

# SUPPORTING QI ACTIVITY IN END OF LIFE CARE

Quality improvement for primary  
and community care

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# INTRODUCTION

## Purpose of document

This document has been designed by Macmillan Cancer Support to provide information, tools and examples of best practice in relation to the new quality improvement module in the 2019–20 GP Contracts on end of life care. This document is designed to provide GP practices and Primary Care Networks with examples of successful quality improvement initiatives related to end of life care and guidance on where to find supporting tools and resources as needed.

## This document can be used by all

The primary purpose of this document is to be used in a facilitative way across a Primary Care Network area, led by a Macmillan GP or recruited network lead, however it may also be useful to:

- CCG GP leads
- End of life care commissioners
- EOLC Facilitators
- Service Improvement Leads
- GPs
- GP federations and alliances
- Strategic Clinical Leads
- Practice Managers

## Policy context and changes to the GP contract and how this is relevant to end of life care

The NHS Long Term Plan has committed to £4.5 billion more for primary medical and community health services by 2023/24 and as part of that settlement NHS England and the British Medical Association have agreed a five-year GP contract framework from 2019/20. The new contract framework has significant changes, perhaps some of the most noteworthy in over a decade and are seen as being key to delivering the ambitions of the NHS Long Term Plan.



For full details, see the [GP contract agreement England 2019/20](#) on the BMA website.<sup>1</sup>

As part of these changes, 175 QOF points from 28 indicators have been retired, with 101 being recycled into more appropriate indicators and 74 creating a new Quality Improvement domain. For 2019, the new Quality Improvement domain will include two modules – end of life care, and prescribing safety.

For the end of life care quality improvement domain, there is a focus on:

- Early identification and support for people who might die within 12 months
- Well-planned and coordinated care that is responsive to patient needs
- Identification and support for family/ informal care-givers as part of a patient's core support team and as individuals facing bereavement.

The new QOF indicators are:

**QI003:** The contractor can demonstrate continuous quality improvement activity focused on end of life care as specified in the QOF guidance. This is worth 27 points.

**QI004:** The contractor has participated in network activity to regularly share and discuss learning from quality improvement activity as specified by the QOF guidance. This would usually include participating in a minimum of two network peer review meetings. This is worth 10 points.

To achieve these QOF points, practices will need to demonstrate that they have:

- Evaluated the current quality of their end of life care and identified areas for improvement
- Identified quality improvement activities and set improvement goals
- Implemented an improvement plan
- Participated in a minimum of 2 network peer review meetings
- Completed the QI monitoring template
- An increase in the proportion of people who die from advanced serious illness where a family member, NOK or informal care giver had been identified; with an increase in the offer of holistic support before and after death.
- A reliable system in place to monitor and enable improvement based on timely feedback of the experience of care from staff, patients and carers.

GP practices are encouraged to focus any quality improvement activities and goals around:

- An increase in the proportion of people who die from advanced serious illness, who had been identified in a timely manner on a palliative/supportive care register.
- An increase in the number of people who died from advanced serious illness who we offered timely and relevant personalised care and support plan discussions that were documented and shared electronically to support delivery of coordinated care.

# TOOLS, TEMPLATES AND INFORMATION

## Practical Tools for improving quality

### Macmillan's Cancer Care in Primary Care Quality Toolkit for General Practice, Module 4 – End of Life Care

Macmillan's Quality Toolkit for general practice is a practical toolkit containing modules spanning the entire cancer pathway with the aim of improving the quality of cancer care provided within primary care. Module four of this toolkit focuses on Advance Care Planning and appropriate sharing using Electronic Palliative Care Coordination Systems or Enhanced Summary Care Record for advanced serious illness.

This module encourages GP Practices to examine the quality of information contained within their electronic patient records, coding practices around end of life care and to consider how effectively that information is being shared with other appropriate professionals. It is also designed to encourage an analysis of symptom control and care planning for those in the last years of life as well as last weeks and days.

 For more information email [macdocs@macmillan.org.uk](mailto:macdocs@macmillan.org.uk).

### RCGP Palliative and End of Life Care Toolkit

The Palliative and End of Life Care Toolkit provides a collection of tools, knowledge, and current guidance for healthcare professionals to support patients nearing the end of life to live well until they die. The resources include information for patients and those close to them.

