END OF LIFE CARE

A quality improvement toolkit for cancer care in primary care

Primary Care Network:

Practice name:

CCG:

Contact lead:

If you require any further information about this toolkit please email macdocs@macmillan.org.uk

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Contents

Key to the icons in this toolkit

To be done at the start of the toolkit.

Consider discussing at a practice meeting involving clinical and non-clinical members of the practice team. If not done as part of a meeting, ensure all results and learning are shared with the whole practice team.

To be done at the end of the toolkit.

Searches: You will find a list of all searches included at the beginning of each module. This is because you may want to carry out all of the searches in one sitting. If this is the case, please use the list at the beginning of the module as a guide and insert the required information in to the appropriate box within the module. It may be that a non-clinical member of the practice team carries these out.

Identification and support for people with advanced serious illness

Searches

Run all searches listed on pages 4 and 5 of this module at the start of undertaking this activity. As the searches are automated, it will take only a few minutes of your time to run all of the listed searches. Record the outcome of these initial searches in a separate document.

Following completion of the module and of your corresponding quality improvement activity after 6 or 12 months, re-run all of these searches and reflect on the outcome.

Remember to share your work, findings and reflections with your practice and network team.

Finding your searches

To support you in your quality improvement activity, Macmillan Cancer Support has worked with EMIS Web, TPP SystmOne and INPS Vision to develop automated searches that sit within your clinical system.

These searches enable you to evaluate your baseline activity prior to implementation of a quality improvement initiative. You are then able to re-run these searches six or twelve months after implementing a quality improvement initiative to enable you to measure impact.

It is recommended that you run all the relevant searches when you begin and save these results within a separate document to ensure they are not overwritten. Following this, you have the option to run each of the searches over a period of either six months (searches 1–16) or twelve months (searches 17–32) to fit in with your quality improvement plans. Below is a list of all the searches available:

1.	Patients in need of Palliative care in last 6 months
2.	Patients in need of Palliative care and Palliative care plan review in last 6 months
3.	Patients in need of Palliative care AND full palliative care template in last 6 months
4.	Patients in need of Palliative care and MDT in last 6 months
5.	Patients in need of Palliative care and preferred place of death discussed in last 6 months
6.	Patients in need of Palliative care and DNA CPR discussed in last 6 months
7.	Patients in need of Palliative care and OOH informed of care plan in last 6 months
8.	Patients in need of Palliative care and assessment of needs in last 6 months
9.	Patients in need of Palliative care and psychological assessment completed in last 6 months
10.	Patients in need of Palliative care and social needs assessment completed in last 6 months
11.	Patients in need of Palliative care and anticipatory medicines prescribed in last 6 months
12.	Patients in need of Palliative care and benefits discussed with patient in last 6 months
13.	Patients in need of Palliative care and carer support offered in last 6 months
14.	After death review place of death achieved in last 6 months
15.	After death review of palliative end of life care patient in last 6 months
16.	After death palliative care patient- bereavement support offered in last 6 months
17.	Patients in need of Palliative care in last 12 months
18.	Patients in need of Palliative care and Palliative care plan review in last 12 months
19.	Patients in need of Palliative care AND full palliative care template in last 12 months
20.	Patients in need of Palliative care and MDT in last 12 months
21.	Patients in need of Palliative care and preferred place of death discussed in last 12 months
22.	Patients in need of Palliative care and DNA CPR discussed in last 12 months
23.	Patients in need of Palliative care and OOH informed of care plan in last 12 months

24.	Patients in need of Palliative care and assessment of needs in last 12 months
25.	Patients in need of Palliative care and psychological assessment completed in last 12 months
26.	Patients in need of Palliative care and social needs assessment completed in last 12 months
27.	Patients in need of Palliative care and anticipatory medicines prescribed in last 12 months
28.	Patients in need of Palliative care and benefits discussed with patient in last 12 months
29.	Patients in need of Palliative care and carer support offered in last 12 months
30.	After death review place of death achieved in last 12 months
31.	After death review of palliative end of life care patient in last 12 months
32.	After death palliative care patient- bereavement support offered in last 12 months

