



Royal College of
General Practitioners

RCGP Commissioning Guidance in End of Life Care

Guidance for GPs, Clinical Commissioning Group advisers
and commissioners in supporting better care for all people nearing
the end of their life

Prof. Keri Thomas and Dr David Paynton



March 2013





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A logical six-step framework and overview to support GP commissioners to deliver practical improvements in their Clinical Commissioning Group (CCG), aligned with national policy and quality standards. A collaboration between the RCGP End of Life Care Team of the Clinical Innovation and Research Centre and the RCGP Centre for Commissioning.

March 2013

Production of this guidance

This guidance was produced following three end of life care commissioning workshops (April, September and November 2012) and wide consultation with key stakeholders and commissioners. We are very grateful to all who contributed in whatever capacity.

Further additional information is available on the RCGP website, e.g. the development of the Quality, Innovation, Productivity and Prevention (QIPP) Right Care outcome metrics, use of the Patient Charter in GP practices

– *Matters of Life and Death* booklet, further RCGP guidance on supporting carers, Dying Matters Coalition, GSF Primary Care Accreditation process, Electronic Palliative Care Coordination Systems update, etc.

Caring for people nearing the end of their lives is part of the core business of general practice. The GP and the primary care team occupy a central role in the delivery of end of life care in the community. This role is greatly valued by patients and remains pivotal to the effective provision of all other care. Care of the dying is a litmus test for the health service, and challenges general practice to respond with the best that the profession has to offer – clinical expertise, considered professionalism, personalised care and human compassion. The importance of the holistic role of the family doctor is poised to come into its own in a way never previously encountered.

(RCGP End of Life Care Strategy, approved by Board, June 2009)

NHS End of Life Care Strategy affirms the importance of commissioning in end of life care

Commissioning is the single key mechanism for making sure that the right services are available to meet local need, and that they are sensitive to the needs of those approaching the end of life regardless of their condition.

(*End of Life Care Strategy: second annual report, 2010*)

The NHS Commissioning Board's objective is to pursue the long-term aim of the NHS being recognised globally as having the highest standards of caring, particularly for older people and at the end of people's lives.

(NHS Mandate, November 2012)

The NHS belongs to the people – it is there to improve our health and well-being, supporting us to keep mentally and physically well, to get better when we are ill and when we cannot fully recover and to stay as well as we can and when we cannot fully recover to stay as well as we can till the end of our lives.

(NHS Constitution, March 2012)

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Foreword

Caring for people as they approach the end of life has always been a fundamental part of being a GP. In 2009, the College affirmed the importance of end of life care as a key priority.

While other demands on the GP's time and energy will come and go, the stark fact of our mortality will remain the same. ... Our aim is that high quality care for people nearing the end of their life becomes the legacy of this, the baby boom generation.

(RCGP End of Life Care Strategy, 2009)

Since then, in addition to being a key provider of care, our responsibilities as GPs have widened in England to include the role of commissioners of services in local communities. It will be GPs in their practices who will be the bedrock of any improvement in end of life care, but also, working in the new CCG groups with other practices, it is up to us as GPs to put in place the wider systemic changes required.

This new RCGP clinical commissioning guidance addresses both of these challenges. It is one of the outputs from the newly formed RCGP Centre for Commissioning and builds on years of work from the

RCGP End of Life Care Strategy team, one of CIRC's first priority areas. It can be used to help GPs in their practices consider how they can influence the system around them to provide quality care for people nearing the end of life, along with other imperatives such as care for those with multiple long-term conditions, frailty and dementia, and reducing avoidable hospitalisation.

This complex area will always be challenging, but I applaud the inclusive way in which a wide range of partners have worked together in the production of this guidance and the clear way in which it takes us through a step-by-step approach, made tangible through case histories and vignettes. It will be of great benefit to all GPs involved in strategic planning and commissioning in their area.

If we can get it right for people nearing the end of life, then, probably, we can get it right for everyone else. I affirm the College's continued and increasing commitment to promote excellence in end of life care and I commend this guidance as practical support to GPs who want to make a difference for their most seriously ill patients in their final years of life.

**Prof. Clare Gerada MBE FRCP FRCPsych FRCGP
Chair, RCGP**

March 2013

Foreword

End of life care affects everyone, patients and practitioners alike, because death awaits us all. Dying is an intensely personal experience not only for individuals but also for their families, carers and anyone who knows them. Ideally, end of life care should be able to assure effective control of pain and nausea as well as opportunities for fulfilment of the person's known wishes and desires at his or her most crucial time of life.

Thus, Advance Care Planning must be an integral part of end of life care and yet the system has to be flexible enough to cope with people's differing perspectives – some people value quality of life over quantity of life while others desire the opposite. Health practitioners must be able to deal with a broad spectrum of desires and expectations, and must be prepared to cope if and when these change.

The Gold Standards Framework (GSF) and the Liverpool Care Pathway (LCP) are intensely humane and well thought-out processes. Their algorithms are designed

to ensure proper attention to the importance of communication between patients, health practitioners, families, carers and friends. The LCP pays particular regard to providing opportunities to say farewell and goodbye, to make bequests, to resolve past disputes, to reassure and to comfort. At the same time end of life care can ensure that the clinical/medical context supports the dying person's dignity and wellbeing for as long as desired. The pain of bereavement and depression suffered when a loved one dies can be alleviated if the family realise that, thanks to successful end of life care, the person's final wishes had been realised. Often this means dying at home with the family present or alternatively dying in an intensive care unit to facilitate organ donation.

I hope that this commissioning guidance will encourage GPs and CCGs to make commissioning end of life care a major 'must-do' priority and welcome the publication of this clear-cut and succinct document.

Harvey Ward
Lay Chair, RCGP Patient Partnership Group

Preface

Care for people nearing the end of life is one of the most important challenges that we face as an ageing population. It's like a flashing blue light signalling an urgent 'life and death' situation but happening in slow motion, the ordinariness of which may disguise its imminence and significance. As death affects us all, and living well to the end of life is something we would all hope to do, we are challenged at numerous levels – as people with our own families, friends and communities, as GPs caring for our patients and now as commissioners with responsibility for delivering cost-effective care centred on people's needs and wishes. The impact of getting end of life care right will be widely felt in all domains of care and by large numbers of the population. So the significance of making improvements in end of life care cannot be overstated.

Primary care is central to this challenge. Since the expansion of our concepts of end of life care in the NHS and recognition that it includes all people nearing the end of life with any condition in any setting (defined by the General Medical Council as those likely to die in the next 12 months), the role of primary care has become even more central to getting this right. With the NHS End of Life Care Programme and Strategy in England (2008), great strides have been made, but with heightened awareness comes the realisation of how far we still have to go.

In this country we have a strong tradition of excellence in palliative care as the founding nation of the modern hospice movement, and in the 2010 International Quality of Death Audit the UK was considered the best in the world. While referral to palliative care services is greatly valued, particularly for people with cancer, the challenge we face as GP providers and commissioners is to move beyond this to the greater population who need our help – to include all people in the final year or so of life, particularly the elderly frail, with dementia, long-term conditions and multi-morbidities.

With the RCGP End of Life Care Strategy in 2009, the College affirmed that this was a priority for the College as a part of core general practice. As RCGP Clinical Champion/expert in end of life care for the last few years, I have watched the College's increasing emphasis on this significant commitment. A number of initiatives and outputs have been developed including the Patient Charter (see p. 37), and one of the most important of

these is this guidance, to support GPs both as providers and as commissioners of services.

There are challenges for commissioners. With the need for commissioners to improve both quality and save costs with the NHS QIPP agenda, end of life care is recognised as a prime example of a potential 'win-win' for commissioners (as recognised in the King's Fund Commissioning Report). However, this is an incredibly complex and multifaceted subject, covering a broad range of conditions and issues. The default position is often overuse of hospitals, but we know that hospital is not a good place to be for many elderly people (NHS CEO David Nicholson, *Independent*, 21 January 2013). The image of trolley deaths and 'institutionalised dying' is a haunting indictment of our beloved NHS. However, at its best, care can be really excellent – in the community, in hospices, hospitals and elsewhere – and brings us back to the reason that we came into health care. So improving community care and reducing inappropriate hospitalisation is doubly beneficial, meeting the wishes of patients and carers and is often most cost-effective. So as commissioners this is one of our greatest challenges.

The scope of this guidance is to support CCGs, mainly in England, to improve commissioning that will affect all people as they near the end of their life. For devolved nations this will also be relevant, but varied policy initiatives will apply and reference is made to Scotland, Wales and Northern Ireland policies for further reading. We are embracing care well beyond just cancer care, particularly focusing on the needs of the ageing population with complex multi-morbidities including dementia (as in the other four target areas; see p. 9). We mainly consider care for adults but point to further information on care for children. We are focused on patients' outcomes, although are aware of the difficulties in this area, and include the latest information from the National Institute for Health and Clinical Excellence, QIPP and the developing National Commissioning Board and Outcomes Framework. We would in the end measure our success by the way that people nearing the end of life are cared for in a community – both by the patients' and families' experience of care and by some suggested specific proxy indicators. It is beyond the scope of this document to consider matters of euthanasia and physician-assisted suicide.

The aim of this RCGP commissioning guidance on EOLC is to provide guidance, support and information to enable and support GPs and other CCG commissioners to develop a practical approach to improving end of life care in their local area.

(Prof. Keri Thomas, RCGP Clinical Expert)

With the recent media attention on end of life care and the debate around the use of the Liverpool Care Pathway (LCP) (which the College supports backed by good communication with families and appropriate training), this matter has again been brought to the public's attention and further consultation is underway. In addition, the College has always supported the GSF as an example of good practice, and now endorses the Gold Standards Framework (GSF) Primary Care Accreditation and GSF RCGP Quality Hallmark Award as one of the means of achieving the high standards to which we aspire (see picture on p. 34). The College is

developing work on Advance Care Planning further but discussion with patients and families is always intrinsic to primary care. There are other quality improvement tools, programmes and resources, and many examples are cited here or referenced for further information. I, as both GSF National Clinical Lead and RCGP EOLC Lead, other College Leads, stakeholders and providers of end of life care are all working towards the greater aim of improving care for all people nearing the end of life in this country. This guidance, which will be updated in light of changing future policy, will we hope be of practical help to you as motivated GPs in your CCG areas. There is much to do but we have confidence that we can make a real difference in this most important area of end of life care.

Prof. Keri Thomas
RCGP Clinical Expert, End of Life Care Clinical Lead,
National GSF Centre for End of Life Care, Hon. Professor
End of Life Care, University of Birmingham

Preface

This guidance is designed to help interested GPs with some of the key issues in commissioning end of life care. Commissioning end of life care should be seen as leading a system change and not just a contracting exercise.

One way or another commissioning of effective end of life care will be one of the priorities for a CCG. CCGs have, however, a number of competing priorities and so there are some important principles in line with emerging national policy that we would encourage clinical commissioners to follow. These include delivering:

- *integrated care* – working in partnership with the respective local authority, public health and other partners to develop joint commissioning arrangements that are accountable to the Health and Wellbeing Board. There should be thinking about how end of life commissioning might sit within the wider co-morbidity commissioning agenda. Services should be developed around the patient pathway – streamlined not silo based
- *personalised care* – taking into account the views of the local population through consultation with patients and carers to inform commissioning decisions. Care should be outcome focused but centred on wider outcomes, rather than process metrics and those related to patients and their carers
- *clinical commissioning* – approaching commissioning systematically and ensuring primary care as micro-commissioners is actively involved. Micro-commissioning should be seen as the day-to-day clinical decisions that may have a cost impact on the local system.

Our current approach to end of life care too often leads to poor and distressing care for people for whom active curative medicine is no longer appropriate. If we get it right we improve care for those who may die in the immediate future and their carer. At the same time and as a by-product we also find improving the quality of care really can lead to a reduction in cost.

End of life care is an area where you can improve quality while improving productivity, because the user's desired outcome (usually to avoid hospital admission where possible and die at home) is the same as the system's.

(Tessa Ing, EOLC Lead,
Department of Health, England)

There are a number of definitions of commissioning but for the purpose of this document commissioning should be seen as leading change in the local health system. Contracting and procurement is only part of this but should be seen as secondary to the need to develop a better sustainable system in which patients and the population feel supported and have access to the most appropriate cost-effective services to meet the need.

GPs are asked to look at this document from the perspective of their individual clinical practice, the performance of their own practice and primary care team aggregating up to their CCG.

We have tended in the past to focus on contracting for activity rather than commissioning for outcome but population and individual outcomes can only be delivered by whole-system change. Crucial to this is strengthening the links with Local Authorities, including housing and collaborative commissioning with Social Services.

Different options will work in different areas. While this document is aimed mainly at commissioners, we need to move away from over-prescriptive specifications in favour of allowing providers to innovate locally if whole-system outcomes are to be achieved. At the same time we all have a duty to share good practice across the country.

This document is not a detailed 'how to' commissioning document but is designed to ensure that all GPs are aware of some of the key principles that their CCGs should be following, to understand their contribution to the process and, acting as intelligent, informed members, to hold their CCG to account.

Dr David Paynton FRCGP
National Clinical Lead for RCGP Commissioning Centre

Acknowledgements

The authors give their kind thanks to Christine Johnston, Simon Chapman, Anita Hayes, Lucy Sutton, Catherine Millington Sanders and Julie Armstrong-Wilson. Thanks to Rigoberto Pizzaro-Duhart, Joseph Boyle, Amina Abdul Majeed and Ann-Marie Lawrence for administrative support. Thanks also to the following people for taking part in the workshops and/or providing helpful feedback during the consultation:

- National Council for Palliative Care (NCPC) – Eve Richardson and Simon Chapman
- NHS End of Life Care Programme – Anita Hayes
- Clinical Lead for the Department of Ageing and Health, St Thomas’ – Rebekah Schiff
- British Geriatrics Society – Martin Vernon, Tom Thorpe, Jackie Morris and Finbarr Martin
- Care Quality Commission – Alan Rosenbach and David Haslam
- Marie Curie – Teresa Tate, Michael Cooke and David Shaw
- Macmillan Cancer Support – Deepa Doshi
- National Care Association and English Care Commission Association – Mandy Thorn and Martin Green
- National Care Forum – Sharon Blackburn
- QIPP Right Care Team – Muir Gray, Mehrunisha Suleman and Anant Jani
- Association for Palliative Medicine – Bee Wee
- Children’s Palliative Care Together for Short Lives – Katrina McNamara
- Royal College of Nursing – Lynn Young (Patient Charter work)
- RCGP – Neil Hunt (CEO), Imran Rafi and Martin Thompson
- RCGP CIRC Clinical Champions for Dementia – Louise Robinson and Jill Rasmussen
- RCGP Patient Partnership Group – Antony Chuter (Patient Charter) and Harvey Ward
- Help the Hospice – Robert Melnitschuk and Karen Lynch
- Princess Alice Hospice – Lesley Spencer
- Trinity Hospice – Stephen Deas
- NHS Milton Keynes, Public Health – Nicholas Hicks
- London Procurement Programme, Commissioning – Michael McHugh
- Brighton General Hospital – Sarah Rogers
- Lancashire North CCG – Peter Nightingale
- NHS Bournemouth – Cath Granger
- Hillingdon PCT – Esme Young
- Independent Commissioning Adviser, Devon – Lorna Potter
- Westongrove Partnership – Jo Withers.