 You can access the RCGP Toolkit [here](#).<sup>2</sup>

### Palliative Care Templates in GP IT systems

Macmillan has worked collaboratively with healthcare system provider EMIS Health to develop an integrated palliative care template within EMIS Web. Palliative care templates provide professionals with a structure from which they can initiate a conversation with patients and their loved ones which is both holistic and appropriately recorded in the patient notes. We are also in the process of developing a patient information leaflet to embed within this template with guidance on how to access Macmillan support and information, highlighting resources that may be helpful at this time of need. We are now working with each of the main GP IT providers to replicate this template and the supporting information contained within it.

### Macmillan Primary Care Webpage

Macmillan's webpage for Primary Care contains a number of resources to support Primary Care Professionals in delivering good quality end of life care.

 See [www.macmillan.org.uk/gp](http://www.macmillan.org.uk/gp) which contains links to education modules, guidance for professionals and relevant information for patients, as well as key picks from Macmillan's [10 Top Tips series](#).<sup>3</sup>

Some of particular interest will be:

- [Primary Care Ten Top Tips for Advance Care Planning](#)
- [Primary Care Ten Top Tips for Supportive and Palliative Care Meetings](#)
- [Primary Care Ten Top Tips for DNACPR](#)

There are many other resources for patients, carers and professionals on topics such as advanced disease, end of life and bereavement freely available to order from the Be Macmillan website:

 You can access and order any of these resources [www.bemacmillan.org.uk](http://www.bemacmillan.org.uk)

#### Life QI

Life QI is a web software platform built to support and manage quality improvement work in health and social care.

 You can find out more information [www.lifeqisystem.com](http://www.lifeqisystem.com)

#### NHS Support

NHS Improvement has a number of resources and examples on their website to help with your QI activity.

 You can access these at <https://improvement.nhs.uk/resources/pdsa-cycles>.

#### Daffodil Standards for GPs

The Daffodil Standards is a free, evidence-based, structured approach to help your GP practice to consistently offer the best end of life care for patients.

 More information on the [Daffodil Standards](#) can be found on Marie Curie's website.<sup>4</sup>

## Practical tools for identification

#### Scottish Comparator Tool for identification

In Scotland a tool has been developed to support the earlier identification of people who would benefit from a palliative approach to their care. This tool comparator enables healthcare professionals to decide upon which of the various identification tools can be used to support earlier identification in practice.

 You can access the tool [here](#).<sup>5</sup>

#### Supportive & Palliative Care Indicators Tool (SPICCTM)

The SPICCTM is a tool to help identify people at risk of deteriorating and dying and is freely available to download.

 You can access the tool [www.spict.org.uk](http://www.spict.org.uk)

#### Gold Standards Framework (GSF) Proactive Indicator Guidance (PIG)

THE GSF PIG is a tool designed enable the earlier identification of people nearing the end of their life who may need additional supportive care.

 You can access the tool [here](#).<sup>6</sup>

## Practical tools for carer support and assessment

### The Carer Support Needs Assessment Tool (CSNAT)

The CSNAT is an evidence-based tool that facilitates tailored support for informal carers – family/friends of adults with long term life-limiting conditions. The research underpinning this tool was informed by carers and practitioners.

It comprises 14 domains (broad areas of need) in which carers commonly say they require support. Carers may use this tool to indicate further support they need both to enable them to care for their family member or friend and to preserve their own health and well-being within their caregiving role.

It is short and simple to use for both carers and practitioners using a simple question and answer format to ask family carers which areas they need more support with.

CSNAT is protected by copyright, organisations need a licence to use the tool. Completion of CSNAT training is also required. The CSNAT tool and online training are available free of charge for healthcare professionals in non-commercial settings.



You can access more information about this assessment tool at <http://csnat.org>

## Practical tools for gathering patient and carer experience of care and support at end of life

### **Palliative care Outcome Scale (POS)**

The POS measures are a family of tools to measure patients' physical symptoms, psychological, emotional and spiritual, and information and support needs. They are a validated instrument that can be used in clinical care, audit, research and training.

