky commissioning	2014	BMJ 348	UK	NA not a research study	CCGs	Feature, narratives of success stories from commissioners	<ul style="list-style-type: none"> • Identifies factors that help contribute to successful service • i.e, intervention workers with specialist training working with families with daily tasks; • Effective service needs characteristics such as standard assessment, clear treatment pathway, evidence-based measurements, but should also not increase GPs workload. 	<ul style="list-style-type: none"> • No structured academic study. This is a collection of quotations taken from CCGs across 3 services in England
Kumar G; Quigley J; Singh M et al.	Do local enhanced services (LES) in primary care improve outcomes?	2014	Quality in primary care, 22, 157-169	UK (database searches made May-June 2013)	Examine the role of local enhanced services that have been commissioned in the UK, and their role in driving health/economic outcomes.	Organisations searched; CCGs PCT, Scottish National Health Board	Literature Review	<ul style="list-style-type: none"> • Identified common themes that explain success/failure of LES • i.e, national framework in place and financial incentives gives greater motivation for service provision • i.e. depends on GPs willingness to participate (which is motivated by existing treatment delivery hierarchy to support LES implementation and financial 	<ul style="list-style-type: none"> • Only 14 (of 459 abstracts) LES reported data on outcomes • Evidence is limited/poorly reported outcomes • Not clear if LES will continue to play a role in in clinical commissioning

								incentives) <ul style="list-style-type: none"> •Service provision (e.g. National Dementia Strategy) may affect clinical and process-related outcomes of an LES. 	
Lingard JM; Cooper V; Connell M	The personalisation challenge	2013	Tizard Learning Disability Review, 19(1), 3-10	UK (Leicester; Leicestershire & Rutland; Northamptonshire & Nottinghamshire (project run between 2011-2012))	Examine personalisation plans for families, and identify barriers and solutions.	Families of services for main project. Additional feedback from commissioners.	Project log of barriers and solutions; Interview with a joint commissioner; Feedback on project from 2 Care Managers	<ul style="list-style-type: none"> •Identifies some information on commissioning; commissioner stated; •They have health team members who work with complex cases; •Strategic commissioning plan in place and a joint commissioning team who work from common plan; •Have external advice to draw up tender process (input from NDTi (national development team for inclusion) who act as 'critical friend' & RIPFA (research in practice for adults)) •A viable personalisation plan in place ('viable' as plan goes beyond identifying an empowering lifestyle for individual, but needs all key people signed up to the actions) •The learning from the project will contribute to the national development agenda 	<ul style="list-style-type: none"> •Information is limited (feedback component was supplementary information and not the primary aim of the project). •14 care managers approached, only 2 responded.
Lotinga A; Glasby J	New conversations with new players? The relationship between primary care and social care in an era of clinical commissioning	2012	Journal of Integrated Care, 20(3), 175-180	UK (Birmingham)	Identify issues for policy and practice against the backdrop of changes taking place in health and social care. Also explore opportunities for joint work at CCG level	25 stakeholders (Lead GPs, councillors, local authority managers, PCT cluster managers & service users)	Case study (outcomes from workshops)	<ul style="list-style-type: none"> •Key issues identified for future policy/practice; •Faster access to more joined-up services keep people healthy in community for longer; •With lack of shared records and no local directories of available services, participants felt the system was a long way from getting the basics right; •New developments (i.e. community matrons could offer positive service to people in need; •While "single point of access" projects have been started, these often did not mean speaking to somebody direct but leaving message in queuing system; •Joint commissioning between primary and social care positive step forward 	<ul style="list-style-type: none"> •Some information identified but very limited. More detail required on the process of commissioning

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22	McDermott I; Checkland K; Harrison S; Snow S; Coleman A	Who do we think we are? Analysing the content and form of identity work in the English National Health Service	2013	Journal of Health Organisation and Management, 27(1), 4-23	Data drawn from wider study, England NHS carried out April 2009-June 2010	To offer a novel approach to triangulation (comparison of multiple data sources) using "identity work" with managers as the interview content.	PCT commissioning managers and GPs and managers working on Practice Based Commissioning	Data collected from semi-structured Qualitative Interviews AND observation of commissioning meetings	<ul style="list-style-type: none"> •Commissioners unclear about the exact nature of what they do - 'a style of discourse'; "I'm not sure, I haven't had a job description and I'm not really sure what my terms are" •Commissioning process described as a cycle; •"providing a local service that is convenient, and cost effective, commissioning is the process of assessing that, making it happen and reviewing it afterwards"; •"the decision to commission/decommission a service comes from strategic objectives of the PCT... it's getting value for money, good quality care from the services you've commissioned" •Higher level of certainty about what commissioning is 'not' rather than what it is. 	<ul style="list-style-type: none"> •Aim of paper is methodological (i.e. using discourse analysis ("Styles of Discourse" offer a look at <i>what</i> is said and <i>how</i> it is said) but offers some information on commissioning •Commissioners – uncertainty about their identity and the activity of commissioning/not confident about what commissioning is.
23 24 25 26 27 28 29 30 31 32 33 34 35 36 37 38 39	Oates J; Jerram S; Wilson I.	Clinical commissioning: the nurse's role.	2014	Nursing Standard, 29(6), 52-59.	England (Brighton and Hove CCG used as example)	Gather insight into the role of nurses in clinical commissioning.	NA	Review	<ul style="list-style-type: none"> •Member practices take part in decision making at a local level (GP chair takes time out of clinical practice) •Nursing input is vital to success of any healthcare commissioning approach (they have no conflict of interest i.e. not employed by local provider, they bring expertise and knowledge and balanced view of clinical and management agenda and Nurses champion the patient voice/patient experience); •Getting clinical commissioning right is a balance between fulfilling statutory duties and exercising statutory powers, whilst representing the interests of the membership and managing members' conflicts of interest, between responding to patient and public views and ensuring efficient and equitable use of public funds. 	<ul style="list-style-type: none"> •More a summary of the history of commissioning and how it evolved rather than a detailed discussion of the processes. •Focuses on one CCG as an example (and authors state Brighton and Hove CCG is not typical of CCGs)
40 41 42 43 44 45 46 47 48 49	Olphert A M	Commissioning end-of-life care.	2014	British Journal of Nursing, 23(13), 744-	UK	A nurses understanding of	Chief Nurse and director of	Narrative	<ul style="list-style-type: none"> •EoL care commissioning should be 	<ul style="list-style-type: none"> •Identifies challenges for

			745.		the challenges in arranging EoL care	CCG		considered in relation to multimorbidities, long-term conditions, the elderly frail and those with dementia (i.e, a need for identifying those at risk of dying within 12m, anticipatory care planning, supporting patients and their carers in taking control) <ul style="list-style-type: none"> •EoL care involves a large number of third-sector providers, so host-commissioning (i.e, on behalf of several organisations) is important. 	EoL commissioning but focus of paper is heavily based on suggestions for better commissioning rather than decision making processes involved
Perkins N; Coleman A; Wright M; Gadsby E; McDermott I; Petsoulas C; Checkland K	The 'added value' GPs bring to commissioning: a qualitative study in primary care	2014	British Journal of General Practice. 64(628), e728-e734.	England April-September 2013	Explore key assumptions underpinning CCGs and examine the claim GPs bring 'added value' to the commissioning process	40 clinicians and managers across 7 CCGs (1 nurse clinical lead; 6 managers; 33 GPs)	Qualitative Interviews	<ul style="list-style-type: none"> •GPs detailed knowledge of their patients help improve service design •Close working relationship between GPs and managers strengthens manager's ability to negotiate •Described concern over large workloads •In PCTs clinicians have little role or responsibility in decision making, but clinicians in <i>lead roles</i> feel they have 'ownership' of the decisions made by the CCG 	<ul style="list-style-type: none"> •mostly clinicians opinions, further exploration needed – a follow-up study by these authors will examine opinions in more detail – i.e, their practical operation in real world
Quayle A; Ashworth D; Gillies A	BSS 11000 for Health Commissioning; Lessons from history for managing the commissioning relationship	2013	Clinical Governance: An International Journal. 18(1), 18-29.	England 2013	To consider how the collaborative business standard (BSS 1000) and case studies from other domains can be applied to the commissioning process in health services.	Sectors outside Health Service (i.e, criminal justice)	Case Studies	<ul style="list-style-type: none"> •Existing traditional processes (buyer/seller system) will not deliver the benefits anticipated by policy, to CCGs in the direction they are being asked to move. •A richer collaborative approach i.e, The business collaborative approach, that use management support structures, are considered best practice and adopting this in health service will be helpful in transition to more efficient system of resource acquisition improvement. •Identifies the "commissioning cycle" – a process by which best quality care and outcomes are to be achieved. •External support for clinicians to gain skills & knowledge required to succeed as commissioners 	<ul style="list-style-type: none"> •CCGs are still being formed and so opportunities for studying this are limited – that's why it is necessary to use case studies from other domains
Radford K; Crompton A; Stainer K	Commissioning vocational rehabilitation	2013	Journal of Health Services Research and Policy.	UK (Nottinghamshire, Derbyshire,	Understand the barriers and enablers to	16 Commissioners responsible for	Semi-structured one-to-one interviews	<ul style="list-style-type: none"> •Block contracts/tariffs create problems for being able to quantify spend in stroke rehab 	<ul style="list-style-type: none"> •Absence of evidence creates a perception that the need for vocational

	after stroke: Can the Cinderella services get to the ball? A qualitative study		18(Suppl.1) 30-38.	Lincolnshire)	commissioning vocational rehabilitation after stroke	commissioning stroke services		<ul style="list-style-type: none"> •Despite national policy, ambiguity remains surrounding whether vocational rehab after stroke is responsibility of health or social care •Commissioners focus on demand-led acute stroke services, leaving little resource for community services •In times of budget restriction, commissioners focus on most vulnerable to maintain independence and reduce care home admission 	rehabilitation is minor.
Raymond M; Warner A; Davies N; Nicholas N; Manthorpe J; Iliffe S	Palliative and end of life care for people with dementia: lessons for clinical commissioners	2014	Primary Healthcare Research and Development. 15, 406-417.	N/A (Not restricted to UK research papers) project conducted 2011-2015	Synthesise information about end of life care in people with dementia, using review papers	English language papers 2000-2011	Review of reviews	<ul style="list-style-type: none"> •Health and social care commissioning is influenced by many factors other than research evidence; political pressure; ideological stance; the need to take action •Lack of specificity in the literature regarding research questions/priorities. •Narrative reviews have a tendency to offer over-contextualised recommendations i.e. "more inter-agency working is needed" 	<ul style="list-style-type: none"> •The critical interpretative synthesis method is criticised for relying on subjective judgements of its' authors •Overview could be limited because it only focuses on palliative care in dementia •Broad reviews (i.e. Cochrane) may not be conclusive •Rapid appraisal runs the risk of missing useful evidence
Russell J; Greenhalgh T; Lewis H; MacKenzie I; Maskrey N; Montgomery J; O'Donnell C	Addressing the 'postcode lottery' in local resource allocation decisions: a framework for clinical commissioning groups.	2013	Journal of the Royal Society of Medicine. 106(4), 120-123.	UK 2011	Report how the National Prescribing Centre (NPC) competency framework was developed to present potentially transferrable methodology.	Steering group of academic, practitioners and opinion leaders in local decision making. Also individuals with expertise in resource allocation (local, regional, national)	Report	<ul style="list-style-type: none"> •With individual funding requests there isn't much evidence, so have to use judgement. Local evidence and experiential knowledge play a role in improving quality of judgements in decision-making •Competency framework – tool being used by some CCGs - it is useful 'starting point' to help them in making complex resource allocation decisions 	<ul style="list-style-type: none"> •Identifies the use of a competency framework in a specific setting. •Descriptive, no real detailed information on how this translates into commissioning decision making
Shaw S E; Smith J A; Porter A; Rosen R; Mays N	The work of commissioning: a multisite case study of healthcare	2013	BMJ Open. 3(9), e003341	England 2010-2012	Examine work involved in commissioning long-term condition services, including	Primary care trust managers and clinicians; general practice-based	Case study, mixed methods (qualitative interviews, observations,	<ul style="list-style-type: none"> •It takes years to commission something (time-consuming) Minimum 1 year typically (assessing needs, reviewing evidence, developing service 	<ul style="list-style-type: none"> •Focused on long-term commission services, not able to observe contractual or

	commissioning in England's NHS				factors inhibiting/facilitating commissioners in making service change	commissioners; NHS Trust and Foundation Trust senior managers & clinicians; voluntary sector and local government representatives	documents)	specification) <ul style="list-style-type: none"> •Progress seems to speed up once a firm decision is made regarding moving ahead with service design (i.e. referral procedures, staffing established within months rather than years) •Success viewed in relation smooth/efficient running, less emphasis on delivery model in place •Contributions vary at different stages of the commissioning process (i.e. service user input in planning stages) •Significant work(and time) involved; convening wide-ranging groups of people; developing/sustaining strategic partnerships; establishing, running and managing formal meetings for service development work 	transactional elements of commissioning discussions. <ul style="list-style-type: none"> •Annual commissioning cycle regarded as useful model but in reality, the time consuming work does not follow the neat stages set out in the cycle •Scale of commissioning work not always proportionate to its impact/service gains
Simkiss D E	Community care of children with complex health needs	2012	Paediatrics and Child Health, 22(5), 193-197	England	Discuss working, commissioning and care pathways for care of children with complex health needs.	N/A – summary of guidance, reports and policy	Symposium	<ul style="list-style-type: none"> •Emphasises the importance of joint commissioning in a complex healthcare setting, including integrated care pathways and understanding role of other practitioners/agencies •Where peoples' needs are greater than the provision of one service, the emphasis is on co-ordinated care by multi-disciplinary teams/inter-agency working alongside government guidance. •Network of support – namely key worker listening to person's needs 	<ul style="list-style-type: none"> •Focus is on children with complex health needs in community care, difficulties translating to EoL/Dementia •Limited detail on commissioning 'process'
Simmonds R L; Shaw A; Purdy S	Factors influencing professional decision making on unplanned hospital admission: a qualitative study	2012	British Journal of General Practice, 62(604), e750-756.	South West England, 2010-2011	Identify factors influencing professional decision-making around unplanned hospital admission.	19 professionals (primary, emergency and social care sectors) from 3 PCTs	Qualitative Interviews	<ul style="list-style-type: none"> •If market approach is adopted by GP led CCGs, financial incentives influence clinician decision making in primary care/incentivising people for wrong reason/drive down quality •At senior level what is being promised is not being delivered due to staffing issues and under-resourcing of services (necessary funding not in place) •For robust decision making in health and social care, professionals emphasise the value of supportive inter-professional 	<ul style="list-style-type: none"> •Only a few participants recruited from each service as a first qualitative study of decision making regarding unplanned hospital admissions, so views may be from a specific perspective •Sampled to maximise variation in professional groups represented - this

