Commissioners' checklist for end of life care

London
Strategic Clinical Networks

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INTRODUCTION

An integrated commissioners' checklist for commissioning services which will provide excellent care to people at end of life in all care settings

This document is primarily aiming to advise those commissioning end of life care. It is designed to be used as a resource for end of life care commissioners to review their existing services and to use those parts that are most relevant or needed locally. It may also assist commissioners who are working together to commission their end of life care specialist palliative services and developing a jointly agreed specification.

Background

The End of Life Clinical Network has produced this checklist with input from a wide range of professionals and would like to thank all those who have been involved.
Its aims are to:

- Ensure the particular needs of people at end of life are considered when commissioning services (in both health and social care settings);
- Be useful for all and not specific to any particular condition, service or setting;
- Achieve excellent quality care;
- Be used throughout the commissioning cycle, from tendering of services to on-going evaluation and is compatible with the assessment, planning, contracting and monitoring. It does not in any way replace the NICE support for commissioners of end of life care and recommends that NICE guidelines are used alongside this checklist (a reference to NICE guidance can be found at the end of this document);
- Take into consideration the requirements of CQC that services are safe, effective, caring, responsive and well-led;
- Support service providers and Health and Wellbeing Boards;
- Be available in a format to assist patients and carers in accessing the best aspects of care and knowing what should be available;
- Link to the London Social Care Partnership End of Life Care Charter (2014).

How to use the checklist

This list of aims applies across all levels of care and within services both in primary and secondary care. The level of detail for each stated aim would depend on the service being commissioned and the local needs. When commissioning a service the particular diversity of the population being served should be a key consideration (eg culture, ethnicity, age, gender, learning disability, mental health, sexuality and spiritual needs).

The checklist aligns closely to the *Ambitions for Palliative and End of Life Care*.

A glossary is available at the end of the document.

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GETTING STARTED

Foundation: Leadership

Aims	Steps to take
Ensure leadership structure and system for commissioning and monitoring end of life care	» Establish oversight or steering group » Establish clear lines of reporting » Establish governance systems » Establish a senior person in each NHS Trust, CCG and adult social services that has responsibility for monitoring end of life care provision within their organisation to promote integrated end of life care. » Encourage a lead GP in each GP practice

Foundation: Evidence and information

Aims	Collecting pre-commissioning data and evidence

Complete CCG/borough based needs assessment and mapping	» Mapping local demographics and demand: population and population requiring end of life care (now and in the next 5-10 years) numbers, diagnoses, age, illnesses, deprivation, faith belief and cultural mix, place of death
	» Providers of end of life care:
	  » What services are currently commissioned and provided throughout borough – generic, specialist, health (primary, secondary, tertiary care), social, third sector, with availability over 24 hour period;
	  » What are the funding sources for each of these areas of care
	  » What outcomes do they report / how do they communicate and plan services, is there equity of access in relation to the demand / need;
	  » Current and future capacity modelling;
	» Facilitators of end of life care:
	  » Policies and procedures related to end of life care;
	  » Availability and use of EPaCCS, (e.g. Coordinate My Care (CMC), Health Analytics, or EMIS Web) or other system with an out of hours provider within community and hospital and other settings;
	  » Availability of and use of other records related to end of life care – including holistic assessment, ACP documentation, care in the last days of life, bereavement care / risk
	  » Availability of pharmacy/ies with an available stock of standard EoLC drugs for use both within and out of working hours
	  » Proformas / means of communication when patient moves between settings
	  » Provision of education related to end of life care – in all settings
	  » Public engagement methods – for example user groups, PALS, Healthwatch
	  » Local incentives related to end of life care – DES, LES etc.
	» Outcomes related to end of life care at baseline:
	» Process metrics and recent trends – numbers of deaths, location of deaths / DIUPR, numbers of patients on EPaCCS (e.g. CMC or Health Analytics) GP end of life care registers, number of admissions from nursing / care homes at end of life, no of referrals to SPC and bereavement services, no of bed days in the last year of life, fast track continuing care numbers/ costs, national care of the dying in hospital audit results, CQC report on end of life care
	» Outcome metrics - bereaved relatives surveys (including, but not only VOICES), complaints (in all settings), patient feedback / in depth interviews of experience of care, staff feedback on quality of care, confidence with provision of end of life care etc.;
	» Service / organisation (i.e. SPC / hospice / hospice at home) reported metrics – process and outcomes
	» Patient reported outcome measures (see Cecily Saunders Institute for more information.)