 The scale can be accessed <https://pos-pal.org>

### **Outcome Assessment and Complexity Collaborative (OACC) Suite of Measures**

The Outcome Assessment and Complexity Collaborative (OACC) has collated a suite of fit-for-purpose outcome measures designed to help palliative care services to measure, demonstrate and improve care for patients and their families. It contains patient and carer reported measures.

 The OACC can be accessed [here](#).<sup>7</sup>

### **Sweeney Programme**

The Sweeney Programme is founded on the belief that staff can provide the best care by stepping back and seeing the experiences through the patient's eyes. The unique improvement programme equips staff with the tools to do this and enables staff to step into patients' shoes and see care through their eyes. Using tried, tested and effective tools and experiential techniques, the programme helps staff get as close to experiencing the patient's journey as possible.

The programme builds the capacity of staff in frontline teams to drive sustainable, bottom-up change in their services using insights into patients' experience of care and techniques

such as patient shadowing and filmed patient interviews to help staff to question their own routines and practices and see them in a new light.

 See the [Sweeney Programme](#) for more information.<sup>8</sup>

### **National Bereavement Alliance**

The NBA aims to ensure that all people have awareness of and access to support and services throughout their bereavement experience. Their website contains a number of useful resources including training for people working with bereaved people and can be found <https://nationalbereavementalliance.org.uk>

### **Local Bereavement Surveys**

A regular survey of the experiences of informal carers/those important to the person who has died can provide a useful proxy measure of patient experiences of end of life care provision, where it is difficult to gain patient experience directly.

This toolkit, whilst now several years old, still provides some helpful advice and guidance on how to introduce a local version of the national VOICES survey, using only the sections of the survey relevant to your area – eg the GP or community care sections.

The toolkit was developed by Dr Katherine Hunt, Senior Research Fellow, University of Southampton and Professor Julia Addington-Hall, Professor of End of Life Care, University of Southampton.

 You can access the toolkit [here](#).<sup>9</sup>

## Helpful sources of information and data on Palliative and End of Life Care

### Ambitions for Palliative and End of Life Care

The National Palliative and End of Life Care Partnership consists of organisations representing health and social care, statutory and voluntary bodies, and people with personal and professional experience, speaking with one voice. It is a broad partnership of national organisations working in England, sharing a deep commitment to improving end of life care in our country.

 Resources and information are available on the website <http://endoflifecareambitions.org.uk>

### Macmillan Rich Picture

Macmillan Cancer Support has produced a Rich Picture on people at the end of life and whilst this has a cancer focus, there is some useful information which is generic and helpful in setting the context around palliative and end of life care.

 You can find this document [here](#).<sup>10</sup>

### National End of Life Care Intelligence Network (NEoLCIN)

The NEoLCIN is part of Public Health England and provides information and intelligence to improve the collection and analysis of information related to the quality, volume and costs of care provided by the NHS, social services and charities to adults approaching the end of life. This intelligence will help drive improvements in the quality and productivity of services.

 You can access more information on the NEoLCIN [www.endoflifecare-intelligence.org.uk/home](http://www.endoflifecare-intelligence.org.uk/home)

## Atlas of Variation for Palliative and End of Life Care

Public Health England (PHE) has published the Atlas of variation in palliative and end of life care for England.

The Atlas contains 29 indicators such as causes of death and indicators of the quality of care in hospitals and in the community. It also contains 29 maps exploring palliative and end of life care over three sections, namely: the need for palliative and end of life care, the role of hospitals in palliative and end of life care and palliative and end of life care in the community.

The Atlas provides a useful palliative and end of life care resources section which signposts

key guidelines and policy statements. This together with information on local performance can be used to highlight and improve services.

The Atlas contains useful resources on palliative and end of life care. For example, such as CCG and local authority End of Life Care Profiles and End of life care data to inform Sustainability and Transformation Partnerships (STPs).

 You can access the Atlas <http://tools.england.nhs.uk/images/EOLCatlas/atlas.html>

## Education Resources for primary care professionals

### Training Modules – Macmillan LearnZone

LearnZone is an online platform with multiple free learning resources, online courses, and professional development tools. Some that may be of particular interest are:

- Advance Care Planning – an e-learning module for professionals exploring when and how to start conversations with patients about future care planning.