								working, with a patient-centred ethos. <ul style="list-style-type: none"> •Inter-organisational politics between hospitals, commissioners and primary care raised as an issue impacting decision making. 	gave less scope for fine-grained exploration of factors influencing decision-making within each group.
Smith D	Commissioning. Joined up thinking.	2013	The Health Service Journal, 123(6361), 30.	UK	Describe his vision for joining up health and social care commissioning in the future	Clinical Commissioning Group chief officer and director of health and adults services for local authority	Commentary	<ul style="list-style-type: none"> •Vision for change; a system where one governance structure is in place (one budget, one team of staff who commission across health and social care) •Strategy is working on ground, gathering evidence of how service provision is improving lives of residents •Operating separate funding systems across health and social care is considered significant barrier for true integration 	<ul style="list-style-type: none"> •Sets out goals for improving commissioning across health and social care rather than describe existing processes.
Smith P; Mackintosh M; Ross F; Clayton J; Price L; Christian S; Byng R; Allan H	Financial and clinical risk in health care reform: a view from below	2012	Journal of Health Services Research and Policy, 17(suppl 2), 11-17.	UK, 1995; 2007	Examine the interaction between financial and clinical risk	Managers and front line professionals (GPs, nurses, social workers, therapists, home carers)	Qualitative Interviews; Documentary analysis of policies and procedures; Observations	<ul style="list-style-type: none"> •2 overarching policy drivers – care closer to home and multidisciplinary working to promote co-ordinated care, social inclusion, emphasizing independent living. This brought clinical risk created due to services undergoing considerable change. •Financial decision-making delegated to smaller groups led by GPs •Financial incentives work (payment by unit of activity) to change professionals' behaviour by subjecting people to increased perceived clinical risk •Incentives which are too specific can cause demotivation, 'box-ticking' and 'blame culture' 	<ul style="list-style-type: none"> •Lots of recommendations negates from existing commissioning processes.
Yong V	Integrating care: a new model of service delivery for complex cases	2012	Progress in Neurology and Psychiatry, 16(1), 4-5.	UK	Discusses potential opportunities to deliver new model of multidisciplinary care	Trustee of Primary Care Mental Health and Education (Primhe)	Commentary	<ul style="list-style-type: none"> •Identifies a need for integrated psychobiosocial services for complex and expensive areas of healthcare •Proximity of services for complex cases i.e. have multiple disciplines in same building/mental health service operating from GP surgery •Working models that could be rolled out into physical health – a multidisciplinary 	<ul style="list-style-type: none"> •Identifies problems in service provision in secondary care for complex/medically unexplained symptoms and suggests recommendations for change/ a new model of care.

								community team is best example of excellent practice	•Little information on decision making/commissioning processes
Wye L; Brangan E; Cameron A; Gabbay J; Klein J H; Pope C	Evidence based policy making and the 'art' of commissioning – how English healthcare commissioners access and use information and academic research in 'real life' decision-making: an empirical qualitative study.	2015	BMC Health Services Research, 15(1), 430.	UK, February 2011-May 2013	To understand commissioners' information seeking behaviour and the role of research in their decisions.	52 commissioners (chairs of commissioning organisation, directors, public health consultants) from four commissioning organisations	Mixed case study; Qualitative interviews, observation, documentary data	<ul style="list-style-type: none"> •The 'art of commissioning' described as commissioners pragmatic selection of different types of evidence gathered from a range of sources to build a case (i.e. best practice guidance, clinicians' views of services). •Despite academic research being considered implicit in the system, this was less useful and not accessed directly and those who did use Google Scholar. The only Journals mentioned were BMJ and BJGP. •Demand for research evidence reduced innovation because commissioners could not wait until an initiative was "piloted and proven" 	<ul style="list-style-type: none"> •Documentary data, not in the field constantly, potential for information to disappear, morph or reappear elsewhere without researcher's knowledge. •The presence of researchers in ethnographic studies have the potential to change the dynamics of the meetings observed.
Wye L; Brangan E; Cameron A; Gabbay J; Klein J; Pope C	Knowledge exchange in health care commissioning: case studies of the use of commercial, not-for-profit and public sector agencies, 2011-14.	2015	Health Services and Delivery Research, 3(19).	UK, 2011-2014	To study knowledge exchange between external providers and health-care commissioners; to learn about knowledge acquisition and transformation, the role of external providers and the benefits of contracts between external providers and health-care commissioners.	92 Interviews with external consultants and their clients.	[REPORT] Mixed case study of 8 cases; interview, observation and documentary data	<ul style="list-style-type: none"> •Commissioners wanted information to build a cohesive & persuasive case to determine a course of action. •Fast and flexible media (conversations and stories rather than written documents) preferred for knowledge exchange with commissioners. Commissioners need knowledge providers who could keep up as the commissioning landscape was ever changing and re-prioritising. •Commissioners use helpful sources of information; interpersonal relationships people placement, organisational processes/structures best practice from elsewhere, software tools/training. •Key ingredients for successful contracts included external consultants' having excellent understanding of clients' needs (then revisiting the brief to ensure output was relevant to ever-changing commissioning context). 	<ul style="list-style-type: none"> •Despite substantial access to providers, views from NHS clients and commissioners were difficult to obtain due to the turbulence of 2012 Act meaning NHS professionals were preoccupied with the danger of losing their jobs.

									<ul style="list-style-type: none"> •'Mindlines' – guidelines for handling complex situations (training, experience, interactions, reading, local circumstances, collective views of colleagues on how things should be done). 	
Wye L; Brangan E; Cameron A; Gabbay J; Klein J H; Anthwal R; Pope C	What do external consultants from private and not-for-profit companies offer healthcare commissioners? A qualitative study of knowledge exchange.	2015	BMJ Open, 5(2), e006558	UK, February 2011-May 2013	To understand how commissioners and external consultants work together, the process of knowledge exchange and the perceived impact on commissioning decisions.	92 Interviews with external consultants and their clients.	Mixed case study of 8 cases; interview, observation and documentary data	<ul style="list-style-type: none"> •External provider involvement (technical applications, expertise, outsourcing) ,improves the quality of commissioning •Success of one commissioning contract was due to input of analysts –analytical, clinical and managerial expertise (standard team of professionals from each group) provides 'data-driven' commissioning. •Importance on clients undertaking the work themselves (i.e. audit data collection) rather than relying on external providers, but often limited time/capacity was reported due to departure of experienced NHS commissioning staff. 	<ul style="list-style-type: none"> •Entering field via external provider may have affected NHS recruitment. •One provider steered researchers away from less successful contracts, and authors would have liked to recruit more 'negative' cases from this provider. 	

Reporting Checklist

1. contributorship statement
Research design: RL, LR, EM, CG. Data collection and data analysis: RL, ZG, NB. The first draft was written by: RL, ZG, NB and was edited by all authors. All authors approved the final version of the manuscript.
2. competing interests
There are no competing interests
3. funding
Department of Health National Institute for Health Research (NIHR) Applied Research Programme Grant: RP-PG-0611-20005
4. data sharing statement
No additional data are available

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4 **dementia**

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33 **Key Words: commissioning, end-of-life care, dementia, health and social care**

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35 **Word Count: 3907**

ABSTRACT

Objectives

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

Design

Mixed-methods study; narrative review and qualitative interviews.

Setting

8 NHS clinical commissioning groups and 5 Adult Services across England.

Methods

Narrative review of evidence; 20 semi structured interviews (telephone and face-to-face) with professionals involved in commissioning end of life care for people with dementia.

Main outcome measures

Summary of the existing evidence base for commissioning, commissioners' approaches to the commissioning process for end of life care for people with dementia in England.

Results

In the context of commissioning end of life care 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 end of life care is limited with considerable uncertainty as how clinical commissioners in England undertake the process to ensure future services are evidence-based.

Strengths and limitations of this study

- The use of a multimethod approach (narrative review, interviews with CCGs) allowed for triangulation of our findings.
- The evidence identified in the review may be limited given that 'commissioning' is a relatively new term in England.
- 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.

- The study highlights that information on commissioning specifically for health and social care in England is limited; this is mirrored in commissioners' accounts.

INTRODUCTION [450 words]

As populations rapidly age, policy is increasingly focussed on improving the quality end of life (EoL) care for older people and those living with non-cancer related long term illness^{1,2}. For people with dementia and their families the organisation and provision of care, towards and at the EoL, continues to be challenging³⁻⁷, with very few dying at home and around a third dying in acute hospitals⁸. The costs of dementia care, especially in the last year of life, are also considerable⁹. With an ageing population potentially rapidly increasing such costs⁹, it is crucial to explore more cost-effective, integrated models of care¹⁰. The purchasing or contracting of care services, also termed service commissioning, is a complex process; a 'balance' between fulfilling statutory powers, managing stakeholder conflicts of interest, responding to patient and public views and ensuring efficient and equitable use of public funds¹¹.

In 2011, the commissioning of healthcare services in England has involved clinicians via newly formed clinical commissioning groups (CCGs). CCGs are organisationally separate structures to those providing care, with responsibility for a significant proportion of the health care¹². To date, guidance to assist commissioners in organising better quality EoL care for people with dementia has been limited^{13,14}, this is in contrast to independently developed evidence-based guidance available to health care providers^{15,16}. In England, 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^{17,18}. There is an urgent need to develop evidence-based guidance for commissioners responsible for organising and co-ordinating care towards and at the end of life for those with dementia in order to improve quality of services¹⁹.

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 end of life care for people with dementia currently undertaken?
- What are the main factors that influence the decision making of commissioners when commissioning end of life 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 principle data sources: the findings of a narrative review of current evidence and policy, and semi-structured 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 on-going organisation of commissioning has had – and will have – in this area of care.

METHODS [373]

This study is part of a five 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.

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3 A mixed methods approach was utilised incorporating:

- 4 i) a narrative literature review, to identify current policy and academic literature which would
5 outline in theory what constituted good practice in this area and;
6 ii) Qualitative data collection, via in depth 1-1 interviews with commissioners, to explore their
7 perceptions of the priorities for end of life care for people dying with or from dementia and the
8 barriers and enablers to commissioning EOL services for this population.
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10 11 **i) Narrative Review**

12 Details of the search strategy and study selection criteria are given in Box 1 (available as
13 supplementary data). The first search was undertaken in January, 2014, with an updated search on
14 in January, 2016.. This was enhanced through an iterative snowball technique to manually identify
15 further documents as the literature was reviewed. Only studies reported in English were considered
16 for inclusion. Abstracts were scrutinised by independent reviewers (NB and ZG) and when
17 agreement was achieved, the retrieved articles were screened according to the inclusion criteria (see
18 Box 1). Disagreements were resolved through discussion with a third reviewer (RL). 45 full text
19 papers were reviewed, 42 of which met the inclusion criteria.
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21 22 **ii) Qualitative 1-1 interviews**

23 Semi-structured interviews, either by telephone or face-to-face, were undertaken between October
24 2014 and January 2016; participants had lead responsibility for the commissioning of relevant
25 services (Table 1). Interviewees were identified through responses to regional and national calls for
26 participation and direct emails to local authorities (LAs) and CCGs. The initial interview schedule was
27 developed from our literature search. The content of the schedules was adapted progressively as we
28 as we carried out the interviews and included the following: how EoL care for dementia is
29 commissioned; whether existing national or local guidance is used; preferred structures; criteria for
30 effectiveness and factors which influence, either positively or negatively, the commissioning process.
31 We aimed to identify participants who had experience of commissioning from a range of
32 community-based providers. All interviews were recorded and transcribed verbatim, and checked
33 and anonymised by the researcher prior to analysis. The transcripts were analysed using a thematic
34 approach²⁰.
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40 41 **Table 1: Study participants**

42 43 **RESULTS**

44 45 **i. Narrative Review [1154]**

46 47 *Commissioning: policy guidance and strategies*

48 We identified 19 national policy documents relevant to the commissioning of: i) EoL care in
49 dementia; ii) dementia care in general and iii) EoL care in general (See Table 2, available as
50 supplementary data). There appeared to be a gap in the guidance and strategies for EoL care
51 specifically for people with dementia despite a policy consensus that the quality of care for people
52 with dementia needed to be improved. Recent documents emphasised: individualised care; working
53 collaboratively in partnership; skills development of the workforce at all levels and better
54 understanding and knowledge of the dying trajectory in dementia. There was agreement across the
55 documents that quality improvement should be linked to measurable outcomes and that
56 commissioners must take measurably into account when commissioning services. However the
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3 emphasis was on encouraging a flexible approach to commissioning care in different situations and
4 geographical localities. There were no definitive rules or frameworks for the commissioning
5 processes and the practicalities of how improvements could be achieved remained unclear and open
6 to interpretation.
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10 *Commissioning: review of academic literature*