1. Introduction: why this is important

Context in end of life care

End of life care (EOLC) is one of the greatest challenges we face as a society and a health system. Currently, although well regarded internationally (the UK came top of the Quality of Death Audit), we know there are serious problems and we are not yet getting it right.

End of life care in numbers

- 1% of the population dies each year in the UK.
- 75% of deaths are from non-cancer/long-term/frailty conditions.
- 85% of deaths occur in people over 65.
- 54% die in hospital and 35% at home (18% home, 17% care home).
- 40–50% of those who died in hospital could have died at home (National Audit Office report, 2009).
- 70% of people do not die where they choose.
- £3200 – the cost of every hospital admission – average three in final year.
- Hospital deaths are expensive and many could be avoided or shortened.
- There is a need to develop community care and reduce hospitalisation.
- Everyone has a part to play – need to enable all.
- Workforce training is crucial, particularly for generalist frontline staff.
- Workforce and resources are limited – we need to use both optimally.
- There is a need to improve coordinated cross-boundary integrated care.
- Use of incentives can be helpful to improve care, e.g. Quality and Outcomes Framework (QOF), Commissioning for Quality and Innovation (CQUIN), etc.
- Culture is important. The quality of care is as important as the quality of treatment.

Key messages

- EOLC is important and affects us all – our patients, our families, our society.
- Most die in old age of non-cancer/co-morbidity/frailty/dementia.
- Too few people die at home/in their place of choice/their usual place of residence.

Source: National Audit Office report, National End of Life Care Intelligence Unit, etc.

Why is EOLC important for commissioners? Issues facing commissioners of EOLC

Commissioners and providers of EOLC will therefore need to work more intelligently and efficiently if they are to ensure that the increasing care requirements of a growing number of patients nearing the end of life can be fulfilled with the same or fewer resources.

As a result of the UK's ageing population, the number of deaths per year are expected to rise by 17% between 2012 and 2030. In addition, many more people will be dying at an older age and will therefore be likely to have more complex needs and multiple co-morbidities as they near the end of their lives. These demographic changes will undoubtedly have a significant impact on the level and intensity of provision that is necessary, and will require change in the way that services are commissioned.

As well as taking account of the pressures of an ageing population that is living longer with increasingly complex disease and co-morbidities, the provision of EOLC must also address the full range of conditions and diseases that people experience. Historically, EOLC has been associated with those suffering from cancer, but future provision must also cater for the full range of other conditions that can be present at the end of life, such as long-term illnesses (e.g. respiratory, cardiac and

neurological diseases) or diseases associated with older age such as dementia.

Alongside these demographic pressures, the current financial crisis is also likely to have an impact on the provision of EOLC – reducing spending, staff and services, which could have a detrimental effect on quality.

GMC definition of EOLC

People are 'approaching the end of life' when they are likely to die within the next 12 months (GMC 2010). This includes people whose death is imminent (expected within a few hours or days) and those with:

- advanced, progressive, incurable conditions
- general frailty and co-existing conditions that mean they are expected to die within 12 months
- existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- life-threatening acute conditions caused by sudden catastrophic events.

Source: King's Fund Report, September 2011.

Using the RCGP commissioning cycle systematically allows GPs to:

- identify what we know now about the current service and why EOLC commissioning is important
- consider what outcomes we would wish for the individual and the population
- review current and potential future providers
- review how we monitor the outcomes/indicators identified.

One of the critical aspects of EOLC commissioning is to consider how it integrates with other changes occurring, especially in relation to the work on multi-morbidities, long-term conditions, the elderly frail and those with dementia. This means:

- identifying those patients at risk of dying in the next year
- integrated anticipatory care planning with a lead professional

- supporting patients and their carers to take greater control.



Figure 1: The Clinical Commissioning Cycle

Source: Fernandes A. Guidance for Commissioning Integrated Urgent and Emergency Care: a 'whole system' approach. London: Royal College of General Practitioners, 2011, p. 32.

The work on multi-morbidities will also lead to a change in funding regimes, moving away from Payment by Results (PbR) towards 'A Year of Care' and other mechanisms for creating incentives that bring commissioning partners together and promote integrated working with provider services to deliver agreed outcome measures.

In an NHS where growth will at best be in line with inflation, the rise in multi-morbidity means improving EOLC is not a 'nice to do' initiative but will be an essential part of a Clinical Commissioning Group (CCG) change programme. A CCG that is not in some way considering EOLC as part of its responsibility and remit will be less able to meet many of its other priorities as restated again in the recent NHS Mandate.

NHS Mandate affirms importance of EOLC

The first Mandate (13 November 2012) between the government and the NHS Commissioning Board, setting out the ambitions for the health service for the next two years, has included EOLC within its first priority. The government has identified the following priority areas where it is expecting particular progress to be made:

'Improving standards of care and not just treatment, especially for older people and at the end of people's lives.' Through the Mandate, the NHS will be measured for the first time by how well it achieves the things that really matter to people. These areas correspond to the five parts of the NHS Outcomes Framework.

What do we know about the current system of EOLC?

The role of primary care is critical in any new system to support EOLC, both as a provider of care and a designer of services. At a practice level it is important that GPs are auditing the current outcomes (such as the examples given in the case histories and on p. 4) for those people who have died, so GPs are aware of the current service and how far away it is from delivering the desired outcomes. We would recommend that practices do this collectively to inform local CCGs of the current picture to complement the information held centrally.

One area sometimes neglected is to understand the current provision of EOLC in care homes. Care homes

will play a significant role in EOLC in any future model of care so any system change must take into account their specific function.

Building a picture of the current service overall is also important if changes are to be supported by the Health and Wellbeing Board. A key piece of work in understanding the current picture is financial appraisals of direct and indirect spend on EOLC. This will probably be undertaken by the financial officers and presented at a high level so that clinical commissioners can understand the key principles. The financial appraisal will include the money required for those eligible for funded NHS care (continuing care).

What outcomes are right for individuals and the local population?

EOLC is a clinical topic that crosses a number of professional and organisational boundaries. This means that delivering outcomes requires integrated commissioning with joint objectives and pooled budgets.

Service provision in turn will also need to be integrated with social care, independent and voluntary services as well as specialist palliative care providers working together to achieve the outcomes. As well as incentives such as the QOF and CQUIN, a small number of lead indicators should be agreed (such as those suggested on p. 20) that are tailored to your local CCG's aims, and should support providers, including primary care, to determine the best way of delivering these outcomes.

Who are the current and future providers?

Procuring a different service does not necessarily mean changing providers or open tender, as CCGs can re-procure with an existing provider. However, in order that the best outcomes are delivered for patients, the CCG will need to explore new arrangements with the existing and/or new provider.

There are very real opportunities in commissioning EOLC, especially in developing new partnerships with voluntary sector organisations as providers or advocates, both small local charities and larger national organisations that provide a service across many CCGs (see Department of Health website). Wide engagement with all providers, current and potential, is recommended before any formal procurement process.

Procuring a new service is an opportunity to develop a coalition of providers and/or one lead provider acting as 'Prime Contractor' on behalf of the coalition. Whatever model is adopted, providers must share the same

objectives as the clinical commissioners.

Whatever market intervention decision is made by the CCG, it will have to be supported by the Health and Wellbeing Boards as being in the best interest of patients and the local community.

Traditionally, contracts in the NHS have been based on activity such as number of beds or nurse contacts and have tended to over-specify. As commissioning becomes more sophisticated the best forms of procurement include developing contracts that enable providers to innovate so that the outcomes can be delivered. This is a new way of working within the NHS and it is important that these objectives are achievable. We would encourage open sharing of good practice for the benefit of all. Whatever the decision, the CCG will need to ensure its decision is supported by the Health and Wellbeing Board as part of the joint commissioning process.

Monitoring outcomes

Once a service has been procured, we all have a responsibility to support the service, monitor progress through an understanding of practice data and feed back to the CCG constructively. This means practices and CCGs periodically auditing their patients' and carers' experience of the new service. This process should be used as a springboard to instigate and monitor change where the desired outcome has not yet been achieved.

Whatever mechanism for outcome monitoring is in place, it is essential that the CCG ensures a continual process of patient and carer feedback both formally and informally. Continual training, education and feedback for the whole workforce, including primary care, need to be built and budgeted into the CCG plans for EOLC. It is important to note that micro-commissioning is defined as 'the day to day clinical decision on behalf of patients which have a cost implication on the local health and social care system'.

2. The RCGP commissioning guidance in end of life care

Executive summary: six steps in EOLC commissioning

This is a complex area involving a large number of providers, services and cross-cutting agendas. A simplified model in line with current policy and National Institute for Health and Clinical Excellence (NICE) Quality Standards is presented here as a six-step approach, with practical applications described in the case history examples. Further resources and references are included later.

One: *aim – all people approaching the end of life and their carers and family receive well-coordinated, high-quality care in alignment with their wishes and preferences.* Measured by reported satisfactory experience of care by those affected and key outcomes measures (see below).

Two: *goals in line with the Quality, Innovation, Productivity and Prevention (QIPP) agenda – delivering quality care that is good value and cost-effective*

Three: *sectors working together in collaboration:* health (adult child, mental, physical, spiritual); social care (Local Authorities, Health and Wellbeing Board); and voluntary/third sector/independent sector (hospice, charitable, independent and patient/users' groups).

Four: *target areas that overlap with EOLC – EOLC must be included in these intersecting areas to enable effective improvement, i.e. long-term conditions, out of hospital care, elderly frail and people with dementia.*

Five: *domains of care (as in the Gold Standards Framework's (GSF) five standards for accreditation).*

- Right person: identifying people nearing the end of life earlier and their carers.
- Right care: clinical care, provision of services, shared decision making, ACP, discussions, spiritual care.
- Right place: reducing hospitalisation, improving integrated cross-boundary care, improving community services to enable more home deaths, reducing hospitalisation and out-of-hours crises.
- Right time: proactive care, care at each anticipated stage, care for the dying in the final days and care for the body after death.
- Every time: consistently for patients, carers and family, workforce and organisations; identifying and proactively supporting carers and family, and after death in bereavement; enabling the generalist workforce to work optimally and ensuring training and support; knowledge, skills and attitudes; strategic planning and resourcing leading to consistency of care, embedding in structures, e.g. operating framework, organisational quality assurance and accreditation, quality accounts and accountability.

Six: *areas of outcome measures (see p. 20).*

1. *Quality accountability report* – key outcome measures, patient/carer feedback of experience of care and accreditation of organisations.
2. *Right person* – people who are approaching the end of life (final year or so) are recognised early.
3. *Right care* – people whose care planning has been recorded and care tailored to meet needs.
4. *Right place* – people enabled to live and die where they choose.
5. *Right time* – people who receive timely, proactive anticipatory care, including in the final days.
6. *Every time* – consistency of care delivery; workforce trained and enabled; family and carers supported.

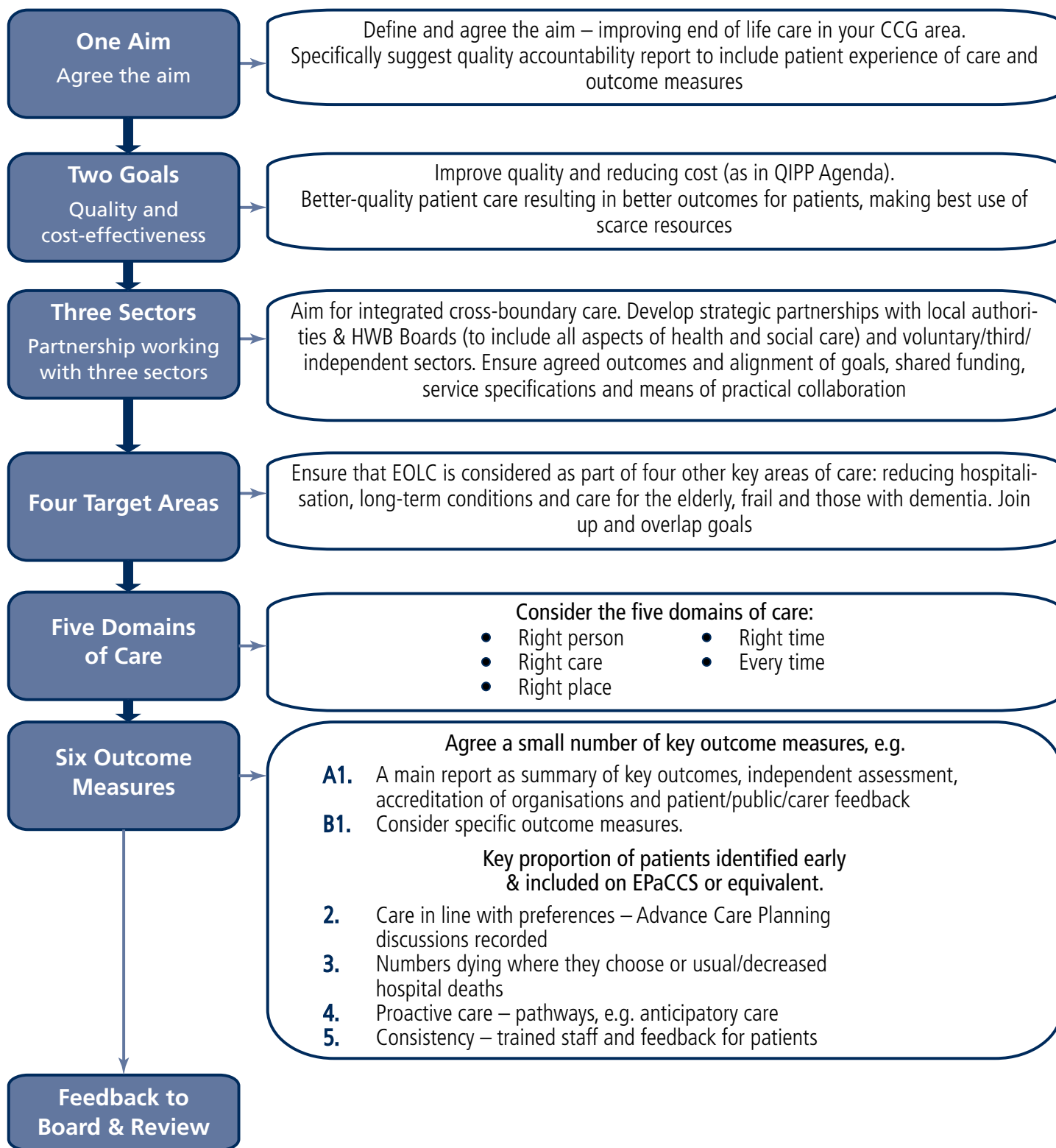


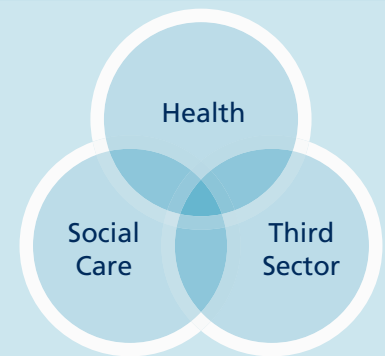
Figure 2: Six steps to improving EOLC commissioning

Three Sectors

Partnership working
with three sectors

New CCGs are encouraged to think creatively beyond current service models, to include innovative ways of working with others, e.g. in the voluntary sector, patient groups, churches/fairth groups and others interested in supporting local communities. There is untapped potential here that presents considerable opportunities for locally owned and managed innovation.

