Wales

MACMILLAN CANCER QUALITY TOOLKIT
FOR PRIMARY CARE

Practice name

Practice code

Health board

Cluster

Contact email for toolkit clinical lead

FFRAMWAITH CANSER
GOFAL SYLFAENOL MACMILLAN
PRIMARY CARE CANCER
FRAMEWORK

MACMILLAN CANCER SUPPORT
RIGHT THERE WITH YOU

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.

Extra information and resources are available.

Action is required by your practice.

Helpful information or evidence.

Acknowledgements

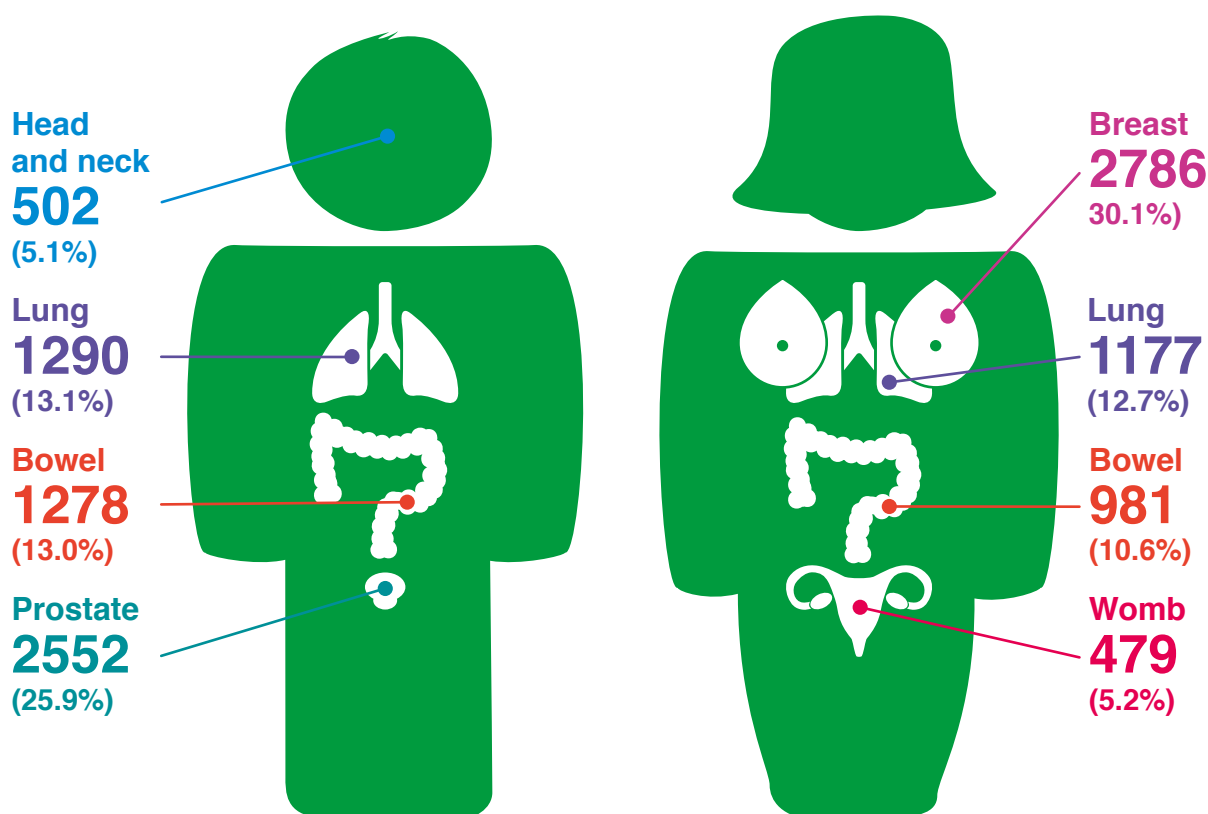We would like to express our gratitude to the Macmillan Primary Care Cancer Framework programme team in Wales for sharing their knowledge and expertise and providing crucial and valuable support in the production of this toolkit. We'd also like to express our thanks to the Macmillan GP advisers and Macmillan end-of-life GP facilitators in Wales and colleagues from the Wales Cancer Network for their support in developing the toolkit.

Background to cancer in Wales

In 2015, 19,088 people were diagnosed with cancer in Wales (9,837 men and 9,251 women). This total represents a 10% increase (1,699 more cases) on the figure from 2005[1].

As with many other illnesses, the incidence of cancer is greater in more deprived areas in Wales (local authority and health board level) than in less deprived areas. The stage someone's cancer is diagnosed is also more likely to be at an advanced stage in a more deprived area[2]. For example, head and neck, pancreas and lung cancers are typically more prevalent in deprived areas, and between 2012 and 2016 almost half of these cancers were diagnosed at stage four in Wales.

Overall, the most common cancers in Wales in 2015 were breast, prostate, lung, bowel and melanoma[1]. Since 2001, it's also been identified that the incidence rates for head and neck cancer, melanoma and liver cancer are increasing in Wales.

Head and neck 502 (5.1%)

Lung 1290 (13.1%)

Bowel 1278 (13.0%)

Prostate 2552 (25.9%)

Breast 2786 30.1%)

Lung 1177 (12.7%)

Bowel 981 (10.6%)

Womb 479 (5.2%)

Source: Welsh Cancer Intelligence and Surveillance Unit (WCISU) 2017

In the future, the incidence rate of cancer in Wales is expected to continue to rise by approximately 2% each year. This is because people are living longer and we have a growing population of older people. By the end of 2030, it's estimated that 220,000 people will be living with cancer in Wales[3]. As a result, the demand on NHS services will continue to increase[4].

Estimated number of people in Wales living with cancer: Now and in the future

2015	130,000
2020	160,000
2030	220,000
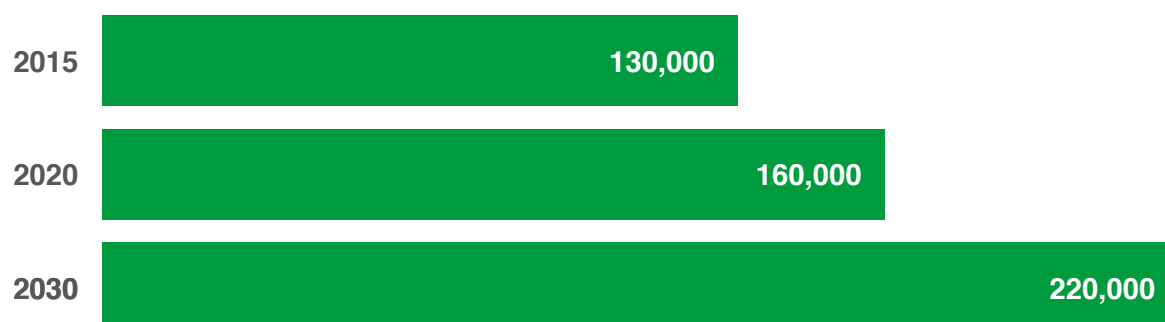
Source: Welsh Cancer Intelligence and Surveillance Unit 2017

Cancer is a leading cause of death in England and Wales[5], although the long-term trend of an increasing number of cancer deaths per year has slowed down since 2010. However, data from 2001–2005 and 2013–2017 shows cancer mortality in the most deprived areas in Wales has increased by 14% in comparison to the least deprived areas[6].

In relation to cancer types, there has been a decline in mortality rates for lung, bowel, breast and prostate cancers. However, the greatest cancer death inequality in Wales relates to lung cancer, with much higher rates found in the most deprived areas compared to the least deprived areas[6].

Over the past 20 years, the one-year and five-year survival rates for most cancer types have increased in Wales[7]. However, these rates are lower compared to the rest of the UK and most other European countries[8].

Several factors contribute to differences in cancer survival rates, including cancer type and the stage at which a cancer is diagnosed. Importantly, the stage a cancer is diagnosed may be affected by a number of factors. These include the uptake of cancer screening programmes, the time it takes people to seek health advice when they recognise a problem, and the accessibility of primary care and diagnostic services. After diagnosis, people's access to effective treatments and care, as well as their general health, can also impact on survival rates[7].

Overall, it is very good news that cancer survival rates in Wales have increased. But this will lead to more people accessing primary and secondary care services in the future. In addition, the ageing population of Wales means people diagnosed with cancer are increasingly likely to have other conditions and complex health needs. Again, this means current pressures felt in primary and secondary care will continue to increase.

Wales Cancer Patient Experience Survey (WCPES)

In 2017, the second **WCPES** provided valuable insight into people's experience of cancer care in Wales. Completed by 6,714 people, the survey showed that overall perceptions of cancer care in Wales are very high. The majority of respondents (93%) rated their care positively and stated they were treated with dignity and respect (89%).

The survey also identified a number of areas for improvement, including four which were also singled out as priorities in the **Cancer Delivery Plan for Wales 2016–2020**. These are detecting cancer earlier; delivering fast, effective treatment and care; meeting the needs of people with cancer; and improving cancer information.

In relation to primary care and detecting cancer earlier, 19% of respondents took at least three months to see a doctor after they thought something was wrong. The majority of patients (61%) saw their GP once or twice before going to hospital; while 6% said they saw their GP five times or more before being referred for investigations. These findings highlight the importance of increasing people's awareness of the signs and symptoms of cancer and attendance of cancer screening programmes to help detect cancer earlier.

In relation to meeting the needs of people with cancer and improving cancer information, only 18% of respondents said they'd received a care plan. While less than half (45%) said the potential impact of their cancer on their day-to-day activities had been completely discussed with them.

Out of all the people who needed help or care from their GP or surgery after leaving hospital, only 56% said they 'definitely' received this support. The survey also revealed that people who were given the opportunity to discuss their needs and/or received a care plan had more positive experiences across their patient journey.

Introduction

This toolkit aims to encourage and support primary care teams to improve the quality of care they provide to people with cancer. This ambition also aligns with a priority area of the Welsh government's primary care strategy: to improve access to and the quality of primary care services across Wales.

Using learning acquired from the development of similar toolkits for England and Scotland, we have carefully designed this toolkit for Wales. This has involved working with a wide range of primary care colleagues across Wales.

Included in the toolkit are five modules which cover the whole clinical pathway, from prevention and diagnosis to end of life care. Many of these areas align with the **Macmillan Primary Care Cancer Framework programme** workstreams.

As your primary care team works through the modules, they will be asked to undertake audits, reflect on current practice and complete small case studies. They will also be signposted to best practice information, resources and tools. This will help your team develop improvement plans that answer the following questions:

- How can we support Public Health Wales' national screening programmes?

- What can we do to ensure prompt recognition and early detection of cancer?

- How can we support people with cancer throughout treatment?

- How can we support people after cancer treatment and with the potential late effects of treatment?

- How can we support people with advanced cancer?

- How can our whole primary care team work together to improve cancer care?

You can find out more information on how to carry out improvement work in your practice at the **Institute for Healthcare Improvement website**.

This toolkit's overall objectives

1. To enable a whole primary care team to review and improve services that diagnose, care for and support people living with cancer.

2. To create a framework of peer support that helps primary care teams to provide seamlessly coordinated care and high-quality patient experiences.

3. To provide a current picture of cancer services in primary care, which will support future developments in Wales.

Practice commitment

GP practices who wish to participate are required to complete three of the five modules in the toolkit, which should take just over six months to complete. This time period will allow your practice to collect baseline data, develop and implement improvement plans, and collect end-of-project data to measure success.

Included in your three modules must be module four (Cancer care reviews and long-term consequences of cancer and its treatment), which is mandatory. When choosing your other modules, you should consider which ones will benefit your practice the most.

Practices will also be required to complete a short baseline survey before they begin the modules and a post-toolkit evaluation survey.

Toolkit instructions

As you work your way through this toolkit, please take the key steps listed in the below 'toolkit checklist'. You may also find it helpful to tick these steps after you have completed them.

We've also produced more detailed instructions on what actions you need to take to successfully complete the toolkit. These follow the 'toolkit checklist'.

Toolkit checklist

Baseline (0 months)

Nominate an individual to be the clinical lead for the toolkit

Schedule baseline and six-month practice meetings

Complete the MCQT baseline evaluation survey

Access the toolkit searches on your IT system

Run the baseline searches and complete the spreadsheet in **Appendix 1**

Complete baseline questions for your three modules

Save your toolkit data – you will need this document again to enter your six-month data

Submit your baseline module data to:

Implement your improvement plans for all three modules over the next six months

Post toolkit (6 months)

Access your saved spreadsheet and toolkit

Access the toolkit searches on your IT system

Run post-toolkit searches and complete the spreadsheet in **Appendix 1**

Complete six-month questions for your three modules

Save your toolkit data – this document should now include both baseline and six-month data

Submit your baseline and six-month module data to:

Complete the MCQT post-toolkit evaluation survey

toolkit detailed instructions

1. **Nominate an individual to be the clinical lead for the toolkit.**
   - You may also wish to nominate a lead for each of the modules you undertake.
   - These individuals should ensure that learning from the modules is shared with the whole practice team, as well as other health and care professionals in your cluster, if you wish.

2. **Schedule baseline and six-month practice meetings.**
   - This is to ensure that all members of your primary care team can participate in discussions.