11 The existing evidence from the academic literature explored commissioning on a general level, with
12 less focus on the decision making process for condition specific commissioning; there was little
13 evidence specific to EoL care. Three core themes were identified: (1) the importance of joint
14 commissioning; (2) a lack of clarity in the commissioning process; and (3) facilitators and barriers to
15 commissioning. The main conclusions drawn from the review of the included papers [n = 42] are
16 summarized in table 3 (available as supplementary data).
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19 *Commissioners and service providers favour a joint commissioning approach*

20 The favouring of 'joined up' services (i.e. the integration of social and health care services) and
21 delivery by multi-disciplinary teams is advocated as more likely to deliver better services, including
22 to those care homes²¹⁻²³. At the local level, a joint commissioning approach is thought to deliver
23 better outcomes for less money²⁴, however we did not find any evidence to support this in the
24 literature. Co-ordinated care by multi-disciplinary teams, and inter-agency working alongside
25 government guidance, are seen as crucial elements of delivery in area like dementia where the need
26 is greater than the provision of one service²³. Commissioners are assigned a key role in building
27 relationships and focusing on common values and a shared purpose²⁵. A joined-up approach is also
28 favoured at the monitoring stage, where frontline staff are encouraged to feed back on the process,
29 so commissioners can learn from their experience and knowledge²¹.
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33 *Lack of clarity about the nature of commissioning and who should play what role*

34 In the ideal commissioning scenario, commissioners examined the complete care system with the
35 aim of 'binding the component parts together'²⁶, a system with one governance structure, one
36 budget and one integrated health and social care team²⁷. Our review illustrates, however, that the
37 reality of commissioning is distinctly different. Some commissioners are unclear about the exact
38 nature of their role "I'm not sure, I haven't had a job description and I'm not really sure what my
39 terms are"²⁸. Checkland and colleagues²⁹ trace this problem to the foundation of the CCGs, when
40 national guidance regarding CCG structures and governance was non-prescriptive. As a result, local
41 CCG structures and governance arrangements are very diverse with inconsistencies regarding size of
42 governing body, membership and names used for subcommittees. 'Engagement' can mean different
43 things to different groups, and although membership of a CCG is now compulsory for GP practices, it
44 has yet to be fully understood what this membership means and how active engagement might be
45 affected by the trend to form larger organisations²⁹.
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49 *Facilitators and barriers influencing commissioning*

50 In contrast, commissioners described how the implementation of specific local enhanced services
51 (LES), additionally remunerated initiatives over and above core services, was facilitated by coherent
52 evidence-based guidance to support staff and enable decision-making. A national framework
53 (Competency Framework) was a useful tool utilised by some CCGs to help them make complex
54 resource allocation decisions^{30,31}; such an approach was considered 'best practice'. This is a process
55 whereb two or more CCGs work together to commission the same service for which they are jointly
56 responsible; this allows a sharing of risk and transfer of skills and support. It also suggested that
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3 CCGs should seek and act upon the views of the practice population, to facilitate a more efficient
4 system of continual resource acquisition³². The value of supportive inter-professional working was
5 also emphasised, with a patient-centred ethos, resulting ideally in a joined-up approach to
6 commissioning³³, for example, nursing input is considered vital to the success of any healthcare
7 commissioning approach³⁴. The involvement of external providers was also felt to improve the
8 quality of commissioning. In a mixed case study, Wye and colleagues³⁵ describe the success of
9 commissioning contracts being due to collaboration with external parties for their analytical, clinical
10 and managerial expertise.

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13 Commissioners required information to build a cohesive and persuasive case to determine and
14 influence a course of action. They preferred knowledge exchange which is fast and flexible, for
15 example, conversations and patient stories, rather than research papers³⁶; “working on the ground”
16 involved the gathering of evidence to determine how local service provision is improving patients’
17 lives²⁷. This experiential knowledge and local evidence played a key role in improving the quality of
18 judgements in decision-making³⁰. In handling complex situations, commissioners rarely accessed
19 explicit evidence from research but instead relied on internalised guidelines, or ‘Mindlines’ built on
20 training, experience, interactions, local circumstances, and collective views of colleagues on how
21 things should be done³⁶. More recently, “the art of commissioning” has been described³⁷ whereby
22 commissioners pragmatically select different types of evidence from a range of sources (i.e, best
23 practice guidance, clinicians’ views of services, academic research evidence) to build a case.

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26 Success or failure of LES) was largely dependent on GPs’ willingness to participate; this willingness
27 was motivated by existing treatment delivery, hierarchy to support LES implementation and financial
28 incentives³¹. One of the reasons for potential non-participation was increased workload^{38,39}; other
29 contributory factors included: convening wide-ranging groups of people; developing and sustaining
30 strategic partnerships and establishing, running and managing formal meetings for service
31 development work³⁹. Other reported features impeding commissioning were a lack of shared
32 records and local directories of available services²² as well as out-dated block contracts and tariffs⁴⁰.
33 These aspects were compounded by inter-organisational politics between hospitals, commissioners
34 and primary care, which could impact on decision-making³³. Commissioners’ focus on demand-led
35 services was also reported as a growing area of concern⁴⁰. Whilst there was an acknowledgement
36 that local ‘markets’ need to offer both quality and choice of services for commissioners to
37 consider²¹, there was concern that, under new regulations introduced under the Health and Social
38 Care Act 2012 market forces rather than local commissioning decisions, would ultimately determine
39 how care is provided. There were fears that this may ultimately lead to privatisation of health care in
40 the UK, place commissioning groups (and GPs) into a difficult position and will ultimately damage the
41 trust between GPs and their patients⁴¹.

42 43 44 45 46 47 **Qualitative data: Interviews [1160]**

48 We interviewed 20 commissioners from 8 clinical commissioning groups (CCGs) and 5 local authority
49 adult services across England.

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51 Thematic analysis of the interviews with commissioners revealed many commonalities with the key
52 themes from the review, but also generated an additional four key themes:

- 53
54 (1) organisation of commissioning;
55 (2) commissioning expertise;
56 (3) end of life care and dementia: integration issues and
57 (4) the art of specification.
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Theme 1: Organisation of commissioning

Current commissioning of dementia services in England is centred on Government priority namely early diagnosis and intervention with 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 pointed out that it was often difficult to identify how much funding has been specifically allocated to dementia care [CR09, 375-8], 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, 31-3]. Such financial pressure and loss of staff (e.g. redundancies) had a negative impact on relationships / networks [CR11, 276-7]. 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, 100-4]. Strategies for improving the current situation therefore focus on working towards a more integrated approach to commissioning social and health care.

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]. Whilst Adult Social Care has a longstanding 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 didn't cover everything – 'dementia seems to have been outside that box' [CR10].

Theme 3: EoLC and dementia – integration issues

A common theme emerging from the interview data was the necessity for a more integrated approach to commissioning, i.e. stronger collaborative working between health and social care in order to improve EoL care services for people with dementia. Such a step has already proved successful in Wales [CR13]; '*...we have, in Wales, a more integrated approach to care*', however closer collaboration in England is impeded by structural and organisational barriers. Based on our interviews, 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 commissioners*' [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*

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3 *constraints often make you, or encourage you to kind of cut out parts of the process'* [CR04], with
4 agencies frequently involved in the decision-making process often geographically dispersed;
5 rendering face to face meetings a difficult task. Furthermore, more collaborative approaches were
6 hampered by historically embedded organisational structures and an unwillingness to '[look] outside
7 the box' as agencies '*just keep doing things the way that they've done them*' [CR09 / CR07]. One
8 interviewee pointed out that '*it's just trying to bring two cultures together in terms of local
9 government and NHS, two sets of performance indicators, two sets of financial arrangements,
10 particularly two kinds of organisations or sets of organisations that are under extreme financial
11 pressure*' [CR02]. Consequently, people spoke different 'languages';

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

18 19 20 *Theme 4: Specification – an emerging art form*

21 One interviewee regarded commissioning as a '*developing process*' [CR07], with the concept of
22 specification; a structured description of what the provider requires from a service, also referred to
23 for quality measurement. Considered to be '*an emerging art form*';

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

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31 It remained unclear, where the process started. While some began with '*informal discussions*' [CR07]
32 at the local level, others started at the national level by looking at '*what's happening nationally [...]
33 and then how [...] that feeds down to a local [...] level [...]*' [CR12]. Commissioners were fully aware of
34 the importance of contract specifications; '*if you don't put it in the contract, that's your legal
35 agreement about what should be provided. So if things go wrong, then you have no recourse really
36 on the provider*' [CR10]. Commissioners had high expectations of their service providers. Referring
37 to the provision of quality '*quality service [...] within the budget constraints*' [CR12]. Additional
38 expectations include sufficiently trained staff and an efficient monitoring system. However, a
39 unified system of negotiating and recording these expectations within contracts was lacking. While
40 one interviewee stated that '*we have a high expectation that providers that we're commissioning
41 services from will meet the requirements that we've set out in the service specification [...] with
42 robust monitoring of that*' [CR06, 480-3], others claimed that contracts were not specific enough.
43 This might be to do with the type of contracts currently in use (block contracts vs generic/standard
44 contracts) but also the high number of agencies involved in the process. As a result, contracts were
45 perceived to be '*unbelievably complicated*' [CR05].

46 47 48 49 50 51 **DISCUSSION (770)**

52 A number of key issues were identified from both the analysis of the review papers and the
53 qualitative data. While some guidance exists for the commissioning of end of life care for people
54 with dementia, commissioners experience difficulty in finding useful and practical guidance to assist
55 them in their role within a context of budget constraints and conflicting national priorities for
56 dementia. As a result commissioners rely on local knowledge and experience rather than evidence-
57 based data. In England, the current organisation of commissioning is suffering from a number of
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3 pressing demands, including political pressure, financial constraints and a lack of accountability and
4 guidance. These demands leave commissioners with an overwhelming and complex workload. Our
5 integrated findings suggest a more joined-up approach to commissioning as a solution to these
6 problems, although the detail as to how this is best achieved in practice remains unclear.
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9 In England, the commissioning process is also strongly dependent on individual commissioners'
10 expertise, to see the entire care system and 'bind the component parts together'²⁶. Our interviews
11 have revealed that many clinical commissioners are still familiarising themselves with the new health
12 care organisational structure. In doing so, they are drawing heavily on guidance, which is often non-
13 standardised, fragmented, and difficult to comprehend; such guidance often does not cover areas of
14 care, such as dementia, which are considered to fall 'outside the box'. Stronger collaboration, even
15 to the point of full integration, between health and social care was considered the ideal, but is
16 difficult to achieve, despite the perceived benefits of such an approach for dementia in light of the
17 complexity of the illness. Notwithstanding the evidence base for integrated health and social care is
18 limited especially on cost effectiveness⁴², although positive examples of intentional case studies of
19 integrated care for older people with complex needs have been reported⁴³. The art of contract
20 specification for a service is a complex issue. Our interviews confirmed findings from the literature
21 review about the importance of collaborating with local teams and drawing on experiences of
22 neighbouring authorities. However, participants commented that many contracts were too generic;
23 a similar problem has been reported for the provision of stroke rehabilitation services⁴⁰. Besides
24 having a legal role, contracts are now essential tools for holding providers to account, shaping the
25 delivery of service and controlling costs. Service commissioners need access to rapid evidence
26 appraisal to help them incorporate scientific data into a process that one of our participants
27 described as the 'art of contract specification'. Compare this need to the current process to update
28 national guidance on dementia care which is estimated to take around two years to complete (NICE
29 2006).
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32 Varieties of partnership working, differing levels and forms of expertise and uncertainties over
33 responsibility all characterise the move towards 'decentralisation' of care services. Checkland and
34 colleagues²⁹ recognise the implications of this as distilled in the formation of CCGs. Combined with
35 existing divisions between health and social care and budget reductions,, commissioning for end of
36 life care for people with dementia is fraught with difficulties. National policy and guidance are not
37 necessarily attuned to the practical day to day problems faced by commissioners. However, despite
38 the perceived 'user' need for national commissioning guidance, it is unlikely such documents will be
39 able to overcome all of the structural and procedural challenges detailed above; it could help by:
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- 42 • Recognising the challenges explicitly in order for commissioners to feel supported
- 43 • Prioritising the areas commissioners should focus on based on current evidence, including
44 the specification of contracts and monitoring
- 45 • Being concise, grounded in existing evidence base, and clearly referenced to provide a
46 recognised signpost
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48 Our ongoing research seeks to to develop practical and evidence based guidance to help
49 professionals working in a very difficult area; for political-economic, social and demographic reasons
50 these difficulties look set to increase during the 21st century.
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53 **Strengths and weaknesses**

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55 The paper reports the results of the first study to explore the processes involved in commissioning
56 end of life care for people with dementia. Through an evidence synthesis of current policy and
57 qualitative data from commissioners themselves such a mixed-methods approach allows us to 'test'
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findings from a narrative review against accounts from commissioners. However, there are a number of limitations. 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 (i.e. 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 (e.g. "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.

ACKNOWLEDGMENTS

This paper presents independent research funded by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research programme (Grant Reference Number RP-PG-0611-20005). The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.

The National Institute for Health Research (NIHR) aims at supporting and translating research evidence into NHS practice. The research was conducted by a multi-disciplinary research team and facilitated by the collaborative partnerships between Newcastle, Glasgow Caledonian, Hertfordshire and London Universities, and the Glasgow School of Art.