 The resource can be found <https://learnzone.org.uk/macprofs/238>

- Foundations in Palliative Care – This resource is designed for use in facilitated learning sessions for groups.

 The resource can be found <https://learnzone.org.uk/courses/course.php?id=318>

### End of Life Care for All (e-ELCA)

The e-learning programme End of Life Care for All (e-ELCA) aims to enhance the training and education of the health and social care workforce so that well-informed high quality care can be delivered by confident and competent staff and volunteers to support people wherever they happen to be. The programme is managed by Health Education England's e-Learning for Healthcare programme in partnership with the Association for Palliative Medicine e-ELCA sessions have been highlighted as a resource to help with implementation of the NICE Guidelines on improving care for people who are in their last days of life (Care of Dying Adults in the Last Days of Life).

 You can access information about this e-learning programme [www.e-lfh.org.uk/programmes/end-of-life-care](http://www.e-lfh.org.uk/programmes/end-of-life-care)

## Resources for patients which may benefit professionals

### End of Life: A Guide

Macmillan Cancer Support has developed an information booklet in collaboration with Marie Curie entitled End of Life: a guide. This booklet explains what happens at the end of life and how to plan for it. It gives information about issues such as choosing where to be looked after, sorting out unfinished business, getting financial help, who can help if you're being cared for at home and what to expect in the last few days of life. It also has information for relatives and friends involved in the person's care. Whilst this is aimed at the public, it is also a resource which may be helpful to have available in GP practices, not just for the benefit of patients but practice staff may also find this helpful. This may be particularly beneficial to non-clinical staff such as receptionists who often deal with patients and their carers without always understanding what end of life care is about or how to deal with difficult situations.

 You can access the guide [here](#).<sup>11</sup>

### Find me Help

Find Me Help is an online directory which lists some national and local services for people in the last years of life, their families, carers and friends.

 You can access the Find me Help directory <http://help.dyingmatters.org>

### Your Life, Your Choices

This booklet which is aimed at patients, but may also be helpful to carers or practice staff, talks about how patients can plan ahead for their future care.

There are many other resources for patients, carers and professionals on topics such as advanced disease, end of life and bereavement freely available to order from the Be Macmillan website:

 You can access and order any of these resources [www.bemacmillan.org.uk](http://www.bemacmillan.org.uk)

### Sources of support for carers

- Carers UK: Expert advice and support for all the UK's carers [www.carersuk.org](http://www.carersuk.org)
- Carers Trust: Network of local support for carers [www.carers.org](http://www.carers.org)
- Carers Direct: [www.nhs.uk/carersdirect](http://www.nhs.uk/carersdirect)
- For cancer specific carers support there is a [guide](#) for health and social care professionals.<sup>12</sup>

# EXAMPLES OF BEST PRACTICE

## General Principles of Good EOLC in the Community

Through previous investment in a number of sites across the UK, Macmillan has gathered evidence on the key principles of enhanced community end of life care that are critical to the delivery of a high-quality service. Over the next three years Macmillan will be investing further in sites across the UK to continue learning how best to deliver these principles. We recognise that outside of these sites full delivery of all the principles may not be possible; however, it may be useful to consider these principles at a Primary Care Network level and how your service can work collaboratively with specialist palliative care and community services to work towards these:

- Co-ordinated and integrated care across teams and boundaries
- Multi-skilled and multi-professional teams
- Rapid Response to unscheduled care needs
- Learning and development for specialist and generalist staff

- Dedicated support from a Consultant in Palliative Medicine
- Early Referral into Specialist Palliative Care

 For more information about Macmillan's End of Life Care Strategy and investment sites please email Monica Burchell, **E8@macmillan.org.uk** End of Life Care Programme Manager, Macmillan Cancer Support.

 See Macmillan's website for more information about the evidence from Midhurst, [Macmillan Specialist Care at Home](#),<sup>13</sup> and the [North Manchester Macmillan Palliative Care Support Service](#)<sup>14</sup>

## Scotland

### Quality improvement initiative

In Scotland, QOF was replaced in its entirety in 2016 by a new funding formula and quality framework – Improving Together – which places an obligation on practices to participate, as part of a ‘GP cluster’, in a new framework for quality improvement more suited to a holistic approach to quality and outcomes of personalised care.