3. **Complete the MCQT baseline evaluation survey.**
   - The clinical lead for the toolkit should complete this survey before starting any of the modules.
   - The link to this online survey was emailed to your practice along with this toolkit.

4. **Access the toolkit searches on your IT system.**

EMIS
Population reporting > EMIS library > Clinical utilities > Third sector partnerships > Macmillan Cancer Support > Quality toolkit

Vision
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)

5. **Run baseline searches and complete the spreadsheet.**
   - The clinical lead, facilitated by an administration person, should run the baseline searches and complete the spreadsheet in **Appendix 1** ('GP practice search data spreadsheet')**.**
   - You will need this information to complete the toolkit, and it must be submitted along with your module data.
   - These searches will take approximately 20 minutes to complete.

6. **Complete baseline questions for your three modules.**
   - **All three modules can and should be started at the same time** to ensure your practice completes data collection within the six-month time period.

7. **Save your spreadsheet (see Appendix 1) and toolkit data.**
   - You will need these documents again to enter your six-month data.

8. **Submit your baseline module data to:**

   - **Important:** Please ensure no personal information about any patient is included.

9. **Implement your improvement plans for all three modules over the next six months.**
   - Access your saved toolkit, which contains your baseline data.

11. **Access the toolkit searches on your IT system.**
    - See note 4 **(on page 10)**.

12. **Run post-toolkit searches and complete the spreadsheet in Appendix 1 – six-month data column**
    - See note 5 **(on page 10)**.

13. **Complete six-month module questions for all three modules.**

14. **Submit your spreadsheet and toolkit to:**

    - **Important:** Please ensure no personal information about any patient is included.
    - These documents should now contain both your baseline and six-month data.

15. **Complete the MCQT post-toolkit evaluation survey.**
    - The clinical lead for the toolkit should complete this survey **after** completing the toolkit.
    - The link to this online survey was emailed to your practice along with this toolkit.

Module One
Detecting cancer earlier

Searches for this module

Search number	Search description
7	DNA/No response to bowel screening programme in last month
8	DNA/No response to bowel screening programme in last six months
9	Bowel screening programme invitation letter in last six months
10	Bowel screening programme invitation letter in last month
11	Bowel screening telephone invitation in last six months
12	Bowel screening telephone invitation in last month
12a	Advice about bowel cancer screening in last six months
12b	Advice about bowel cancer screening in last month

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

Introduction

Early diagnosis is crucial for improving patient outcomes for many cancers, as early detection offers the best chance for effective treatment options and survival[1]. Encouraging people to participate in cancer screening programmes run by Public Health Wales is one of the best ways for your practice to take an active role in the early detection of breast, bowel and cervical cancer.

Practices can also aim to prevent and improve outcomes by addressing risk factors, as approximately 40% of cancers can be prevented through changes in lifestyle[2]. Therefore, it's crucial primary care teams inform patients of cancer risk factors and lifestyle choices they can make to reduce their risk of cancer.

This module is designed to help practices review and improve their approaches and processes for detecting cancer early, with a specific focus on prevention and screening.

The objectives for this module are to:

1. Increase your practice's knowledge of preventable risk factors for cancer and how you can promote these to patients.

2. Increase your practice's awareness of Public Health Wales' cancer screening programmes and local uptake rates.

3. Increase your practice's knowledge of the risks and benefits of Public Health Wales' bowel screening programme.

4. Establish a whole practice process that improves the coding of and follow-up with people who do not take up bowel screening after it's been promoted to them.

Module top tips

Before you start, please remember the following tips to support completion of this module. And if you're ever unsure about how to use this toolkit, please see **page 10** for full instructions.

1. Nominate an individual with a clinical background to be the lead for this module. This individual should ensure that learning from the module is shared with the whole practice team. We also encourage practices to liaise with colleagues in their cluster to discuss issues and share learning.

2. Schedule practice meetings in advance to ensure that all members of your primary care team can participate in baseline and six-month discussions.

3. Some of the questions in this module may be completed by an individual team member. If this happens, please ensure that what they learn is discussed and shared with your wider team.

Practice meeting discussions

We suggest your team uses practice meetings to complete some questions in this module. We recommend that these discussions involve your whole primary care team, including clinical and non-clinical roles.

To help facilitate these meetings, we have included all questions that require a practice discussion below:

Questions to be discussed at the beginning

Q8. Reflecting on the section above, discuss as a whole practice team how you currently carry out opportunistic health promotion to help prevent cancer. Also cover how your practice's approach could be improved, detailing what changes could be made for each clinical role.

Q17. In consideration of this, discuss with your whole practice team how you currently contact non-responders to bowel screening. Consider both clinical and non-clinical roles in your discussion and complete the relevant box below.

a) If your practice has a process, describe this and reflect on how this could be improved. Summarise your action plan in the box below.

b) If your practice does not have a process, reflect on how your practice will implement a process for contacting non-responders. Summarise your action plan in the box below.

Questions to be discussed at the end

Q20. As a whole practice team, reflect on any changes made for contacting bowel screening non-responders. Identify learning points and highlight factors that supported or hindered your new or improved practice process.

Section one: Prevention

1. **Many cancers can be prevented through lifestyle changes.**

   Spend a couple of minutes looking at the major risk factors listed on Cancer Research UK's infographic[3].

4 IN 10 CANCER CASES IN WALES CAN BE PREVENTED...

...MAKE A CHANGE TO REDUCE THE RISK OF CANCER

- **Be smoke free**
- **Keep a healthy weight**
- **Avoid certain substances at work**
  such as asbestos
- **Be safe in the sun**
- **Protect against certain infections**
  such as HPV and H.Pylori
- **Eat a high fibre diet**
- **Drink less alcohol**
- **Avoid unnecessary radiation**
  including radon gas and x-rays
- **Cut down on processed meat**
- **Avoid air pollution**
- **Breastfeed if possible**
- **Minimise HRT use**
- **Be more active**

●●● Larger circles indicate more Wales cancer cases

Circle size here is not relative to other infographics based on Brown et al 2018.
Source: Brown et al, British Journal of Cancer, 2018

LET'S BEAT CANCER SOONER
cruk.org/prevention

GIG CYMRU NHS WALES | Uned Gwybodaeth a Gwyliadwriaeth Canser Cymru / Welsh Cancer Intelligence and Surveillance Unit

CANCER RESEARCH UK

2. Run a search to identify how many of your practice's patients have a BMI over 30 and include the result below?

Note: This is a Quality and Outcomes Framework (QOF) search under obesity, so it will not appear in your list of searches.

Public Health Wales Observatory report on Obesity in Wales (2019) highlighted that 24% of adults in Wales are obese.

Please discuss questions 3 to 7 with **at least two** other members of your practice:

3. What do you think are the main cancer types that patients with a BMI over 30 are at risk of?

Review this infographic and compare your answers. In the box above, note any learning points and ensure this information is shared with your whole practice team.

4. Do you include risk of cancer in health advice given to patients who are obese?

| Never | Rarely | Sometimes | Often | Always |

5. Do you include risk of cancer in health advice given to patients who smoke?

| Never | Rarely | Sometimes | Often | Always |

6. For each of the following, indicate what actions (if any) your practice takes to encourage your patients to:

a) Stop smoking

b) Keep a healthy weight

7. What local referral options are available to help patients stop smoking and manage their weight?

List these in the box below and ensure this information is shared with your whole practice team. Please consider sharing this information with colleagues in your cluster too.

a) Stop smoking services

b) Weight management services

Approximately 7,200 cancer cases (37.8%) could be prevented in Wales every year. In 2015, tobacco smoking (16.1%) and overweight and obesity (5.4%) were the biggest risk factors causing cancer in Wales[4].

8. Reflecting on the section above, discuss as a whole practice team how you currently carry out opportunistic health promotion to help prevent cancer. Also cover how your practice's approach could be improved, detailing what changes could be made for each clinical role.

For further information and resources to help your practice carry out opportunistic health promotion, please use the following links:

- **Help Me Quit Wales**

- NICE's **Physical activity: brief advice for adults in primary care**

- **Cancer Research UK's Obesity, weight and cancer**

- Public Health Wales' **Making Every Contact Count: e-learning and resources**

Section two: Understanding cancer screening programmes

9. **Using** Public Health Wales' Screening for Life data**, what is the most recent breast screening coverage data for your:**

    Cluster (%)   Health board (%)

    a) Reflect on any differences between the data for your cluster and health board in the box below:

10. **Using** Public Health Wales' Screening for Life data**, what is the most recent bowel screening coverage data for your:**

    Cluster (%)   Health board (%)

    a) Reflect on any differences between the data for your cluster and health board in the box below:

11. **Using** Public Health Wales' Screening for Life data**, what is the most recent cervical screening coverage data for your:**

    Cluster (%)   Health board (%)

    a) Reflect on any differences between the data for your cluster and health board in the box below:

12. **How do you ensure that all members of your practice team are familiar with national cancer screening programmes and the criteria for them, including age ranges?**

    Also, where does your team direct patients who require additional help, eg people with learning difficulties?

13. **Visit Public Health Wales' bowel screening website and refresh your understanding of the benefits and risks of bowel screening. After visiting this website, summarise anything new you have learnt and share with your whole practice team.**

Section three: Contacting screening non-responders

14. Does your practice have an agreed approach for identifying non-responders to the following screening programmes?

Bowel	Yes	No	Data not available
Breast	Yes	No	Data not available
Cervical	Yes	No	Data not available

15. Does your practice have an agreed approach for contacting non-responders to the following screening programmes?

Bowel	Yes	No
Breast	Yes	No
Cervical	Yes	No

Note: You can identify non-responders to cervical screening using a QOF search.

Contacting non-responders to bowel screening

16. Run search 8 and record the number of non-responders to the bowel screening programme in the last six months.

Evidence shows that contacting non-responders about bowel cancer screening and getting a family doctor to endorse the screening can improve uptake.

17. In consideration of this, discuss with your whole practice team how you currently contact non-responders to bowel screening. Consider both clinical and non-clinical roles in your discussion and complete the relevant box below.

a) If your practice **has** a process, describe this and reflect on how it could be improved. Summarise your action plan in the box below.

b) If your practice **does not** have a process, reflect on how your practice will implement a process for contacting non-responders. Summarise your action plan in the box below.

For further information on how to improve or create an action plan for contacting non-responders, please use this link:

- **Bowel Screening Wales information resources**

Note: Your process should incorporate **promotional materials** distributed by Screening for Life.

For the **next six months**, ensure that your practice implements your new or improved process. We recommend that you also use the following codes going forward:

- **9Ow2:** No response to bowel cancer screening programme invitation (result may be coded automatically within EMIS)

- **9Ow4:** Bowel cancer screening programme telephone invitation

- **9Ow5:** Bowel cancer screening programme letter invitation sent

- **8CAy:** Advice given about bowel cancer screening

18. **To monitor your progress, we recommend you run searches 7, 10, 12 and 12b on a monthly basis for the next six months. If this is feasible for your practice, record in the box below the number of non-responders during each month, the number of patients who were contacted during each month and how contact was made (telephone or letter).**

	Month 1	Month 2	Month 3	Month 4	Month 5	Month 6
Number of non-responders						
Number of patients contacted						
Number of patients contacted by telephone						
Number of patients contacted by letter						
Number of patients who received bowel screening advice in the past month						

19. Using the information from your spreadsheet (six-month data), record the number of:

a) Non-responders in the last six months **(Search 8)**

b) Non-responders contacted in the last six months via letter **(Search 9**)

c) Non-responders contacted in the last six months via telephone **(Search 11)**

d) Number of patients who received bowel screening advice in the last six months **(Search 12a)**

e) Using the numbers recorded for **19b and 19c**, identify how many non-responders you contacted did subsequently go on to uptake screening. **You can obtain this information by building a search based on the Read codes provided in this module.***

Non-responders contacted via letter who went on to have screening

Non-responders contacted via telephone who went on to have screening

*We recognise this will require your practice to build your own searches. However, it would be beneficial for your practice to capture this data for quality improvement purposes.

20. As a whole practice team, reflect on any changes made for contacting bowel screening non-responders. Identify learning points and highlight factors that supported or hindered your new or improved practice process.

21. **If you have any additional comments in relation to any of the questions in this module, please write these in the box below.**

Did you know that your practice or a patient can request to receive a replacement bowel cancer screening test kit? This can be done by completing this **form** or emailing **this address**.

If you or a member of your practice wishes to continue using this module for quality improvement purposes, you may continue using the codes and searches. For ease, all codes can be found in **Appendix 2**.

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

Further reading and useful resources

Public Health Wales' **Understanding behavioural change conversations in Wales**

Macmillan Cancer Support's physical activity resources for health professionals

Breast Test Wales

Breast Test Wales information resources

Cervical Screening Wales

Cervical Screening Wales information resources

Bowel Screening Wales

Bowel Screening Wales information resources

Wales local bowel screening engagement team contact information

**Cancer Research UK's Engaging primary care in bowel screening:
GP good practice guide for Wales**

Module two
Prompt recognition and early referral

Searches for this module

Search number	Search description
5	Fast track cancer referral in last six months
13	Cancer diagnoses in last six months with two-week wait (2ww)
14	Fast track cancer referral information given
15	Fast track cancer referral
17	Cancer diagnoses in last six months

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

Introduction

Five-year cancer survival rates in Wales are lower than the rest of the UK and several European countries[1]. Differences in stage at diagnosis and access to optimal treatment are likely to be major contributing factors to cancer survival in Wales.