The authors wish to thank all of the commissioners who took part and gave of their time in this way.

Reporting Checklist

- a. contributorship statement
Research design: RL, LR, EM, CG. Data collection and data analysis: RL, ZG, NB. The first draft was written by: RL, ZG, NB and was edited by all authors. All authors approved the final version of the manuscript.
- b. competing interests
There are no competing interests
- c. funding
Department of Health National Institute for Health Research (NIHR) Applied Research Programme Grant: RP-PG-0611-20005
- d. data sharing statement
No additional data are available

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BMJ Open

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

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2016-013554.R1
Article Type:	Research
Date Submitted by the Author:	18-Oct-2016
Complete List of Authors:	Gotts, Zoe; Newcastle University, Institute of Health & Society Baur, nicole; Newcastle University, Institute of Health & Society Mclellan, Emma; Newcastle University, Institute of Health & Society Goodman, Claire; University of Hertfordshire, Centre for Research in Primary and Community Care Robinson, Louise; Institute for Health and Society, Newcastle University lee, richard; Newcastle University, Institute of Health & Society
Primary Subject Heading:	Health services research
Secondary Subject Heading:	Palliative care, Medical management
Keywords:	Adult palliative care < PALLIATIVE CARE, Clinical governance < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Dementia < NEUROLOGY, Change management < HEALTH SERVICES ADMINISTRATION & MANAGEMENT

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Key Words: commissioning, end-of-life care, dementia, health and social care**Word Count: 3907**

ABSTRACT

Objectives

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

Design

Mixed-methods study; narrative review and qualitative interviews.

Setting

8 NHS clinical commissioning groups and 5 Adult Services across England.

Methods

Narrative review of evidence; 20 semi structured interviews (telephone and face-to-face) with professionals involved in commissioning end of life care for people with dementia.

Main outcome measures

Summary of the existing evidence base for commissioning, commissioners' approaches to the commissioning process for end of life care for people with dementia in England.

Results

In the context of commissioning end of life care 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 end of life care is limited with considerable uncertainty as how clinical commissioners in England undertake the process to ensure future services are evidence-based.

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.

INTRODUCTION

As populations rapidly age, policy is increasingly focussed on improving the quality end of life (EoL) care for older people and those living with non-cancer related long term illness^{1,2}. For people with dementia and their families the organisation and provision of care, towards and at the EoL, continues to be challenging³⁻⁷, with very few dying at home and around a third dying in acute hospitals⁸. The costs of dementia care, especially in the last year of life, are also considerable⁹. With an ageing population potentially rapidly increasing such costs⁹, it is crucial to explore more cost-effective, integrated models of care¹⁰.

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 Mannion¹¹, 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 health care¹². To date, guidance to assist commissioners in organising better quality EoL care for people with dementia has been limited^{13,14}, this is in contrast to independently developed evidence-based guidance available to health care providers^{15,16}. In England, the cost of care provision for people with dementia is met through a (varying) combination of an individual's capital, local authority budgets and health care 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^{17,18}. There is an urgent need to develop evidence-based guidance for commissioners responsible for organising and co-ordinating care towards and at the end of life for those with dementia in order to improve quality of services¹⁹.

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 end of life care for people with dementia currently undertaken?
- What are the main factors that influence the decision making of commissioners when commissioning end of life 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 principle data sources: the findings of a narrative review of current evidence and policy, and semi-structured 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 on-going organisation of commissioning has had – and will have – in this area of care.

METHODS

This study is part of a five 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 utilised incorporating:

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

i) Narrative Review

Details of the search strategy and study selection criteria are given in Box 1 (available as supplementary data). The first search was undertaken in January, 2014, with an updated search on 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 Box 1). Disagreements were resolved through discussion with a third reviewer (RL). 45 full text papers were reviewed, 42 of which met the inclusion criteria.

ii) Qualitative 1-1 interviews

Semi-structured 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). Interviewees responded to regional and national calls for participation and direct emails to local authorities (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 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 approach²⁰.

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

Ethical approval

Ethical approval for the study was granted by Newcastle University Faculty of Medical Science Ethics Committee (Ref 00776/2014). NHS Assurance for interviews with commissioners was granted by North East & Cumbria, West Midlands and Wessex Clinical Research Networks (Ref 162985).

RESULTS

i. Narrative Review

Commissioning: review of policy, guidance and strategies

We identified 19 documents relevant to the commissioning of: i) EoL care in dementia; ii) dementia care in general and iii) EoL care in general (See Table 2 in supplementary data). 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; skills 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 measurably 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 summarized in table 3 (see supplementary data).

Commissioners and service providers favour a joint commissioning approach

The favouring of 'joined up' services (i.e. the integration of social and health care services) and delivery by multi-disciplinary teams is advocated as more likely to deliver better services, including to those care homes²¹⁻²³. At the local level, a joint commissioning approach is thought to deliver better outcomes for less money²⁴, however we did not find any evidence to support this in the literature. Co-ordinated care by multi-disciplinary teams, and inter-agency working alongside

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3 government guidance, are seen as crucial elements of delivery in dementia care, where the need is
4 greater than the provision of one service²³. Commissioners are assigned a key role in building
5 relationships and focusing on common values and a shared purpose²⁵. A joined-up approach is also
6 favoured at the monitoring stage, where frontline staff are encouraged to feed back on the process,
7 so commissioners can learn from their experience and knowledge²¹.
8

9 10 *Lack of clarity about the nature of commissioning and who should play what role*

11 In the ideal commissioning scenario, commissioners examined the complete care system with the
12 aim of 'binding the component parts together'²⁶, a system with one governance structure, one
13 budget and one integrated health and social care team²⁷. Our review illustrates, however, that the
14 reality of commissioning is distinctly different. Some commissioners are unclear about the exact
15 nature of their role "I'm not sure, I haven't had a job description and I'm not really sure what my
16 terms are"²⁸. Checkland and colleagues²⁹ trace this problem to the foundation of the CCGs, when
17 national guidance regarding CCG structures and governance was non-prescriptive. As a result, local
18 CCG structures and governance arrangements are very diverse with inconsistencies regarding size of
19 governing body, membership and names used for subcommittees. 'Engagement' can mean different
20 things to different groups, and although membership of a CCG is now compulsory for GP practices, it
21 has yet to be fully understood what this membership means and how active engagement might be
22 affected by the trend to form larger organisations²⁹.
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25 26 *Facilitators and barriers influencing commissioning*

27 In contrast, commissioners described how the implementation of specific local enhanced services
28 (LES), additionally remunerated initiatives over and above core services, was facilitated by coherent
29 evidence-based guidance to support staff and enable decision-making. A national framework
30 (Competency Framework) was a useful tool utilised by some CCGs to help them make complex
31 resource allocation decisions^{30,31}; such an approach was considered 'best practice'. This is a process
32 where two or more CCGs work together to commission the same service for which they are jointly
33 responsible; this allows a sharing of risk and transfer of skills and support. It also suggested that
34 CCGs should seek and act upon the views of the practice population, to facilitate a more efficient
35 system of continual resource acquisition³². The value of supportive inter-professional working was
36 also emphasised, with a patient-centred ethos, resulting ideally in a joined-up approach to
37 commissioning³³, for example, nursing input is considered vital to the success of any healthcare
38 commissioning approach³⁴. The involvement of external providers was also felt to improve the
39 quality of commissioning. In a mixed case study, Wye and colleagues³⁵ describe the success of
40 commissioning contracts being due to collaboration with external parties for their analytical, clinical
41 and managerial expertise.
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45 Commissioners required information to build a cohesive and persuasive case to determine and
46 influence a course of action. They preferred knowledge exchange which is fast and flexible, for
47 example, conversations and patient stories, rather than research papers³⁶; "working on the ground"
48 involved the gathering of evidence to determine how local service provision is improving patients'
49 lives²⁷. This experiential knowledge and local evidence played a key role in improving the quality of
50 judgements in decision-making³⁰. In handling complex situations, commissioners rarely accessed
51 explicit evidence from research but instead relied on internalised guidelines, or 'Mindlines' built on
52 training, experience, interactions, local circumstances, and collective views of colleagues on how
53 things should be done³⁶. "The art of commissioning" has been described³⁷ whereby commissioners
54 pragmatically select different types of evidence from a range of sources (i.e, best practice guidance,
55 clinicians' views of services, academic research evidence) to build a case.
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3 Success or failure of LES was largely dependent on GPs' willingness to participate; this willingness
4 was motivated by existing treatment delivery, hierarchy to support LES implementation and financial
5 incentives³¹. One of the reasons for potential non-participation was increased workload^{38,39}; other
6 contributory factors included: convening wide-ranging groups of people; developing and sustaining
7 strategic partnerships and establishing, running and managing formal meetings for service
8 development work³⁹. Other reported features impeding commissioning were a lack of shared
9 records and local directories of available services²² as well as out-dated block contracts and tariffs⁴⁰.
10 These aspects were compounded by inter-organisational politics between hospitals, commissioners
11 and primary care, which could impact on decision-making³³. Commissioners' focus on demand-led
12 services was also reported as a growing area of concern⁴⁰. Whilst there was an acknowledgement
13 that local 'markets' need to offer both quality and choice of services for commissioners to
14 consider²¹, there was concern that, under new regulations introduced under the Health and Social
15 Care Act 2012 market forces rather than local commissioning decisions, would ultimately determine
16 how care is provided. There were fears that this may ultimately lead to privatisation of health care in
17 the England, place commissioning groups (and GPs) into a difficult position and will ultimately
18 damage the trust between GPs and their patients⁴¹.

22 23 24 **ii. Interviews with commissioners**

25 We interviewed 20 commissioners from 8 clinical commissioning groups (CCGs) and 5 local authority
26 adult services across England.

27
28 Thematic analysis of the interviews with commissioners revealed many commonalities with the key
29 themes from the review, but also generated an additional four key themes:

- 30 (1) organisation of commissioning;
- 31 (2) expertise in commissioning;
- 32 (3) end of life care and dementia: integration issues
- 33 (4) 'specification' as an emerging art form

34 35 36 *Theme 1: Organisation of commissioning*

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

50 51 52 *Theme 2: Expertise in commissioning*

53 Commissioners interviewed were fully aware of their responsibilities: 'if I'm the commissioner, then
54 it's my responsibility, my accountability, to choose the correct provider' [CR04]. Whilst adult social
55 care has a longstanding history of commissioning services, CCGs were new to the process and still
56 developing these skills; several felt that training, such as the CCG leadership course, could support
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3 this. Such training is important; as commissioning guidance is currently non-standardised and
4 fragmented, interviewees therefore increasingly resorted to 'see[ing] what other people have done
5 elsewhere' [CR01]. Some also stated that it was difficult for commissioners to understand and apply
6 current guidance due to the complexity of information available; '*so for a long time we've had non*
7 *cancer patients on our list and we've used it as, as a framework loosely, not as detailed as it's got to*
8 *lately'* [CR05]. Multiple forms of guidance could appear at the same time with no clear stated
9 relationship [CR11]. There was also criticism that guidance didn't cover everything – 'dementia
10 seems to have been outside that box' [CR10].
11

12 *Theme 3: EoLC and dementia – integration issues*

13 A common theme was the necessity for a more integrated approach to commissioning, i.e. stronger
14 collaborative working between health and social care in order to improve EoL care services for
15 people with dementia. It was proposed by one interviewee that such a step proved successful in
16 Wales [CR13]; '*...we have, in Wales, a more integrated approach to care'*, however closer
17 collaboration in England is impeded by structural and organisational barriers. We identified a lack of
18 communication/engagement between clinicians and social services as a core issue. Many
19 interviewees blamed clinicians' failure to engage with providers and their lack of clinical
20 championship in dementia.
21

22 '*..they've pulled their clinical engagements staff out because of resources at their end, and it*
23 *was basically since the introduction of 111'* [CR11]

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

26
27 Other participants admitted that '*we've very much left the commissioning around end of life care*
28 *largely to our health commissioners'* [CR02]. The lack of interaction between health and social care
29 was regarded as historically rooted and compounded by geographical and temporal issues. A
30 number of interviewees mentioned that clinicians were under extreme time constraints; '*time*
31 *constraints often make you, or encourage you to kind of cut out parts of the process'* [CR04], with
32 agencies frequently involved in the decision-making process often geographically dispersed;
33 rendering face to face meetings a difficult task. Furthermore, more collaborative approaches were
34 hampered by historically embedded organisational structures and an unwillingness to '*[look] outside*
35 *the box'* as agencies '*just keep doing things the way that they've done them'* [CR09 / CR07]. One
36 interviewee pointed out that '*it's just trying to bring two cultures together in terms of local*
37 *government and NHS, two sets of performance indicators, two sets of financial arrangements,*
38 *particularly two kinds of organisations or sets of organisations that are under extreme financial*
39 *pressure'* [CR02]. Consequently, people spoke different 'languages';
40

41 '*the language of commissioning gets in the way... we kind of talk about integrated care*
42 *provision in adult social care and we're talking about integration to mean social care in the*
43 *NHS, when, whereas colleagues in the NHS may be talking about integrating between acute*
44 *and primary, or community services'* [CR02].
45

46 *Theme 4: 'Specification' as an emerging art form*

47 One interviewee regarded commissioning as a '*developing process'* [CR07]. Within this process
48 'specification' – as a structured description of what the provider requires from a service – was
49 considered to be '*an emerging art form'*:
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51 '*I would suggest because historically with [community] providers you've had a block contract,*
52 *so they get a certain amount of money for a wide generic range of services, there hasn't*
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3 *been a great deal of detail into what they should provide under that block contract [...]. So*
4 *locally we have, with the integrated care teams, been specifying more in detail what we*
5 *want them to try and achieve' [CR07].*
6