Real integration of care can only occur when there is information sharing and real-time electronic links (see example on p. 14).



Service providers

Service providers to consider while commissioning from different sectors (some overlapping) to achieve right person, care, place and time (as in illustrated examples). This is not an exhaustive list as many different services are available in local areas. These include general and specific areas:

General areas

- Strategic multidisciplinary workforce planning and service provision.
- Providers of training and assessment for workforce.
- Independent quality assurance or accreditation providers.
- Information transfer – IT services – including use of registers, e.g. Electronic Palliative Care Coordination Systems (EPaCCS).
- Psychology, counselling and allied health professionals.
- Children and transitions-related services.
- May include others under Any Willing Provider remit.

Health related

- Primary care – GPs and GP practices.
- Community nursing services.
- Out-of-hours provider services.
- Emergency services.
- Acute hospital services.
- Specialist palliative care, hospice and home care provision.
- Pharmacy – 24/7 access to palliative care drugs.
- Access to equipment.
- Rapid-response services or night sitting, e.g. Marie Curie.

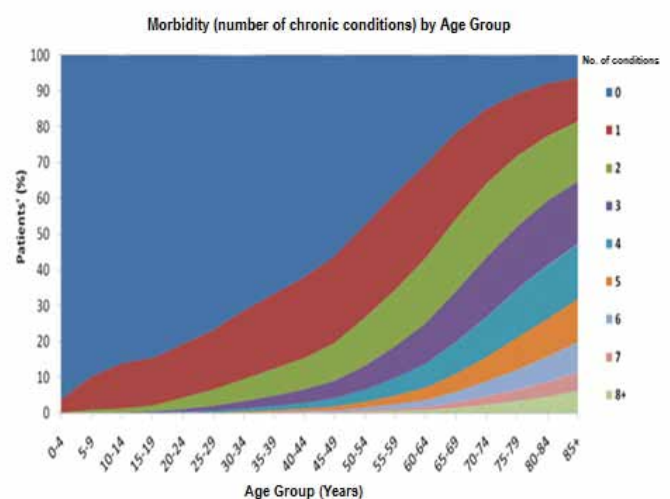


Figure 3: Multi-morbidity and complexity

Source: reproduced from Barnett K, Mercer SW, Norbury M, et al. Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. *Lancet* 2012; **380(9836)**: 37–43 with permission from Elsevier.

Social care

- Local authorities and public health.
- Care homes – nursing, residential and others.
- Domiciliary care services/continuing care services.
- Respite or emergency carer support.
- Social workers and benefits advisers/housing.
- Other social care services integrating health/social care.

Voluntary sector/independent groups

- Bereavement services, e.g. Cruse or others.
- WRVS, local support agencies or charities.
- Spiritual care providers, e.g. churches, chaplains, faith groups, etc.
- Hospices, Macmillan and other voluntary groups.
- Independent providers of care homes, service provision for healthcare workers at home, etc.
- Including patient/carer advocacy groups and those providing services.
- An opportunity to engage more fully in local community-led projects and bring in expertise from national organisations, customised locally.

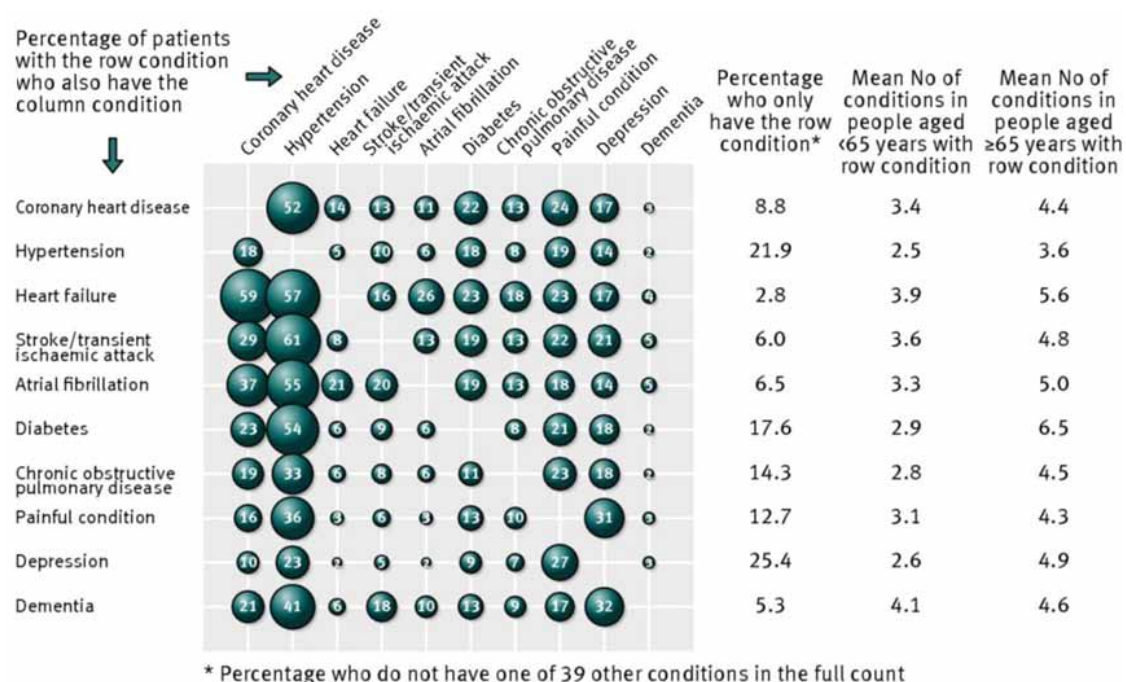


Figure 4: Co-morbidity of ten common conditions among UK primary care patients

Source: reproduced from Guthrie B, Payne K, Alderson P, et al. Adapting clinical guidelines to take account of multimorbidity. British Medical Journal 2012; 345: e6341 doi: 10.1136/bmj.e6341 with permission from BMJ Publishing Group Ltd.

Four Target Areas

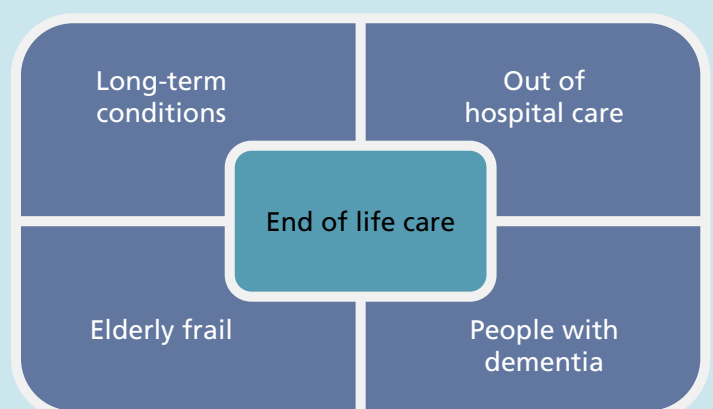
EOLC overlaps with a number of significant areas – they cannot be improved unless the care for people nearing the end of life is in relation to effectively commissioning care. While some CCGs might not give it such a high priority, it affects a number of crucial areas that most CCGs will be addressing, most of which have a significant impact on the overall budget. It is important that EOLC is considered alongside these four areas:

- *long-term conditions* – these account for the greatest burden of disease while more people live longer with life-limiting conditions. Many die of these conditions, or the compounding effect of multi-morbidities. There has been good progress in this area, but some are still not recognising the important connection between managing long-term conditions and improving EOLC
- *out of hospital care/reducing hospitalisation* – patients in the final year of life account for a disproportionate number of the hospital population. To reduce this number and enable people to be cared for in their preferred place there is a need for better community services, the ‘economic no-brainer’ of reducing admissions and enabling more to die at home etc.
- *elderly frailty* – 85% of people who die are over 65 and most have multi-morbidities and frailty – this is now the biggest cause of death in most developed countries
- *people with dementia* – a third of people over 65 will die of or with dementia, and cognitive failure/dementia contributes significantly to the multi-morbidity.

Case history examples

‘What good looks like’ can best be described through a typical case history, examples of which are included here in sample stories from each of the four organisational levels from pages 10–19:

1. *The individual* – the patient and family, carers, staff member, e.g. *Doris*.
2. *The group/organisation* – what this looks like for a GP practice team, care home, hospital, etc.), e.g. *Goodcare Practice*
3. *The community* – in this case the CCG area, including Local Authority and other partners, e.g. *Nicetown CCG*
4. *The national picture* – in relation to national quality markers and standards in EOLC – *England policy*.



Four intersecting areas that relate to EOLC.

Five Domains of Care

1. Right person

Planning EOLC includes all those who might be considered to be in their last year of life (as with the GMC definition). However, for some with life-limiting conditions such as dementia, this might require planning earlier than the final year. It is important that these people nearing the end of life are *identified early* to enable better planned and coordinated care in line with their needs and wishes. Evidence confirms that, if identified early and included on the register, more patients will receive proactive, coordinated care with reduced hospitalisation. The helpful *key ratio*, indicating early recognition, is the number of patients on the register over total number of deaths. The average in 2011 was about *25% of all deaths* on the register with 25% of these being non-cancer patients (GSF National Primary Care Audit).

Identification is key to triggering *active, coordinated, supportive care*, including community nurses, specialists and others, to discuss these patients and proactively initiate supportive care; GPs help to coordinate the *full multidisciplinary team* at the team meetings, and use the register to systematically coordinate better proactive care.

Locality-based registers, EPaCCS, are developing across the country, and the GP's Palliative Care Register patients can be included on this, to enable wider awareness of the details and preferences (see p. 36). Also, such earlier identification in hospitals, care homes and others is a useful development.

Case study: Doris

Doris is an 84-year-old woman, with heart failure, COPD and early dementia, who moved into a local care home following a recent crisis admission to hospital. The GSF-accredited care home codes her 'green' and she is included on the GP practice Palliative Care Register. She is discussed briefly when the GP does his usual weekly proactive visit. When she worsens some months later, she is coded yellow and the care home and GP ensure

the right anticipatory support is in place to enable her to remain at home. A weekend emergency call does not lead to an admission as the care home is prepared and her preferences known. She dies in the care home as she wishes, with her family around her. An after-death analysis and significant event analysis (SEA) help the staff debrief and reflect on any improvements they could have made in her care.

Case study: Goodcare Practice

The Goodcare practice team identifies early its patients who are nearing the end of life (using tools such as the Prognostic Indicator Guidance and others), including those with non-cancer, from care homes and children. The GPs *proactively visit the care homes* once a week and find use of the coding in the care homes a more efficient way to work together. They are included on their *Palliative Care Register*, and following a recent drive to increase use they are now attaining a key ratio of 50% of all deaths on the register. They are prioritised (e.g. using the *redlamber/green needs-based coding*

system) and their care is discussed at monthly meetings. Inclusion of patients on the register is discussed with the patient and family and a leaflet is given to support further discussions (and *RCGP Patient Charter* information). Information is included on the locality register (*EPaCCS*) available for others.

Case study: Nicetown CCG

The CCG has 25 GP practices; all claim their QOF Palliative Care Points (have a register and hold meetings – Foundation Level GSF). They receive information from the NHS End of Life Care Programme and the *Find the 1% campaign* and are seeing some rises in their key proportions from the original 20% figure. Most use the *GSF Prognostic Indicator Guidance* or other tool. Five have done further training (e.g. *Next Stage GSF Going for Gold*) and two have been *accredited with the GSF RCGP Quality Hallmark Award*, with a trebling of numbers identified, nearing 50–60%, and inclusion of

care home residents and more non-cancer patients (see Appendix). Many have attended further *communication skills* training given by their hospice. Of the 76 care homes, over half have done GSF training and most are accredited, with some re-accredited after three years. This has led to better team working with GPs and earlier identification of patients on their register. The CCG has a *Locality Register/EPaCCS* for use by other providers, and monitor regularly the increasing proportion included on it.

Five domains of care (as in the GSF's five standards for accreditation)

- **Right person** – identifying people nearing the end of life earlier and their carers.
- **Right care** – clinical care, provision of services, shared decision-making ACP discussions, spiritual care.
- **Right place** – reducing hospitalisation, improving integrated cross-boundary care, improving community services to enable more home deaths, reducing urgent care and out-of-hours crises.
- **Right time** – proactive care, care at each anticipated stage, care for the dying in the final days, and care for the body after death.
- **Every time** – for carers and family – for workforce, for organisations.

2. Right care

People nearing the end of life require care that is appropriate to their *clinical and individual personal needs* – the right kind of care for them. This relates to both clinical needs and service provision. Patients' personal needs relating to their wishes and preferences can be established through shared decision making or ACP discussions. *Specific clinical tools* used to assess clinical symptoms are helpful, such as pain assessment tools for people with dementia (e.g. Doloplus etc.), and guidance on best clinical care or referral discussed *with the appropriate specialists*, related to the patient's condition (e.g. palliative care specialists, heart failure, dementia, etc.). A clinical management care plan is developed relating to the best course of action for each person, and reviewed regularly. It is also important to discuss with the patient and his or her family any future plans and wishes. The discussion process is

best held by someone who knows the patient, can be systematically recorded, continually reviewed over a period of time, and is also opportunistic – ensuring that the patient has the time and space to make his or her views and preferences heard and noted, for others involved to be aware of. This includes, in most cases, an advance statement including *preferred place of care*, the resuscitation discussion about *Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)* and sometimes also *Advance Decisions to Refuse Treatment (ADRT)*, and *the proxy spokesperson* or Lasting Power of Attorney care (see examples in Appendix). It also can open up deeper issues related to spiritual care and 'getting their house in order', and guidance on how this person wishes to live and die. Specific best-interest guidance is given for people with dementia or who lack capacity (see resources).

Case study: Doris has ACP discussion documented and communicated to others

Following Doris's admission to the care home, she and her daughter were given a leaflet explaining the idea of ACP discussions ('Planning Your Future Care' – see resources) and were offered a time to have the discussion with a senior member of staff. Both Doris and her daughter enjoyed the meeting and felt it had been helpful to consider options and wishes for future care. Doris's daughter felt it was good to have been able to make her feelings known early, as it might be more difficult when her dementia worsened. They discussed her wish to see the seaside again, her love of

her grandchildren, and her preference for no heroics but to die peacefully, with her family around her at the home. This was documented using the care home's ACP documentation and communicated to the GP, and her wishes were made known to the GP practice team at their next meeting, and to the out-of-hours provider. This ensured she remained at the care home when there was an emergency call one weekend. When she died, the family felt that her wishes had been listened to and respected, and were very satisfied with her care.