The Wales Cancer Patient Experience Survey (WCPES) highlighted that 19% of respondents took at least three months to see a doctor after realising something was wrong. Sixty-one per cent of people also said they saw their GP once or twice before being referred to hospital, while a minority (6%) revealed that they saw their GP at least five times before being referred to hospital.

To ensure more people are diagnosed earlier with cancer, and to improve access to optimal treatment, NICE's **Suspected cancer: Recognition and referral** guidelines were updated. It now includes a lower threshold for referring people who present with concerning symptoms and supports GPs to give them direct access to diagnostic tests[2]. However, we understand it is difficult to get the right balance between ensuring worrying symptoms and signs are recognised and acted upon and not over referring, which can cause anxiety in patients and overwhelm the system.

Overall, it is crucial that people who may have cancer are identified at an early stage, the possibility of a cancer diagnosis is communicated appropriately, and information is provided according to a person's wishes[2]. In addition, effective safety netting and consistent coding of information are essential to ensure patients are appropriately monitored and followed-up if symptoms worsen or if new symptoms develop[3].

This module is designed to help your practice review and improve their approaches and processes for recognition and referral, providing information to people when cancer is suspected, and safety netting.

The objectives for this module are to:

1. Improve your practice's application of NICE *Suspected cancer: Recognition and referral guidelines* (2017) and increase the awareness and use of summaries to support this.

2. Improve your practice's processes relating to when information is provided to a patient if a clinician suspects cancer and refers them urgently.

3. Improve your practice's coding and safety netting of urgent referrals for suspected cancer.

4. Improve the quality of safety netting advice your practice gives to patients with 'low risk but not no risk symptoms' who may not be referred urgently.

4. Increase your practice's awareness and use of the Macmillan Cancer Decision Support tool.

Module top tips

Before you start, please remember the following tips to support completion of this module. And if you're ever unsure about how to use this toolkit, please see **page 10** for full instructions.

1. Nominate an individual with a clinical background to be the lead for this module. This individual should ensure that learning from the module is shared with the whole practice team. We also encourage practices to liaise with colleagues in their cluster to discuss issues and share learning.

2. Schedule practice meetings in advance to ensure that all members of your primary care team can participate in baseline and six-month discussions.

3. Some of the questions in this module may be completed by an individual team member. If this happens, please ensure that what they learn is discussed and shared with your wider team.

Practice meeting discussions

We suggest your team uses practice meetings to complete some questions in this module. We recommend that these discussions involve your whole primary care team, including clinical and non-clinical roles.

To help facilitate these meetings, we have included all questions that require a practice discussion below:

Questions to be discussed at the beginning

Q8. In consideration of the above, reflect as a whole practice team how you opportunistically discuss the signs and symptoms of cancer with patients (where appropriate). Briefly describe your practice's approach and discuss how this could be improved. Detail what changes you could make for each practice role.

Q10. Discuss as a whole practice team what direct access you have to diagnostics (eg radiological) in your area. Identify a member of your team to collate this information and list in the box below. Make this information available to all referring clinicians.

Q11. In consideration of the above, discuss in a practice meeting the following questions:

a) Currently, where and how do you seek advice for patients who present with vague symptoms that could be cancer? If this advice comes from a person, list their clinical role and how you access them.

b) What referral options do you have locally for patients who present with vague symptoms that could be cancer?

Q14. With this in mind, and reflecting on patients who have been referred on an **urgent suspected cancer (USC) pathway**, discuss with your whole practice team what information you currently provide to patients and how this information is shared.

Summarise in the box below what information and support is routinely offered/discussed with a patient who has been referred on an USC pathway. Reflect on how this could be improved and consider all clinicians in any potential changes. Summarise your action plan in the box below.

Q19. In consideration of this, discuss with your whole practice team what systems or processes your practice has in place for safety netting **USC referrals**. You may wish to focus on the roles of both clinical and non-clinical staff.

a) If your practice **has** a system or process, describe this and reflect on how this could be improved. Summarise your action plan in the box below.

b) If your practice **does not** have a system or process, please discuss with your whole practice team how you will implement a new approach for the safety netting of **USC referrals**. Summarise your action plan in the box below.

Q21. In consideration of this, discuss with your whole practice team what approaches are currently used and what information is recorded for the safety netting of these patients. For example, consider a patient with new onset dyspepsia but no red flag symptoms.

Briefly describe your current approach. Identify learning points and proposed changes in order to develop a standardised practice approach for the safety netting of patients.

Questions to be discussed at the end

Q17. As a whole practice team, reflect on the changes made in the last six months. Identify learning points and highlight any factors that supported or hindered your new or improved approach to patient information and support following a USC referral.

Q20. After six months, reflect as a whole practice team what has resulted from you making changes to your process. Identify learning points and highlight factors that supported or hindered your new or improved safety netting processes for patients referred on an USC pathway.

Section one: Patient awareness of signs and symptoms

1.   **Are you aware of the NHS calendar of national campaigns and awareness days?**

        Yes   No

2.   **Does your practice promote the NHS calendar of national campaigns and awareness days?**

        Yes   No

The importance of patient awareness of cancer signs and symptoms is supported by the **Routes to Diagnosis** data in England. It indicates that the one-year survival rate for people who present through emergency routes is notably lower than people who are referred by their GP on a suspected cancer pathway. **Macmillan Cancer Support and WCISU** is currently collating similar data for Wales.

The following questions will help you review routes to diagnosis at your practice.

3.   **Using the information from your spreadsheet (0-month data), record the number of 'fast track referrals' in the last six months (Search 5). This will allow you to calculate your conversion rate for USC referrals.**

        If this search is **not** available, please tick this box

Going forward, we recommend that you use the following code for USC referrals: **8HHt**. Please ensure this information is shared with your whole practice team.

4.   **Using the information from your spreadsheet (0-month data), record the number of patients who were diagnosed in the last six months via an urgent suspected cancer (USC) referral (Search 13).**

5.   **Using your answers to questions 3 and 4, calculate your conversion rate and record the number in the box below.**

6.   Using the information from your spreadsheet (0-month data), record the number of cancer diagnoses in the last six months (Search 17).

7.   Using the results of search 17, alongside information contained within patient notes, please record the number of:

a) Emergency presentations*

b) Routine referrals*

c) Other referrals (please give details)

*Please retain the name of one patient (either routine referral or emergency presentation) to support the completion of section four in this module.

Increasing patient awareness of the signs, symptoms and risk factors for cancer is essential if we are to encourage earlier presentation to GPs.

8.   In consideration of the above, reflect as a whole practice team how you opportunistically discuss the signs and symptoms of cancer with patients (where appropriate). Briefly describe your practice's approach and discuss how this could be improved. Detail what changes you could make for each practice role.

For further information, please use the following links:

● **NHS national campaigns and awareness days**

● **NHS signs and symptoms of cancer**

Section two: Application of the NICE guidelines

The NICE *Suspected cancer: Recognition and referral* guidelines were updated in 2015 **(NICE NG12)**. This section of module two will guide your practice through the key recommendations of the guidelines in relation to diagnostic process, patient information and support and safety netting.

9.   **How do clinical members of your team access NICE *Suspected cancer: Recognition and referral* guidelines (either as a whole or as part of a summary)? Detail below by clinical role.**

If you were not aware of recommended summaries of the NICE guidance, or do not currently use them, you can access them using the following links:

- **Macmillan's Rapid referral guidelines** (Note: there may be some variation as NG12 has been updated in relation to faecal immunochemical testing)

- **C the Signs**

- **CRUK's Suspected cancer recognition and referral symptom reference guide**

- **Adult cancers infographic – Referral pathways by presenting symptom (Will Stahl-Timmins 2017)**

Please ensure that summaries are made available to your whole practice team and on all desktops in clinical rooms.

The diagnostic process

The updated NICE guidelines also recommend that GPs have direct access to diagnostic tests for many symptoms. However, we recognise that these tests are not currently available in all health boards in Wales.

10. **Discuss as a whole practice team what direct access you have to diagnostics (eg radiological) in your area. Identify a member of your team to collate this information and list in the box below. Make this information available to all referring clinicians.**

The NICE guidelines also state that when clinicians are uncertain about the interpretation of symptoms and signs, or whether they should refer a patient, they should consider a discussion with a specialist.

11. **In consideration of the above, discuss in a practice meeting the following questions:**

a) Currently, where and how do you seek advice for patients who present with vague symptoms that could be cancer? If this advice comes from a person, list their clinical role and how you access them.

b) What referral options do you have locally for patients who present with vague symptoms that could be cancer?

You can find further information on the Rapid Diagnostic Centre in Wales **here**.

Patient information and support

12. **Earlier in this module (Question 6), you performed search 17 to identify all new cancer diagnoses in the previous six months. Record this number below.**

13. **Earlier in this module (Question 4), you performed search 13 to identify the number of patients who were diagnosed in the last six months via an USC referral. Record this number below.**

NICE recommends that patients who are referred on an USC pathway should be given information about their referral (according to their wishes) and reassurance, when appropriate, to encourage them to attend appointments.

14. **With this in mind, and considering patients your practice has referred on an USC pathway, discuss with your whole practice team what information you currently provide to these patients and how this information is shared.**

Summarise in the box below what information and support is routinely offered/discussed with a patient who has been referred on an USC pathway. Reflect on how this could be improved and consider all clinicians in any potential changes. Summarise your action plan in the box below.

For further information to support practice improvement, please use the following links:

- **RCGP's Primary Care Cancer toolkit**

- NHS **Patient information leaflet for urgent referrals**

15.   Does your practice have a system in place for coding USC referrals?

Yes   No

a) If yes, please provide details in the box below.

For the next six months, implement your new or improved plan.

16.   Using the information from your spreadsheet (six-month data), record the number of patients who were diagnosed in the last six months via a USC referral (Search 13).

17.   As a whole practice team, reflect on the changes made in the last six months. Identify learning points and highlight any factors that supported or hindered your new or improved approach to patient information and support following a USC referral.

Safety netting

18. Does your practice have a system to ensure that patients referred via USC have been seen by a specialist?

Yes   No

Safety netting is a crucial component of primary care consultations[2]. It has many elements and is an important way to ensure that patients are monitored and followed up in a timely fashion[4].

19. In consideration of this, discuss with your whole practice team what systems or processes your practice has in place for safety netting USC referrals. You may wish to focus on the roles of both clinical and non-clinical staff.

a) If your practice **has** a system or process, describe this and reflect on how this could be improved. Summarise your action plan in the box below.

b) If your practice **does not** have a system or process, please discuss with your whole practice team how you will implement a new approach for the safety netting of **USC referrals**. Summarise your action plan in the box below.

To help your practice improve or develop a safety netting system, use the following link to access a number of helpful resources:

● Macmillan's e-learning module **Coding and safety netting in the context of cancer**

For the next six months, ensure your practice implements your new or improved process.

20. After six months, reflect as a whole practice team what has resulted from you making changes to your process. Identify learning points and highlight factors that supported or hindered your new or improved safety netting processes for patients referred on an USC pathway.

Safety netting is also important for patients with a **low risk but not no risk of cancer** who do not meet referral criteria for urgent suspected cancer referral[2].

21. In consideration of this, discuss with your whole practice team what approaches are currently used and what information is recorded for the safety netting of these patients. For example, consider a patient with new onset dyspepsia but no red flag symptoms.

Briefly describe your current approach. Identify learning points and proposed changes in order to develop a standardised practice approach for the safety netting of patients.

Section three: Macmillan Cancer Decision Support (CDS) Tool

22.   Before today, were you aware of the Macmillan Cancer Decision Support tool?

Yes   No

23.   Have you used this tool in practice?

Yes   No

The Macmillan Cancer Decision Support (CDS) tool estimates the risk of a patient having an undiagnosed cancer. This is based on recent investigation results and symptoms and signs coded in their clinical notes. This tool is recognised as a key driving force for the early diagnosis of cancer and supports GPs to 'think cancer' in low risk situations[5].

If this tool is **not** currently available at your practice, please take the following actions:

●   Click on this **link** for instructions on how to access the tool on your system.

●   Ensure that the tool is turned on at your practice.

●   Disseminate information from the CDS promotion pack to all clinical staff so they are aware of how to use the tool and how it can benefit them.

Now familiarise yourself with the tool

For those patients identified in **Question 7** as being diagnosed via a routine referral or emergency presentation, consider using the symptom checker function to calculate their risk of cancer at the time of consultation. This calculation can be done by inputting the presenting signs, symptoms and any accompanying investigations.

Note: You do not have to save scores to the files of patients.

24.   After using the tool, please consider whether using it at the time of presentation may have altered your level of perceived risk. Note your thoughts in the space provided.

25. **For those who have not previously used the CDS tool, would you consider using the tool again?**

Yes   No

a) If **yes**, how will your practice make this tool available?

b) If **no**, explain in the box below any factors preventing your practice from making the tool available?