EMIS Web

To access the searches, follow the below pathway on your EMIS Web system:

Population Reporting> EMIS Library> SNOMED Searches> EMIS Clinical Utilities> Third Sector Partnerships> Macmillan Cancer Support> Quality tool kit

INPS Vision

To access the searches, follow the below pathway on your INPS Vision system:

Right click Vision+ icon > Download Web files > Under heading: Practice alerts & lists > Cancer care in primary care: Quality toolkit (Macmillan)

Right click Vision+ > Open Practice reports > Practice lists > Cancer care in primary care: Quality toolkit (Macmillan)

TPP SystmOne

To access the searches, follow the below pathway on your TPP SystmOne system:

- Access the library in SystmOne via System > Resource Library.

- Type 'macmillan' as a search term and you will see the table below:

- Download any resources you do not have locally on your SystmOne module (right-click and download resource).

- Once downloaded add the templates/view and to where you want to use them (tree or toolbar).

Name	Type	Guidance
Macmillan Quality Toolkit for Cancer in Primary Care Reports – Read Usage Guidance!	Report	Downloads all the reports required to support the Macmillan Quality toolkit. **Read the usage guidance.**
Macmillan End of Life Care QOF QI Reports – Read Usage Guidance!	Report	Downloads all the reports required to support the QOF QI EOL Module. **Read the usage guidance.**
Macmillan Palliative Care Template 2019	Template	Template to support QOF QI EOL.
Macmillan Cancer Care Review Template 2019	Template	Template for use in performing a good quality cancer care review with a patient.
Macmillan Cancer Quality View	View	View to see what items have been entered on the last care review.
Cancer Care Review – how are you going?	Word Letter Template	Template letter to send to patients before their review.

Note: When accessing the Cancer Care Review and Palliative Care templates within the SystmOne Resources Library please utilise the National templates that have been developed by Macmillan and Nottingham as described in the above table.

Please do not upload a Practice/CCG-specific template to the Library. This causes confusion among users who will not know which template is the original and most up to date version.

Introduction

This module supports practices and primary care networks to undertake quality improvement in end of life care. This module has been developed in alignment with the 2019/20 GP Contract Agreement. Some of the central changes from this agreement will be explored in this introduction as well as being embedded within activities throughout the module. A significant emphasis has been placed in the 2019/20 QOF contract on improvements to end of life care at primary care level. This is through the new QOF element – Quality Improvement.

The Quality Improvement module within the 2019/20 QOF contract focuses on:

1. **Early identification and support for people who might die within 12 months.**

2. **Well-planned and coordinated care that is responsive to the patient's needs.**

3. **Identification and support for family/informal care-givers both as part of the patient's core support team and as individuals facing bereavement.**

Practices will be expected to focus their QI activities on:

1. **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.**

2. **An increase in the number of people who died from advanced serious illness who were offered timely and relevant personalised care, and support plan discussions that were documented and shared electronically to support delivery of coordinated care.**

3. **An increase in the proportion of people who died from advanced serious illness where a family member, Next of Kin or informal care giver had been identified; with an increased offer of holistic support before and after death.**

4. **A reliable system in place to monitor and enable improvement based on timely feedback of the experience of care from staff, patients and carers.**

> **In advance of completing this module, you may want to consider identifying current issues in relation to end of life care within your practice and identifying SMART outcomes to tackle these. Upon completion of the module, print out a copy of the completed PDF, along with the data from your initial baseline searches and post-six or twelve-month searches to take to your next GP Network Peer Support Meeting. This will ensure that learning is shared across your network.**

Alongside these changes to QOF, we have also seen an increased focus on personalised care and Primary Care Networks within the 2019/20 GP contract agreement for England and the NHS England Long-Term Plan. The NHS England vision for universal personalised care is central to a new service model in the Long-Term Plan whereby, particularly through newly created primary care networks, people will have more options, better support and joined-up care at the right time and in the correct care setting. Roll out of this model starts in 2019 and by 2023/24, the Comprehensive Model for Personalised Care aims to reach 2.5 million people.