Case study: Goodcare Practice

The goal for this high-aspiring practice is that every person on its Palliative Care Register is offered an ACP discussion that is recorded and communicated (with permission) to appropriate other providers of care via the EPaCCS. Its previous ACP rate was about 10% but currently it is attaining 70% of patients on the register with recorded ACP discussions. This is noted as an excellent feature in their GSF Accreditation, endorsed by the RCGP, and the practice encourages others to do the same.

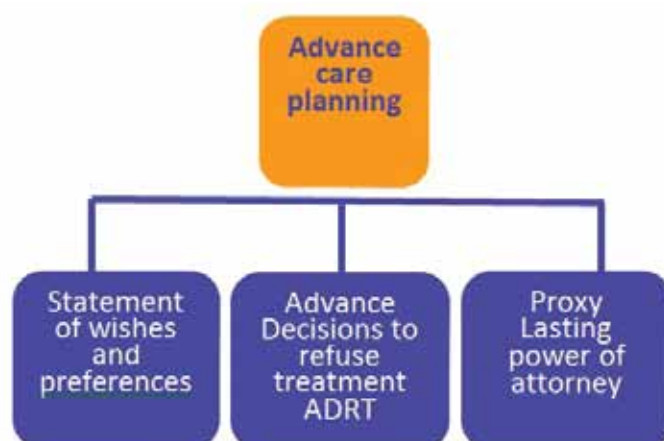


Figure 5a: Advance Care Planning

Source: Gold Standards Framework. Used with permission.



Figure 5b: Advance Decisions to Refuse Treatment

Source: National End of Life Care Programme. Used with permission.

Case study: Nicetown CCG

This CCG aims to have every practice recording ACP discussions for over 60% of patients on its register in the next year – it is currently at an average of 20% and 50% for care home residents. It is supporting practices further with teaching of communication skills run by the local hospice and better 24/7 specialist palliative care support, plus better use of early alerting IT support from its IT provider and increased use of EPaCCS. The CCG agreed its local clinical assessment tools and local ACP/DNACPR tools and regularly monitors its proportions of ACP discussions recorded. The local patient group feed back its experience of care delivered in alignment with preferences. It supports training from the hospice.

3. Right place

There is an increasing focus on *reducing inappropriate hospitalisation and improving community provision of care* for people living at home. This is particularly important for patients with dementia and other co-morbidities, as an admission may cause disorientation and can worsen their condition. People nearing the end of life should receive consistent, high-quality care wherever they are, provided by the generalist frontline providers of care (GP, community nurses, care homes staff, hospice, hospital teams, care assistants, etc.) as well as appropriate specialist support. Most people spend most time at home or in their care home, and evidence confirms that *most would prefer to live and die at home*. Although not everyone wants to discuss their preferences, most patients want to avoid crises and inappropriate hospital stays. The prospect of emergency admissions, crisis ambulance calls and trolley deaths is one that everyone would seek to avoid. So the

challenge is to deliver good-quality care in all settings and to enable more people to stay at home/in their care home and to rely less on hospitals as a safety net emergency service. This links with other CCG priorities. Therefore it is recommended that all CCGs:

- develop services that provide planned, coordinated care across organisational boundaries
- ensure information is shared with all providers involved in the care of the patient having obtained their consent to do so, e.g. EPaCCS
- reduce avoidable hospital admissions
- provide relevant information regarding support services to facilitate reduced length of stay and rapid discharge where admission is essential
- develop monitoring system to audit outcomes.

Case study: Mary and Tom

Mary, an 84-year-old with severe heart failure, leg ulcers and early dementia, had expressed a wish to remain at home to the end, with her husband Tom. She had repeated emergency admissions with breathlessness one winter and the GP practice included her on its *Palliative Care Register* and discussed her care with social services. Supported by their GP and district nursing team, Mary and Tom were given *Continuing Care Funding* to help them remain at home, accessed additional *domiciliary care support*, supported with respite care from a local *voluntary organisation*, and

night sitting at the very end from local care providers and *Marie Curie*. Its out-of-hours medical service was aware of Mary's condition and her preferences through the *handover/electronic alerting* form linked to the EPaCCS. The required anticipatory medicines were already in the home in case she worsened and Tom was helped by the *OTs with home adaptations* and a special mattress to prevent ulcers – all of which helped to keep Mary at home. She lived for five months after that last admission and died peacefully at home with Tom as she had wished.

Case study: Goodcare Practice

To ensure that all their patients nearing the end of life received high-quality care and died where they would wish, the practice:

- built on the QOF-Level GSF to systematise its care. It included more non-cancer patients on the register, e.g. Next Stage GSF Going for Gold, Find the 1% or other GP training
- accessed all relevant social care and voluntary sector organisations to support home care and reduce hospitalisation
- through audit, measured numbers dying in usual place of residence or preferred place of care
- undertook an SEA when there were unexpected hospital deaths or other crises
- supported local care homes and progressed to GSF Accreditation itself.

Case study: Nicetown CCG

Reducing avoidable hospital admissions was one of its agreed goals and it *monitored admission rates and numbers dying in usual place of residence* against national benchmarked data. It works with other partners to increase home care, e.g. out-of-hours providers, domiciliary care and voluntary support agencies. It invests

in *further training* for care assistants and domiciliary care. It increased its *intermediate care* beds in GSF-accredited care homes, improved *support for all care homes* and observed CQC ratings. It reviews and monitors outcomes for patients regularly, supported by their *patient reference group*.

4. Right time

It is important to provide proactive care to keep ahead of the crisis-led system that can develop in EOLC. This includes for example:

- care planning for those with long-term conditions and ACP discussions to seek people's views and preferences
- planning care for patients in their last days of life, with the use of a care pathway if used
- routine anticipatory prescribing to prevent patients experiencing unnecessary symptoms
- access to medicines – ensures access for carers having to use pharmacy out of hours
- care and support of family members assessed with supporting information to guide carers through the dying process and in bereavement.

Case study: Ted

Ted's diagnosis of lung cancer was discussed with him at the hospital and he was referred to a *specialist lung cancer nurse* who saw him at home. Together with his local *social worker* they developed a plan that included an outline of what to expect, what to do and who to call if his condition worsened. He lived alone but later found it hard to cope, and had a spell of two weeks in the local *hospice* to control his pain. Following a time at home he received care from *Marie Curie nurses* for

two nights. He later needed further care so went to a *care home*, which had been trained in using an adapted version of an *integrated care pathway for the final days* and was supported by the local *Macmillan nursing team*. He worsened quickly, was coded red and died on the Liverpool Care Pathway in the care home. In a later *VOICES questionnaire*, his family felt sad but very satisfied with the care, saying that there was nothing more that could have been done.

Case study: Goodcare Practice

The practice is committed to ensuring all dying patients receive care at the right time for them, with proactive anticipatory care. It monitors its key ratios as a practice, and over 50% of all people who died on the register had died in their preferred place of care. It proactively

supports care homes, who use the adapted integrated care pathway in the dying stage. It undertakes an *after-death analysis and SEA* following each death and reviewed Ted's care in the light of the *VOICES questionnaire and feedback* from his family.

Case study: Nicetown CCG

As part of the aim to reduce hospitalisation, the CCG assesses reasons for unplanned admissions and focuses on preventable causes, such as lack of out-of-hours information or services. It has developed with the local hospice an appropriate plan for care of the dying in the final days, and the care homes use this or LCP. It has Macmillan teams for cancer patients, but particularly

looks at those non-cancer patients whose access to other support services can be limited and work with local voluntary sector organisations and *Marie Curie* in this area.

5. Every time: for family and carers, for the workforce and embedding best practice

Family and carers' views

There is only one chance to get it right in EOLC. Although death is the final outcome for all, 'death is not seen as failure, but a bad death is'. It is even more important therefore to ensure that the care and support provided is of the highest possible quality, responsive to needs and delivered in a systematically organised way to as many patients as possible regardless of diagnosis or setting. The experience of care by both patients and their family or carers is increasingly recognised as a key indicator to measure. Feedback from carers (such as the VOICES questionnaire) is a well-validated tool to assess provision and highlight further areas to improve, as is other public engagement and work with Health and Wellbeing Boards. Bereavement support is also crucial, with GPs being the first signposters to other local bereavement services.

Workforce

The greatest resource of the NHS and social care is the people, and the compassion and care with which

they deliver these services is particularly important at this time. So it is important to invest in workforce training and enablement, and to assess staff views of confidence, competency, capacity and training (see p. 32 for examples).

Embedding and sustaining best practice

In all quality accounts and assessments, there is a need to build in sustainability and measures to ensure consistency of care. This also helps assess the areas that are strong and working well and those that require further work in future. So overall assessments and developments of required standards can be of help in sustaining good practice and improving them further.

One measure commonly used is the number of organisations receiving objective quality assurance or accreditation such as GSF-Accredited care homes and practices in an area, or those in receipt of other quality assurance awards or assurance processes.

Case study: the Patel family

The Patel family included 15 members across three generations, all living in the same road and all registered with the Goodcare Practice. As the older three family members became more frail and gradually deteriorated they were included on the practice Palliative Care Register, their care was discussed at team

meetings and they accessed appropriate help from social services. They all died at home, within months of each other and with the rest of the family supporting them. The family was pleased with the care and there were no crisis calls.

Case study: Goodcare Practice

The practice developed annual audits, as part of the GSF Going for Gold training and accreditation including Significant SEAs and views from patients, carers and staff. The practice developed and owned its Goodcare

Practice EOLC protocols to ensure sustained good care, a key feature of GSF Accreditation, and included an induction for all new staff.

Case study: Nicetown CCG

Family and carers' needs are identified, including support available for children. Carers should be identified and offered an assessment of need in their own right. Formalised assessments are available from social care. Communication between primary care and social care colleagues should be ensured.

The educational needs of the workforce are assessed with appropriate metrics and a training lead is in charge of accessing and disseminating information about what is available in the locality. This includes support from hospices and specialist palliative care plus national providers of training such the GSF Centre in End of Life Care, which supports the training of generalists in EOLC in all settings (see Appendix for quality standards). Some e-learning and other resources

are also available through local areas, through the NHS End of Life Care Programme, Macmillan and others (see resources section).

The CCG is committed to improving EOLC as one of its key areas, supported by the Health and Wellbeing Boards. This is reported to the Board on a quarterly basis using suggested quality accounts and qualitative feedback from patient groups and use of questionnaires.

Provider contracts should highlight the skills required to facilitate EOLC and have outcome measures in all provider contracts. Services should be decommissioned where they fail to meet outcomes identified in the contract negotiation rounds.

Nationally available resources and guidance support

- NHS End of Life Care Strategy and Programme.
- NICE Quality Standards in End of Life Care.
- Care Quality Commission (CQC) Care Home standards in end of life care.
- NEoLC toolkit, ELQuA, NHS End of Life Care Intelligence Network.
- Dying Matters and National Council for Palliative Care.
- CCG Quality Markers and CQUIN targets.
- Practice QOF Palliative Care points.
- Marie Curie Atlas.
- Gold Standards Framework – GSF Accreditation for GP practices, care homes, hospitals, etc.

See the resources on pp. 39–41.

Six Outcome Measures

Six suggested indicators or measures of EOLC in a CCG

These indicators are in line with current nationally recommended outcome measures, and were developed following the two consultation workshops and in collaboration with the RCGP EOLC/QIPP teams, and in consultation with NICE. They are not the final version of the suggested indicators, as this is likely to change with new recommendations from the National Clinical Director. There might also be possible revision

in the National Outcomes Framework with feedback following piloting of the NICE Commissioning Outcomes Framework (COF) indicators in 2014. Currently the two key NICE indicators are feedback on patients' experience of care and numbers dying where they choose (cf. p. 26). However, this provides a working plan of a handful of key measures indicating progress and success in EOLC in an area for CCGs to use to.

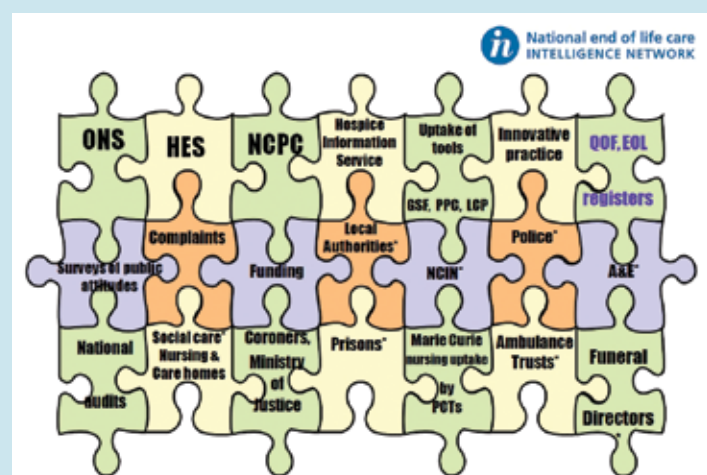
1. Quality Accountability Report

Suggested overall summary accountability report to indicate assessment and progress of EOLC in a CCG

1. *Patient/carer feedback* – feedback on patient experience of care, e.g. VOICES, feedback from user experience, public engagement (see p. 27).
2. *Independent quality assessment/assurance*, e.g. organisation accreditation (see p. 32).
3. *Key outcome measures*, e.g. key ratios (see below).

Figure 6: Compendium of data sources

Source: National End of Life Care Programme. Used with permission.



1.1 Patient/carer feedback

- Feedback on patient experience of care, e.g. feedback questionnaires, VOICES, feedback from user experience, public engagement complaints, SEAs, etc.

1.2 Independent quality assurance

- E.g. organisation accreditation (see p. 32) – *every time*.
- Consistency of care.
- Family and carers supported.
- Workforce staff trained and enabled.

1.3 Key outcome measures

- E.g. key ratios (see below).
- Percentage proportion of more specific targets, which are related to *Right Care metrics* (as used in GSF Accreditation – see GSF and RCGP websites for more details).

2. Right person

People whose increasing needs are recognised early:

- number of identified patients on register/total number of deaths
- number of patients on the register with non-cancer diagnosis (equity of access)
- number of carers offered assessment and care in bereavement.

3. Right care

People with recorded ACP discussion and care tailored to meet needs:

- number of patients offered ACP discussions/ numbers on the register
- process in place for carer feedback following death to assess care aligned to preferences.

4. Right place

People able to live and die where they wish:

- number of patients who die in usual place of residence and preferred place of choice/number on register
- hospitalisation rates, length of stay, rates of emergency admissions, etc.

5. Right time

People who receive timely proactive anticipatory care (including in the final days):

- numbers of patient for whom anticipatory care plan was used, e.g. handover form out of hours, anticipatory prescribing
- care plan for the final days, e.g. use of LCP or equivalent.

6. Every time

Consistency of care delivery – workforce trained and enabled, family and carers supported.

- evidence of consistency and sustainability of patient outcomes, e.g. regular audit feedback or monitoring, embedding in policy and protocols or external accreditation.