26. **If you have any additional comments in relation to any of the questions in this module, please write these in the box below.**

If you or a member of your practice wishes to continue using this module for quality improvement purposes, you may continue using the codes and searches. For ease, all codes can be found in **Appendix 2.**

GPs reported that 19% of patients would not have been referred without use of the CDS tool[5].

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

Further reading and useful resources

Macmillan's signs and symptoms of cancer

Macmillan's Primary care top 10 tips for multiple or vague symptoms

Wales Cancer Network's Detecting Cancer Earlier Programme

Cancer Research UK's Safety netting summary

Module three
Support through treatment

Searches for this module

Search number	Search description
16	Cancer diagnoses ever
17	Cancer diagnosis at the last six months
18	Cancer diagnosis over five years ago
19	Cancer diagnosis in last six months with treatment coded
22	Contact made with patient after cancer diagnosis

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

Introduction

Following a cancer diagnosis, many patients increasingly contact their GP practice for medical advice[1]. To better support these patients, it's important that key information about their cancer diagnosis, key worker and treatment are documented on their patient record. This information also needs to be clearly highlighted to practice staff so they can effectively identify, assess and manage any concerns or risks.

People receiving cancer treatments are at risk of significant complications from treatment; and if they become unwell, they will require rapid clinical assessment. Tools such as the Oncology/Haematology Treatment Toxicity Risk Assessment Tool for primary care professionals (UKONS and Macmillan Cancer Support) and services such as acute oncology services (AOS) can help improve the clinical management of these patients[2] and ensure they get the support they need.

The **Wales Cancer Patient Experience Survey (WCPES)** highlighted that almost two-thirds of respondents (65%) felt that the different people caring for them always worked well together. However, a minority of respondents felt that those caring for them worked well some of the time (8%) or not at all (2%). It is crucial that care is effectively coordinated between primary, community and secondary care, which includes establishing clear lines of communication and access to specialist advice.

This module encourages your whole practice team to review and improve your approach for supporting patients through treatment.

The objectives for this module are to:

1. Review and improve your practice's process for contacting people following a diagnosis of cancer.

2. Ensure the consistent coding of cancer diagnoses and treatment.

3. Improve your practice's assessment and management of people who have received cancer treatment.

4. Review and promote effective communication pathways between primary and secondary care when advice is needed during treatment or when problems occur.

Module top tips

Before you start, please remember the following tips to support completion of this module. And if you're ever unsure about how to use this toolkit, please see **page 10** for full instructions.

1. Nominate an individual with a clinical background to be the lead for this module. This individual should ensure that learning from the module is shared with the whole practice team. We also encourage practices to liaise with colleagues in their cluster to discuss issues and share learning.

2. Schedule practice meetings in advance to ensure that all members of your primary care team can participate in baseline and six-month discussions.

3. Some of the questions in this module may be completed by an individual team member. If this happens, please ensure that what they learn is discussed and shared with your wider team.

Practice meeting discussions

We suggest your team uses practice meetings to complete some questions in this module. We recommend that these discussions involve your whole primary care team, including clinical and non-clinical roles.

To help facilitate these meetings, we have included all questions that require a practice discussion below:

Questions to be discussed at the beginning

Q3. Discuss the results of the above searches with your whole practice team. In this meeting, reflect on your current practice for contacting new cancer patients specifically about their diagnosis. Please complete the relevant box below.

a) If you **have** a process, describe this and reflect on how this could be improved. Summarise the actions your practice will take going forward.

b) If your practice **does not** have a process, please discuss with your whole practice team how your practice will implement a process for contacting new cancer patients specifically about their cancer diagnosis. Summarise your action plan in the box below.

Q12. Discuss with your whole practice team how a patient's history of cancer treatment is highlighted to administration staff/the reception team and complete the appropriate box below:

a) If this information **is currently highlighted** to administration/reception staff receiving a call from a patient, briefly explain how. In addition, reflect on how this process could be improved and summarise any actions your practice will take going forward.

b) If this information **is not currently highlighted** to administration/reception staff receiving the phone call, reflect on what your practice can do to address this. Summarise your action plan in the box below.

Q14. Discuss with your whole practice team how practice staff are made aware that patients currently receiving cancer treatment should be prioritised for urgent clinical triage. Complete the appropriate box below.

a) Briefly explain how staff, both clinical and non-clinical, **are made aware** of the need to prioritise these patients. Reflect on how your process could be improved and summarise the actions your practice will take going forward.

b) If practice staff **are currently not made aware** of the need to prioritise these patients, reflect on what the practice could do to address this. Summarise your action plan in the box below.

Q17. Discuss your answers to **Questions 15 and 16** with your whole practice team. Produce a list of useful local contacts and resources for use in your practice. Ensure that these are available to all staff and locums. Consider sharing this information with colleagues within your cluster.

Q24. In a practice meeting that is attended by various practice roles, consider and discuss how each of the following three case studies would be managed using the **UKONS and Macmillan Cancer Support tool**.

In preparation for this meeting, ensure that everyone who is discussing these cases has a copy of the UKONS and Macmillan Cancer Support tool.

Questions to be discussed at the end

Q5. As a whole practice team, reflect on any changes that were made in **the last six months**. Summarise learning points and highlight any factors that supported or hindered the implementation of your new or improved process for contacting new cancer patients specifically about their diagnosis.

Q8. As a whole practice team, reflect on the changes that were made in the last six months, particularly in relation to any differences between **Questions 6 and 7**. Summarise learning points and highlight any factors that supported or hindered the recording of treatment modality and key worker information.

Section one: Communication and documentation at the point of diagnosis

This section covers contact with a patient at the point of diagnosis or soon after it. This is different from a cancer care review, which is covered in module four.

1. Do you routinely contact new cancer patients specifically about their diagnosis

Never   Rarely   Sometimes   Often   Always

2. Using the information from your spreadsheet (0-month data), record the number of cancer diagnoses in the last six months (Search 17).

Note: A Read code starting with **'M'** is a morphology code and not a diagnosis code. If coded with a morphology code, the patient **will not** be added to the cancer register. If you can't find a code specific to a person's cancer, we recommend that you use a more general code and the free text option for specifics.

a) Using the results of **search 17**, please select the **last 10 cases** (or as many as you have if less than 10) from your list of identified patients. Review their patient notes and record the number of patients who were contacted specifically about their diagnosis.

Number of cases reviewed

Number of patients contacted

Diagnosis can be a very difficult time for patients, meaning support from their primary care team is essential. We know patients value engagement from their GP or practice nurse and opportunities to discuss their diagnosis and ongoing treatment with a medical professional they know and trust[3].

3. Discuss the results of the above searches with your whole practice team. In this meeting, reflect on your current practice for contacting new cancer patients specifically about their diagnosis. Please complete the relevant box below.

a) If you **have** a process, describe this and reflect on how this could be improved. Summarise the actions your practice will take going forward.

b) If your practice **does not** have a process, please discuss with your whole practice team how your practice will implement a process for contacting new cancer patients specifically about their cancer diagnosis. Summarise your action plan in the box below.

The following resources could be used at the point of diagnosis or for inviting patients to a cancer care review. The wording of the letter can (and should) be adapted to meet the needs and processes of your practice, according to the timing of cancer care reviews within your practice:

- See **Appendix 3** for a patient letter template.

- A copy of the National Cancer Survivorship Initiative's 'concerns checklist', which is referenced in the letter template, can be accessed here: **Identifying your concerns**

For the **next six months**, implement your new or improved process and ensure that the following code – **8CL0** (Cancer diagnosis discussed) – is used for all new cancer patients who are contacted specifically about their diagnosis.

Ensure your whole practice team is made aware of the process and the code.

4. Using the information from your spreadsheet (six-month data), record the number of:

a) Cancer diagnoses in the last six months (Search 17)

b) Patients who were contacted in the last six months (Search 22)

5. As a whole practice team, reflect on any changes that were made in the last six months. Summarise learning points and highlight any factors that supported or hindered the implementation of your new or improved process for contacting new cancer patients specifically about their diagnosis.

Section two: Recording of treatment information

6. Using the results of search 17 at the beginning of this module (Question 2), please select the last 10 patients (or as many as you have if less than 10) from your list of identified patients. Review the notes of these patients and complete the table below. You do not need to contact patients for this information.

For each patient, please indicate where treatment modality and key worker information were recorded by indicating **yes or no** in the boxes below.

Note: If a patient had surgical treatment only or has **not** had chemotherapy, immunotherapy or radiotherapy, please write **not applicable**.

Patient	Treatment modality*				Key worker**			
	Coded	Alert on patient notes	Documented in patient letters	Provide any comments if needed	Coded	Alert on patient notes	Documented in patient letters	Provide any comments if needed
1								
2								
3								
4								
5								
6								
7								
8								
9								
10								

* Chemotherapy, radiotherapy or immunotherapy

** The Cancer Delivery Plan for Wales: 2016–2020 states that each health board should assign a named key worker to coordinate care for the person living with cancer for the duration of their treatment in secondary care and subsequently within primary care. It is not always a clinician who is a key worker.

For the **next six months**, ensure that you use the following codes to allow for easier identification of key workers and treatment modalities. We recommend using the following codes and sharing this information with your whole practice team:

Cancer key worker: **9NNc.00**

Radiotherapy treatment: **7L2.00**

Chemotherapy: **8BAD.00**

Immunotherapy: **5A86.00**

Hormone treatment   **7Q0J0**

Note: In addition to the suggested codes, we recommend documenting the site of radiotherapy and/or the agent used for chemotherapy/immunotherapy. Then ensure the code is listed as a high priority.

7. **From your list of identified patients from search 17 (Question 4a), please select the last 10 patients (or as many as you have if less than 10). Review their patient notes and complete the table below. You do not need to contact patients for this information.**

For each patient, please indicate where treatment modality and key worker information were recorded by indicating **yes or no** in the boxes below.

Note: If a patient had surgical treatment only or has **not** had chemotherapy, immunotherapy or radiotherapy, please write **not applicable**.

Patient	Treatment modality*				Key worker**			
	Coded	Alert on patient notes	Documented in patient letters	Provide any comments if needed	Coded	Alert on patient notes	Documented in patient letters	Provide any comments if needed
1								
2								
3								
4								
5								
6								
7								
8								
9								
10								

* Chemotherapy, radiotherapy or immunotherapy

** The Cancer Delivery Plan for Wales: 2016–2020 states that each health board should assign a named key worker to coordinate care for the person living with cancer for the duration of their treatment in secondary care and subsequently within primary care. It is not always a clinician who is a key worker.

8. **As a whole practice team, reflect on the changes that were made in the last six months, particularly in relation to any differences between Questions 6 and 7. Summarise learning points and highlight any factors that supported or hindered the recording of treatment modality and key worker information.**

Section three: Treatment summaries

9. **Have you received a treatment summary for any patients who were diagnosed in the past 12 months**

     Yes   No

10. **Out of the information you currently receive about a cancer patient (eg via treatment summaries, discharge summaries or clinic letters from an oncology department), what information do you routinely code in patient records?**

While we are aware that it is not yet common practice, secondary care should produce a treatment summary (see **Appendix 4**) after each phase of active treatment[4]. The aim of this summary is to highlight essential treatment information to the patient and their primary care team. This document (in the form of a template or letter) outlines the treatment received, ongoing care plan, potential consequences of treatment and any recommended actions for the GP and primary care team.

Section four: Access to clinical advice and assessment

11. When patients undergoing treatment contact the surgery, is their history of cancer treatment highlighted to administration staff/the reception team receiving the phone call?

Yes   No

There will be occasions when patients seek medical advice via primary care. It is important that information regarding current diagnosis and treatment are documented in patient records and clearly highlighted to practice staff, including reception/administration staff.

12. Discuss with your whole practice team how a patient's history of cancer treatment is highlighted to administration staff/the reception team and complete the appropriate box below:

a) If this information **is currently highlighted** to administration/reception staff receiving a call from a patient, briefly explain how. In addition, reflect on how this process could be improved and summarise any actions your practice will take going forward.

b) If this information is not currently highlighted to administration/reception staff receiving the phone call, reflect on what your practice can do to address this. Summarise your action plan in the box below.

13. Are all practice staff, including non-clinical staff, aware of the need to prioritise patients currently receiving cancer treatment for urgent clinical triage?

Yes   No

Patients receiving cancer treatment are at risk of significant complications from treatment. If they become unwell, they will require rapid clinical assessment. For example, patients who are receiving or have received immunotherapy may present with complications during treatment or up to at least 12 months afterwards[5]. Patients who have received systemic anti-cancer therapy (SACT) are at risk of complications for up to eight weeks after their last treatment.

14. Discuss with your whole practice team how practice staff are made aware that patients currently receiving cancer treatment should be prioritised for urgent clinical triage. Complete the appropriate box below:

a) Briefly explain how staff, both clinical and non-clinical, are made aware of the need to prioritise these patients. Reflect on how your process could be improved and summarise the actions your practice will take going forward.

b) If practice staff are currently not made aware of the need to prioritise these patients, reflect on what the practice could do to address this. Summarise your action plan in the box below.

15. When patients are unwell during their cancer treatment, what resources or tools do you use to guide your clinical management? List these in the box below.