The Improving Together framework provides an alternative route to continuously improve the quality of care that patients receive by facilitating strong, collaborative relationships across GP clusters and localities. At the heart is learning, developing and improving together for the benefit of local communities. GP clusters are at the heart of identifying priorities locally of which primarily lead the improvement agenda.

GP practices engage in quality improvement activities that are agreed at GP cluster level quality improvement planning. Practices participate in a cluster quality peer review process, whereby their quality improvement activity and quality data will be reviewed by their local GP cluster.

In addition to this, through the strategic framework for action on end of life and palliative care and the national palliative care enhanced service (DES), practices are supported to ensure that they identify appropriate patients for the palliative care registers and that these patients have electronic palliative care summaries completed and available in the out of hours period. GP practices are asked to (i) Do an annual multidisciplinary review of all deaths within the practice, (ii) explore whether people could have been identified earlier. (iii) develop an action plan.

Over the past two years Healthcare Improvement Scotland has been working with five different community based test sites to explore how to improve identification and care co-ordination in palliative care. One of the outputs from this was the development of a Palliative Care Identification Tools Comparator<sup>15</sup> and a compilation of Evidence of what works<sup>16</sup> in continuity and care co-ordination in palliative and end of life care.

## Milton Keynes

### **Increasing the number of people identified at end of life and offered an advance care plan**

The GP-ACP pilot started in February 2018 with eight Milton Keynes practices. The idea behind the project was to increase the number of people identified at end of life and therefore increase the number of people offered an advance care planning conversation. There were a significant proportion of patients in the final years of life being admitted to and dying in hospital unnecessarily – by extrapolating national data, the pilot estimated that around four people a week were dying in Milton Keynes General Hospital who had no medical need to be there.

While the GP practices mostly had a palliative/supportive care register and received QOF points for keeping this register, there was variance in terms of whether monthly MDT meetings were held, what disease groups were identified and the overall number of people on that list. Due to these factors, it also meant that few patients had an advance care plan, despite a locally produced document developed by the local hospice and hospital to support these conversations.

It was identified that this may be because there was a lack of sufficient clinical time to have an advance care planning conversation

– with a ten-minute consultation simply not being long enough – and that staff within the practices lacked the confidence to have these important conversations.

In the Milton Keynes area, they used funding to free up clinical time for a practice nurse and a GP per practice to allocate to advance care planning discussions. In addition, there was a significant education and training component to increase confidence in professionals, including a 2-day training course ran by a Macmillan GP.

Undoubtedly, the project demonstrated that by freeing up staff time, they were able to significantly increase the total number of advance care plans in place for patients at end of life from a total of 2 across the pilot sites in 2017 to >130 ACPs completed in 2018.

With such positive results, the pilot team were able to demonstrate to the CCG the significant impact these changes had and agreed to fund the project for the remainder of GP practices in Milton Keynes. While there are still some practices that are not able to participate, over 75% of the primary care population now benefit from increased clinical time to support advance care planning conversations and more chance of being identified as being in end of life.

## Cheshire

### The Cheshire End of Life Partnership

In Cheshire the End of Life Partnership (EoLP) was developed to lead and to facilitate a more joined up ‘whole systems’ approach’ to end of life care across health, social and voluntary care sectors including with members of the public.

This ‘whole systems approach’ is lead and facilitated by EoLP through a number of approaches:

- Education and training
- Compassionate communities
- Care coordination
- Cheshire EPAIGE  
[www.cheshire-epaige.nhs.uk](http://www.cheshire-epaige.nhs.uk)
- Advanced dementia consultancy
- Audit, evaluation and data dashboards

- Strategic Collaborative Cheshire Forum- (Commissioners & Providers)
- 3 Year Strategic Plan for Palliative & End of Life Care

Examples of whole system projects led by EoLP that help to improve identification and holistic management of people approaching the end of life include a pan-Cheshire approach to EPaCCS (Electronic Palliative Care Coordination Systems) and the development of Care Coordination models that have compassionate communities and workforce education as integral components. Examples of how experience of care is being used to inform service development include carrying out a local needs-based assessment with bereaved carers and professionals.