Six areas of outcome measures

1. **Quality accountability report** – key outcome measures, patient/carers feedback of experience of care and accreditation of organisations.
2. People who are approaching the end of life (final year or so) are recognised early.
3. People whose care planning has been recorded and care tailored to meet needs.
4. People enabled to live and die where they choose.
5. People who receive timely proactive anticipatory care, (including in the final days).
6. Consistency of care delivery – workforce trained and enabled, family and carers supported.

(See p. 32.)

3. Next steps: how to do it

Translating plans into action: effective implementation in your CCG

Think in terms of leading a local system change rather than a service re-design. It is important that if EOLC is included as a priority in your commissioning intentions, or other intentions, that the detail is outlined elsewhere and formalised, e.g. in your local EOLC Strategy, Implementation Plan or Operating Plan. This detail should be agreed by all stakeholders through an EOLC Group, which implements the plan, regularly reviews progress and reports to the CCG Board. Once the overall outcome and implementation plan are determined then the measures, in line with NICE guidance, can be used to assess and monitor progress, and benchmark against

others. Potential target measures can be included in your Strategy, Implementation or Operating Plan.

You need to determine a joint outcome you wish to achieve, e.g. an increased number of people dying at home/usual place of residence or in their preferred place of care, and other wellbeing outcomes, such as maintaining choice and control, quality of life and bereavement care. Suggested outcomes are given on p. 27, but local communities should affirm their own, aligned to national priorities.

The most significant common thread running through all three initial domain visions (of the new NHS Commissioning Board) is the need to improve the quality of primary care.

Commissioning is about quality improvement yet so many people think of it only as a transactional process. It is Plan, Do, Study and Act (PDSA). We should start with where we are (Joint Strategic Needs Assessment) and plan where we want to be. Procurement and contracting are part of the doing but as much of the doing is also about simple improvement or re-design and requires programme and project management not just procurement and purchase. Then we need to study what impact we are having. The system is complex and

there are unintended consequences. By studying outcomes and process and project implementation we can make a judgement as to what we might wish to do in-year or in the next round of commissioning to remain true to our purpose. Plan, Do, Study and Act. The contribution clinicians can make to quality improvement is enormous. That is why clinicians should contribute to commissioning.

(Dr Martin McShane, National Clinical Director, Domain 2 NHS Commissioning Board, January 2013)

Additional considerations based on the six-step plan in CCG Commissioning for EOLC

1. *One aim* – focus on EOLC as a key area itself or a contributory part of others. Develop an EOLC working group and clinical champions. Align it with other relevant areas as indicated, e.g. reduced hospitalisation, long-term conditions, dementia, etc.
2. *Two goals* – agree the main outcomes you are seeking, related to both improved quality and improved cost-effectiveness. In the case of EOLC there can be a ‘win-win’ of improving home care and community death rate and improving quality in line with personal preferences.
3. *Three sectors* – develop partnerships. Work across health and social care and with other partners. Work closely with Health and Wellbeing Boards, regional partners and networks. Consider joint commissioning for EOLC with social services and possibility of joint budgets.
4. *Four target areas* – develop a reporting system to the CCG Board to include EOLC within the other four target areas. Report on progress against aims to the board. Include this in the operating plan and create a business case for further developments. Include it in contracts, e.g. integrate EOLC into service specifications to ensure full implementation and sustainability.
5. *Five domains of care* – develop area-wide services and tools to encourage against these domains, e.g. use of locally agreed APC tool and reporting process with urgent care and ambulance, development of EPaCCS in local area where possible to ensure improved communication and information transfer.
6. *Six outcome measures* – to include as quality accountability report. Report against key performance indicators, outcomes framework and defined goals. Formalise reporting to keep it easy and simple. Use externally supplied information, e.g. from EOLC Intelligence Network.

What can help lever and influence change in your area?

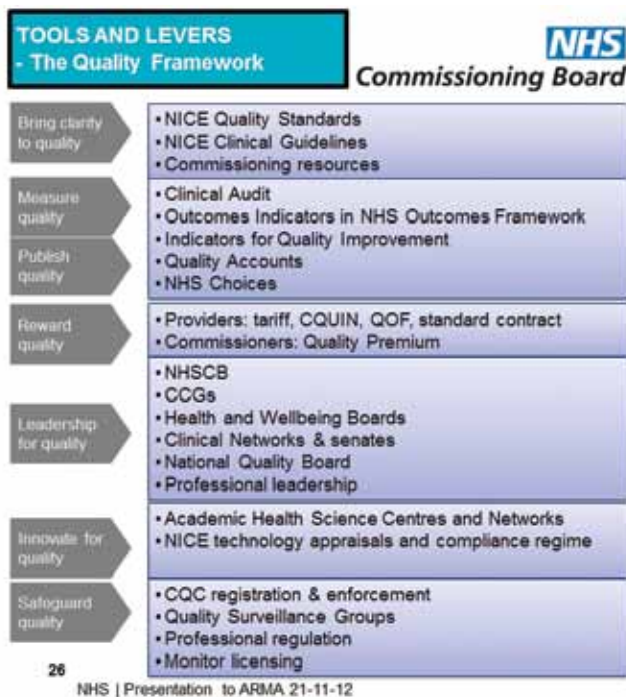


Figure 7: Tools and levers

Source: Martin McShane. Used with permission.

This will require close working with the relevant leads and determining common agendas or areas of concern that can be jointly addressed.

Many of these documents may only include high-level statements and it is important that EOLC is one of these. However, when other areas such as reducing hospitalisation/urgent care, long-term conditions, frail, elderly and dementia are priorities, this obviously overlaps considerably with care for patients in the final year of life, so shared common agendas and measures are essential. Some people may still not be aware that the breadth and scope of consideration in EOLC are now much larger than the earlier focus on cancer patients, hospices and specialist palliative care. It might thus need to be pointed out that this comprises many other areas not previously included, such as care homes, care of the elderly and impacting on the generalist workforce. Early communication with the public is essential to avoid misunderstanding.

Clinicians can contribute to this by thinking about the three Is.

- What is the *impact* we want to see?
- What are the *inputs* we will need to deliver it?
- What *influence* can I have to support those inputs to generate that impact?

Source: Dr Martin McShane, National Clinical Director, Domain 2 NHS Commissioning Board.

Most are familiar with the change management ideas used by the Institute for Healthcare Improvement and the NHS Institute – PDSA (see Figure 8). PDSA cycles form part of the improvement guide, which provides a framework for developing, testing and implementing changes leading to improvement. The model is based in scientific method and moderates the impulse to take immediate action with the wisdom of careful study. The framework includes three key questions and a process for testing change ideas. The questions are ‘What are we trying to accomplish?’ ‘How will we know if a change is an improvement?’ and ‘What changes can we make that will result in improvement?’

If EOLC is important to your CCG, it is essential to reflect this in your local strategic policy documents, with regular reports to the CCG Board and Health and Wellbeing Board. This will ensure effective implementation of your plans, maintenance as a priority, future funding and longer-term sustainability of this important work.

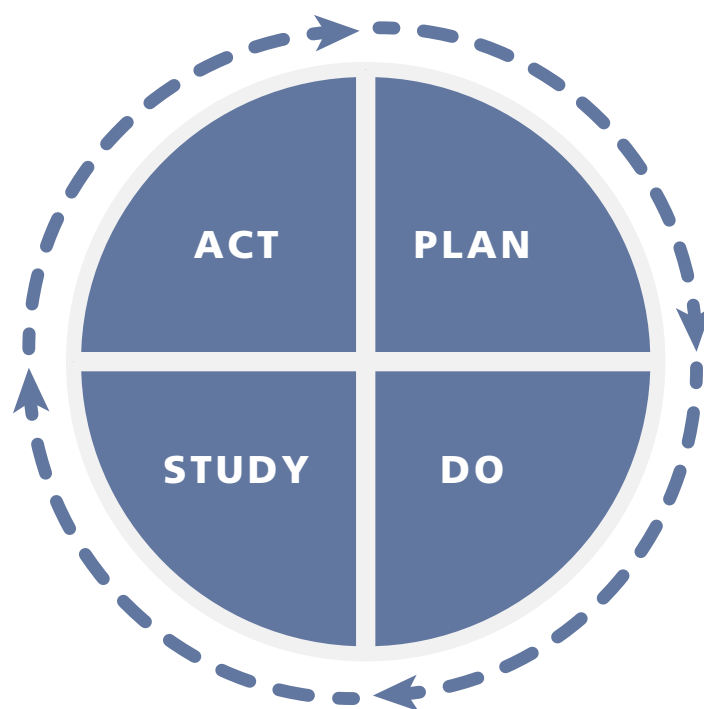


Figure 8: The PDSA cycle

Identifying a CCG and social care EOLC lead

Identifying a lead will focus leadership and implementation of the work. To achieve the required changes across the whole system the strategy needs to focus on integration across health, social care and third

sector, and needs to be reflected through both health and social care strategy documents. The key influential documents at this present time are shown on Table 1.

Table 1: Key influential documents

To influence local policies	New national policies (England)
<p>The CCG Commissioning Intentions and Operating Plan.</p> <p>The Joint Strategic Needs Assessment, often led by directors of public health.</p> <p>The Health and Wellbeing Strategy, which is led by the Local Authority’s Health and Wellbeing Board</p>	<p>Outcomes – NHS Outcomes Framework.</p> <p>Mandate – new NHS Mandate.</p> <p>Constitution – new NHS Constitution</p>

Improving end of life care requires a whole system change

There are a number of strands that will need to come together if care across a local health and social care system is going to improve. Figure 9 illustrates some of the strands that need to be in place and shows the

required composite approach in the commissioning of complex areas. However, Figure 9 carries a health warning: it is not definitive and does not reflect a priority order.

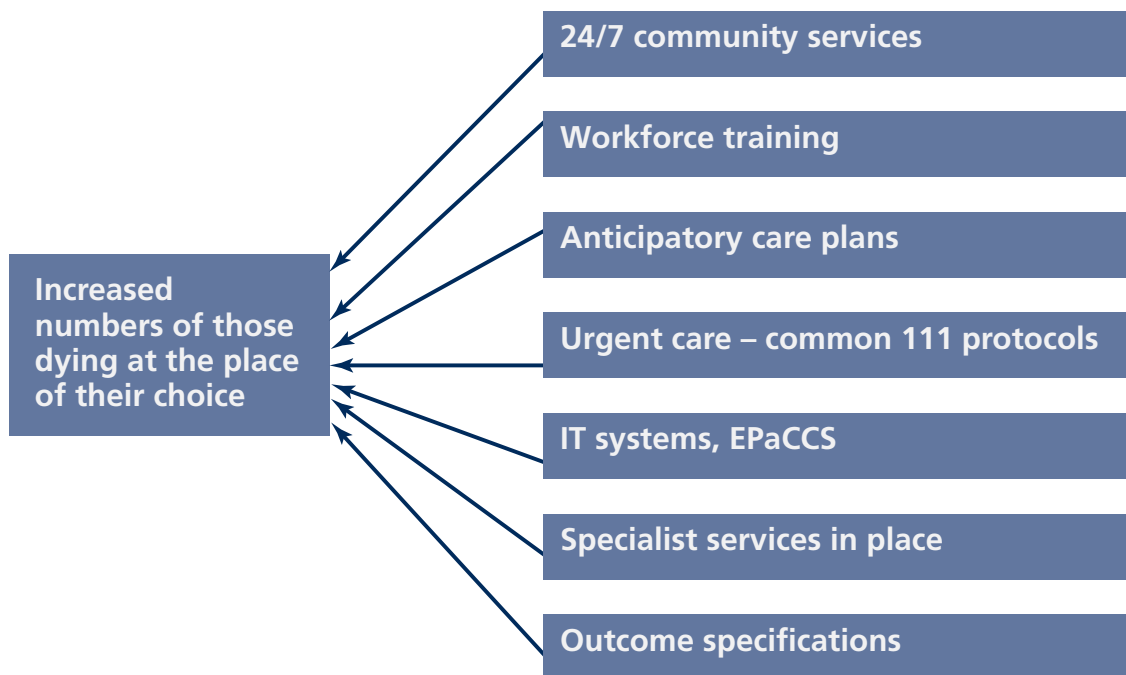


Figure 9: Components in commissioning

Source: David Paynton. Used with permission.

We recommend that local clinical commissioners develop their own driver diagram. They can thus plan a delivery programme over two to three years as part of implementation, often with the use of the PDSA cycle. Although it may take two to three years to fully implement, it will only be when all the strands lock into

place that the full benefits will be achieved. Health and social systems do not change overnight. At the heart of clinical leadership is the ability to take a longer-term view and understand how the different strands interconnect.

Additional information

Domain 2 – enhancing the quality of life for people with long-term conditions (LTC)

End of Life Care is one of the eight areas included in Domain 2 of the new NHS Commissioning Board related to attaining person-centred, coordinated care for all people with long-term conditions. Martin McShane (Domain 2 Lead) describes three generic components to providing person-centred, coordinated care for those with long-term conditions and affirms that *primary care is at the heart of this*. These are:

1. **Good primary care** – improving the quality of primary care, and embedding a proactive approach to identifying LTCs and supporting individuals to manage their LTCs
2. **Putting patients in charge and giving them ownership of their health** – including increased use of developments in technology and policy such as telehealth and telecare, access to health coaching, personal health budgets, and providing people with their care records

3. **Coordination and continuity of care** – integrating the services people receive from health and social care providers around the individual’s needs and personal goals, supported by record sharing between providers, and universal care planning through care consultations and written care agreements.

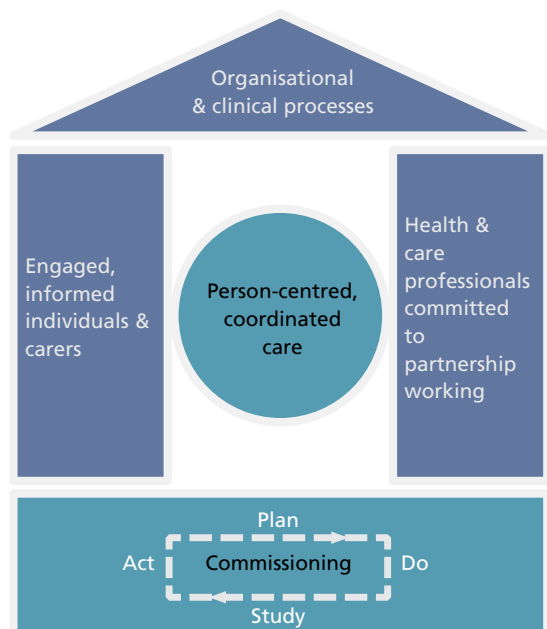


Figure 10: Person-centred integrated care

Source: House of Care Domain 2, derived from Year of Care Programme.

The key role of primary care as provider and now as commissioner is central to the vision of progress within the newly formed NHS.

(Dr Martin McShane, Clinical Director, Domain 2, November 2012)

Measuring outcomes, NICE Indicators, estimating cost-effectiveness and patient feedback

The NICE Quality Standards in End of Life Care

These standards (see Appendix, p. 38) were developed by the EOLC Topic Expert Group in 2012 following wide and extensive research and consultation. These standards form the basis for future assessment and suggested measurements are included on the relevant sections’ website. The working group for this RCGP guidance focused on reducing these to a limited number of key measurable standards, plus using a

composite measure of patient experience of care – the Quality Assessment given here. These are in line with NICE standards and metrics.