The universal model for personalised care has made explicit reference to the need to continually improve choice at the end of life through the promotion of the six Government commitments for end of life care and other elements of the Ambitions for Palliative and End of Life Care. The aim of this commitment is: better identification of people who are likely to die within the next 12 months; better, proactive conversations for people to identify their wishes and preferences; and integrated services which wrap around people, facilitated by improved sharing of key information.

From 2019, practices will come together to form primary care networks through the introduction of a new Network Directive Enhanced Service. This will require GP practices to become part of a network covering 30-50,000 people – to share decision-making regarding funding, workforce and service provision creating integrated teams of GPs, community health and social care staff focused on local population need. Each of these changes will have a significant impact on the delivery of care for people approaching end of life.

As patterns of illness change due to advances in medical treatments and technology, the role of the GP in supportive, palliative and end of life care is ever more challenging. Multi-morbidity and complexity are rising and more people, of all ages and with a wide range of conditions, can be considered to have physical, psychological, social, and spiritual supportive and palliative care needs[1]. Prolonged functional decline results in difficulties identifying the end of life, particularly for those with non-malignant conditions, but also for those with treatable but not curable cancer.

The General Medical Council defines people as "approaching the end of life" when they are likely to die within the next 12 months[2]. This was the basis of the 'find your 1%' campaign as this group is approximately 1% of a GP's registered list[3]. This group includes those:

1. **Whose death is imminent (expected within a few hours or days)**

2. **With advanced, progressive, incurable conditions; general frailty and co-existing conditions; including those where there is a risk of dying from a sudden acute crisis in their condition.**

The term 'supportive care' is used to describe care given to improve the quality of life in patients who have a serious or life-threatening disease, but who may well live longer than one year.

The goal of supportive care is to prevent or treat as early as possible the symptoms of a disease, side effects caused by treatment of a disease, and psychological, social, and spiritual problems related to a disease or its treatment[4]. This group can form up to 2% of a GP's registered list, and are often the same people that have been identified as being at risk of unplanned hospital admissions.

A proactive approach to care, with the opportunity for individual care planning and open and honest conversations with patients and their families is necessary. Integrating a supportive and palliative approach earlier on into chronic disease pathways, rather than only at the end, can improve the quality of a patient's experience. Analysis of data from the National Survey of Bereaved People in England in 2015 (Voices) confirmed that Advance Care Planning was strongly associated with lower rates of hospital death and improvements in a range of quality outcomes.

ACP is possible if it becomes 'everyone's business' in a healthcare community. Community nurses, care administrators and volunteers, as well as GPs, all play a valuable role in supporting the process. ACP is voluntary, and due to its sensitive nature should only be offered if the patient wants to talk, and if time is available for a meaningful conversation to be had. When ACP has been undertaken, a document such as the Preferred Priorities for Care could be used to record and share important information, providing the patient gives consent. Many people with cancer, as well as those with other life limiting disease, will benefit from the early offer of ACP conversations.

Electronic Palliative Care Co-ordination systems (EPaCCs) or equivalent systems are an electronic way to capture and share information from ACP with other health professionals working in unscheduled care. EPaCCS are electronic registers, tools, and processes for sharing data that aim to enable access to information about dying patients. Striking outcomes have been reported around EPaCCS, such as 77.8% of 'Coordinate My Care' patients dying in their preferred place[5]. EPaCCS and similar alternatives have, however, been extremely challenging to develop and implement.

Additional information in Summary Care Records can also provide good end of life data. Sharing a patient's wishes can help to prevent avoidable admissions to hospital and also futile or unwanted attempts at resuscitation[6]. This module encourages GP Practices to examine the quality of information contained within their electronic patient records, 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 the last weeks and days.

Activities

1. **Approximately 1% of patients on a GP's registered list will die each year[7]. Supportive and palliative care registers help practices to identify when patients are in the last years of life (not just the last year), indicating when the offer of ACP conversations should be considered.**

   a) What proportion of your practice population are currently on a supportive and palliative care register? (Search will be in the QOF GP Contract so not included in the list of EMIS searches).