16. **What local professionals are available when you wish to seek advice about a patient undergoing cancer treatment? List their clinical roles in the box below.**

17. **Discuss your answers to questions 15 and 16 with your whole practice team. Produce a list of useful local contacts and resources for use in your practice. Ensure that these are available to all staff and locums. Consider sharing this information with colleagues within your cluster.**

Communication pathways between primary and secondary care

18. **Please discuss with at least two other members of your practice team what experiences you have had in trying to obtain urgent advice regarding an unwell cancer patient.**

a) What **has** worked well and why?

b) What **hasn't** worked well and why?

19. To improve the support provided to patients undergoing cancer treatment, please suggest any improvements to current communication pathways between primary and secondary care services in your area.

If you're not aware of any tools to assist with the clinical management of patients who are unwell, the following section provides information on tools that may benefit your practice.

Acute oncology support service (AOS)

20. Before today, were you aware of the Acute oncology support service?

Yes   No

21. Do you have access to an Acute oncology support service?

Yes   No

An **Acute oncology support service** brings together multidisciplinary clinical expertise to support the rapid identification and appropriate prompt management of patients who present acutely with complications following their cancer treatment, complications as a consequence of their cancer, or with a previously undiagnosed cancer.

The Acute oncology support service (AOS) support app is a free service provided by Velindre Cancer Centre in Cardiff, which can be downloaded to iOS and Android mobile phones. The app provides clinical staff with rapid access to emergency protocols when treating cancer patients with an unplanned emergency.

The support tool for Cancer Emergencies
Download for free now on iOS and Android
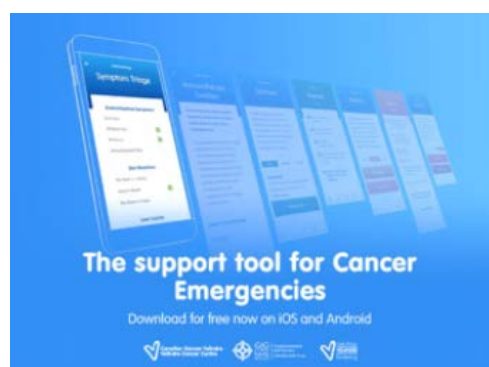
Going forward, you may find it beneficial to use this app to aid the clinical management of patients who become unwell while undergoing treatment. If you wish, click on the relevant link below to download this app to your device. Please ensure this information is shared with your whole practice team.

iOS link

Android link

Note: Contact details for your local AOS service are provided in the app.

Oncology/Haematology Treatment Toxicity Risk Assessment Tool for primary healthcare professionals – UK Oncology Nursing Society (UKONS) and Macmillan Cancer Support

22. Before today, were you aware of the UKONS and Macmillan Cancer Support tool?

Yes   No

23. Have you used this tool previously?

Yes   No

This is a **risk assessment tool** that uses a red, amber and green (RAG) scoring system to identify, prioritise and manage the symptoms of patients contacting primary care for assessment and advice.

It applies to patients who have:

- received chemotherapy/systemic anti-cancer therapy (SACT)

- received any other type of anti-cancer treatment, including radiotherapy

- received cancer or treatment-related immunosuppression, eg for acute leukemia or corticosteroids.

Going forward, you may wish to use this risk assessment tool, which can be found here. Please ensure information about it is shared with your whole practice team.

24. In a practice meeting that is attended by various practice roles, consider and discuss how each of the following three case studies would be managed using the UKONS and Macmillan Cancer Support tool.

In preparation for this meeting, ensure that everyone who is discussing these cases has a copy of the **UKONS and Macmillan Cancer Support tool**.

Case studies

Case study 1 – Chemotherapy (discuss version 1 and 2)

64-year-old with colorectal cancer.

Presentation: phone call to the surgery from patient's wife wanting an appointment with practice nurse. She says his operation wound is weeping.

Surgery three months ago. Receiving adjuvant chemotherapy, which started 10 days ago.

Cycle one: oxaliplatin (IV) and capecitabine (oral) chemotherapy, currently taking capecitabine twice daily.

History: wound has been red and painful for four days; now has small open area and weeping clear/pinkish fluid.

Version 1

Temp 37.3, feeling cold and shivery, generally unwell.

Feeling very tired, in bed/resting most of the day, doesn't feel strong enough to come to the surgery.

Bowels open intermittent watery and soft 3–4 times daily (no change from pre-chemo).

Nauseated and eating little, drinking good amounts, urine output about the same as usual.

Mouth painful with some ulcers – making eating painful.

Has taken co-codamol this morning for pain.

Version 2

Version 2

Temp 36.8.

Feeling more tired than usual, taking afternoon naps, walked to the post box this morning.

Bowels open intermittent watery and soft 3–4 times daily (no change from pre-chemo).

Mouth tender but eating and drinking well, no ulcers.

No nausea or vomiting.

Case study two – Chemotherapy

53-year-old woman with breast cancer.

First chemotherapy treatment with IV flurouracil, epirubicin and cyclophosphamide, yesterday morning.

Patient concern: vomiting since yesterday evening (now 10am and has vomited after trying to take oral antiemetics).

Vomited numerous times (more than six times) since yesterday evening.

No diarrhoea or constipation.

No mouth soreness.

Hasn't checked temperature – can't put thermometer in mouth as gags, not feeling feverish.

Exhausted and has hardly slept due to nausea and vomiting.

Eaten nothing, sips of water but they haven't stayed down for long, passing urine but looks darker than usual.

No other toxicities.

Has ondansetron, dexamethasone and metoclopramide tablets prescribed by cancer team but can't keep them down.

No other regular medication.

Case study 3 – Immunotherapy

62-year-old male with metastatic melanoma.

Has had three cycles of ipilimumab (IV immunotherapy)

Patient concern: has had diarrhoea for three days, has contacted for advice as loperamide is not working, requesting a prescription for a different anti diarrhoeal medication.

History: watery stools for three days, 3–4 times a day for two days, and then at least 6–8 times in the last 24 hours (has lost count). No problems with diarrhoea with previous cycles.

Has taken loperamide for three days but does not seem to have helped.

No nausea or vomiting.

Has crampy abdomen pains for 24 hours – new pain and getting worse.

Temp 37.4.

Feeling washed out and not able to do as much as usual.

Passing urine but looks darker than usual.

Eating small amounts and drinking usual amount.

No other toxicities.

25. **After considering the three case studies above using the UKONS and Macmillan Cancer Support tool, please complete the following questions:**

a) If you haven't used this tool previously, would you now consider using the tool?

Yes   No

b) If **yes**, please explain how you will make the tool available going forward.

c) If **no,** please explain what factors are preventing your practice from using the tool.

After considering the case studies, please see Appendix 5 for key learning points for each case study.

26. **If you have any additional comments in relation to any of the questions in this module, please write these in the box below.**

If you or a member of your practice wishes to continue using this module for quality improvement purposes, you may continue using the codes and searches. For ease, all codes can be found in **Appendix 2**.

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

Further reading and useful resources

NICE's guidance on the complications of cancer

Macmillan's Treatment summary: How-to guide

UKONS and Macmillan Cancer Support's Oncology/Haematology Risk Assessment Tool for primary healthcare professionals booklet

Primary Care One website and links to useful resources to manage symptoms

Macmillan's Support for primary care

Module four
Cancer care reviews and long-term consequences of cancer and its treatment

Searches for this module

Search number	Search description
16	Cancer diagnosis ever
17	Cancer diagnosis in the last six months
18	Cancer diagnoses over five years ago
22	Contact made with patient after diagnosis
23	Cancer care reviews in last six months
24a	Cancer care review in last six months and discussion about psychological counselling
24b	Cancer care review in last six months and discussion about employment counselling
25	Cancer care review in last six months and benefits counselling
26	Discussion about complications of treatment
27	Cancer diagnosis discussed
32	Macmillan information offered in last 12 months

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

Introduction

Consecutive national cancer plans, including the Welsh government's Cancer Delivery Plan for Wales 2016–2020, have highlighted the importance of person-centred care and meeting the needs of people living with cancer. The Wales Cancer Patient Experience Survey (2017) highlighted that the majority (91%) of respondents felt their GP was well informed about their treatment and care. However, for patients who required help or care from their GP practice after leaving hospital, only 56% stated that they definitely received the help they needed.

A **cancer care review (CCR)**, if carried out and documented effectively, offers an opportunity to plan care holistically and meet the needs of people living with cancer. Just under half (48%) of WCPES respondents reported that they had an opportunity to discuss their needs and develop a care plan. This presents a key area for improvement, as those who had the opportunity to discuss their needs reported more positive experiences across all phases of the patient journey.

The rise in the number of cancer survivors and demands on secondary care has led to an increase in patients that require assessment and management in primary care. Cancer treatment is often invasive and can have both short and long-term consequences. These can be physical, social or psychological in nature and arise days, months and even years after treatment. Failure to identify and effectively manage these distressing problems can compromise survival, recovery and quality of life for the patient and their carers[1].

This module encourages your whole practice team to review and improve their approach to cancer care reviews and the long-term support offered to patients.

The objectives for this module are to:

1. Increase your primary care team's knowledge of the holistic needs of people living with cancer and the support they need after treatment.

2. Ensure your practice adopts a structured, holistic approach to cancer care reviews.

3. Promote the role that practice nurses can play in carrying out holistic cancer care reviews and managing the long-term needs of people living with cancer.

4. Increase your practice's knowledge of the long-term consequences of cancer and its treatment.

Module top tips

Before you start, please remember the following tips to support completion of this module. And if you're ever unsure about how to use this toolkit, please see **page 10** for full instructions.

1. Nominate an individual with a clinical background to be the lead for this module. This individual should ensure that learning from the module is shared with the whole practice team. We also encourage practices to liaise with colleagues in their cluster to discuss issues and share learning.

2. Schedule practice meetings in advance to ensure that all members of your primary care team can participate in baseline and six-month discussions.

3. Some of the questions in this module may be completed by an individual team member. If this happens, please ensure that what they learn is discussed and shared with your wider team.

Practice meeting discussions

We suggest your team uses practice meetings to complete some questions in this module. We recommend that these discussions involve your whole primary care team, including clinical and non-clinical roles.

To help facilitate these meetings, we have included all questions that require a practice discussion below:

Questions to be discussed at the beginning

Q4. Discuss as a whole practice team how cancer care reviews are currently offered and completed within your practice. Reflect on any procedures in place, the content of CCRs and the recording of CCR information on a patient's record. Summarise your practice approach in the box below.

Q5–20. (Section two, page 68). We recommend that you discuss and complete this section in a practice meeting so knowledge and experiences can be shared among colleagues.

Q19. In a practice meeting, discuss as a whole team how your practice will improve the quality of its cancer care reviews. Consider who carries out the reviews, the content covered and the recording of relevant information on a patient's record. In the box below, summarise the actions your practice will take going forward.

Q26. In a practice meeting, reflect on the most common long-term consequences of cancer and its treatment that you and your colleagues routinely encounter. Summarise learning points in the box below and ensure this information is shared with your whole practice team.

Questions to be discussed at the end

Q24. As a whole practice team reflect on how your improvement plan for cancer care reviews went. Summarise any learning points and highlight any factors that supported or hindered the action plan for improving the quality of cancer care reviews.

Section one: Cancer care reviews (CCRs)

1. Using the information from your spreadsheet (0-month data), record the number of new cancer diagnoses in the last six months (Search 17).

Note: A Read code starting with **'M'** is a morphology code and not a diagnosis code. If coded with a morphology code, the patient **will not** be added to the cancer register. If you can't find a code specific to a person's cancer, we recommend that you use a more general code and the free text option for specifics.

2. From the list of patients identified from search 17 (Question 1), select the last 10 patients who received a cancer care review (this may be less than 10 in smaller practices) and review their patient notes.

Number of patient records reviewed

In the boxes below, record the number of CCRs which were completed by the:

GP

Practice nurse

Other (please specify)

3. Using the information from your spreadsheet (0-month data), record the number of completed cancer care reviews in the last six months (Search 23).

Provide comments regarding any differences between your answers for **Questions 1 and 3** in the box below.

4. **Discuss as a whole practice team how cancer care reviews are currently offered and completed within your practice. Reflect on any procedures in place, the content of CCRs and the recording of CCR information on a patient's record. Summarise your practice approach in the box below.**

Section two: Improving the quality of cancer care reviews

This next section will help your practice improve the quality of your cancer care reviews. We recommend that you complete this section immediately after the audits and reflection above. We also suggest that you discuss and complete this section in a practice meeting so knowledge and experiences can be shared between colleagues.

It's important that this review covers a range of holistic topics, including the social, psychological and practical aspects of cancer, and not just medical and physical concerns. It's also important that these discussions are driven by the patient and based on their specific needs[2].

A good quality cancer care review should involve the following:

- Discussion around diagnosis to ensure understanding of it

- Treatment discussion that covers the possible impact on quality of life, including how someone might be affected physically, emotionally and financially

- Medication review

- Discussion about the information needs of the patient and their carers

- Physical activity advice and signposting to local support services

- Signposting to Macmillan Cancer Support and other appropriate organisations

5. **After considering how your practice currently carries out cancer care reviews, discuss the CCR good practice above and note how your practice could adopt these elements to better support its patients.**

Physical activity

Physical activity can help patients to recover physically and mentally from cancer treatment. It has also been shown to decrease the chance of recurrence and people being diagnosed with a second type of cancer[3].