GETTING STARTED

Foundation: Evidence and information	
Aims	**Collecting pre-commissioning data and evidence**
Development of service specifications, service redesign and setting of key performance indicators for health and social care aims, strategy, and key enablers and outcomes (using this checklist).	» Use local data for a comparison or gap analysis with national data and key documents that outline what end of life care should look like: » NICE Quality Standards for end of life care » NICE guidance for commissioners on end of life care » Ambitions for palliative and end of life care » Every moment counts » One chance to get it right » Local data: JSNA, public health, local authority and voluntary sector information; » e-ELCA National end of life education resource, » London wide end of life care education guidance and case study resource
Aims	**Data and evidence collection throughout the commissioning cycle**
~1% of population registered with each GP die per year and ~75% of these have predictable deaths so should have been identified within the 1%. (The NHS Improving Quality website provides CCG based data on number and location of death.)	Outcomes » Increase in number of patients on EPaCCS (e.g. CMC, Health Analytics or EMIS Web) palliative care register i.e. number of identified patients » Check / incentivise each practice has a regular meeting to discuss these patients » Incentivise for that number to increase towards 1% by xxx date. Measures » Number of patients on EPaCCS (eg CMC or Health Analytics) reported by practice, with incentivisation to increase by locally decided % each year; » Presence of regular multidisciplinary meeting to discuss end of life care patients within primary care
Include identification of patients approaching end of life care in service specification for acute trust providers.	Outcomes » Patients in their last year of life are identified and offered end of life care services including a discussion about PPD and the opportunity to achieve this. Measures » Number of patients put on an EPaCCS system by an acute provider » Use of Gold Standard Framework prognostic indicator guide » Use of SPICT (spict.org.uk) » Evidence of link with frailty hub / long term condition hubs within the locality » NHS Improving Quality data on CCG number and location of deaths.
Reduction in deaths in hospital	Outcomes » Patients achieve their preferred place of care and preferred place of death Measures » Target set to reduce hospital deaths by x% each year; » Number of patients dying in preferred place of care; » Number of deaths in hospital » Number of deaths at home » Number of deaths in hospice » End of life care facilitator role within acute settings. » 30 day readmission rates for patients with long term conditions and other life threatening illnesses

MAKING IT HAPPEN

Foundation: Personalised care planning	
Aims	**Outcomes and measures**
An assessment tool is in use for patients and carers, which includes the assessment of physical, psychological, social and spiritual needs of both patients and carers.	Outcomes » Assessments completed for patients and carers. Measures » Percentage of patients on EOLC register with a completed care plan » Social care assessment formats have key questions to prompt timely end of life care discussions.
Individualised care plan for all patients	Outcomes » Patients feel supported and in control of their care. Patient only needs to tell their story once. Measures » Number of care plans offered (data aligned to each provider) » Number of care plans created » Number of care plans regularly reviewed and updated (frequency of review)
Information for patients and carers: leaflets, web page, directory of services etc.	Outcomes » Information available to patient in a range of formats which are easy to read and in appropriate languages; » Staff are aware of appropriate information to signpost patients and carers to » Patients and carers feel they have appropriate information to understand their circumstances. Measures » Patients and carers surveys » Friends and family test results » Range of formats appropriate to patient and carer needs.
The following documents are available and used where appropriate: capacity assessment, ADRT, PPC, LPA, care in the last days of life documentation.	Outcomes » Patients are able to undertake Advance Care Planning and so receive care in line with their wishes; » Professionals are aware of patient and carers' wishes; » Care is delivered in line with the Mental Capacity Act (2005). Measures » Care plan includes reference to these documents » Each provider organisation has a policy and trained staff to use these documents.
Robust way to review care plans	Outcomes » The care plan is up to date and there are opportunities to review the care plan » The care plan is reviewed with the patient and carers, commensurate with the condition and any changes in circumstances » A formal review process is in place. Measures » Number and frequency of GP end of life care meetings; » Gold Standard framework » Evidence from multi-disciplinary team meetings discussing care plans » Audit of care plans.