The current position in 2013 is that the two EOLC indicators suggested by NICE below will undergo testing and piloting for potential inclusion in the Clinical Commissioning Group Outcomes Indicator Set (CCG OIS) – formerly known as the Commissioning Outcome Framework (COF). However, these are still under review and there is no guarantee they will be included. Meanwhile, other suggested outcomes are given, to be agreed by the CCGs. It is likely that by the end of 2013/March 2014, these outcomes measures will be confirmed by the National Commissioning Board. The current CCG OISs for EOLC being tested are:

- *ELC05* – of people who have stated their preferred place of death, the proportion who die in their preferred place of death
- *ELC28* – of people closely affected by a death, the proportion who report a satisfactory experience of communication, information, coordination of care, addressing their own needs, care around the time of death and bereavement care.

In addition, the newly developed online assessment tool ELQuA can be helpful in assessing the progress of service development in your own area (see www.elcqua.nhs.uk).

The NHS National Outcomes Framework

The NHS National Outcomes Framework in England is central to defining the measurable outcomes to which CCGs will respond, and each CCG is establishing its own outcome assessments. Although currently in transition and subject to change, some of the key indicators are suggested here with actions to be locally developed (see Table 2). The suggested six outcome measures included here were developed based on the NICE Quality Standards in EOLC and debated at the QIPP workshops and through consultation (see the six outcomes on p. 20). Some of these were piloted in the GSF Going for Gold Accreditation GP practices with considerable success. This demonstrated the practical benefit of assessing such measures and that such aspirations can be realised and measured in practice at grassroots level.

Table 2: National Outcomes Framework 2012/13/14 – specific areas for action in EOLC

Domain 2: Enhancing quality of life for people with long-term conditions	The main section that includes EOLC – including 2.4 and also other areas: 2.4 Improving health-related quality of life for carers. 2.1 Ensuring people feel supported to manage their conditions. 2.2 Improving functional ability in people with long-term conditions. 2.3.i Reducing time spent in hospital by people with long-term conditions. 2.6 Improving the ability of people with dementia to cope with symptoms
Domain 4: Ensuring that people have a positive experience of care	Important sections also in relation to EOLC: 1 Improving people's experience of outpatient care. 4.2 Improving hospitals' responsiveness to personal needs. 4.6 Improving the experience of care for people at the end of their lives – bereaved carers' views on the quality of care in the last three months of life. 4.9 Improving people's experience of integrated care
Domain 3: Helping people to recover from episodes of ill health or following injury	Less relevant domain but some sections might be of relevance (though most in Domain 2): 3b Effective recovery from illnesses and injuries requiring hospitalisation. 3.4 Effective recovery following a stroke. 3.6 Helping older people to recover their independence after illness or injury
Domain 1: Preventing people from dying prematurely	These and other areas might be taken into consideration, but not as relevant to EOLC as other domains, e.g.: 1.5 Excess under-75 mortality rate in adults with serious mental illness

CCG Outcomes Indicators Set

The NHS Commissioning Board is providing each CCG and Health and Wellbeing Board with an outcomes support pack that provides comparative information at CCG and Local Authority level. These packs include benchmarking information relating to the CCG Outcomes Indicator Set where data are available. Further detailed information will be released by the Health and Social Care Information Centre through its indicator. See the Outcomes Indicators fact sheet (www.commissioningboard.nhs.uk/files/2012/12/ois-fact.pdf) and *The NHS Outcomes Framework 2013/14* document (www.dh.gov.uk/health/2012/11/nhs-outcomes-framework).

Patient Reported Outcome and Experience measures (PROMS and PREMS) – seeking feedback from people, families and carers

This is recommended as one of the most important outcomes measures, and feedback on patients' experience of care is vital in the assessment of all services in future. The government's recommended

use of the 'Friends and Family Test' being piloted in hospitals is an indication of this.

Several tools and resources can support you to better gauge feedback from patients and carers. The first national VOICES survey, undertaken by the Office for National Statistics on behalf of the Department of Health, showed helpful indicators of quality of care – being treated with dignity and respect, pain relief, etc. – with tailored feedback for each area (see www.dh.gov.uk/health/files/2012/07/First-national-VOICES-survey-of-bereaved-people-key-findings-report-final.pdf).

Other indicators, questionnaires and patient feedback methods are being locally developed, and these form a vitally important aspect of outcomes measures in line with the NOF Guidance. Examples include feedback from families on collection of death certificates, Patient Partnership Group surveys and questionnaires, Family Perceptions of Care reports from relatives of residents of care homes, etc.

Example of good practice: NHS Shropshire CCG and patient involvement

NHS Shropshire CCG is working with the patients it will serve to make sure the contracts it tenders under Any Qualified Provider (AQP) are tailored exactly to their needs. When services are commissioned under AQP, patients can choose from a range of different healthcare providers that the CCG has approved as meeting NHS standards and prices. The CCG has appointed a dedicated patient involvement officer who partners patients with commissioners to ensure their views are fully taken into account in commissioning.

We are committed to engaging and communicating with patients and the public in order that their views can influence the way services are developed, improved and provided now and in the future. In particular we will look at ways to reach out to individuals and those groups of people

that are often hardest to reach. We strongly believe that this will result in services that are accessible, meet need, and people-centred whilst also being safe, clinically effective and efficient.

(Bharti Patel-Smith, Director of Governance and Involvement, NHS Shropshire)

The work of the EOLC Intelligence Network

The NHS EOLC Intelligence Network (see www.endoflifecare-intelligence.org.uk) produces a helpful range of specific information related to each area, through which you can benchmark your CCG's service provision, leading to more focused commissioning. This includes examining the range of causes for hospital admissions and watching key trends over time.

There are various guides to support you in estimating an economic appraisal for your area and cost-effectiveness, including the National Audit Office EOLC report and the NHS EOLC Programme QIPP costing information guides.

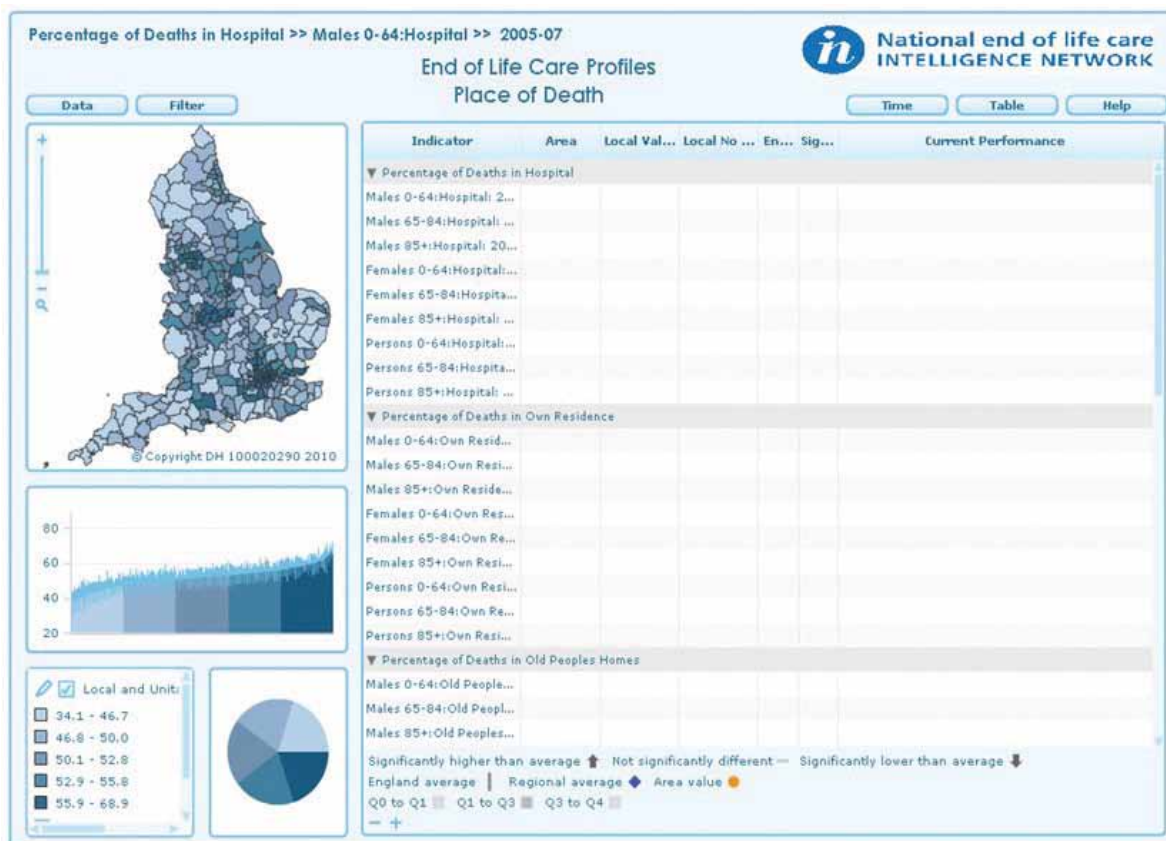


Figure 11: End of life care profiles

Source: National End of Life Care Intelligence Network.

Care in different settings and subjects: key points

Strong and proactive partnerships between GPs and care homes are essential to delivering good care. The benefits of good GP involvement in care are seen by patients, care homes and the whole health and social care system.

(Martin Green, Chief Executive, ECCA DH, Independent Sector Dementia Champion, Chair, International Longevity Centre UK)

Community care at home

- Repeated surveys show that about two-thirds of people would prefer to die at home (including their care home) despite most still dying in hospital. However, this proportion is decreasing with efforts to improve home care for the last ten years.
- A key factor to providing community care is proactively commissioning 24-hour district nursing services – can people in your area contact a nurse at all times?
- The ‘dying in usual place of residence’ or DIUPR measure including care homes is slightly different from preferred place of care, but is also a useful measure.
- In a few areas the numbers dying in usual place of residence is just overtaking the number of hospital deaths – an encouraging sign of progress.
- The National Primary Care Audit (GSF Centre/Omega 2011) showed that about 25% of patients were included on the GPs’ Palliative Care Register; 23% were non-cancer patients but all those on the Palliative Care Register received better coordinated care.
- Care provision at home must include other services in addition to primary care teams including community nurses, community matrons, palliative care teams, proactive and emergency care, respite, domiciliary care, Marie Curie and other services, night sites, health care at home workers, equipment, etc.

Care homes

- This is a key area for quality improvement in EOLC with significant impact on quality and cost-effectiveness.
- Important area for good integrated working with NHS, social care and independent providers, and where the provision of services can be suboptimal.
- About a fifth of the population die in care homes.
- A majority of people with dementia live in care homes.
- Care home residents are often complex with multi-morbidities plus a majority have a degree of dementia.
- The average length of stay is now under a year.
- Avoidable admissions from residents of care homes are noted to be a significant factor in reducing hospitalisation and about half the admissions from care home residents could be avoided (National Audit Office report).
- Reducing hospitalisation for people with dementia is of particular importance due to the increased morbidity and mortality following admission to hospital.
- CQC is currently reviewing its standards and remit.
- Several training programmes support the improvements in the quality of care in care homes and better collaboration with hospices and specialist palliative care services.
- There is an increasing use of formalised ACP discussions in care homes.
- There is greater awareness of the importance of GP collaboration. Many areas support GPs to provide proactive visits, and anticipatory care, thereby preventing crisis admissions. This recommended good practice is supported locally by some QOF Local Enhanced Services financial incentives, but many areas suggest proactive visiting as standard practice.

Urgent care

- Crises occur at all times, but, for many, out-of-hours care is the crucial period.
- Introduction of the 111 urgent care services and communication of special patient notes or EOLC patients as priority to out-of-hours providers is increasing.

- Improved information transfer for patients on the GPs' Palliative Care Register and use of 'handover forms' is a QOF- and GSF-recommended best practice, and can be part of EPaCCS.
- The RCGP's urgent care guidance provides useful information on this area (see Appendix) including out-of-hours EOLC issues.
- Macmillan produced out-of-hours palliative care guidance and a training pack, and has other helpful resources and e-learning on its website.
- As patients cross boundaries of care, particularly with hospitals, they can fall between the gaps.
 - Particular barriers to good cross-boundary care are therefore communication and information transfer including interoperability of IT systems, raising the levels of awareness and training of staff in each setting so there can be a common understanding across sectors and engaging the public so that culture changing is addressed.
 - The aim is to follow the patient pathway across different settings of care, using a common vocabulary and plan. In some areas this can be GSF programmes or other EOLC vehicles in the different settings. London's Coordinate my Care EPaCCS system or Dorset's Summary Care Record (SCR) use are examples of good practice that demonstrate real improvement.

Hospital

- Consideration of out-of-hospital care, preventing admissions, reducing length of stay and increasing discharge, plus improving care for patients who die in hospital are key areas for CCG commissioners.
- Over half of the population die in hospital and for many this is not their preferred place of care. Hospital admissions are appropriate in many cases, and there will always be significant hospital mortality, though efforts are being made to decrease admission rates and lengths of stay.
- Reducing the Standard Hospital Mortality Ratio (SHMR) and increasing the numbers dying in the community (usual place of residence or preferred place of care) is a key focus in many areas and subject of many CQUINs.
- Most CCGs will be developing targets for out-of-hospital care or reducing hospitalisation, particularly focusing on these most vulnerable patients, as described in the four intersecting target areas (cf. p. 9). This can potentially provide the 'win-win' of enabling more patients to die where they choose, while also reducing costs.

Improving integrated cross-boundary care

- Integrated cross-boundary care is the ideal model to work towards in a CCG community, focused on the patient's particular needs and preferences, using patient feedback to improve services. This will require integrated working with health and social care and other providers.

Care for children nearing the end of life

- Care for children with life-limiting conditions in an area usually includes specific tertiary services, plus specialised community support and some local children's hospices.
- Therefore, care for all children with life-limiting conditions needs to be included in any strategic planning, despite the relatively small numbers involved. They are likely to have particular needs and require focused service provision, with particular emphasis on long-term care and support for families (see resources section).

The role of specialist palliative care and hospices

- The UK's world-leading and extensive provision of hospice and specialist palliative care service in the community and in hospitals is greatly valued.
- Traditionally, the focus is still mainly on care for people with cancer, although most services also include some non-cancer patients.
- Therefore, specialists play an invaluable role in the care for many people with cancer and some other conditions. They are a strong and highly valued resource for each area (see resources section).

Example of integrated cross-boundary care using GSF

Dorset, Bournemouth and Poole introduced the Gold Standards Framework for Care Homes (GSFCH) training programme to over 110 care homes to build on the widespread use of GSF by GPs. It was quickly recognised that these care homes were beginning to have a greater impact than anticipated. As a result other GSF programmes (in community hospitals, Next-Stage Primary Care Going for Gold, etc.) were commissioned and this builds on and supports other end of life care initiatives, including the use of the SCR as the shared electronic record (EPaCCS). Our aim is to develop integrated top-quality end of life care in every setting and to support better cross-organisational communication and coordination communication.