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

28
29 A number of key issues were identified from both the analysis of the review papers and the
30 qualitative data. While some guidance exists for the commissioning of end of life care for people
31 with dementia, commissioners experience difficulty in finding useful and practical guidance to assist
32 them in their role within a context of budget constraints and conflicting national priorities for
33 dementia. As a result commissioners rely on local knowledge and experience rather than evidence-
34 based data. In England, the current organisation of commissioning is suffering from a number of
35 pressing demands, including political pressure, financial constraints and a lack of accountability and
36 guidance. These demands leave commissioners with an overwhelming and complex workload. Our
37 integrated findings suggest a more joined-up approach to commissioning as a solution to these
38 problems, although the detail as to how this is best achieved in practice remains unclear.
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41 In England, the commissioning process is also strongly dependent on individual commissioners'
42 expertise, to see the entire care system and 'bind the component parts together'²⁶. Our interviews
43 have revealed that many clinical commissioners are still familiarising themselves with the new health
44 care organisational structure. In doing so, they are drawing heavily on guidance, which is often non-
45 standardised, fragmented, and difficult to comprehend; such guidance often does not cover areas of
46 care, such as dementia, which are considered to fall 'outside the box'. Stronger collaboration, even
47 to the point of full integration, between health and social care was considered the ideal, but is
48 difficult to achieve, despite the perceived benefits of such an approach for dementia in light of the
49 complexity of the illness. Notwithstanding the evidence base for integrated health and social care is
50 limited especially on cost effectiveness⁴², although positive examples of intentional case studies of
51 integrated care for older people with complex needs have been reported⁴³. The art of contract
52 specification for a service is a complex issue. Our interviews confirmed findings from the literature
53 review about the importance of collaborating with local teams and drawing on experiences of
54 neighbouring authorities. However, participants commented that many contracts were too generic;
55 a similar problem has been reported for the provision of stroke rehabilitation services⁴⁰. Besides
56 having a legal role, contracts are now essential tools for holding providers to account, shaping the
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3 delivery of service and controlling costs. Service commissioners need access to rapid evidence
4 appraisal to help them incorporate scientific data into a process that one of our participants
5 described as the 'art of contract specification'. Compare this need to the current process to update
6 national guidance on dementia care which is estimated to take around two years to complete (NICE
7 2006).
8

9
10 Varieties of partnership working, differing levels and forms of expertise and uncertainties over
11 responsibility all characterise the move towards 'decentralisation' of care services. Checkland and
12 colleagues²⁹ recognise the implications of this as distilled in the formation of CCGs. Combined with
13 existing divisions between health and social care and budget reductions,, commissioning for end of
14 life care for people with dementia is fraught with difficulties. National policy and guidance are not
15 necessarily attuned to the practical day to day problems faced by commissioners. However, despite
16 the perceived 'user' need for national commissioning guidance, it is unlikely such documents will be
17 able to overcome all of the structural and procedural challenges detailed above; it could help by:

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

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26 Our ongoing research seeks to to develop practical and evidence based, small-scale guidance
27 'intervention' to help professionals working in a very difficult area; for political-economic, social and
28 demographic reasons these difficulties look set to increase during the 21st century.
29

30 31 **Strengths and weaknessse**

32
33 The paper reports the results of the first study to explore the processes involved in commissioning
34 end of life care for people with dementia. Through an evidence synthesis of current policy and
35 qualitative data from commissioners themselves such a mixed-methods approach allows us to 'test'
36 findings from a narrative review against accounts from commissioners. However, there are a number
37 of limitations. Our sample comprised participants who responded to our requests for an interview
38 and so may have over-represented those wanting to critique the commissioning process. In
39 conducting comprehensive electronic searches for the identification of papers for the review, some
40 studies may have been overlooked because no hand-searches of journals were carried out.
41 Manuscripts included were limited to English language databases and papers published in English
42 only. Restriction on the time period (i.e. 2012 and later) for searches may have restricted the scope
43 of findings, and, when interpreting the findings of the papers selected, it is possible that over time
44 terminology could have changed (e.g. "contracting"/"commissioning"). We identified
45 methodological inconsistencies across the studies included in the review; it was often unclear how
46 authors identified participants or determined their sample sizes, which were often small. Further,
47 there was ambiguity in establishing a specific time period for the research. Few studies illuminate
48 the actual commissioning process, instead making comparisons between the old and new systems.
49 Although this narrative review was carried out in a structured and systematic way, this was not a
50 systematic review, as such, the quality of the manuscripts were not assessed for their quality.
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53 54 **ACKNOWLEDGMENTS**

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56 This paper presents independent research funded by the National Institute for Health Research
57 (NIHR) under its Programme Grants for Applied Research programme (Grant Reference Number RP-
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PG-0611-20005). The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.

The National Institute for Health Research (NIHR) aims at supporting and translating research evidence into NHS practice. The research was conducted by a multi-disciplinary research team and facilitated by the collaborative partnerships between Newcastle, Glasgow Caledonian, Hertfordshire and London Universities, and the Glasgow School of Art.

The authors wish to thank all of the commissioners who took part and gave of their time in this way.

Reporting Checklist

- a. contributorship statement
Research design: RL, LR, EM, CG. Data collection and data analysis: RL, ZG, NB. The first draft was written by: RL, ZG, NB and was edited by all authors. All authors approved the final version of the manuscript.
- b. competing interests
There are no competing interests
- c. funding
Department of Health National Institute for Health Research (NIHR) Applied Research Programme Grant: RP-PG-0611-20005
- d. data sharing statement
No additional data are available

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Additional supplementary data: Box 1 Inclusion criteria and search strategy**Criteria for inclusion: Types of studies***

Participants: Professionals who commission end of life and/or dementia services, from across social and health care. Service providers may also participate in these studies.

Interventions: Any /local authority/clinical commissioning group involved in commissioning services for a health care environment. Outcome measures were not used as inclusion/exclusion criteria.

Search strategy: A web-based search for national policy and guidance documents, based on the following search topics: End of life care and dementia; End of life care; Dementia. Reference chaining from documents referenced in policy and guidance documents.

English language academic literature papers (descriptive, discursive, and empirical) published 2012-2015 inclusive, which detail factors and process influencing the process of commissioning services for health and social care, in-keeping with commissioning reforms following the Health & Social Care Act 2012; in particular the establishment of clinical commissioning groups.

Local policy documents, such as dementia strategy for a local authority area, identified by service commissioners interviewed as part of the study or identified through web-based searches using search terms relevant to the locality. Online-based searches of Web of Knowledge (including MEDLINE); Scopus; Oxford Journals; The Kings Fund.

An iterative snowball technique was employed, manually identifying further documents from the bibliographic entries of the ones already retrieved; in addition, abstracts and posters from conferences were included in the search

Search terms: commissioning; commissioning health social care; commissioning dementia; commissioning end of life. Reference chaining from included literature.

Documents were included, if their titles suggested that they detailed commissioner's experiences of the commissioning process AND/OR service provider's experiences of the commissioning process AND/OR factors which enable or inhibit the commissioning process AND/OR compare commissioning arrangements. Other studies were considered eligible if they offered a relevant and rigorous analysis of the commissioning process for end of life and/or dementia care. Searches yielded a total number of 45 papers and their relevance for the study was ascertained through reading the abstract. Returns are displayed in the table below.

**only studies published in the English language were considered and were restricted to those published 2012 and later.*

Question	Pubmed	Web of Science	Scopus	Proquest*	Proquest Social Sciences Premium Collection only	Ovid (all)	JSTOR	NHS Evidence	AMED	BNI	CINAHL	EMBASE	Health Business Elite	HMIC	PsychINFO	Medline
commission* AND care AND dementia AND (palliati* OR "end of life" OR terminal)	6	8	13	548	534	1210	509	1417	0	2	2	11	0	7	2	3
commission* AND care AND dementia	84	81	116	2685	2458	5390	1931	3042	0	29	38	68	22	68	45	44
commission* AND care AND (palliati* OR "end of life" OR terminal)	325	364	363	9836	5859	11156	12187	4254	36	36	95	236	55	129	48	148

*including 'British Periodicals (1691-1939)', 'Periodicals Archive Online' and 'Proquest Social Sciences Premium Collection'

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Additional supplementary data: Box 2 Interview Topic Guide**Commissioning end of life care in dementia: your experiences and views**

1. Introduce self and remind the respondent about the project
2. Explain purpose of the interviews: to better understand how services are commissioned and to consider how this should be done in the future.
3. Ask interviewee to describe their current role and their involvement in the commissioning of end of life care and dementia services.
 - a. What are the key things they look for when commissioning services?
 - b. Who do they involve in the decision-making process?
 - c. What type of providers do they commission?
 - d. What guidelines do they use when commissioning services?
 - e. Is commissioning end of life care different for dementia?
 - f. Ideally, how should commissioning of these services be organised and conducted in the future?
 - g. Are there any things you require further information on in terms of commissioning?
4. Explore respondent's views on good/best practice in end of life care for people with dementia.
 - Key components (for person with dementia, carers and staff)
 - How it differs from/is similar to end of life care in other conditions
 - Perceived value of existing EOLC frameworks to dementia
5. Check whether respondent can think of anyone else involved in commissioning who might be able to help us with the study
6. Thanks and arrangements for sending feedback on the results of WS6

Additional supplementary data: Table 2; Policy Documentation

Name of document	Key aim / purpose
Guidance Documents	
<i>End of Life Care for People with dementia: Commissioning Guide; Implementing NICE Guidance</i> (National Institute for Health and Clinical Excellence, 2010)	EoL care and dementia care commissioning; sets out key issues from start (planning from point of diagnosis, integrated care, supporting carers) specifying EoL care service components.
<i>Guide to commissioners on End of Life Care for Adults</i> (National Institute for Health and Clinical Excellence, 2011)	EoL care commissioning; addresses how to identify people at EoL where death will occur within 12 months (identification/assessment; holistic support; access to services; care in the last days of life; care after death; workforce)
Commissioning Guidance for Specialist Palliative Care: Helping to deliver commissioning objectives (Association for Palliative Medicine of GB and Ireland; Consultant Nurse in Palliative Care Reference Group; Marie Curie Cancer Care; National Council for Palliative Care; Palliative Care section of the Royal Society of Medicine, 2012)	EoL care commissioning; focus on specialist palliative care by multi-professional teams in advanced cancers; end stage organ failures; neurodegenerative diseases; advanced dementia/Alzheimer's, allocation set locally.
<i>RCGP Commissioning Guidance in End of Life Care</i> (Royal College of General Practitioners, 2013)	EoL care commissioning; 6 steps; Quality accountability report, Right person, Right care, Right place, Right time, Every time. Targets all people approaching EoL including their carers/families
Guidance for commissioners of dementia services; Joint Commissioning Panel for Mental Health, Feb 2013	Dementia care commissioning; sets out 6 key principles underpinning dementia commissioning (seamless services; services commissioned on basis of need and should be age-sensitive; different services needed at different times; mainstream health and social care services should be dementia friendly; care should be delivered in partnership; care should be personalised)
Support for commissioning dementia care; National Institute for Health and Clinical Excellence, April 2013	Dementia care commissioning; promotes an integrated whole-systems approach with focus on improving early diagnosis, living well with dementia and supporting carers. Gives measurable outcomes.

Policy documents	
<i>Care towards the end of life for people with dementia: An online resource guide</i> (NHS End of Life Care Programme Improving End of Life Care, 2010)	EoL care and dementia care; aimed at professionals working in health and social care in EoLC for pwd. 6 steps (Discussions as EoL approaches, assessment, care planning & review, co-ordination of care, delivery of high quality services in different settings, care in the last days of life, care after death)
One Chance To Get It Right: Improving people's experience of care in the last few days and hours of life; Leadership Alliance for the Care of Dying People (LACDP), June 2014	EoL care; focuses on achieving five Priorities for Care to make the dying person the focus of care in the last few days and hours of life. Emphasises care should be individualised/reflect the needs and preferences of the dying person and those who are important to them.
The Prime Minister's Challenge on dementia: annual report of progress; Department of Health, May 2013	Dementia; to improve QoL for pwd, their families/carers. Need individualised, joined up care. Proposed changes - (timely diagnosis; better quality care; reduce stigma by increasing understanding and awareness across society; build national capacity and capability in dementia research)
Dementia Quality Standard; National Institute for Health and Clinical Excellence, June 2010	Dementia; set out "aspirational but achievable markers of high quality cost effective care" covers care provided by health and social care for pwd in hospital, community, home-based, residential and specialist settings
Commissioning for Quality and Innovation (CQUIN) 2013/14 Guidance; NHS Commissioning Board, Feb 2013	Commissioning; to secure improvements in quality of services and better outcomes for patients, alongside strong financial management. Goals for 2013/14 (friends and family test, NHS safety thermometer, improving dementia care, venous thromboembolism – funding to be split evenly among the 4 goals)
The Mandate: a mandate from the government to the NHS Commissioning Board: April 2013 to March 2015; Department of Health, Nov 2013	Commissioning; to make partnership working a success. Sets out 5 main areas to improve (corresponds to NHS Outcomes Framework); preventing people from dying prematurely; enhancing quality of life for people with long-term conditions; helping people recover from episodes of ill health or injury; ensuring people experience better care; providing safe care.
Strategy Documents	