6. **Discuss what generic local physical activity support services are available for patients in your area. List the services in the box below and ensure that this information is shared with your whole practice team. Consider sharing this information with colleagues in your cluster.**

7. **Discuss what cancer specific local physical activity support services are available for patients in your area. List the services in the box below and ensure that this information is shared with your whole practice team. Consider sharing this information with colleagues in your cluster.**

For further information on physical activity services which you or a patient can access, please use the links belows:

- **Macmillan Cancer Support's physical activity resources**

- **National Exercise Referral Scheme (NERS)**

- **Macmillan Cancer Support's 'In Your Area' search tool**

- **DEWIS Wales** – Details of local wellbeing services

- **INFOENGINE** – Directory of third sector services in Wales

Smoking

Evidence shows that if a person is being treated for cancer, stopping smoking may help their treatment work better. It can also help their body respond to their treatment and heal more quickly. A patient is also likely to have fewer side effects from cancer treatment if they do not smoke, and side effects tend to be less severe. Stopping smoking may also lower the risk of cancer coming back after treatment[4].

8.   If a patient is a smoker, do you routinely discuss smoking cessation advice with them?

Never   Rarely   Sometimes   Often   Always

9.   If a patient is a smoker, do you routinely refer them to a stop smoking service?

Never   Rarely   Sometimes   Often   Always

10.   Provide any additional comments about Questions 8 and 9 in the box below.

For further information on smoking cessation services and resources, please use the following links:

- NHS Wales' **Help Me Quit website**

- **Macmillan Cancer Support's Maintaining a healthy lifestyle – Giving up smoking**

Psychological effects of cancer

Many patients are affected psychologically by their cancer and treatment, which can impact on their quality of life from diagnosis onwards[1].

11. Discuss what generic local psychological support services are available for patients in your area. List the services in the box below and ensure that this information is shared with your whole practice team. Consider sharing this information with colleagues in your cluster.

12. Discuss what cancer specific local psychological support services are available for patients in your area. List the services in the box below and ensure that this information is shared with your whole practice team. Consider sharing this information with colleagues in your cluster.

For further information on the psychological consequences of cancer, please use the following links:

- **Macmillan Cancer Support's Fatigue and the psychological effects of cancer**

- **Macmillan Cancer Support's 'In Your Area' search tool**

- **DEWIS Wales** – Details about local wellbeing services

- **INFOENGINE** – Directory of third sector services in Wales

Work and cancer

13. **If a cancer patient is in work or looking for work, do you routinely discuss with them how they can remain in work?**

Never   Rarely   Sometimes   Often   Always

14. **If a cancer patient is in work or looking for work, do you routinely discuss with them how they can return to work?**

Never   Rarely   Sometimes   Often   Always

Individuals may choose to carry on working during cancer treatment (with reduced hours or flexibility to allow for appointments and recovery). Or they may return to work following treatment, with support from their employer.

It is important to note that people living with cancer are protected against discrimination by the **Equality Act of 2010**. Employers must consider making reasonable adjustments to help patients create a 'new normal'.

15. **Discuss what local cancer support services are available in your area to help people stay in or return to work. List the services in the box below and ensure that this information is shared with your whole practice team. Consider sharing this information with colleagues in your cluster.**

For further information on helping your patients return to or remain in work, please use the following links:

● Macmillan's **The Equality Act 2010 and cancer: How it affects you**

● Macmillan's **'In Your Area' search tool**

Supported self-management programmes

Increasingly, cancer patients with non-complex needs are being moved to supported self-management, so they feel empowered and take an active role in their own care[5]. Self-management is a term used to describe 'the actions taken by people to recognise, treat and manage their own health'. This may occur independently or in partnership with the healthcare system[6].

16. Discuss what self-management programmes are available for cancer patients in your area. List the services in the box below and ensure that this information is shared with your whole practice team. Consider sharing this information with colleagues in your cluster.

For further information on self-management programmes that may benefit your patients, please use the following links:

- **The HOPE programme**

- **Education Programmes for Patients (EPP)**

- **Thrive and Survive (North Wales only, through patient forum)**

- **Breast Cancer Care's Moving Forward course**

The role of practice nurses

17.   Do the practice nurses at your practice routinely carry out cancer care reviews?

Yes   No

Practice nurses now lead on a large proportion of chronic disease management in primary care[6]. Given that 70% of people with cancer (1.8 million people in the UK) also have one or more serious long-term health conditions[7], practice nurses are uniquely placed to complete cancer care reviews.

The **Macmillan Framework for Cancer in Primary Care** has developed a guide to help practice nurses carry out high-quality cancer care reviews. It's based on a Macmillan pilot project by Juliet Norwood, who won RCN Wales' Primary Care Nursing Award in 2018. You can access the guide, which is called *A practice nurse's guide to cancer care reviews*, **here**.

Macmillan also offers a **cancer course for practice nurses**, which nurses from your practice can attend for free. This offers several benefits, including increased knowledge of cancer and its treatment, awareness of services and support, and confidence to manage cancer as a chronic condition[8].

Discuss with your practice nurses whether they would be interested in attending this course.

18.   How many were interested?

19.   If there was no interest in the practice nurse course, can you explain why this is the case?

Cancer care review template

A cancer care review template has been integrated into and is available within Vision and EMIS systems. Please familiarise yourself with it. This template, the reflections above and the links below will help your practice improve the quality of cancer care reviews.

Alternatively, if you can't access the CCR template on your system, you can use the National Cancer Survivorship Initiative's **Identifying your concerns checklist** and **care plan**. Ensure that the information recorded on these forms is coded on a patient's record.

Helpful Macmillan resources

● **Carrying out an effective cancer care review**

● **Recovery package resources including the electronic holistic needs assessment (eHNA)**

● **Support programme to help key workers deliver HNAs**

● **Treatment and recovery resources for professionals**

20. **In a practice meeting, discuss as a whole team how your practice will improve the quality of its cancer care reviews. Consider who carries out the reviews, the content covered and the recording of relevant information on a patient's record. Summarise in the box below the actions your practice will take going forward.**

For the **next six months**, please implement your action plan and refer to **Appendix 2** for codes you may find useful.

Section three: Six-month review of cancer care reviews

After six months, complete the following section.

21. **Using the information from your spreadsheet (six-month data), record the number of new cancer diagnoses in the last six months (Search 17).**

22. **Using the information from your spreadsheet (six-month data), record the number of completed cancer care reviews in the last six months (Search 23).**

Provide comments regarding any differences between **Questions 21 and 22** in the box below.

23. **From the list of patients identified from search 17 (see Question 21), select the last 10 patients who received a cancer care review (this may be less than 10 in smaller practices) and review their patient notes.**

Number of patient records reviewed

In the boxes below, please record the number of CCRs which were completed by the:

GP

Practice nurse

Other (please give details)

24. **In the last six months, have practice nurses carried out cancer care reviews at your practice?**

Yes   No

a) If **no**, please explain what factors prevented practice nurses from carrying out cancer care reviews at your practice.

25. **As a whole practice team reflect on how your improvement plan for cancer care reviews went. Summarise any learning points and highlight any factors that supported or hindered your action plan for improving the quality of cancer care reviews.**

Section four: Long-term consequences of cancer and its treatment

Approximately 33,000 people in Wales are facing poor health or disability after a cancer diagnosis.

Different treatments can lead to physical consequences that affect different parts of the body, as well as psychological consequences. These issues may arise any time after treatment, including decades later[1].

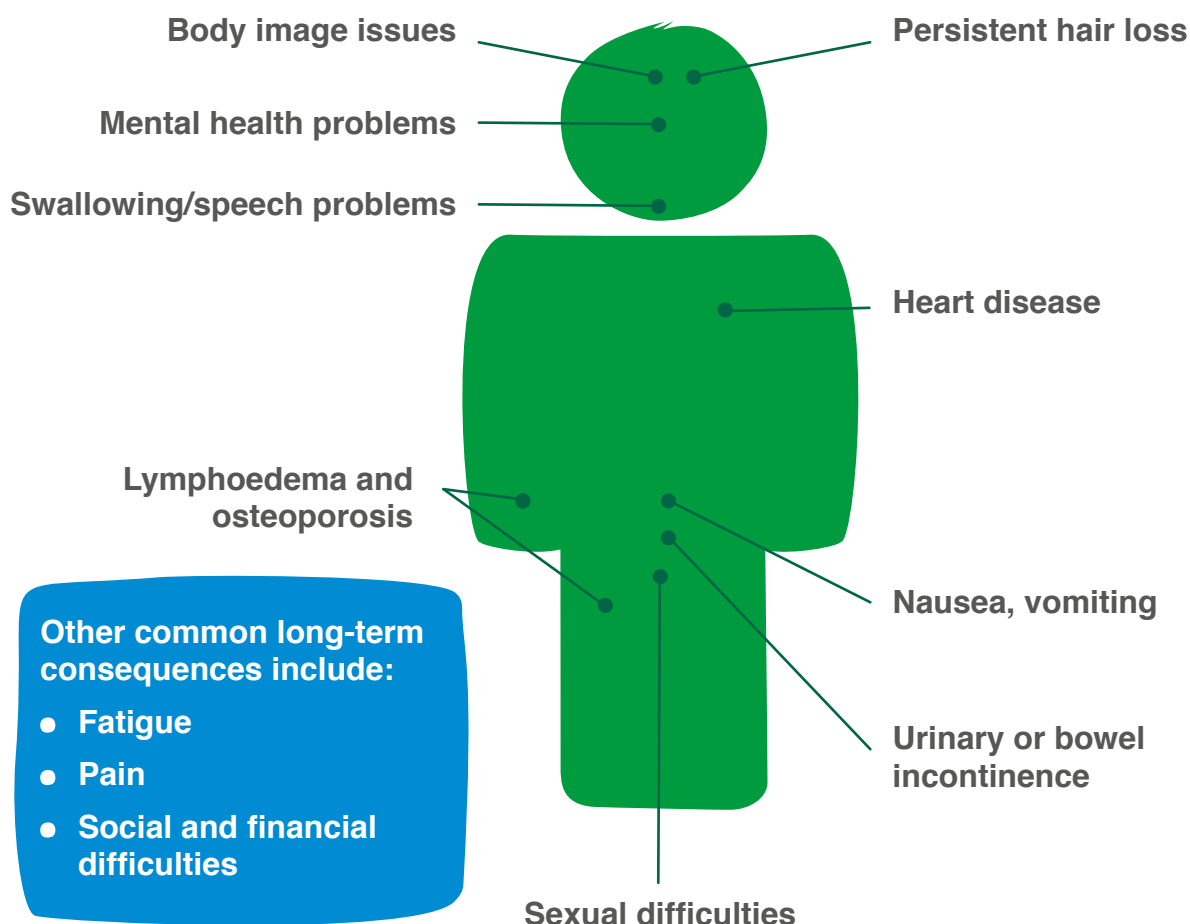Spend some time familiarising yourself with the **Macmillan and RCGP Consequences of Cancer toolkit**. You may find the sections on 'Identifying patients at risk of consequences of treatment' and 'Managing consequences of treatment' particularly useful.

Coding will help you and members of your practice to recognise problems caused by cancer treatments (eg chemotherapy), especially if these treatments were not undertaken recently.

26. **Review the infographic below for some of the long-term consequences of cancer and its treatment. Ensure that this information is shared with your whole practice team.**

Examples and estimated prevalence of long-term consequences of cancer and its treatment in Wales (2015)*

Body image issues

Mental health problems

Swallowing/speech problems

Persistent hair loss

Heart disease

Lymphoedema and osteoporosis

Nausea, vomiting

Urinary or bowel incontinence

Sexual difficulties

Other common long-term consequences include:

- **Fatigue**
- **Pain**
- **Social and financial difficulties**

15,000

people are living with mental health problems, which can include moderate to severe anxiety.

13,000

people are living with moderate to severe pain after curative treatment.

22,000

people are experiencing chronic fatigue.

22,000

people are having sexual difficulties

*Rates based on those in Macmillan Cancer Support's **Throwing light on the consequences of cancer and its treatment** (2013), and applied to the estimated cancer prevalence in Wales in 2015. These rates are generally UK rates or English rates rather than Welsh specific.

27. In a practice meeting, reflect on the most common long-term consequences of cancer and its treatment that you and your colleagues routinely encounter. Summarise learning points in the box below and ensure that this information is shared with your whole practice team.

28. Using the information from your spreadsheet (0-month data), record the total number of cancer diagnoses ever (Search 16).

29. Using the information from your spreadsheet (0-month data), record the number of patients who were diagnosed over five years ago (Search 18).

30. **From your list of patients identified from search 18, please select five patients and review their notes. For each patient, please complete the questions below.**

	Patient				
	1	2	3	4	5
Is the previous cancer diagnosis coded as a priority?* (Yes/No)					
Is the treatment coded in the GP record? (Yes/No)					
Is the treatment coded as a priority? (Yes/No)					
List three potential consequences of treatment that you would need to be aware of for each patient.					
Please list if any of the patient's subsequent health concerns could be related to their cancer and/or treatment.**					

* This refers to the coding priority (0, 1, 2 and 3).
** Up to five clinicians need to pick a patient that they know well to complete this question.

a) Reflect on your answers to question 30 (page 81) and note any learning points in the box below. Ensure that any learnings are shared with your whole practice team.