   Estimating a prognosis is increasingly challenging with the high incidence of comorbidity in our ageing population. The SPICT or The Gold Standards Framework introduction to proactive indicator guidance may be a useful resource for this.

   b) As a practice, how do you identify patients who may be suitable for addition to the supportive and palliative care register?

2. a) **Do you consider the addition of patients on existing long term condition registers to your palliative care register as and when appropriate?** This can ensure that patients are added to the appropriate registers in a timely and proactive manner.

   Yes   No

   b) **Do you consider the addition of patients who have a treatable but not curable cancer to the palliative care register?** This could include those with metastatic prostate or breast cancer for example.

   Yes   No

   - If yes, how do you identify these patients?

3. **The use of a structured template can support consistent reporting and coding, contributing to improved continuity of care.**

   a) Are you aware of the Macmillan Palliative Care Template within your IT system?

   Yes   No

b) Drawing on the searches that you ran at the beginning of this module, note the outcome of search 3 or 19 (select the appropriate search depending on whether you are running these searches to reflect a 6 or 12 month period) below.

This search will detail the proportion of patients currently on your supportive and palliative care register who have been reviewed using the palliative care template or local equivalent (where the codes are aligned to the template).

What proportion on your supportive and palliative care register have been reviewed using this template?

c) Who carried out these reviews?

d) As a practice, agree a process to use the Macmillan palliative care template or a local equivalent to review anyone on the palliative care register going forward.

e) After six or 12 months, run search 3 or 19 again and note the result here.

4. **Does your practice use prompts, such as a coded <u>Cancer Care Review</u> prompt or Frailty Index (eFI) to promote the offer of ACP discussions and inclusion on a register?**

     Yes   No

If no, discuss as a Practice what the added value may be in this.

5. **Is written material available to support ACP conversations, such as the booklet *Your Life, Your Choices, Planning Ahead*?**

     Yes   No

If yes, please list what information is available and if not, visit **Be.Macmillan** to order relevant resources.

6. **We recognise that meetings have been removed from the 2019/2020 Quality and Outcomes Framework but acknowledge that patients value care that is high quality and coordinated. Efficient meetings in a primary care setting are of great importance in ensuring that the physical, social, psychological and spiritual dimensions of care are delivered effectively.**

   a) How often do you hold supportive and palliative care meetings?

   b) Who attends these meetings? Please tick all that apply

District Nurses	Practice Nurses
Community Matrons	Community Specialist Palliative Care Nurses
GPs	Palliative Care Consultants
GP Registrars	Practice Manager
Medical Students	Social prescriber or care navigator
Clinical Nurse Specialists	Care home staff
Social worker	Administrative members of staff
Other members of Practice team*	

   If other members of the practice team, please expand

   c) As a practice how do you record the discussions you have in these meetings?

   Use code 98G going forward.

   d) An effective supportive and palliative care meeting should be prepared for in advance, should prioritise patients according to need and emphasise the importance of communication with the patient and their family among other things.

   ● Using this top tips resource as a guide, consider if and how the quality of these meetings within your practice could be improved. List your thoughts below.

7. **Informing out of hours professionals regarding patients on the palliative care register is important to ensure continuity of care. Most areas have introduced a form of Electronic Palliative Care Coordination Systems (EPaCCs).**

   a) What proportion of patients on your supportive and palliative care register have been added to this system?

   b) If you do not currently use EPaCCs, how do you go about notifying out of hours staff?

   c) Do you code when out of hours services are notified about a patient?

      Yes   No

      If not, use the code 9e02 going forward and utilise existing palliative care templates or local equivalents which have the relevant codes built in.

8. **General Practice is facing challenges with regard to increasing demand and limited resources. Sharing of tasks to trained personnel can make the process of improving supportive and palliative care more achievable.**

   a) Do you have a trained co-ordinator or administrator to help run meetings and to communicate outcomes to relevant colleagues?

      Yes   No

   b) Do you have a named clinical lead for end of life care in your practice?

      Yes   No

9. **Carers play a vital role in supporting people with cancer and it is important that their needs for information, advice and support are addressed.**[8]

   a) Do you have a dedicated carers lead within your practice?