(Cath Granger, Service Improvement Manager, NHS Bournemouth and Poole and Dorset Cluster PCT)

Care for people with dementia nearing the end of life

In light of its increasing prevalence, care for people with dementia has become a national priority and is recognised to be one of the most important areas that require improvement in this country (see resources section). It is estimated that one in three people die with or of dementia, and a survey reported in the Prime Minister's Dementia Challenge suggests that dementia is feared more than any other condition. Since the Department of Health's Dementia Strategy in January 2011, there has been an increasing focus on helping people with dementia live well in the community and

this will be a significant focus for the future. Improving dementia care is one of the five statements in the NHS Mandate (November 2012) and is a key part of the National Outcomes Framework Domain 2 Outcome Measures.

EOLC for people with dementia, supporting people living well to the end of life, effectively begins from diagnosis or shortly afterwards, and can extend for several years. Support for carers and families is a crucial element and needs to be recognised as a particular instance for informed discussion with families, which may differ from the usual rules of patient confidentiality in other conditions. There has been a recent launch by the Prime Minister's office, working with the Alzheimer's Society, for development of 'dementia friends' and 'dementia friendly' communities. Some training in dementia care is available and there will need to be provision for dementia care and training in all areas.

To implement effective dementia care, a key focus from the National Clinical Director in Dementia Care is to improve early awareness and diagnosis, uptake of ACP discussions, and symptom management, especially pain relief, and to increase the emphasis on reducing hospitalisation for people with dementia. Pain is often under-treated and disguised in dementia and can cause disruptive behaviour that can then be inappropriately managed and sometimes leads to avoidable hospital admissions. Hospital admissions for people with dementia are significantly more likely to lead to increased mortality and morbidity, i.e. they can do more harm than good.

CCGs are therefore advised to include dementia as a key part of their strategy and outcome measures, including efforts to reduce inappropriate hospitalisation, particularly from care homes. EOLC will be a key part of the CCG dementia plans.

Workforce planning, training and quality assurance accreditation

The importance of training the workforce

Change management requires a skilled workforce. Although it is recognised that training and enablement underpins workforce development, in times of financial hardship training budgets may be squeezed despite an acknowledgement that services can be radically improved through quality improvement and training. National and local resources can support this, and with the development of Health Education England and Local Education and Training Boards the training required to support the growing educational needs of the workforce can be locally determined and enhanced.

National guidance is available from Skills for Health and Skills for Care guidance on EOLC competencies. Other education is available from many national and local sources, e.g. many hospices and specialist palliative care providers run locally relevant training and the e-learning e-ELCA programme commissioned by the NHS End of Life Care Programme is a useful free resource. The need for good training has been enforced in the debate about the LCP for the dying and the importance of communication with families and carers at all times, especially during the final days of life. Communication skills to support ACP discussions are available, such as that run by the NCPC and local experiential learning from hospices and other expert groups (see resources page for more details).

Quality assurance is also available through UKAS standards, Investors in People and specific peer-reviewed accreditation processes. The National Skills Academy and the Social Care Institute for Excellence provide guidance within social care.

GSF and quality assurance and accreditation

The GSF Centre is one example of a quality improvement education provider. It is the UK's biggest provider of generalist EOLC training and accreditation quality assurance assessments for several settings. GSF for Primary Care at basic Foundation level was mainstreamed to all general practices through the QOF in 2006, and 95% of practices claim these palliative care points, though their implementation of GSF can be variable. The GSF Care Homes programme is widely used across the country with over 2000 care homes trained and hundreds accredited or re-accredited after three years. GSF is endorsed by all major EOLC policy and guidance. The GSF Centre provides training and accreditation programmes for many settings and subjects, plus resources and support tailored to improve local implementation of policy into practice. Several programmes are available locally through the GSF Regional Centres, online or the VLZ.

GSF Accreditation and the Quality Hallmark Award is a widely recognised quality assurance scheme in EOLC. The GSF Care Homes accreditation process is endorsed by all major care home providers. It is recognised by the CQC as part of the Quality Risk Profile, and by several leading commissioners and contracting authorities. It provides quality assurance that care homes are meeting the standards required. The GSF Primary Care Quality Hallmark Award, endorsed by the RCGP, demonstrates what can be achieved by motivated practices and hospital accreditation is planned for 2014.

How can the RCGP help you?



Royal College of General Practitioners

In 2009 the Royal College of General Practitioners (RCGP) affirmed the importance of End of Life Care, as a priority within the college (see www.rcgp.org.uk/endoflifecare). Amongst other developments, an EOLC working group was formed to further develop the RCGP End of Life Care Strategy, which included representatives from all four nations in the UK group and separate groups for each nation. The group has produced the following (included on the website above):

- general guidance on policy, clinical support and means of improving EOLC in the UK and localised information for each nation, GPWSIs and other developments available on the RCGP EOLC microsite
- update on QOF information and Prognostic Indicator Guidance, with the National GSF Centre in End of Life Care
- the RCGP RCN Patient Charter in End of Life Care (June 2009) with an introductory letter to all RCGP members
- *Matters of Life and Death* guidance booklet, suggesting the possible uses of the patient charter and guidance on improving care in each GP practice
- this current EOLC guidance for GP CCG commissioners in England.

The RCGP Centre for Commissioning

The main purpose of the Centre for Commissioning (CfC) is to support GPs to become 'intelligent members' of their CCG so they can contribute to the commissioning agenda, support their CCG as micro-commissioners and hold their CCG to account for the local health system in which they work (see www.rcgp.org.uk/commissioning). By being more aware and owning some of the principles behind commissioning decisions for EOLC GPs in their surgery will be able to participate more fully in day-to-day clinical care individually and as a practice.

- *Strategic intent* – encourage local commissioners and their member practices to consider EOLC as one of their local priorities, building capacity in the community while promoting dignified and compassionate care.
 - Encourage clinician commissioners to consider the wider changes in their local end-of-life system, focusing on anticipatory care planning, the role of primary care and partnership working across the local health and social system
 - Demonstrate effective partnership working and clinical leadership to implement recommendations in the NHS Mandate.
 - Improve the health and wellbeing of the population by value-for-money outcome-based commissioning.
- (Dr David Paynton, RCGP Centre for Commissioning Lead)**

For other helpful resources from the RCGP and CIRC Clinical Champions including dementia, carers' support and care planning, see the RCGP website and list of further reading (on p. 45).

Appendix I: examples of best practice



Royal College of
General Practitioners



GSF RCGP Quality Hallmark Award for Accredited Practices

Figure 12 shows a summary of cumulative results and key ratios from all practices, before and after the GSF Going for Gold Training Programme. The accreditation process examines the feedback and measurable changes in practices, demonstrating improvement in good-quality EOLC for their patients (see www.goldstandardsframework.org.uk).

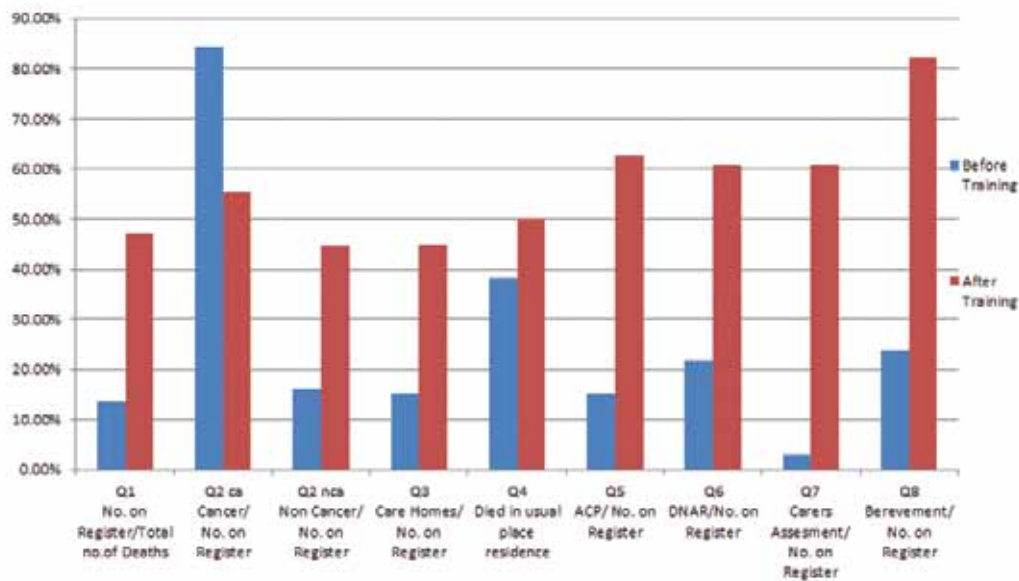


Figure 12: Summary of improvements in the GSF-Accredited GP practices
Source: Gold Standards Framework. Used with permission.

The first practices to undertake the distance learning training Next-Stage GSF Going for Gold Programme, attaining GSF Primary Care Quality Accreditation, were endorsed by the RCGP in November 2012.



The GSF Quality Hallmark Award was presented to the first seven GP practices by RCGP CEO Neil Hunt at the Annual National GSF Conference. All practices demonstrated significant improvements in care, attaining a high standard of patient outcomes, with evidence of sustainability through development of practice protocols and ongoing audit measures.

Figure 13: Neil Hunt presenting awards to GSF-Accredited practices at the National GSF Conference, 28 November 2012, London

Examples of best practice – the improvements that can be achieved by practices

GP practices undertaking Going for Gold and GSF Accreditation have shown:

- trebling of number of patients on Palliative Care/ GSF Register (range 32–69%)
- trebling of non-cancer and care home patients on Palliative Care Register (13–44% and 15–44% respectively)
- quadrupling of numbers with recorded ACP, DNAR, etc. (15–62%, 14–60%)
- increasing numbers dying in usual place of residence (38–50%)
- carers' assessment and bereavement protocols increased several-fold (3–60% and 23–82% respectively)
- development of practice protocols to enable sustained long-term quality improvement in all.

NHS End of Life Care Programme, Dying Matters and Find Your 1% campaign

The National End of Life Care Programme and Dying Matters have developed a practical tool to help GPs identify those patients who may be in their last year of life and talk to them about their preferences (see www.dyingmatters.org/gp). As well as links to useful sources of information, the pack contains postcards with support and advice on:

- identifying people at the end of life
- having EOLC conversations
- putting plans in place
- managing and coordinating care
- space to include local information such as the telephone numbers of hospices, palliative care teams and pharmacies that stock palliative care drugs.

Hard copies of this pack can be ordered by emailing information@eolc.nhs.uk.



Figure 14: Find your 1% campaign

Source: National End of Life Care Programme. Used with permission.

The National GSF Centre for End of Life Care runs Training and Accreditation for primary care teams, care homes, acute and community hospitals, domiciliary care, dementia care and other areas. It is the only such award in EOLC for primary care.

The GSF Accreditation and the Quality Hallmark Award are recognised as independent indicators of quality for quality assurance by CQC, several PCT commissioners, the London Procurement Programme and others. For more details see the GSF website.

The GSF Centre shares information with the Care Quality Commission about care homes who have achieved GSF Accreditation. This information will be included in the Quality and Risk profiles that CQC holds for each registered provider ... used by CQC inspectors to inform assessment of risks to the quality of services.

(Lisa Annaly, Head of QRP Intelligence
Directorate, CQC)

The Dying Matters Coalition has announced the launch of a DVD aimed at boosting GPs' confidence in EOLC conversations. *How Long Have I Got, Doc?* was announced to coincide with the release of the evaluation of the Dying Matters GP Pilot. The evaluation revealed that increasing GPs' confidence in talking to patients about dying and death can transform their EOLC (see www.nhsevents.org/img/events/215/jackie%20lynton.pdf).

The role of informatics and Electronic Palliative Care Coordinating Systems (EPaCCS)

The NHS End of Life Care Strategy identifies the need to improve coordination of care, recognising that people at the end of life frequently receive care from a wide variety of teams and organisations. The development of EPaCCS supports both crisis and ACP and allows communication of people's care preferences and key details about their care. With appropriate consent and governance, EPaCCS can provide access to up-to-date information for all health and social care providers who have a legitimate relationship with a patient, across a range of settings, 24/7. EPaCCS aims to support patient care coordination, improve patient choice and quality of care, and is highlighted as a critical success factor for EOLC.

There is a national information standard for the

core content to be recorded in EOLC coordination systems, both electronic and paper-based (ISB 1580). The standard requires all contracts for new EPaCCS signed since March 2012 to specify compliance with the standard IT systems; existing EPaCCS are required to comply by December 2013. The information standard provides us with guidance to help achieve this in the UK. Useful resources for the above can be found on the EOLC website (see resources).

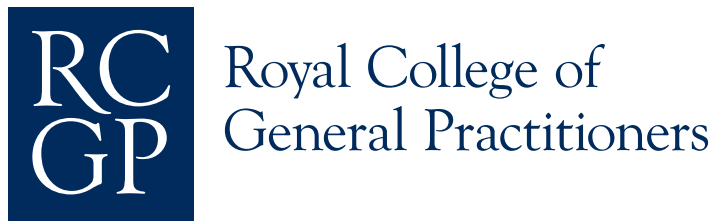
It is envisaged that EPaCCS will include communication with many services and providers – GP practices, out-of-hours services, ambulance service, A&E and acute services, community, social care, care homes, specialist palliative care services and others.

A note on patients' consent

Patients' consent must be sought before inclusion on the EPaCCs or locality register. In a similar way it is recommended good practice that patients included on the GPs' Palliative Care or GSF Register are also offered an explanatory discussion describing what this might mean for them and beginning an ACP discussion (and giving them a leaflet such as 'Planning

Your Future Care' – see resources). In the light of the current constitutional consultation, it is possible that in future people will be offered a discussion and will give consent before being included on any such register or pathway, including the LCP or other. More details will be available later.

RCGP RCN Patient Charter



- We suggest that you discuss the Charter as a primary healthcare team. This includes working with community nursing, social care and palliative care teams. Seek views from your patient group and talk about it with patients and carers who you are supporting. They may be happy to help others and to share their experience.
- Decide whether you feel able to sign up to the Charter and add the name and contact number for the relevant person within your practice at the bottom of the Charter.
- Give the Charter to patients and the carers of people who are nearing the end of their life, e.g. those on the practice Palliative Care/GSF Register. It may lead to further discussion and a need for some clarification.
- Display the Charter in your waiting room and include it in your practice information pack.
- Use the Charter as a standard against which to review your care. Such review or audit could be included as one of the aspects of your own appraisal, revalidation or practice accreditation.
- If you feel you need help in implementing certain aspects of the Charter or require further training and support, discuss this with your local palliative care/EOLC team or facilitators. Visit the RCGP website at www.rcgp.org.uk/endoflifecare, the GSF at www.goldstandardsframework.org.uk or the National End of Life Care Programme at www.endoflifecareforadults.nhs.uk.
- Further information and guidance is available to download from the RCGP website at www.rcgp.org.uk/endoflifecare.