MAKING IT HAPPEN

Foundation: Shared records	
Aims	**Outcomes and measures**
Information about patients who are approaching the end of life care is available in the right format at the right time to the right people.	Outcomes » Staff have access to patient records and these are read; » All services have accurate information about patient wishes » Patients are at the centre of support plans and patients are able to access their own records » Documents are easy for everyone to understand. Measures » Number of crisis/emergency care plans completed » Number of patients on EPACCS Coordinate My Care or Health Analytics system with complete and finalised records » Audit of EPACCS » Reduction in inappropriate London Ambulance Service transfers to A&E
A coordination centre directs all community specialist palliative care and end of life care needs from a single point of access	Outcomes » The patient and carers have a single point of contact » Reduced inappropriate transfers to hospital » Reduced delayed discharges. Measures » Presence of a team within each setting that coordinates care and discharge.

Foundation: Involving, supporting and caring for those important to the dying person	
Aims	**Outcomes and measures**
Carers needs are met	Outcomes » Carers feel fully supported » Carers feel listened to and have their own needs acknowledged and met, allowing carers to focus on their caring role. Measures *Health and social care work together to identify and meet carers' needs* » Number of carers needs assessments offered (to be locally agreed) » Number of carers referred to specialist support services » Number of referrals to respite services » Number of referrals to information services » Carers questionnaire » Number of referrals to carers organisations received » Number of assessments completed » Number of referrals to adult social services for carer's assessment under the Care Act.
Bereaved carers assessment and service	Outcomes » Carers in need of bereavement support are identified and their needs assessed » Staff are able to identify bereavement risk factors and signpost to appropriate support, including access to counselling as appropriate Measures » Availability of services for bereaved carers » Number of assessments offered » Number of assessments completed » Number of type of referrals made to bereavement services » Bereavement information provided to carers when medical certificate issued » Evaluation of complaints relating to end of life care

Foundation: 24/7 access	
Aims	**Outcomes and measures**
Effective equipment contracting for end of life care patients	Outcomes » Patients have timely access to required equipment; » Hospital discharges are not delayed by equipment requests. Measures » Time of response to request (hours/days) » Speed of delivery (number of days/hours) » Availability of requested equipment » Number of delayed transfers of care due to lack of equipment.
Fast track continuing healthcare	Outcomes » Eligible people have access to fast track continuing health care. Measures » Number of fast track requests made for continuing health care » Speed of outcome within 48 hours » Number of fast tracks and how you meet them » Number of requests granted » Number of days from request to decision » Reduction in number of days for hospital stays » Patient access to personal health budgets » Joint commissioning policy and procedures between CCG and social services is in place » There is a specialist approved provider list for end of life care.
Provision of 24/7 specialist palliative care	Outcomes » Access to 24/7 specialist palliative care services » Clearly identified points of access, particularly out of hours. Measures *Health and social care work together to identify and meet carers' needs* » Arrangements for 24/7 specialist support in place » How often is the service used » Number of calls, responses and time taken
Provision of 24/7 district nursing	Outcomes » Patients and carers have rapid access to district nursing in and out of hours » Clearly identified points of access, particularly out of hours » Access to night support or similar. Measures » Is a service in place and how often is it used » Service activity
24/7 access to end of life care medications and pharmacy services	Outcomes » Patients receive symptom and pain relief when required and without delay » Pre-emptive prescription of injectables » Patients and carers have rapid access to pharmacy and medications » Clearly identified points of access, particularly out of hours » Improving quality of care people in the last days of life: ways to get the medication right for further information here. Measures » Pharmacy available and stocked 24/7 » Number of times requested medicine is/is not available » Time of response to request (hours/days) » Pathway in place and how often is it used