<p>End of Life Care Strategy – Fourth Annual Report; How people die remains in the memory of those who live on; (Department of Health, 2012)</p>	<p>EoL care; Responsibility for EOLC and EOLC Strategy moves from DH to NHS Commissioning Board from April 2013. National End of Life Care Intelligence Network (NEoLCIN) set up to address the lack of routine data, information and intelligence on EOLC. Hospitals should follow the 6 steps in EoLC (Advance Care Planning, Electronic Palliative Care Co-ordination Systems, the AMBER Care Bundle, the Rapid Discharge Home to Die Pathway, the Live Pool Care Pathway)</p>
<p>End of Life Care Strategy: Promoting high quality care for all adults at the end of life. (Department of Health, 2008)</p>	<p>EoL care; outlines recommendations for good EoL care (good death indicators, high quality EoL care available to all – hospital/home, stepped care pathway approach, staff knowledge and skills, Gold Standards Framework)</p>
<p>Living well with dementia: A National Dementia Strategy Putting People First (Department of Health, Feb, 2009)</p>	<p>Dementia; to make significant improvements to dementia services across 3 key areas; improved awareness; earlier diagnosis and intervention; higher quality of care. Identifies 17 key objectives.</p>
<p>Non-Governmental Organisation Documents</p>	
<p><i>Positive Partnerships Palliative Care for Adults with Severe Mental Health Problems</i> (National Council for Hospice and Specialist Palliative Care Services and Scottish Partnership Agency for Palliative and Cancer Care, 2000)</p>	<p>EoL care and dementia care; to promote both physical and psychosocial wellbeing using a palliative care approach. Key principles (focus on QoL i.e, good symptom control; whole person approach i.e, persons past life experience/current situation; care of both the person with the life threatening disease and those that matter to them; respect for patient autonomy and choice (e.g. place of care, treatment options); emphasis on open and sensitive communication which extends to patients, informal carers and professional colleagues).</p>
<p><i>My life until the end, Dying well with Dementia</i> (Alzheimer’s Society, 2012)</p>	<p>EoL care and dementia care; reports 7 key issues surrounding EoL care from the perspective of pwd and their carers (public awareness, Care planning and Proxy decision making, Dignity, Pain, Withholding and withdrawing treatment, Emotional and Spiritual concerns, Place of care and death)</p>
<p>The End of Life Care strategy: New Ambitions; The National Council for Palliative Care, Nov 2013</p>	<p>EoL care; identifies challenges in EoL care with emphasis on locally commissioning personalised care, data and intelligence, conversations surrounding death/dying.</p>

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Clinical Commissioning Groups Supporting improvement in General Practice?: The Kings Fund, Nuffield Trust, 2013	Dementia; examines perceived impact of CCG's using 6 case study sites over 3 years (2012-2015). 3 main areas of focus (nature of relationships being built inside CCG's, role of CCG in supporting quality improvement in general practice, structures and processes used)
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Additional supplementary data: Table 1; Factors influencing the commissioning process: Overview of papers

Author(s)	Title	Year	Citation	Study Country & Date	Research Objectives	Participants	Methods	Main Findings & Conclusions	Study Limitations
<i>Research studies and reviews</i>									
Cass, Elaine	Safeguarding: commissioning care homes	2012	<i>The Journal of Adult Protection</i> , 14(5), pp. 244-7	England		n/a – not a study, but review	Review of two SCIE resources	<ul style="list-style-type: none"> * commissioners can improve quality of residential services through better partnerships working with communities, service users, carers and local voluntary organisations & better use of intelligence from a variety of sources to reduce risk to people in residential care * commissioners need to ensure that local market offers quality & choice, as people do not want to accept poor quality services only because there is nothing else available * commissioners need to ensure that care home staff are properly trained and supported – as they are key to quality & safeguarding → frontline staff should feed into monitoring process, so commissioners can learn from their experience and knowledge 	Recommendations made based on review of two resources
Checkland, Kath et al.	Accountable to whom, for what? An exploration of the early development of Clinical Commissioning Groups in the English NHS	2013	<i>BMJ Open</i> , 3(12),	England, September 2011- June 2012	Explore how CCGs interpret their accountability relationships & how the new system is developing in practice	91 (GPs, managers, governing body members in 8 developing CCGs)	<ul style="list-style-type: none"> * Examination of CCG constitutional documents * 96 Semi-structured interviews in 8 CCGs * Observation in meetings in 8 CCGs (439h) * National web-based survey (only marginally relevant for this article) 	<ul style="list-style-type: none"> * CCGs subject to managerial, sanction-backed accountability to NHS England (NHSE) through annual assessments – however those involved with setting up CCGs do not appreciate either extent of this managerial and fiscal accountability nor its potential impact (e.g. loss of ability to function as autonomous statutory body & loss of income) * CCGs externally accountable to the public and some other newly founded organisations (e.g. economic regulator [Monitor], Health and Wellbeing Boards, Local Medical Committees, etc.) – greater awareness amongst CCGs about this type of accountability * CCGs internally accountable to their members through a two-way process 	Study carried out in the development stage of CCGs

								<p>→ CCG at centre of complex web of accountability relationships which are more complex than for their predecessor organisations, as CCGs accountable to a much wider range of organisations and bodies of people (although external & internal accountabilities are much weaker than accountability to NHSE)</p> <p>→ practical implications (i.e. whether more complex accountability translates into being more responsive or more easily held to account) remains to be seen</p> <p>* one problem: key guidance documents for CCGs provide neither advice on mechanics on accountability relationships nor on how conflicts between them might be resolved</p>	
Checkland, Kath et al.	Primary care-led commissioning: applying lessons from the past to the early development of clinical commissioning groups in England	2013	<i>British Journal of General Practice</i> , 63(614), pp. e611-9	England, September 2011-June 2012	* Evaluate Pathfinder Programme (= programme for aspiring CCGs to find out best way to organise themselves) * relate findings from case studies to what is known from previous research about clinical commissioning	91 mainly medical staff, but also lay members (5), practice managers (3) & LA representative (1) from 8 CCGs	* Systematic review of evidence relating to clinically-led commissioning * 8 case studies supplemented by descriptive information from web surveys * observation of 146 meetings (439h) with governing bodies, GP members, HWBs, locality meetings	<p>* on paper, CCGs have got more autonomy than their predecessors in that they are statutory bodies and carry full budgetary responsibility</p> <p>* guidance re CCG structures and governance was non-prescriptive → emerging structures & governance arrangements very diverse with inconsistencies regarding size of governing body, membership & names used for subcommittees → decision made to identify groups by their functions rather than their names (although the distribution of functions in a site was often more fluid than the nomenclature suggests)</p> <p>* 'grassroot engagement' is regarded as important, but 'engagement' can mean different things to different groups</p> <p>* contrary to previous commissioning organisations, membership in CCGs is compulsory for GPs, which may have a negative impact on their engagement in the long term</p> <p>* what it means to be a member of a CCG has yet to be fully understood and it is possible that the trend to form larger</p>	Study conducted at an early stage in the development of CCGs

								<p>organisations may adversely affect engagement</p> <ul style="list-style-type: none"> * CCGs may find it difficult to move beyond commissioning focused on the immediate needs of patients owing to the ongoing uncertainty about the role of public health in the new system * one area where GPs could make an impact is in engagement with providers around service development and contracting 	
Checkland, Kath et al.	Understanding the work done by NHS commissioning managers	2013	<i>Journal of Health Organization and Management</i> , 27(2), pp. 149-170	England, April 2009-September 2010	Explore micro-processes of daily work by which commissioning managers enact sensemaking in their organisations	41 managers & GPs from 4 PCTs	<ul style="list-style-type: none"> * qualitative case study approach (shadowing managers, meetings [93 hours] observations [60 hours], interviews [41]) * analysis with Atlas.ti 	<ul style="list-style-type: none"> * findings expand understanding of sense-making in organisations and have practical implications for managers of CCGs * shake-up of organisation of NHS provides opportunities for proactive managers to embrace new practices * spatial separation of managers from those setting the direction of commissioning may be problematic * artefacts (such as minutes) will assume greater importance, as discussions will be less informal 	
Checkland, Kath et al.	'Animateurs' and animation: what makes a good commissioning manager?	2012	<i>Journal of Health Service Research & Policy</i> , 17(1), pp. 11-17	England, April 2009-September 2010	Examine managerial behaviour & explore their impact	41 managers & GPs from 4 PCTs	<ul style="list-style-type: none"> * qualitative case study approach (in-depth interviews) * formal & informal observation (150 hours) 	<ul style="list-style-type: none"> * in addition to the skills of a good generic manager commissioning managers will have to work creatively to align objectives and ensure that everyone works towards overall, mutually defined objectives → CCG managers will require deep & contextualised understanding of NHS – this is particularly important, if managers from outside the NHS are brought in → important that organisational processes do not inhibit managerial behaviour (e.g. hot desking inhibits informal networking, cancellation of meetings has negative impact) 	
Clarke, Aileen et al.	Evidence-based commissioning in the English NHS: who uses which sources of evidence? A	2013	<i>BMJ Open</i>	England, 2010-2011	Investigate types of evidence used by health care commissioners and whether decisions were influenced by	345 staff employed at NHS band 7 or above in 11 PCTs representative	<ul style="list-style-type: none"> * Cross-sectional survey * Logistic regression analysis with SPSS 	<ul style="list-style-type: none"> * use of evidence varies according to professional background (public health employees & female employees likely to use empirical evidence, more senior employees more likely to use practical evidence) → practical evidence (local 	PCTs were asked to provide their own lists of relevant participants → potential bias in sampling

	survey 2010/2011				commissioners' experience, personal characteristics or role at work	of all PCTs in England		intelligence, benchmarking data, expert advice) are as influential on decision making as NICE guidance * about 50% of decisions not based on cost-effectiveness * commissioning is undertaken by people with varying professional backgrounds → important to know how personal characteristics can influence commissioning decisions (important implication for future commissioning)	No formal assessment of validity and reliability of survey questions
Coleman, Anna et al.	Joining it up? Health and Wellbeing Boards in English Local Governance: evidence from Clinical Commissioning Groups and Shadow Health and Wellbeing Boards	2014	<i>Local Government Studies</i> , 40(4), pp. 560-580	England, 2011-2	Explore early HWB development	91 mainly medical staff, but also lay members (5), practice managers (3) & LA representative (1) from 8 CCGs	* Case studies * observation of 146 meetings (439h)	* Role definition: little clarity re exact role of Health and Wellbeing Boards (HWBs) * HWBs have no statutory powers → good local relationships required to achieve their goals * development of CCG-HWB relationships affected by many small practical issues, e.g. timing & frequency of meetings, decisions are representations & Chair * HWBs situated at unitary level of local governments → concerns about how far local issues will be reflected in decisions (particularly as CCGs may cover smaller populations than their HWBs) * uncertainty as to how far political complexion of LAs may disrupt work of HWBs → commitment from all partners are required to make CCG-HWB relationship work in practice	Study took place at early development stage of CCGs
Craig, Georgina	Outcomes Based Commissioning: The key to unlock better outcomes	2014	<i>The Health Service Journal</i> , 124(6382), pp. 20-1	Lincolnshire, 2012	Explore how Experience Led Commissioning (working with families, communities and frontline teams) can help develop outcomes frameworks and commissioning intentions	Not stated	Not stated	* commissioners play a key role in uniting providers & communities, build relationships, and help everyone to focus on what they have in common * outcomes based commissioning requires providers to get innovative around how services add value for the people who use them * outcomes based commissioners need to unite and align providers behind common values, a shared purpose and vision	Based on small area

Davies, ACL	This time it's for real: The Health and Social Care Act 2012	2013	<i>The Modern Law Review</i> , 76(3), pp. 564-588	n/a – not a study, but review of Health and Social Care Act 2012	Providing overview of 'market' elements of Health and Social Care Act 2012 Examining whether reforms introduced under Health and Social Care Act 2012 are compatible with constitutional requirements of accountability or the provision of a public service	n/a – not a study, but review of Health and Social Care Act 2012	n/a – not a study, but review of Health and Social Care Act 2012	* reforms threaten accountability for three reasons: they make Secretary of State for Health's relationship with NHS more complex; they create opaque networks of non-statutory bodies which may influence NHS decision-making & greater emphasis on legal regulation will take some aspects of NHS activity out of control of Department of Health → reforms will contribute to 'creeping' privatisation of NHS * private involvement in NHS is not new, but Health and Social Care Act 2012 facilitates greater private participation	
Dickinson, Helen et al.	Beyond the Berlin Wall?: Investigating joint commissioning and its various meanings using a Q methodology approach	2014	<i>Public Management Review</i> , 16(6), pp. 830-51	England, no date	Map out relationships between joint commissioning arrangement, services and outcomes to examine the degree to which joint commissioning leads to better services & outcomes for service users	5 case study sites	POETO (Partnership Online Evaluation Tool with Q methodology)	* joint commissioning has high degree of salience on local level → regarded as something that can deliver better outcomes for less money * on the other hand, joint commissioning is set up to fail by being seen as a way of being able to deliver too many different things to too many different people * understanding what joint commissioning is differs between people in the same organisation → profound implications for how we think about and conceptualise joint working (p. 847) * potential meanings of joint commissioning go way beyond those found in existing literature	Sample drawn on an 'opportunistic' basis
Dickinson, Helen et al.	Making sense of joint commissioning: three discourses of prevention, empowerment and efficiency	2013	<i>BMC Health Services Research</i> , 13(Suppl 1), pp. S6-15	England, no date	Examine type of impacts claimed for joint commissioning within literature	n/a not study, but literature review	Interpretive review	* lack of high quality research evidence on joint commissioning (mostly opinion pieces or voices of those involved in leading such initiatives) * lack of clarity about what joint commissioning is and what it should achieve (i.e. little evidence to link joint commissioning to change in outcomes; no one single definition of joint commissioning;	