31. If you have any additional comments about any of the questions in this module, please write these in the box below.

If you or a member of your practice wishes to continue using this module for quality improvement purposes, you may continue using the codes and searches. For ease, all codes can be found in **Appendix 2**.

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

Further reading and useful resources

Macmillan's Carrying out an effective cancer care review

Macmillan's Tips for managing heart health during and after cancer treatment

Macmillan and RCGP's Consequences of Cancer and Treatment toolkit

Macmillan's Primary care top 10 tips for managing fatigue

Macmillan's Treatment and recovery resources for professionals

Tenovus Cancer Care's Emotional support for people affected by cancer

Cardiff University's Understanding cancer: Patient and professional perspectives

Module five
Identifying and supporting people with advanced serious illness

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

Introduction

On average, 32,000 people die each year in Wales. Out of this number, 75% need palliative care; however, only a quarter of these people (6,000) receive it[2]. This issue is set to heighten in the coming years because Wales has a growing elderly population, leading to more people dying each year. In addition, many of these people will be living with two or more chronic conditions and frailty, which means they won't necessarily follow a predictable path to death[3].

In 2017, the Welsh government launched its **Palliative and End of Life Care Delivery Plan**. In it the government highlights the important role primary care must play to deliver high-quality end of life care for people living in Wales. This includes the early identification of patients requiring palliative care, supporting people so they can live and die well, and delivering fast, effective care[4].

The reason why it's important to identify people who may be in need of palliative care at an early stage is because this helps to ensure that their physical, psychological, social and spiritual needs are met in a timely fashion[4]. This includes people with prolonged functional decline, for example, those with a treatable but incurable cancer. Identifying when they are entering the end of life phase can be difficult, but it's important steps are taken to do this.

Once patients are identified, it is critical that a proactive approach is offered early in chronic disease pathways, rather than care that is reactive and offered only at the end of life. Advance care planning (ACP) is a process that supports people to plan ahead and make decisions and state preferences in the event of losing capacity[3]. Evidence suggests that this can improve patient experience and quality of care, prevent unnecessary emergency admissions to hospital and help people to die in their preferred place of care[5]. Again, primary care has a key role in achieving these outcomes.

This module is designed to help your practice review and improve their approach for identifying and supporting patients with advanced serious illness.

> **ⓘ Which people can be classed as approaching end of life?**
> The General Medical Council defines people as 'approaching the end of life' when they are likely to die within the next 12 months[1]. This group includes those whose death is imminent (expected within a few hours or days):
>
> - with advanced, progressive, incurable conditions
>
> - with general frailty and co-existing conditions that mean they are expected to die within 12 months
>
> - with existing conditions if they are at risk of dying from a sudden acute crisis in their condition
>
> - with life-threatening acute conditions caused by sudden catastrophic events.

The objectives for this module are to:

1. Ensure your practice identifies at an early stage people who should be included on your practice's palliative care register.

2. Review and improve your practice's approach to palliative care meetings.

3. Promote the importance of offering timely advanced care planning discussions with patients.

4. Improve the recording and sharing of information about patients on the palliative care register.

Module top tips

Before you start, please remember the following tips to support completion of this module. And if you're ever unsure about how to use this toolkit, please see **page 10** for full instructions.

1. Nominate an individual with a clinical background to be the lead for this module. This individual should ensure that learning from the module is shared with the whole practice team. We also encourage practices to liaise with colleagues in their cluster to discuss issues and share learning.

2. Schedule practice meetings in advance to ensure that all members of your primary care team can participate in baseline and six-month discussions.

3. Some of the questions in this module may be completed by an individual team member. If this happens, please ensure that what they learn is discussed and shared with your wider team.

Practice meeting discussions

We suggest your team uses practice meetings to complete some questions in this module. We recommend that these discussions involve your whole primary care team, including clinical and non-clinical roles.

To help facilitate these meetings, we have included all questions that require a practice discussion below:

Questions to be discussed at the beginning

Q8. Discuss as a whole practice team how you currently identify patients for inclusion on your palliative care register and complete the relevant box below.

a) If your practice does have an approach or system, briefly describe this, list any tools used and reflect on how this could be improved. Summarise any actions your practice will take going forward.

b) If your practice does not have an approach or system, discuss with your whole practice team how the practice will implement a new approach. Summarise your action plan in the box below.

Q15. In a practice meeting, reflect on the answers given in the previous section and how your practice initiates ACP discussions with patients. Discuss how your practice's approach could improve to ensure timely ACP discussions with patients (eg at recognition of a life-limiting illness) and summarise your action plan in the box below.

Q24. Discuss how information could be better documented and shared following ACP discussions with patients. Outline key actions below that your practice team will implement going forward and ensure that this information is shared with your whole practice team.

Q38. As a whole practice team, and while using **Macmillan's Top tips guide to supportive and palliative care meetings**, consider how the quality of your practice's palliative care meetings could be improved. Summarise your action plan in the box below.

Questions to be discussed at the end

Q10. In a practice meeting, reflect on how your improvement plan went. Identify learning points and highlight any factors that supported or hindered your approach for identifying patients for inclusion to your palliative care register.

Q16. After six months and as a whole practice team, reflect on any changes your practice has made to ensure timely ACP discussions are held with patients. Identify learning points and highlight any factors that supported or hindered these changes.

Q27. As a whole practice team reflect on any differences between your answers to **Questions 17 and 26**. Identify learning points and highlight any factors that supported or hindered changes that were made to improve the recording and sharing of information.

Q39. After six months, reflect on any changes made to the structure of your palliative care meetings. Identify learning points and highlight any factors that supported or hindered the implementation of your action plan for improving the quality of palliative care meetings.

Section one: Identifying patients for inclusion on your palliative care register

1. **What is your practice population?**

2. **How many patients do you currently have on your palliative care register? (Using the QOF search).**

3. **Using your answers to Questions 1 and 2, calculate the percentage of your patients who are on your palliative care register.**

4. **Record the number of patients who were on your palliative care register due to:**

   a) Cancer diagnosis

   b) Other reason

5. **With support from your administration team, if appropriate, identify the last 10 patients to have died who attended your practice.**

   a) How many patients were on the palliative care register?

   b) How many patients were not on the register but who you feel could have been?

Note: Approximately 1% of patients on a GP's registered list will die each year[6].

6. **Does your practice consider adding patients to your palliative care register who have treatable but incurable cancer and may live longer than one year? For example, patients with metastatic prostate or breast cancer.**

   Yes   No

   a) If **yes**, how and when are these patients identified for inclusion on your palliative care register?

7. **In the box below, list guidelines or templates that you currently use to record information about patients who are on your practice's palliative care register.**

Palliative care registers help practices to record when patients are in the last year of life. It is essential that these patients are identified as early as possible to facilitate timely ACP discussions, prevent crisis admissions and ensure people receive the support they want[3].

8. Discuss as a whole practice team how you currently identify patients for inclusion on your palliative care register and complete the relevant box below.

a) If your practice **does** have an approach or system, briefly describe this, list any tools used and reflect on how this could be improved. Summarise any actions your practice will take going forward.

b) If your practice **does not** have an approach or system, discuss with your whole practice team how the practice will implement a new approach. Summarise your action plan in the box below.

Estimating how long a person may live for is increasingly challenging because of the high incidence of co-morbidity in our ageing population[7]. The following tools may help your practice with the early identification of patients who should be placed on your palliative care register:

- **Supportive and Palliative Care Indicators Tool (SPICT)**

- **The Gold Standards Framework prognostic indicator guidance**

- **Welsh Palliative Care Indicator Tool (W-PIT)**

- Palliative Care Wales' **Traffic Lights – Prognostic groups to aid planning for end-of-life care**

For the **next six months**, implement your new or improved approach and ensure that this information is shared with your whole practice team.

9. **After six months, look at your practice's palliative care register again. With support from your administration team, if appropriate, identify the last 10 patients to die who attended your practice (this may be less than 10 in smaller practices). Note: These patients should be different to the patients identified in question 5.**

a) How many patients were on the palliative care register?

b) How many patients were not on the register but who you feel could have been?

10. **In a practice meeting, reflect on how your improvement plan went. Identify learning points and highlight any factors that supported or hindered your approach for identifying patients for inclusion to your palliative care register.**

Section two: Advance care planning (ACP)

This section guides practices through key areas of advance care planning, including introducing ACP to patients, the recording and sharing of information, and providing support to carers and relatives.

Initiating ACP discussions with patients

11. **How often does your primary care team use the following prompts as cues to initiate ACP discussions with patients? Tick one box for each prompt.**

Inclusion on the palliative care register

| Never | Rarely | Sometimes | Often | Always |

Electronic Frailty Index score

| Never | Rarely | Sometimes | Often | Always |

Cancer care reviews

| Never | Rarely | Sometimes | Often | Always |

Prompts from secondary care (eg discharge letter)

| Never | Rarely | Sometimes | Often | Always |

Prompts from other community-based healthcare professionals

| Never | Rarely | Sometimes | Often | Always |

Patient initiated

| Never | Rarely | Sometimes | Often | Always |

Family initiated

| Never | Rarely | Sometimes | Often | Always |

Clinician's judgement

| Never | Rarely | Sometimes | Often | Always |

Other (please specify below)

12. Which professional group(s), if any, initiate ACP discussions with patients at your practice? Please tick all that apply.

General practitioner

Practice nurse

Allied health professional (please specify below)

Palliative nurse

District nurse

Advance care planning nurse

Nursing home matron

Other (please specify below

13. Which professional group(s), if any, have received training in the last five years to hold ACP conversations with patients who are in the last year of their lives? Tick one box for each professional group.

General practitioners

Had training — Has not had training — Not sure

Practice nurses

Had training — Has not had training — Not sure

Allied health professionals

Had training — Has not had training — Not sure

District nurses

Had training — Has not had training — Not sure

Nursing home matrons

Had training — Has not had training — Not sure

Other (please specify below)

a) If staff have **not** received this training, would it be useful for your practice to access further training in this area?

Yes   No

b) If staff **have** received this training, provide information about who delivered the training and any comments on how the training went.

14.   Is patient information about advanced care planning made available in your practice?

Yes   No

a) If **yes**, please list what you currently provide in the box below:

If **no**, the following resources may be useful**:**

- **Macmillan's Your life and your choices: Plan ahead (England and Wales)**

- **Hospice UK's Dying Matters leaflets**

15. In a practice meeting, reflect on the answers given in the previous section and how your practice initiates ACP discussions with patients. Discuss how your practice's approach could improve to ensure timely ACP discussions with patients (eg at recognition of a life-limiting illness) and summarise the action plan in the box below.

You can access further information and resources to help your practice initiate ACP conversations with patients by using the following links:

- **Macmillan's Primary care 10 top tips: Advance care planning**

- **Communication skills in ACP – A short introduction**

- **RCGP Wales' ACP training course**

- **(w)IPADS – A framework for advance care planning in Wales**

- **Macmillan's Taking opportunities to promote advance care planning**

Note: ACP is voluntary, and due to its sensitive nature, it should only be offered to patients who feel comfortable talking about it. If time isn't available to have a meaningful conversation, a patient's request to discuss ACP should be acknowledged and followed up. It's important to note that ACP is not legally binding and patients can change their mind regarding their wishes[1].

For the **next six months**, implement your new or improved approach to making sure timely ACP discussions are held with patients.

16. After six months and as a whole practice team, reflect on any changes you've made to ensure timely ACP discussions are held with patients. Identify learning points and highlight any factors that supported or hindered these changes.

Recording and sharing information

This section guides practices through key areas of advance care planning, including introducing ACP to patients, the recording and sharing of information, and providing support to carers and relatives.

17. **Look at the last five patients who died and were included on your palliative care register. Review their patient notes and complete the table below. You do not need to contact relatives of patients for this information.**

For each patient, please complete the table below, according to what is documented in their patient records. The answers you give should be taken to a practice meeting to be discussed.

	Patient				
	1	2	3	4	5
Had an ACP? (Yes/No)					
Indicate the length of time between first ACP and death.					
Had a 'do not attempt cardiopulmonary resuscitation' (DNACPR)? (Yes/No)					
Key information shared with OOH service? (Yes/No)					
Evidence of anticipatory medication being prescribed? (Yes/No)					
Preferred place of death recorded? (Yes/No)					
Achieved their preferred place of death? (Yes/No)					
Next of kin and their contact details recorded? (Yes/No)					

18. Following an ACP discussion with a patient, how is information documented? (Tick all that apply)

Standard ACP form

Coded on a patient's record

As an alert

Priority code 1 on a patient's record

Patient held record

19. Who do you routinely share ACP information with? List the clinical roles and/or organisations in the box below.

20. Do you have access to the Just in Case (JIC) scheme in your health board? (This may be in the form of a JIC box or bag).

Yes   No

a) If **yes**, have you ever used it?

Yes   No

21. How often do you use the following prompts as cues to notify your local GP's out-of-hours (OOH) service about palliative care patients?