      Yes   No

   b) Do you have a process for identifying and supporting carers within your practice?

      Yes (please outline the process)   No

      Use this code 8O7 for 'carers support offered' going forward.

c) Macmillan GPs have developed a set of <u>tips</u> for supporting carers within Primary Care. At your next practice meeting familiarise yourself with these tips and consider whether any existing processes within your practice could be improved, or any new processes put in place as a result. List your thoughts and action plan below.

10. **A recent pilot found that 60% of the GPs involved did not feel 'confident', or 'very confident' in initiating conversations around end of life, although many were experienced in providing end of life care. After initiating conversations around end of life care, these GPs felt relief and satisfaction with nine out of ten patients continuing the conversation[9].**

a) Have you and the rest of the practice team received training in having important conversations about individualising care for patients in the last years of life?

Yes   No

● If yes, did you find this useful and what was the source of training?

● If not, would it be useful for you to access further training on this if this was available to you?

Yes   No

If yes, please contact **macdocs@macmillan.org.uk** to find out more.

11. **We know that people nearing the end of life who document their decisions in a personalised plan will experience better care[10].**

● Review the **10 Top Tips for Advance Care Planning** as a practice team and discuss how you could structure future conversations around advance care planning. Outline key actions below.

12. With the support of your administrative team if appropriate, look at patients who have died within the last six or 12 months. How many of these were on the supportive and palliative care register?

- On reflection, are there any patients who were not on the register but who you feel should have been?

    Yes   No

Answers given below will need to be taken to a practice meeting to be discussed.

13. The activity undertaken as part of this question can be modified to allow for use as a continuous quality improvement cycle or as part of an ongoing quality improvement project. For example, you may wish to carry this activity out for a smaller number of patients monthly, or to review quarterly.

If you are using the Macmillan Palliative Care template, or coding in line with the template, you can use the automated searches listed at the beginning of this module. These searches will enable you to record and measure impact. Please amend this activity to suit your quality improvement plan as needed.

With the support of your administrative team if appropriate, select five patients (or an alternative number as appropriate for your practice or Quality Improvement activity) **who have recently died and who were on your supportive and palliative care register. Of the records from patients who have died:**

a) Is there evidence of advance care planning (ACP)?

b) Is there evidence of DNA CPR?

Use this code: 67P0 for DNA CPR discussed going forward.

c) How many of these patients had key information shared electronically on EPaCCs, SCR or an alternative system?

d) Early consideration of prescribing anticipatory 'just in case' medications is considered to be good practice to help with pain control etc.[11] How many records show evidence of anticipatory medication being prescribed, or considered?

Use this code: 8B2a for 'anticipatory medicines prescribed' going forward.

e) How many of these five patient records, which include detail about the patient's wishes show that the patient died in the place of their choice?

Use this code for preferred place of death discussed with patient 8CN1 or this code for preferred place of death discussed with family 94ZB.

- Reflect on whether this is going well for patients at your practice.

14. Do you have a bereavement protocol in place to make sure patients have access to bereavement care when someone close to them has died? See Appendix for an example of what this could look like and code 'bereavement support offered' (8O81) going forward.

Yes   No

15. The activity undertaken as part of this question can be modified to allow for use as a continuous quality improvement cycle or as part of an ongoing quality improvement project. For example, you may wish to carry this activity out for a smaller number of patients monthly, or to review quarterly.

If you are using the Macmillan Palliative Care template, or coding in line with the template, you can use the automated searches listed at the beginning of this module. These searches will enable you to record and measure impact. Please amend this activity to suit your quality improvement plan as needed.

Identify five patients (or an alternative number as appropriate for your practice or Quality Improvement activity) from your supportive and palliative care register who are likely to be in the last weeks/days of life.

Of the records from patients with advanced disease and likely to be in the last weeks/days of life.

a) How many records show evidence of having had a discussion with a health professional about their individual needs and wishes (ACP)?

b) Is there evidence of discussions around DNA CPR?