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								joint commissioning used in a variety of ways across health & social care) * three dominant discourses of joint commissioning: prevention, empowerment & efficiency → tensions may exist between the three in practice	
Ellis, Jonathan	Hospices in the UK are losing out under complex new commissioning and contracting arrangements	2013	<i>International Journal of Palliative Nursing</i> , 19(7), pp. 318-9	UK, no date	Examine how new structures introduced with the 2012 Health and Social Care Act affected hospices	Member Hospices of charity 'Help the Hospices' – number not stated	survey	<ul style="list-style-type: none"> * commissioning & contracting have become more complicated under Health & Social Care Act 2012, saddling many hospices with extra bureaucracy & costs * number of commissioners hospices are dealing with now has increased * many hospices have different arrangements with commissioners including service level agreements, block contracts, spot contracts & NHS contract * Introduction of NHS contract required replacing straightforward service delivery with a more complex contract that is not reflective of the relationship between hospices and the NHS and cannot be adapted locally * high level of data reporting required by NHS contract causes concern → new legislation gives commissioners considerable discretion to adopt alternative commissioning and contracting arrangements with charitable providers, but such examples are scarce, as CCGs are risk averse * frozen/reduced funding is a problem, as are short-term contracts → recommendations to improve the situation include: <ul style="list-style-type: none"> * reducing duplication of commissioning arrangements * adapting NHS contract for commissioning hospice care * more flexibility on behalf of the commissioners * developing a national framework for commissioning hospice care * more long-term contracts 	Methodology could have been explained more fully

<p>Gandy, Robert et al.</p>	<p>Using care profiles to commission end-of-life services</p>	<p>2012</p>	<p><i>Primary Health Care Research & Development</i>, 13, pp. 106-119</p>	<p>Liverpool, 2010</p>	<p>Adapting original care profiles structure for commissioning purposes & produce series of care profiles that would cover the full EoLC pathway Identifying any other relevant EoLC support required for patients with specific diseases such as dementia</p>	<p>43 representatives of clinicians, managers, ambulance services, care homes, commissioning, community nursing, GPs, hospices, IT, out-of-hours services, patients, carers, personal social services, palliative care teams, therapy professionals</p>	<p>Iterative approach involving 4 half-day workshops each targeted at forming a case study</p>	<p>* service requirements for EoLC are the same, irrespective of disease → care profiles could be widely adopted for commissioning, not only for EoLC services * care profiles useful for commissioning owing to their flexibility and simplicity * care profiles can also be used to inform patients or carers of what services they can expect * recommendations endorsed by PCT → project considered successful</p>	<p>Tested in only one geographical area</p>
<p>Hudson, Bob</p>	<p>Public and patient engagement in commissioning in the English NHS</p>	<p>2015</p>	<p><i>Public Management Review</i>, 17(1), pp. 1-16</p>	<p>n/a – not a study</p>	<p>Outlining new possibilities for public and patient engagement (PPE) in the context of the Health and Social Care Act 2012</p>	<p>n/a – not a study</p>	<p>Review of existing literature</p>	<p>* PPE has record of low achievement over past half century → can new context of Health and Social Care Act 2012 change this? * Evidence base for effectiveness of PPE in health care is underdeveloped * CCGs have to take into account PPE in decision-making greater conceptual clarity and clearer understandings on purpose of PPE are prerequisites to change</p>	<p>Lacks empirical data</p>
<p>Huxley et al</p>	<p>Better evidence for better commissioning: a study of the evidence base of generic social care commissioning guides in the UK</p>	<p>2010</p>	<p><i>Evidence & Policy: A Journal of Research, Debate and Practice</i>, 6(3), pp. 291-307</p>		<p>To assess the evidence base of published generic social care commissioning guides, published between 2003 and 2008</p>	<p>n/a</p>	<p>Review of commissioning guides</p>	<p>* The guidance reviewed draws on government documents and other published guides, rather than research evidence</p>	
<p>Colville E; Kennedy C</p>	<p>ACP Conversations in clinical practice</p>	<p>2012</p>	<p><i>British Journal of Community Nursing</i>, 17(5), 230-234</p>	<p>England</p>	<p>To establish whether nurses implement new knowledge and</p>	<p>16 nurses (generalist and specialist mix from community</p>	<p>Qualitative semi-structured individual interviews</p>	<p>• Training increased participants' awareness of ACP, validated their knowledge and skills and had positive impact on their practice clinically.</p>	<p>Small-scale exploratory study, participants volunteered (may have previously engaged in ACP).</p>

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					strategies into their practice, following educational intervention of ACP	and hospital settings)		<ul style="list-style-type: none"> • Educational programmes are beneficial and impact clinical care 	
Kmietowicz Z	Blue sky commissioning	2014	BMJ 348	England	NA not a research study	CCGs	Feature, narratives of success stories from commissioners	<ul style="list-style-type: none"> • Identified factors that help contribute to successful service • i.e. intervention workers with specialist training, working with families with daily tasks; • Effective service needs characteristics such as standard assessment, clear treatment pathway, evidence-based measurements, but should also not increase GPs workload. 	Narrative approach
Kumar G; Quigley J; Singh M et al.	Do local enhanced services (LES) in primary care improve outcomes?	2014	Quality in primary care, 22, 157-169	UK (database searches made May-June 2013)	Examine the role of local enhanced services that have been commissioned in the UK, and their role in driving health/economic outcomes.	Organisations searched; CCGs PCT, Scottish National Health Board	Literature Review	<ul style="list-style-type: none"> • Identified common themes that explain success/failure of LES • i.e. national framework in place and financial incentives gives greater motivation for service provision • i.e. depends on GPs willingness to participate (which is motivated by existing treatment delivery hierarchy to support LES implementation and financial incentives) • Service provision (e.g. National Dementia Strategy) may affect clinical and process-related outcomes of an LES. 	Only 14 (of 459 abstracts) LES reported data on outcomes
Lingard JM; Cooper V; Connell M	The personalisation challenge	2013	Tizard Learning Disability Review, 19(1), 3-10	England (Leicester; Leicestershire & Rutland; Northamptonshire & Nottinghamshire (project run between 2011-2012)	Examine personalisation plans for families, and identify barriers and solutions.	Families of services for main project. Additional feedback from commissioners.	Project log of barriers and solutions; Interview with a joint commissioner; Feedback on project from 2 Care Managers	<ul style="list-style-type: none"> • Identified some information on commissioning; commissioner stated; • They have health team members who work with complex cases; • Strategic commissioning plan in place and a joint commissioning team who work from common plan; • Have external advice to draw up tender process (input from NDTI (national development team for inclusion) who act as 'critical friend' & RIPFA (research in practice for adults)) • A viable personalisation plan in place ('viable' as plan goes beyond identifying an empowering lifestyle for individual, 	Information is limited (feedback component was supplementary information and not the primary aim of the project).

								but needs all key people signed up to the actions) <ul style="list-style-type: none"> •The learning from the project will contribute to the national development agenda 	
Lotinga A; Glasby J	New conversations with new players? The relationship between primary care and social care in an era of clinical commissioning	2012	Journal of Integrated Care, 20(3), 175-180	England (Birmingham)	Identify issues for policy and practice against the backdrop of changes taking place in health and social care. Also explore opportunities for joint work at CCG level	25 stakeholders (Lead GPs, councillors, local authority managers, PCT cluster managers & service users)	Case study (outcomes from workshops)	<ul style="list-style-type: none"> •Key issues identified for future policy/practice; •Faster access to more joined-up services keep people healthy in community for longer; •With lack of shared records and no local directories of available services, participants felt the system was a long way from getting the basics right; •New developments (i.e, community matrons) could offer positive service to people in need; •While "single point of access" projects have been started, these often did not mean speaking to somebody direct but leaving message in queuing system; •Joint commissioning between primary and social care positive step forward 	Limited information identified.
McDermott I; Checkland K; Harrison S; Snow S; Coleman A	Who do we think we are? Analysing the content and form of identity work in the English National Health Service	2013	Journal of Health Organisation and Management, 27(1), 4-23	Data drawn from wider study, England NHS carried out April 2009-June 2010	To offer a novel approach to triangulation (comparison of multiple data sources) using "identity work" with managers as the interview content.	PCT commissioning managers and GPs and managers working on Practice Based Commissioning	Data collected from semi-structured Qualitative Interviews AND observation of commissioning meetings	<ul style="list-style-type: none"> •Commissioners unclear about the exact nature of what they do - 'a style of discourse'; "I'm not sure, I haven't had a job description and I'm not really sure what my terms are" •Commissioning process described as a cycle; •"providing a local service that is convenient, and cost effective, commissioning is the process of assessing that, making it happen and reviewing it afterwards"; •"the decision to commission/decommission a service comes from strategic objectives of the PCT. It's getting value for money, good quality care from the services you've commissioned" 	

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								<ul style="list-style-type: none"> Higher level of certainty about what commissioning is 'not' rather than what it is. 	
Oates J; Jerram S; Wilson I.	Clinical commissioning: the nurse's role.	2014	Nursing Standard, 29(6), 52-59.	England (Brighton and Hove CCG used as example)	Gather insight into the role of nurses in clinical commissioning.	NA	Review	<ul style="list-style-type: none"> Member practices take part in decision making at a local level (GP chair takes time out of clinical practice) Nursing input is vital to success of any health care commissioning approach (they have no conflict of interest i.e. not employed by local provider, they bring expertise and knowledge and balanced view of clinical and management agenda and Nurses champion the patient voice/patient experience); Getting clinical commissioning right is a balance between fulfilling statutory duties and exercising statutory powers, whilst representing the interests of the membership and managing members' conflicts of interest, between responding to patient and public views and ensuring efficient and equitable use of public funds. 	Focuses on one CCG as an example
Olphert A M	Commissioning end-of-life care.	2014	British Journal of Nursing, 23(13), 744-745.	England	A nurses understanding of the challenges in arranging EoL care	Chief Nurse and director of CCG	Narrative	<ul style="list-style-type: none"> EoL care commissioning should be considered in relation to multimorbidities, long-term conditions, the elderly frail and those with dementia (i.e. a need for identifying those at risk of dying within 12m, anticipatory care planning, supporting patients and their carers in taking control) EoL care involves a large number of third-sector providers, so host-commissioning (i.e. on behalf of several organisations) is important. 	
Perkins N; Coleman A; Wright M; Gadsby E; McDermott I; Petsoulas C; Checkland K	The 'added value' GPs bring to commissioning: a qualitative study in primary care	2014	British Journal of General Practice. 64(628), e728-e734.	England April-September 2013	Explore key assumptions underpinning CCGs and examine the claim GPs bring 'added value' to the	40 clinicians and managers across 7 CCGs (1 nurse clinical lead; 6 managers; 33 GPs)	Qualitative Interviews	<ul style="list-style-type: none"> GPs detailed knowledge of their patients help improve service design Close working relationship between GPs and managers strengthens manager's ability to negotiate Described concern over large workloads 	

					commissioning process			<ul style="list-style-type: none"> • In PC clinicians have little role or responsibility in decision making, but clinicians in <i>lead roles</i> feel they have 'ownership' of the decisions made by the CCG 	
Quayle A; Ashworth D; Gillies A	BSS 11000 for Health Commissioning; Lessons from history for managing the commissioning relationship	2013	Clinical Governance: An International Journal. 18(1), 18-29.	England 2013	To consider how the collaborative business standard (BSS 1000) and case studies from other domains can be applied to the commissioning process in health services.	Sectors outside Health Service (i.e. criminal justice)	Case Studies	<ul style="list-style-type: none"> • Existing traditional processes (buyer/seller system) will not deliver the benefits anticipated by policy, to CCGs in the direction they are being asked to move. • A richer collaborative approach i.e. The business collaborative approach, that use management support structures, are considered best practice and adopting this in health service will be helpful in transition to more efficient system of resource acquisition improvement. • Identified the "commissioning cycle" – a process by which best quality care and outcomes are to be achieved. • External support for clinicians to gain skills & knowledge required to succeed as commissioners 	Conducted at an early stage in the development of CCGs
Radford K; Crompton A; Stainer K	Commissioning vocational rehabilitation after stroke: Can the Cinderella services get to the ball? A qualitative study	2013	Journal of Health Services Research and Policy. 18(Suppl.1) 30-38.	Nottinghamshire, Derbyshire, Lincolnshire	Understand the barriers and enablers to commissioning vocational rehabilitation after stroke	16 Commissioners responsible for commissioning stroke services	Semi-structured one-to-one interviews	<ul style="list-style-type: none"> • Block contracts/tariffs create problems for being able to quantify spend in stroke rehab • Despite national policy, ambiguity remains surrounding whether vocational rehab after stroke is responsibility of health or social care • Commissioners focus on demand-led acute stroke services, leaving little resource for community services • In times of budget restriction, commissioners focus on most vulnerable to maintain independence and reduce care home admission 	Absence of evidence creates a perception that the need for vocational rehabilitation is minor.
Raymond M; Warner A; Davies N; Nicholas N; Manthorpe J; Iliffe S	Palliative and end of life care for people with dementia: lessons for	2014	Primary Healthcare Research and Development. 15, 406-417.	N/A (Not restricted to UK research papers) project conducted 2011-2015	Synthesise information about end of life care in people with dementia, using review papers	English language papers 2000-2011	Review of reviews	<ul style="list-style-type: none"> • Health and social care commissioning is influenced by many factors other than research evidence; political pressure; ideological stance; the need to take action 	

	clinical commissioners							<ul style="list-style-type: none"> •Lack of specificity in the literature regarding research questions/priorities. •Narrative reviews have a tendency to offer over-contextualised recommendations i.e. "more inter-agency working is needed" 	
Russell J; Greenhalgh T; Lewis H; MacKenzie I; Maskrey N; Montgomery J; O'Donnell C	Addressing the 'postcode lottery' in local resource allocation decisions: a framework for clinical commissioning groups.	2013	Journal of the Royal Society of Medicine. 106(4), 120-123.	England 2011	Report how the National Prescribing Centre (NPC) competency framework was developed to present potentially transferrable methodology .	Steering group of academic, practitioners and opinion leaders in local decision making. Also individuals with expertise in resource allocation (local, regional, national)	Report	<ul style="list-style-type: none"> •With individual funding requests there isn't much evidence, so have to use judgement. Local evidence and experiential knowledge play a role in improving quality of judgements in decision-making •Competency framework – tool being used by some CCGs - it is useful 'starting point' to help them in making complex resource allocation decisions 	Little detailed information on how this translates into commissioning decision making
Shaw S E; Smith J A; Porter A; Rosen R; Mays N	The work of commissioning: a multisite case study of healthcare commissioning in England's NHS	2013	BMJ Open. 3(9), e003341	England 2010-2012	Examine work involved in commissioning long-term condition services, including factors inhibiting/facilitating commissioners in making service change	Primary care trust managers and clinicians; general practice-based commissioners; NHS Trust and Foundation Trust senior managers & clinicians; voluntary sector and local government representatives	Case study, mixed methods (qualitative interviews, observations, documents)	<ul style="list-style-type: none"> •It takes years to commission something (time-consuming) Minimum 1 year typical (assessing needs, reviewing evidence, developing service specification) •Progress seems to speed up once a firm decision is made regarding moving ahead with service design (i.e. referral procedures, staffing established within months rather than years) •Success viewed in relation smooth/efficient running, less emphasis on delivery model in place •Contributions vary at different stages of the commissioning process (i.e. service user input in planning stages) •Significant work (and time) involved; convening wide-ranging groups of people; developing/sustaining strategic partnerships; establishing, running and managing formal meetings for service development work 	