On first inclusion to palliative care register

Never   Rarely   Sometimes   Often   Always

When ACP has been agreed

Never   Rarely   Sometimes   Often   Always

Recognition of last days of life

Never   Rarely   Sometimes   Often   Always

On completion of do not attempt (CPRt)

Never   Rarely   Sometimes   Often   Always

Other (please specify)

22. Which method do you routinely use to notify your out-of-hours (OOH) service? (Please tick only one).

Phone

Fax

Email

Direct access to OOH IT system

Other (specify below)

23. Do you code (using 9e2.00) when the OOH service is notified?

Yes   No

a) If **no**, please explain in the box below.

Yes   No

Following an ACP discussion, a document such as an **advance care planning communication form** could be used to record and share important information, providing the patient gives consent. Sharing a patient's wishes can help to prevent avoidable admissions to hospital and futile or unwanted attempts at resuscitation[8].

24. Discuss how information could be better documented and shared following ACP discussions with patients. Outline key actions below that the practice team will implement going forward and ensure that this information is shared with the whole practice team.

For the **next six months**, implement your new or improved process.
Refer to **Appendix 2** for useful codes that you may wish to use going forward**.**

25. After six months, record the number of patients on your palliative care register (search the QOF GP Contract database). Note: These patients should be different from those recorded in Question 2 at the beginning of this module.

26. **From the patients on your palliative care register select the five people who died most recently. Review their patient notes and complete the table below. You do not need to contact relatives of patients for this information.**

For each patient, please complete the table below, according to what is documented in their patient records. The answers you give should be taken to a practice meeting to be discussed.

	Patient				
	1	2	3	4	5
Had an ACP? (Yes/No)					
Indicate the length of time between first ACP and death.					
Had a 'do not attempt cardiopulmonary resuscitation' (DNACPR)? (Yes/No)					
Key information shared with OOH service? (Yes/No)					
Evidence of anticipatory medication being prescribed? (Yes/No)					
Preferred place of death recorded? (Yes/No)					
Achieved their preferred place of death? (Yes/No)					
Next of kin and their contact details recorded? (Yes/No)					

27. **As a whole practice team reflect on any differences between your answers to Questions 17 and 26. Identify learning points and highlight any factors that supported or hindered changes that were made to improve the recording and sharing of information.**

Support for carers and relatives of people living with cancer

28. **Does your practice have a process for identifying carers?**

Yes   No

29. **Do you currently code this information?**

Yes   No

Please ensure that you code this information going forward. We recommend that you use the following:

● **918A.00 (Carer)**

● **918F.00 (Has a carer)**

Carers play a vital role in supporting people with cancer, and it's important their information, advice and support needs are addressed[9].

30. In consideration of this, review the following documents:

- **Macmillan's Primary care top 10 tips for supporting carers of people living with cancer**

- **Macmillan's Supporting carers of people with cancer: practical guidance for healthcare professionals**

Identify learning points for your practice to improve how you identify and support carers. Summarise key learning points and ensure that this information is shared with your whole practice team.

Did you know that Carers Wales has developed a **'carers emergency card'** to let emergency workers know that the person they are treating is a carer. Carers can obtain a card by calling **029 2081 1370** or by emailing **info@carerswales.org**

31. Do you offer bereavement support for relatives?

Never   Rarely   Sometimes   Often   Always

a) If yes, what support does your practice offer?

b) If no, what factors prevent your practice from offering bereavement support?

Note: It's important that you code bereavement information for a patient and their next of kin (where appropriate).

32. Do you have access to local bereavement support services?

Yes   No

a) If **yes**, please detail below and state how long the average wait is for review?

Death and bereavement affect people in different ways. It is important that support, such as information regarding bereavement services, is available for people who attend your practice[10].

For further information about bereavement support, please use the following links. Ensure you share this information with your whole practice team.

- **Macmillan's Coping with bereavement**

- **Cruse Bereavement Care**

- **Dewis Cymru**

Section three: Palliative care meetings

33.   How often do you hold palliative care meetings?

34.   Who routinely 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

Administrator

Clinical nurse specialists

Pharmacists

Social worker

Care home staff

Other (please detail)

35.   As a practice how do you record the discussions you have in these meetings?

36.   Do you discuss all the patients who are on your palliative care register at every meeting?

Yes   No

a) If **no**, how do you prioritise which patients are discussed?

37.   Are all practice deaths discussed as a group within a practice meeting?

Yes   No

Efficient meetings in a primary care setting are important to ensure that the physical, social, psychological and spiritual dimensions of care are delivered effectively[11]. An effective palliative care meeting should:

- be prepared in advance

- prioritise patients according to need

- emphasise the importance of communication with the patient and their family.

38.   As a whole practice team, and while using Macmillan's Top tips guide to supportive and palliative care meetings, consider how the quality of your practice's palliative care meetings could be improved. Summarise your action plan in the box below.

For the **next six months**, implement your improved palliative care meeting structure and ensure that you use the following code going forward: **98G (Multi-disciplinary meeting)**.

39. **After six months, reflect on any changes made to the structure of your palliative care meetings. Identify learning points and highlight any factors that supported or hindered the implementation of your action plan for improving the quality of palliative care meetings.**

40. **If you have any additional comments about any of the questions in this module, please write them in the box below.**

If you or a member of your practice wishes to continue using this module for quality improvement purposes, you may continue using the codes and searches. For ease, all codes can be found in **Appendix 2**.

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

Further reading and useful resources

Macmillan website's end of life care information

Macmillan's No regrets – How talking more openly about death could help people die well

The National Palliative and End of Life Care Partnership's Ambitions for palliative and end of life care

Palliative Care Wales website

Palliative Care Guidelines

RCGP's Palliative and End of Life Care toolkit

List of abbreviations

ACP	Advance care planning
AOS	Acute oncology service
BMI	Body mass index
CCR	Cancer care review
CDS	Cancer decision support
CRUK	Cancer Research UK
DNA	Did not attend
DNACPR	Do not attempt cardiopulmonary resuscitation
EPP	Education programmes for patients
FIT	Faecal immunochemical testing
JIC	Just in case
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
OOH	Out-of-hours
QOF	Quality outcomes framework
RAG	Red, amber, green
RCGP	Royal College of General Practitioners
SACT	Systemic anti-cancer therapy
SPICT	Supportive and palliative care indicators tool
UKONS	UK Oncology Nursing Society
USC	Urgent suspected cancer
WCISU	Welsh Cancer Intelligence and Surveillance Unit
WCPES	Wales Cancer Patient Experience Survey
W-PIT	Welsh Palliative Care Indicator Tool
2WW	Two-week wait

Appendix 1
GP practice search data spreadsheet

(baseline and six-month data)

Note
- For each search, please enter your practice data (numbers only).

- Some searches may not appear. If this occurs, it means your practice does not use the Read code(s) that are built into the toolkit searches. In this instance, **your answer for that search will be 0**.

- Some searches will appear as part of this toolkit but we are not collating this data (e.g. Searches 1-3).

Searches	Baseline data	
	0 months	6 month
Search 4		
Search 5		
Search 6		
Search 7		
Search 8		
Search 9		
Search 10		
Search 11		
Search 12		
Search 12a		
Search 12b		
Search 13		
Search 14		
Search 15		
Search 16		
Search 17		
Search 18		
Search 19		
Search 20		
Search 22		
Search 23		
Search 24		
Search 24a		
Search 24b		
Search 25		
Search 26		
Search 27		
Search 30		
Search 31		
Search 32		

Appendix 2
Recommended module codes

Module 1 – Detecting cancer earlier

Code	Code title
9Ow2	No response to bowel cancer screening programme invitation
9Ow4	Bowel cancer screening programme telephone invitation
9Ow5	Bowel cancer screening programme letter invitation sent
8Cay	Advice given about bowel cancer screening

Module 3 – Support through treatment

Code	Code title
98CL0	Cancer diagnosis discussed
9NNc.00	Cancer key worker
7L2.00	Radiotherapy treatment
8BAD.00	Chemotherapy
5A86.00	Immunotherapy
7Q0J0	Hormone treatment

Appendix 2 (continued)

Module 4 – Cancer care reviews and long-term consequences of cancer and its treatment

Code	Code title
.8BAV	Cancer review completed
8CP.	Discussion about treatment
8CP3	Discussion about complication of treatment with patient
8B3x.	Medication review done
8CP0	Cancer care plan discussed with patient
6779	Psychological counselling
67H7.	Lifestyle advice regarding diet
67h1.	Lifestyle advice regarding smoking
67H0.	Lifestyle advice regarding alcohol
67H2.	Lifestyle advice regarding exercise
.677H	Cancer information offered
.6743	Benefits counselling
67N0	Advice about work
.9180	Carer's details

Appendix 2 (continued)

Module 5 – Identifying and supporting people with advanced serious illness

Code	Code title
8CM3.00	Palliative care plan review
8B2a.00	Prescription of palliative care anticipatory medication
9NgD.00	Under care of palliative care service
8H7g.00	Referral to palliative care service
94Z2.00	Preferred place of death: hospice
94Z7.00	Preferred place of death: discussion not appropriate
94Z1.00	Preferred place of death: home
94ZC.00	Preferred place of death: care home
94Z4.00	Preferred place of death: hospital
8CN1.00	Preferred place of death discussed with patient
1R1..00	Not for resuscitation
67P1.00	Resuscitation discussed with carer
67P0.00	Resuscitation discussed with patient
6751.00	Bereavement counselling
9Ng7.00	On end of life care register
8CME.00	Has end of life advance care plan
9e2.00	OOH handover form completed
98G..00	Multidisciplinary meeting
918A.00	Carer
918F.00	Has a carer

Appendix 3
Patient contact letter

This is a template letter that can be adapted to suit your practice.
(Remember to enclose the 'concerns checklist', if appropriate).

Practice Name
Address Line 1
Address Line 1
Address Line 1

Telephone number

Dear patient's name

Following your recent appointment with Dr/Mr/Mrs XYZ at XX XX hospital, we would like to invite you to visit the practice to meet with your GP, Dr XYZ, and/or your practice nurse, Mr/Mrs XYZ, to discuss any questions or concerns you may have and the care, information and support we can provide.

Please call reception on telephone number to make an appointment with either your GP or practice nurse and inform the receptionist that it is for a cancer care review, so they can allow longer for your appointment. We can also offer you a telephone appointment with your GP or practice nurse, if this is your preference. This needs to be arranged with our reception as well.

(GP practice, you may want to include the following paragraph or enclose a list of the individual services you offer.)

We have enclosed a 'concerns checklist' for you to complete before your visit. Please bring it to your appointment, or complete it in time for your telephone consultation. We recommend that you spend some time to think about what matters to you before the appointment. You may also find it helpful to discuss your 'concerns checklist' with a partner/friend/carer.

If you feel you do not require an appointment at this time, please contact the surgery and let the receptionist know. If you change your mind, please do not hesitate to get in touch, as this service will continue to remain open to you at the practice.

We look forward to meeting with you,

Appendix 4
Treatment summary template

Please complete this form in BLOCK CAPITALS and black ink.

Patient name: Date of birth:

Address: Record number:

GP contact details: Hospital trust:

Your patient has had the following diagnosis and treatment for cancer and received a summary and ongoing management plan as outlined below. They have/have not received a copy of this summary. (Delete as applicable)

Diagnosis:	Date of diagnosis:	Staging
Summary of treatment and relevant dates:		**Treatment aim:**
Possible treatment toxicities and/or late effects:		**Advise entry on to primary care palliative/supportive care register:** Yes/No/Not yet recommended **DS 1500 application completed** Yes/No/Not yet recommended
Alert symptoms that require referral back to specialist team:		**Contacts for re referrals or queries:** **In hours:** **Out of hours:**
Secondary care ongoing management plan: (tests, appointments etc)		**Other service referrals made: (delete or add)** District nurse Social worker Dietician Clinical Nurse Specialist Psychologist Benefits/advice Service Other
Recommended GP actions in addition to GP cancer care review:		**Additional information including issues relating to lifestyle and support needs:**
Summary of information given to the patient about their cancer and future progress:		

Please take this to your GP appointment where your diagnosis and cancer care will be reviewed with you.

Completing Clinician: **Signature:**   **Date:**

Appendix 5
Learning points from UKONS case studies

Key take home messages from case studies

Case study 1

- The two versions of symptoms show the importance of having a full history of symptoms before deciding on the action which should be taken, eg the co-codamol taken may have masked pyrexia.

- **Version 1 symptoms:** using the primary care UKONS treatment toxicity risk assessment tool, these symptoms should be graded **red**, as generally unwell following chemotherapy means an urgent call should be made a to 24-hour helpline/hospital for bloods and review.

- **Version 2 symptoms:** UKONS tool scores **amber** for signs of wound infection. This may be suitable to manage with primary care review in liaison with the helpline.

- Diarrhoea scores **green**, as no change from baseline.

Case study 2

- UKONS assessment scores **red** for vomiting. Needs to be discussed with helpline.

- May be able to manage in primary care with additional antiemetics. Consultation with helpline is important, as it will be able to advise about antiemetics and appropriate follow up.

Case study 3

- UKONS assessment scores **red** for diarrhoea. Needs to be discussed with helpline.

- Suspect immune related colitis. Needs specialist advise and assessment at a hospital.

- Immunotherapy related diarrhoea may need treatment with steroids, but need advice from prescribing team.

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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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