Foundation: 24/7 access	
Aims	**Outcomes and measures**
Provision of 24/7 and emergency social care	Outcomes » Patients and carers have rapid access to an emergency number » Clearly identified points of access, particularly out of hours » There are joined-up, co-ordinated services and pathways; » Appropriate bypass of A&E Measures » Social services care plans have contingency plans included » Provision of 24/7 access to acute care » Pathway for end of life patients in acute settings.
Availability of out of hours admissions to hospices	Outcomes » When the end of life is identified as imminent, patients are supported in admission to hospice if desired and appropriate Measures » Number of admissions to hospices requested out of hours and number of admissions accepted out of hours » Hospice admissions protocol in place, including provision for out of hours.
Rapid discharge home to die	Outcomes » When the end of life is identified as imminent, patients are supported to return to their chosen place of death. Measures » When the end of life is identified as imminent, patients are supported to return to their chosen place of death.

Foundation: Co-design	
Aims	**Outcomes and measures**
Public and patient involvement in service development and provision	Outcomes » Patients, carers and interested parties are involved in the planning and review of services Measures » Commissioner consults PPI groups on end of life care » Local groups are involved (Dying Matters, Macmillan, etc.) local religious and cultural groups » Linking with schools, funeral homes, law firms, Health Watch » Evidence of use of patient and public feedback in the review of services and commissioning of services » Evidence of public consultation » Percentage or number of surveys offered/completed

Foundation: Education and training	
Aims	**Outcomes and measures**
All staff in all settings are skilled to identify and communicate with patients and their carers.	Outcomes » Sustained improvement in confidence and perceived quality of end of life care delivered by staff » Evidence of learning from patient and bereaved relatives' feedback on end of life care. » Improved bereaved relatives satisfaction with end life care » Professionals feel supported to identify patients in their last year of life » Professionals are able to have effective conversations with patients nearing the end of life about their conditions and their future wishes. » Promoting psychological support for health and social care staff working in environments where death happens frequently Measures » Rise in percentage staff completing palliative care / end of life care study days / communication skills training » Availability of training and completion of training by district nurses and GPs, and in hospital by generic hospital staff; » Staff survey » Development of mandatory training in end of life care in acute hospitals » Development of mandatory training in end of life care in mental health trusts, including both community and inpatient services for older adults » End of life care is included as a priority in NHS trust, CCG and adult social services training plans » Use of online end of life care training (for example e-ELCA).
Staff in all settings are skilled in needs assessment, care planning and advance care planning	Outcomes » All staff in all settings are skilled to communicate with patients and their carers » An integrated health and social care model is promoted within end of life care training. Measures » Number and type of training sessions offered; joint training for health and social care staff where appropriate.

GLOSSARY

Term	Definition
A&E	Accident and Emergency (A&E) department - Deals with life-threatening emergencies; also known as emergency department or casualty.
ACP	Advance care planning (ACP) - A voluntary process of discussion about future care between an individual and their care providers.
ADRT	Advance Decision to Refuse Treatment (ADRT) - Allows a person to make a legally binding refusal of medical treatment in advance of a time when they lose the ability to make the decisions for themselves (Mental Capacity Act 2005). It can be used to set out the specific circumstances in which a person would not want a treatment to be given, or when a treatment should be stopped.
CCG	Clinical commissioning groups (CCGs) - A core part of the government's reforms to the health and social care system. In April 2013, they replaced primary care trusts as the commissioners of most services funded by the NHS in England.
CMC	Coordinate My Care (CMC) - An integrated model of care, underpinned by IT, which is currently being rolled out across London. It provides a personalised urgent care plan which can be prepared and recorded to ensure all care providers can access this information all day, every day.
DES	Directed Enhanced Services - A DES is the name given to directions from the government for GPs to be rewarded for doing extra work to improve the health of their patients.
DIUPR	Deaths in usual place of residence
e-ELCA	End of Life Care for All (e-ELCA) - The e-learning programme which aims to enhance the training and education of the health and social care workforce so that well-informed high quality care can be delivered by confident and competent staff and volunteers to support people wherever they happen to be.
EPaCCS	Electronic Palliative Care Co-ordination Systems (EPaCCS) - Enable the recording and sharing of people’s care preferences and key details about their care at the end of life.
JSNA	Joint Strategic Needs Assessment (JSNA) - Looks at the current and future health and care needs of local populations to inform and guide the planning and commissioning (buying) of health, well-being and social care services within a local authority area.
LES	Local enhanced services (LESs) - Schemes agreed by CCGs in response to local needs and priorities, sometimes adopting national service specifications.
LPA	A lasting power of attorney (LPA) is a legal document that lets you appoint one or more people (known as ‘attorneys’) to help you make decisions or to make decisions on your behalf. This gives you more control over what happens to you if, for example, you have an accident or an illness and can’t make decisions at the time they need to be made (you ‘lack mental capacity’).
PALS	The Patient Advice and Liaison Service (PALS) offers confidential advice, support and information on health-related matters. They provide a point of contact for patients, their families and their carers.
PPC	The Preferred Priorities for Care (PPC) document is designed to help people prepare for the future. It gives them an opportunity to think about, talk about and write down their preferences and priorities for care at the end of life.
SPC	Specialist palliative care (SPC) encompasses hospice care (including inpatient hospice, day hospice, hospice at home) as well as a range of other specialist advice, support and care such as that provided by hospital palliative care teams. Specialist palliative care should be available on the basis of need, not diagnosis.
VOICES	The National Survey of Bereaved People (VOICES, Views of Informal Carers – Evaluation of Services) collects information on bereaved peoples’ views on the quality of care provided to a friend or relative in the last three months of life, for England.