1 2 3 4 5 6 7 8 9 10 11 12 13	Simkiss DE	Community care of children with complex health needs	2012	Paediatrics and Child Health, 22(5), 193-197	England	Discuss working, commissioning and care pathways for care of children with complex health needs.	N/A – summary of guidance, reports and policy	Symposium	<ul style="list-style-type: none"> •Emphasises the importance of joint commissioning in a complex healthcare setting including integrated care pathways and understanding role of other practitioners/agencies •Where people's needs are greater than the provision of one service, the emphasis is on co-ordinated care by multi-disciplinary teams/inter-agency working alongside government guidance. •Network of support – namely key worker listening to person's needs 	
14 15 16 17 18 19 20 21 22 23 24 25 26 27 28	Simmonds R L; Shaw A; Purdy S	Factors influencing professional decision making on unplanned hospital admission: a qualitative study	2012	British Journal of General Practice, 62(604), e750-756.	South West England, 2010-2011	Identify factors influencing professional decision-making around unplanned hospital admission.	19 professionals (primary, emergency and social care sectors) from 3 PCTs	Qualitative Interviews	<ul style="list-style-type: none"> •If market approach is adopted by GP led CCGs financial incentives influence clinician decision making in primary care/incentivising people for wrong reasons drive down quality •At senior level what is being promised is not being delivered due to staffing issues and under-resourcing of services (necessary funding not in place) •For robust decision making in health and social care, professionals emphasise the value of supportive inter-professional working, with a patient-centred ethos. •Inter-organisational politics between hospitals, commissioners and primary care raised as an issue impacting decision making. 	A relatively small number of participants recruited from each service.
29 30 31 32 33 34 35 36 37 38 39 40 41 42 43 44 45 46 47	Smith P; Mackintosh M; Ross F; Clayton J; Price L; Christian S; Byng R; Allan H	Financial and clinical risk in health care reform: a view from below	2012	Journal of Health Services Research and Policy, 17(suppl 2), 11-17.	England, 1995; 2007	Examine the interaction between financial and clinical risk	Managers and front line professionals (GPs, nurses, social workers, therapists, home carers)	Qualitative Interviews; Documentary analysis of policies and procedures; Observations	<ul style="list-style-type: none"> •2 overarching policy drivers – care closer to home and multidisciplinary working to promote co-ordinated care, social inclusion, emphasizing independent living. This brought clinical risk created due to services undergoing considerable change •Financial decision-making delegated to smaller groups led by GPs •Financial incentives work (payment by unit of activity) to change professionals' behaviour by subjecting people to increased perceived clinical risk 	

								<ul style="list-style-type: none"> • Incentives which are too specific can cause demotivation, 'box-ticking' and 'blame culture' 	
Wye L; Brangan E; Cameron A; Gabbay J; Klein J H; Pope C	Evidence based policy making and the 'art' of commissioning – how English healthcare commissioners access and use information and academic research in 'real life' decision-making: an empirical qualitative study.	2015	BMC Health Services Research, 15(1), 430.	England, February 2011-May 2013	To understand commissioners' information seeking behaviour and the role of research in their decisions.	52 commissioners (chairs of commissioning organisation, directors, public health consultants) from four commissioning organisations	Mixed case study; Qualitative interviews, observation, documentary data	<ul style="list-style-type: none"> • The 'art of commissioning' described as commissioners pragmatic selection of different types of evidence gathered from a range of sources to build a case (i.e. best practice guidance, clinicians' views of services). • Despite academic research being considered implicit in the system, this was less useful and not accessed directly and those who did used Google Scholar. The only Journals mentioned were BMJ and BJGP. • Demand for research evidence reduced innovation because commissioners could not wait until an initiative was "piloted and proven" 	The presence of researchers in ethnographic studies have the potential to change the dynamics of the meetings observed (but this a recognised problem).
Wye L; Brangan E; Cameron A; Gabbay J; Klein J; Pope C	Knowledge exchange in health care commissioning: case studies of the use of commercial, not-for-profit and public sector agencies, 2011-14.	2015	Health Services and Delivery Research, 3(19).	England, 2011-2014	To study knowledge exchange between external providers and health-care commissioners; to learn about knowledge acquisition and transformation, the role of external providers and the benefits of contracts between external providers and health-care commissioners.	92 Interviews with external consultants and their clients.	[REPORT] Mixed case study of 8 cases; interview, observation and documentary data	<ul style="list-style-type: none"> • Commissioners wanted information to build a cohesive & persuasive case to determine a course of action. • Fast and flexible media (conversations and stories rather than written documents) preferred for knowledge exchange with commissioners. Commissioners need knowledge providers who could keep up as the commissioning landscape was ever changing and re-prioritising. • Commissioners use helpful sources of information; interpersonal relationships people, placement, organisational processes/structures best practice from elsewhere, software tools/training. • Key ingredients for successful contracts included external consultants' having excellent understanding of clients' needs (then revisiting the brief to ensure output was relevant to ever-changing commissioning context. 	Despite substantial access to providers, views from NHS clients and commissioners were difficult to obtain.

								<ul style="list-style-type: none"> • 'Mindlines' – guidelines for handling complex situations (training, experience, interactions, reading, local circumstances, collective views of colleagues on how things should be done) 	
Wye L; Brangan E; Cameron A; Gabbay J; Klein J H; Anthwal R; Pope C	What do external consultants from private and not-for-profit companies offer healthcare commissioners? A qualitative study of knowledge exchange.	2015	BMJ Open, 5(2), e006558	England, February 2011-May 2013	To understand how commissioners and external consultants work together, the process of knowledge exchange and the perceived impact on commissioning decisions.	92 Interviews with external consultants and their clients.	Mixed case study of 8 cases; interview, observation and documentary data	<ul style="list-style-type: none"> • External provider involvement (technical applications, expertise, outsourcing) improves the quality of commissioning • Success of one commissioning contract was due to input of analysts – analytical, clinical and managerial expertise (standard team of professionals from each group) provides 'data-driven' commissioning. • Importance on clients undertaking the work themselves (i.e. audit data collection) rather than relying on external providers, but often limited time/capacity was reported due to departure of experienced NHS commissioning staff. 	One provider steered researchers away from less successful contracts, and authors would have liked to recruit more 'negative' cases from this provider.
<i>Opinion pieces, editorials and commentaries</i>									
Anderson, David N	Commissioning dementia services	2013	<i>The Psychiatrist</i> , 37(7), p.246	n/a – not a study, but opinion / column	n/a – not a study, but opinion / column	n/a – not a study, but opinion / column	n/a – not a study, but opinion / column	<ul style="list-style-type: none"> * not necessary that whole system is commissioned from one single provider * it is crucial that the whole system has to be commissioned and commissioners need to see the whole system and bind the parts together * new commissioning system creates opportunity to think more imaginatively, something that is needed to meet the dementia challenge 	Opinion piece
Cartmell, Nick	Dementia: commissioning for quality	2012	<i>British Journal of General Practice</i> , 62(595), pp. 64-5	n/a – not a study, but editorial	n/a – not a study, but editorial	n/a – not a study, but editorial	n/a – not a study, but editorial	<ul style="list-style-type: none"> * dementia services currently suffer from 'therapeutic nihilism' and a 'care vacuum' * both can be addressed through locally designed and proactive community service → this is an opportunity for commissioners to improve dementia services * robust quantitative evidence is required to evaluate such new services – in order to obtain such data, services must be 	Editorial

								commissioned for a longer time period than the current 1-2 year pilot studies	
Dixon, Michael	Clinically led commissioning – joyous liberation or here we go again?	2012	<i>Journal of the Royal Society of Medicine</i> , 105, pp. 217-20	n/a – not a study, but an opinion piece	None stated	n/a – not a study, but an opinion piece	n/a – not a study, but an opinion piece	* future of NHS depends on ability of clinicians to make clinical commissioning work * theory that underpins clinical commissioning represents the NHS's best chance of survival	Opinion piece
Dixon, Anna & Ham, Chris	Setting objectives for the NHS Commissioning Board	2012	<i>BMJ</i> , 345:e5893	n/a – not a study, but editorial		n/a – not a study, but editorial	n/a – not a study, but editorial	* NHS Commissioning Board created to separate politicians from management of NHS * Board works under mandate from secretary of state for health * draft mandate setting out objectives and priorities for NHS falls short of what is needed (large number of objectives; vague language in which objectives are expressed; some objectives bear hallmarks of policy leaders) * transactional rather than transformative tone of the mandate is another weakness → mandate needs to be redrafted	Editorial
Gerada, C	What should clinical commissioning groups do on 1 April 2013?	2103	<i>BMJ</i> 2013;346:f1977	n/a – not a study, but an opinion piece	n/a – not a study, but an opinion piece	n/a – not a study, but an opinion piece	n/a – not a study, but an opinion piece	* new regulations under HSCA 2012 are not clear & seem to conflict with previously stated intentions of government (i.e. regulation 5 requires that all services are put out to tender unless there is only one single market) * new regulations have been brought in too hastily & without proper democratic consultation * under new regulations market forces will determine how care is provided → step towards privatisation of health care → new regulation puts commissioning groups (and GPs) into a difficult position and will ultimately damage the trust between GPs and their patients	Opinion piece
Gillen, S	In tune with the times	2013	<i>Nursing Standard</i> , 27(52), p.61	n/a – not a study, but an opinion piece	n/a – not a study, but an opinion piece	n/a – not a study, but an opinion piece	n/a – not a study, but an opinion piece	* Health and Social Care Act 2012 has created new opportunities for nurses (CCGs have legal obligation to appoint a nurse to their governing board)	Opinion piece

								* nurses day-to-day job gives them a good idea of what constitutes service quality	
Holloway, F	The Health and Social Care Act 2012: what will it mean for mental health services in England?	2012	<i>The Psychiatrist</i> , 36, pp. 401-403	n/a – not a study, but an opinion piece	n/a – not a study, but an opinion piece	n/a – not a study, but an opinion piece	n/a – not a study, but an opinion piece	* article focuses on organisational changes to the NHS introduced by Health and Social Care Act 2012 → new management configuration is rather similar to the previous one * some good relationships between local authorities and health services are unravelling owing to the reorganisation	Opinion piece
Smith D	Commissioning. Joined up thinking.	2013	The Health Service Journal, 123(6361), 30.	England	Describe his vision for joining up health and social care commissioning in the future	Clinical Commissioning Group chief officer and director of health and adults services for local authority	Commentary	<ul style="list-style-type: none"> • Vision for change; a system where one governance structure is in place (one budget, one team of staff who commission across health and social care) • Strategy is working on ground, gathering evidence of how service provision is improving lives of residents Operating separate funding systems across health and social care is considered significant barrier for true integration	Commentary
Yong V	Integrating care: a new model of service delivery for complex cases	2012	Progress in Neurology and Psychiatry, 16(1), 4-5.	England	Discusses potential opportunities to deliver new model of multidisciplinary care	Trustee of Primary Care Mental Health and Education (Primhe)	Commentary	<ul style="list-style-type: none"> • Identified a need for integrated psychosocial services for complex and expensive areas of healthcare • Proximity of services for complex cases i.e. have multiple disciplines in same building/mental health service operating from GP surgery Working models that could be rolled out into physical health – a multidisciplinary community team is best example of excellent practice	Commentary

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Reporting Checklist

1. contributorship statement
Research design: RL, LR, EM, CG. Data collection and data analysis: RL, ZG, NB. The first draft was written by: RL, ZG, NB and was edited by all authors. All authors approved the final version of the manuscript.
2. competing interests
There are no competing interests
3. funding
Department of Health National Institute for Health Research (NIHR) Applied Research Programme Grant: RP-PG-0611-20005
4. data sharing statement
No additional data are available