Yes   No

c) How many of these patients have key information shared electronically on EPaCCs, SCR or an alternative system?

d) Early consideration of prescribing anticipatory 'just in case' medications is considered to be good practice to help with pain control etc.[11] How many of these patients would it be appropriate to prescribe anticipatory medication for and if so, has this been done?

Use this code: 8B2a for anticipatory medicines prescribed going forward.

e) Do the patients have a documented preferred place of care/death?

Use this code for preferred place of death discussed with patient 8CN1 or this code for preferred place of death discussed with family 94ZB.

f) Call a practice meeting, or use part of a Supportive and Palliative Care Practice Meeting, to reflect on the responses given for both sections above and if necessary form a plan to improve ACP including documentation and sharing of this information going forward. Detail information about your current plan or improvement plan below.

> **Upon completion of this module, remember to print out a copy of the completed PDF, along with the data from your initial baseline searches and post- six or twelve-month searches to take to your next GP Network Peer Support Meeting. This information can be looked at alongside the initial issues and SMART objectives that you identified to ensure that learning is shared across your network.**

Further reading/useful resources

- https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf

- http://be.macmillan.org.uk/Downloads/CancerInformation/LivingWithAndAfterCancer/MAC15371BereavementE01P04lowres20160129MC.pdf

- www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/palliative-end-of-life-care.html#299994

- www.macmillan.org.uk/_images/no-regrets-talking-about-death-report_tcm9-311059.pdf

- http://endoflifecareambitions.org.uk

Appendix: Springwell Medical Group Protocol for notification of death

Actions for Reception/Admin Staff

Once informed of a patient death the following steps should be taken:

- E-mail all practice staff (there is a group All Staff on the Emis system).
- Leave a message for the District Nurses
- Record patient died and location as significant active on the Emis system.
- Print out an RIP patient summary to be taken to the partners meeting.
- Inform by telephone the hospital records department.
- If diabetic patient complete notification form to the screening department (found on Alchemy in the Diabetes Folder)
- Prescribing staff to inform chemist if relevant.
- Check if patient has ambulance booking. If yes ring to Ambulance Service to cancel.
- Look in Patient Tasks to see if there is anything outstanding. If there is complete.

Actions for Practice Manager

- Record details in the relevant book.
- Add to the agenda for the next partner's weekly meeting.
- Partners to decide if telephone call or visit appropriate.
- If the patient has a Health & Social Care Plan inform Integrated Teams Care Co-coordinator via e-mail.
- Send a sympathy card and information on local bereavement services to the family.

Reviewed 23.2.2007.

References

1. Murray S., Kendall M., Boyd K., et al. Illness trajectorie and palliative care. Br Med J. 2005;330:1007---11

2. General Medical Council. Treatment and care towards the end of life: good practice in decision making 2010 www.gmc-uk.org/guidance/ethical_guidance/end_of_life_care.asp

3. www.dyingmatters.org/gp

4. www.nice.org.uk/guidance/csg4/resources/improving-supportive-and-palliative-care-for-adults-with-cancer-773375005

5. http://coordinatemycare.co.uk/cmc/wp-content/uploads/2014/06/bmjspcare-2015.pdf

6. www.macmillan.org.uk/_images/no-regrets-talking-about-death-report_tcm9-311059.pdf

7. www.dyingmatters.org/gp_page/identifying-end-life-patients

8. www.macmillan.org.uk/documents/aboutus/health_professionals/primarycare/macmillancancersupportrevisedreportfinal.pdf

9. www.dyingmatters.org/gp_page/breaking-news

10. Mullick A. Martin K. Sallnow L. An introduction to advance care planning in practice BMJ 2013; 347:f60

11. www.rcgp.org.uk/clinical-and-research/toolkits/-/media/068342B4A4984C21BB8C101138085620.ashx

12. www.macmillan.org.uk/_images/carers-of-people-with-cancer_tcm9-282780.pdf

We're here to help everyone with cancer live life as fully as they can, providing physical, financial and emotional support. So whatever cancer throws your way, we're right there with you.

For information, support or just someone to talk to, call **0808 808 00 00** (7 days a week, 8am–8pm) or visit **macmillan.org.uk**

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