 If you would like to know how EoLP can support your work please contact them via their website <http://eolp.co.uk>.

## Devon

### Completing an audit of patient deaths in a GP practice

In 2017, Devon won a Health Education England bid and received funding to run a quality improvement project across practices in Devon. This focussed on completing an audit of the records of the last 10-20 patients who had died in the practices, looking at note keeping, coding, whether patients had any recorded wishes, cause of death and considering the 5 priorities of care. The case review sheet on the following page was used to complete this audit.

Once the audit had taken place, Macmillan GPs worked with the practices to run education events to explore how they deliver End of Life care. Practice staff were encouraged to think about the minimum

dataset they need to collect for palliative patients and how they code this. Improving this should help to improve communication within the team and improve use of the EPaCCS system for communication with other healthcare professionals. This information included having a DNR, ACP and Just In Case Box. Furthermore, practice staff were supported to understand the audit and work through what was good about the patient’s care and what could have been done differently.

Many issues were highlighted through the audit – poor coding was a big issue and while free text showed patients were being provided with good care, this wasn’t in an easily accessible format and transfer of this information to EPaCCS was low.

<b>Place of death</b>							
ON GSF register							
<b>Priority 1: Recognition</b> Clear documentation that:							
It has been recognised by a named senior clinician that the patient is in the last few days of life/dying							
Clear documentation justifying the diagnosis of dying is recorded							
Within the week that the patient is dying, the patient’s needs and wishes are reviewed at least once							
<b>Priority 2: Communication</b> Clear documentation that discussions have been held by a named senior clinician regarding prognosis with:							
The patient who is in the last days of life (enter N/A if patient too unwell)							
Family/carer that the patient is now in the last days of life							
Goals of care recorded							
Preferred place of care recorded							
<b>Priority 3: Involve</b> Clear documentation that the dying person had:							
Identified the person(s) they want involved in discussions around their care							
An Advance Care plan							
An ADRT							
an existing Lasting Power of Attorney in place for health and welfare decisions (enter N/A if not appropriate)							
A TEP/DNAR:							
● Discussed with patient and/or carers	●	●	●	●	●	●	●
● Not appropriate to discuss with patient and/or carers	●	●	●	●	●	●	●
EPaCCS data recorded							
Clear documentation that there were discussions with the patient’s identified person(s) regarding the patient’s treatment and care							
<b>Priority 4: Needs</b> Clear documentation that the needs of the families and others identified as important to the dying person were assessed							
<b>Priority 5: Individual plan of care</b> Clear documentation that the patient’s individual plan of care included:							
● symptom control	●	●	●	●	●	●	●
● psychological/emotional support	●	●	●	●	●	●	●
● social support	●	●	●	●	●	●	●
● spiritual/cultural/religious support	●	●	●	●	●	●	●
● ‘support’ to eat and drink as long as they wished to do so	●	●	●	●	●	●	●
Bereavement care – note of care given to family/carers							

## References

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- 9 <https://eprints.soton.ac.uk/352526/1/VOICES%2520Toolkit%2520-%2528with%2520female%2520version%2529.pdf>
- 10 <http://be.macmillan.org.uk/Downloads/CancerInformation/RichPicture/MAC1384117--The-Rich-Picture-on-people-at-the-End-of-life.pdf>
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- 13 [www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/specialist-care-at-home.html](http://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/specialist-care-at-home.html)
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- 16 <https://ihub.scot/media/5909/continuity-and-care-co-ordination-in-palliative-and-end-of-life-care.pdf>

Being told 'you have cancer' can affect so much more than your health – it can also affect your family, your job, even your ability to pay the bills. But you're still you. We get that. And, after over 100 years of helping people through cancer, we get what's most important: that you're treated as a person, not just a patient.

It's why we'll take the time to understand you and all that matters to you, so we can help you get the support you need to take care of your health, protect your personal relationships and deal with money and work worries.

We're here to help you find your best way through from the moment of diagnosis, so you're able to live life as fully as you can. **For information, support or just someone to talk to, call 0808 808 00 00 or visit [macmillan.org.uk](https://www.macmillan.org.uk)**