FURTHER READING

Title	*Link*
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 (2014)	Link
The Outcome Assessment and Complexity Collaborative (OACC) initiative 1.) Outcome measurement in palliative care: The essentials 2.) Introducing the Outcome Assessment and Complexity Collaborative (OACC) suite of measures	Link Link
Ambitions for palliative and end of life care | National Palliative and End of Life Care Partnership (2015)	Link
Improving quality of care people in the last days of life: ways to get the medication right [add link].	Link
The Gold Standards Framework | GSF Centre in End of Life Care	Link
Supportive and palliative care indicators tool (SPICT) | NHS Lothian and the University of Edinburgh Primary Palliative Care Research Group	Link
NICE Quality standards for end of life care for adults (QS13) (2011)	Link
Every moment counts: A narraitve for person centred coordinated care for people near the end of life | National Council for Palliative Care and National Voices (2015)	Link
Commissioning person centred end of life care: A toolkit for health and social care professionals | National End of Life Care Programme (2012)	Link
Care Act 2014	Link
NHS Constitution: The NHS belongs to us all (2013)	Link
Social Care London ADASS and LSCP End of Life Charter	Link
SCIE end of life care hub | Social Care Institute for Excellence	Link
Care planning / House of Care | NHS Improving Quality	Link
Advance care planing: Planning for your future care booklet | Northamptonshire Healthcare NHS Foundation Trust (2016)	Link
Top tips for commissioners: Improving one-year cancer survival | Macmillan (2015)	Link
Health Select Committee Report: End of Life Care	Link
Priorities of care for the dying person | Leadership Alliance for the Care of Dying People (2014)	Link
End of life care atlas | Marie Curie	Link
What is a good death? | London End of Life Clinical Network (2014)	Link
Palliative and end of life toolkit | Royal College of General Practitioners (RCGP)	Link
London End of Life Care Clinical Network Overarching principles for end of life care training (2015) Interactive library of case study examples (2015)	Link Link
NICE Care of dying adults in the last days of life (2015)	Link

About the Strategic Clinical Networks

The London Strategic Clinical Networks bring stakeholders -- providers, commissioners and patients -- together to create alignment around programmes of transformational work that will improve care.

The networks play a key role in the commissioning system by providing clinical advice and leadership to support local decision making. Working across the boundaries of commissioning and provision, they provide a vehicle for improvement where a single organisation, team or solution could not.

Established in 2013, the networks serve in key areas of major healthcare challenge where a whole system, integrated approach is required: Cardiovascular (including cardiac, stroke, renal and diabetes); Maternity and Children's Services; and Mental Health, Dementia and Neuroscience.

Strategic Clinical Networks | NHS England (London Region)
020 7932 3700 | england.london-scn@nhs.net

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