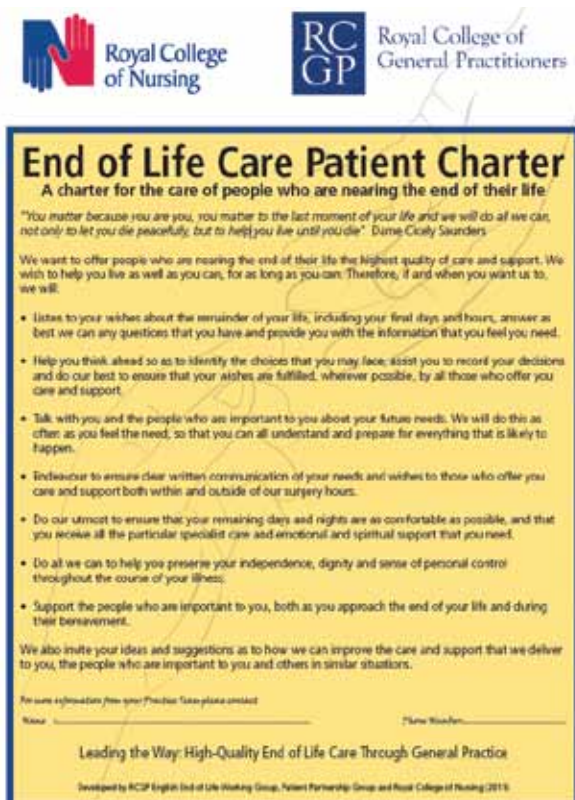


Figure 15: End of Life Care Patient Charter

For more information on using the RCGP RCN Patient Charter, see the RCGP guidance Matters of Life and Death

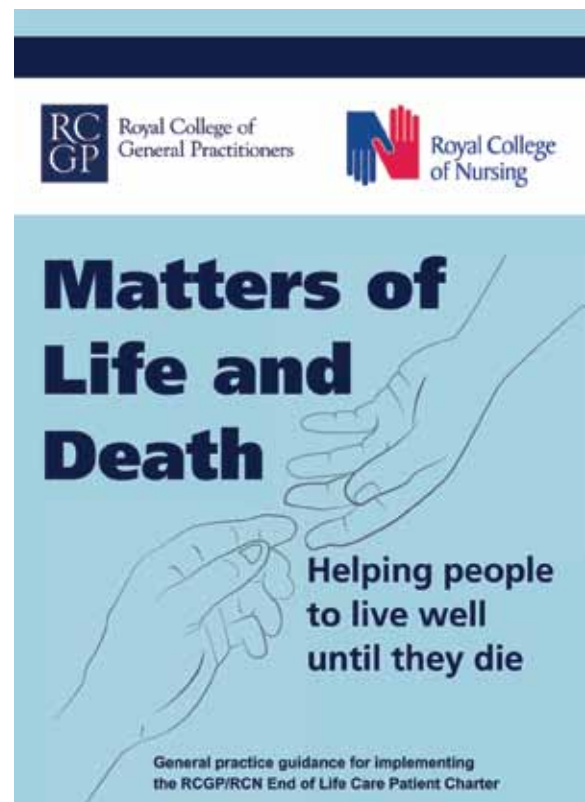


Figure 16: Matters of Life and Death

See www.rcgp.org.uk/clinical-and-research/clinical-resources/~lmedia/Files/CIRC/Matters%20of%20Life%20and%20Death%20FINAL.ashx.

Appendix II: guidance, further reading and other resources



**National Institute for
Health and Clinical Excellence**

NICE EOLC for adults quality standards

1	People approaching the end of life are identified in a timely way.
2	People approaching the end of life and their families and carers are communicated with, and offered information, in an accessible and sensitive way in response to their needs and preferences.
3	People approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, with the opportunity to discuss, develop and review a personalised care plan for current and future support and treatment.
4	People approaching the end of life have their physical and specific psychological needs safely, effectively and appropriately met at any time of day or night, including access to medicines and equipment.
5	People approaching the end of life are offered timely personalised support for their social, practical and emotional needs, which is appropriate to their preferences, and maximises independence and social participation for as long as possible.
6	People approaching the end of life are offered spiritual and religious support appropriate to their needs and preferences.
7	Families and carers of people approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, and holistic support appropriate to their current needs and preferences.
8	People approaching the end of life receive consistent care that is coordinated effectively across all relevant settings and services at any time of day or night, and delivered by practitioners, who are aware of the person's current medical condition, care plan and preferences.
9	People approaching the end of life who experience a crisis at any time of day or night receive prompt, safe and effective urgent care appropriate to their needs and preferences.
10	People approaching the end of life who may benefit from specialist palliative care are offered this care in a timely way appropriate to their needs and preferences, at any time of day or night.
11	People in the last days of life are identified in a timely way and have their care coordinated and delivered in accordance with their personalised care plan, including rapid access to holistic support, equipment and administration of medication.
12	The body of a person who has died is cared for in a culturally sensitive and dignified manner.
13	Families and carers of people who have died receive timely verification and certification of the death.
14	People closely affected by a death are communicated with in a sensitive way and are offered immediate and ongoing bereavement, emotional and spiritual support appropriate to their needs and preferences.
15	Health and social care workers have the knowledge, skills and attitudes necessary to be competent to provide high-quality care and support for people approaching the end of life and their families and carers.
16	Generalist and specialist services providing care for people approaching the end of life and their families and carers have a multidisciplinary workforce sufficient in number and skill mix to provide high-quality care and support.

This NICE quality standard defines clinical best practice within this topic area. It provides specific, concise quality statements, measures and audience descriptors to provide the public, health and social care professionals, commissioners and service providers with definitions of high-quality care.

Other references and web links

National NHS policy

- The Mandate – a mandate from the government to the NHS Commissioning Board: April 2013 to March 2015. Presented to parliament pursuant to Section 13A(1) of the National Health Service Act 2006 (November 2012, Department of Health): www.dh.gsi.gov.uk/mandate.
- The NHS Constitution (8 March 2012, Department of Health): www.dh.gov.uk/constitution.
- The NHS Outcomes Framework 2013/14 (13 November 2012, Department of Health): www.dh.gov.uk/publications/files/2012/11/121109-NHS-Outcomes-Framework-2013-14.pdf.
- Department of Health End of Life Care Strategy: www.dh.gov.uk/health/2012/10/end-of-life-care-fourth/.
- NICE Quality Standards in End of Life Care (November 2011 + COF draft developments): www.nice.org.uk/guidance/qualitystandards/endoflifecare/home.jsp.
- The Palliative Care Funding Review (June 2011): <http://palliativecarefunding.org.uk/PCFRFinal%20Report.pdf>.

Other guidance

- Macmillan Cancer Support and EOLC resources including e-learning and out-of-hours toolkit: www.macmillan.org.uk/Aboutus/Healthandsocialcareprofessionals/Macmillansprogrammesandservices/Palliativeandendoflifecare.aspx.
- King's Fund EOLC commissioning guidance (September 2011), High Impact and Ten Top Tips: www.kingsfund.org.uk/publications/articles.
- The National Audit Office EOLC report (2008): www.nao.org.uk/publications/0708/end_of_life_care.aspx.
- Lien Foundation's Quality of Death Audit: http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf.

- PDSA Improvement Methodology: www.institute.nhs.uk/quality_and_service_improvement_tools/quality_and_service_improvement_tools/plan_do_study_act.html.
- General Medical Council, Treatment and Care towards the End of Life: www.gmc-uk.org/End_of_life.pdf_32486688.pdf.
- Care Quality Commission: www.cqc.org.uk.
- Care Quality Commission, *The State of Health Care and Adult Social Care in England*: www.cqc.org.uk/sites/default/files/media/documents/cqc_soc_201112_final_tag.pdf.
- Palliative Care Funding Review (2011): <http://palliativecarefunding.org.uk/PCFRFinal%20Report.pdf>.

RCGP resources in EOLC

- RCGP End of Life Care Strategy: www.rcgp.org.uk/end_of_life_care/.
- RCGP RCN *Matters of Life and Death* guidance: www.rcgp.org.uk/Clinical-and-research/Clinical-resources/~media/Files/CIRC/Matters%20of%20Life%20and%20Death%20FINAL.ashx.
- RCGP RCN Patient Charter: www.rcgp.org.uk/Clinical-and-research/Clinical-resources/~media/Files/CIRC/CIRC_EOLCPatientCharter.ashx.
- RCGP Centre for Commissioning: www.rcgp.org.uk/revalidation-and-cpd/centre-for-commissioning.aspx.
- RCGP carers' support: www.rcgp.org.uk/clinical-and-research/clinical-resources/carers-support.aspx.
- RCGP urgent and emergency care: www.rcgp.org.uk/revalidation-and-cpd/~media/Files/CIRC/Urgent_emergency_care_whole_system_approach.ashx.
- RCGP, *Care Planning: improving care for people with long term conditions*: www.rcgp.org.uk/clinical-and-research/clinical-resources/~media/Files/CIRC/Cancer/Improving%20the%20Lives%20of%20people%20with%20LTC%20-%202012%2005%2009.ashx.

RCGP policies in other devolved countries

- Scotland: www.rcgp.org.uk/rcgp-near-you/rcgp-scotland.aspx.
- Wales: www.rcgp.org.uk/rcgp-near-you/rcgp-wales.aspx.
- Northern Ireland: www.rcgp.org.uk/rcgp-near-you/rcgp-northern-ireland.aspx.

National End of Life Care Programme Resources and Links

The current NEoLCP website is in transition. However, users can access the following publications via the search tool at www.endoflifecare.nhs.uk:

- *Planning Your Future Care* booklet
- Commissioning Toolkit
- 1% GP pack
- *Finding the Words*
- End of Life Care Quality Assessment Tool
- Electronic Palliative Care Coordination Systems (EPaCCS) data reports (including Coordinate My Care)
- QIPP agenda in EOLC – local and national teams.

Other useful links:

- ELCQuA: www.elcqua.nhs.uk
- on data and statistics: www.endoflifecare.nhs.uk/support-advice/data-statistics.aspx
- National End of Life Care Intelligence Unit: www.endoflifecare-intelligence.org.uk
- E-Learning End of Life Care for All (E-Elca): www.e-lfh.org.uk/projects/end-of-life-care
- End of Life Care Coordination, Core Content, 2011: www.isb.nhs.uk/library/standard/236.

For more information, please see the Public Health England website: www.gov.uk/government/organisations/public-health-england.

National Council for Palliative Care Resources

- Dying Matters: www.dyingmatters.org.
- Find Your 1% – helping GPs deliver quality EOLC: www.dyingmatters.org/gp.

- The Dying Matters Coalition DVD aimed at boosting GPs' confidence in end of life conversations: www.dyingmatters.org/gp_page/dvd.
- Influencing Toolkit: www.ncpc.org.uk/influencing-toolkit.
- Clinical Commissioning Groups Action Sheet: www.ncpc.org.uk/sites/default/files/Action%20Sheet%203%20-%20CCGs.pdf.
- Health & Wellbeing Boards Action Sheet: www.ncpc.org.uk/sites/default/files/Action%20Sheet%204%20-%20Health%20and%20Wellbeing%20Boards.pdf.
- *What about End of Life Care? Mapping England's Health & Wellbeing Boards' vision for dying people*: www.ncpc.org.uk/sites/default/files/NCPC%20Mapping%20EOLC%20Health%20and%20Wellbeing%20strategy%20briefing%20October2012.pdf.

National Gold Standards Framework Centre for End of Life Care

The GSF Centre runs training and accreditation programmes in end of life care in a number of settings, plus guidance, tools and other resources. GSF training programmes currently available are:

- Care Homes
- Primary Care, Next Stage GSF 'Going for Gold'
- Acute Hospitals
- Community Hospitals
- Domiciliary Care
- Dementia Care
- Integrated Cross Boundary Care
- Other Settings.

Please see the GSF website for more information and further resources (which can be accessed via the search tool): www.goldstandardsframework.org.uk. These include:

- GSF Prognostic Indicator Guidance
- National Primary Care Audit in End of Life Care
- Advance Care Planning guidance
- QOF completion.

Marie Curie

- Marie Curie Atlas: www.mariecurie.org.uk/Commissioners-and-referrers/Resources/Marie-Curie-Atlas/, www.mariecurie.org.uk/Documents/HEALTHCARE-PROFESSIONALS/commissioning-services/Q744_Atlas_end%20of%20life%20care_V9_update.pdf.
- Marie Curie publications and evaluations: www.mariecurie.org.uk/en-gb/healthcare-professionals/commissioning-services/publications/?Tab=1.
- Marie Curie Palliative Care Institute Liverpool: www.mcpcil.org.uk/.
- Liverpool Care Pathway: www.liv.ac.uk/mcpcil/liverpool-care-pathway/.

Specialist palliative care

- Help the Hospices – What is Hospice Care? www.helpthehospices.org.uk/about-hospice-care/what-is-hospice-care/.
- Association for Palliative Medicine: www.apmonline.org.
- Association for Palliative Medicine – commissioning guidance for specialist palliative care: www.apmonline.org/documents/135764105191600.pdf.

Advance Care Planning

- NEOFPC ACP Toolkit: www.endoflifecareforadults.nhs.uk/publications/acp-toolkit.
- Thomas K, Lobo B (eds). *Advance Care Planning in End of Life Care*. Oxford: Oxford University Press, 2010.
- GSF Centre – ACP: www.goldstandardsframework.org.uk/AdvanceCarePlanning.html.

Social care

- National Skills Academy for Social Care: www.nsasocialcare.co.uk/.
- Social Care Institute for Excellence: www.scie.org.uk/.
- National Home Care Council: www.nationalhomecarecouncil.co.uk/index.html.

Dementia

- Department of Health, *Living Well with Dementia: a national dementia strategy*: www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_094051.pdf.
- Department of Health, *Prime Minister's Challenge on Dementia: delivering major improvements in dementia care and research by 2015*: www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_133176.pdf.
- Dementia UK: www.dementiauk.org/.
- Alzheimer's Society – dementia-friendly communities: www.alzheimers.org.uk/.

Children's palliative care

- Together for Short Lives: www.togetherforshortlives.org.uk.
- Royal College of Paediatrics and Child Health (RCPCH): www.rcpch.ac.uk.
- *Bringing Networks to Life: an RCPCH guide to implementing clinical networks* (March 2012). Available from the University of York: <http://php.york.ac.uk/inst/yhec/files/resources/KVL132-Final%20Report.pdf>.
- Craft A, Killen S. *Palliative Care Services for Children and Young People in England: an independent review for the Secretary of State for Health*. London: DH, 2007: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_074459.
- Amery J. *Children's Palliative Care Handbook for GPs*. Bristol: ACT, 2011. This provides a practical and emotional support guide for GPs across the UK who face the challenge of working with a child requiring palliative or end-of-life care and their family. It is freely available online from the Together for Short Lives website at: www.togetherforshortlives.org.uk/assets/0000/1057/Children_s_palliative_care_handbook_for_GPs.pdf.

Published by the

Royal College of General Practitioners
30 Euston Square, London NW1 2FB

www.rcgp.org.uk

Registered Charity Number 223106



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