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CANCER SUPPORT

CANCER CARE

IN PRIMARY CARE:

A QUALITY  
TOOLKIT

FOR GENERAL PRACTICE

**Practice Name:**

**Health Board:**

**Contact E-mail:**

Please return this module to [macdocs@macmillan.org.uk](mailto:macdocs@macmillan.org.uk), ensuring that there is no patient identifiable information.  
Please also use this e-mail address for any queries about the modules.

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# Contents

<b>Introduction</b> .....	<b>1</b>
<b>Policy Context</b> .....	<b>2</b>
<b>Commitment</b> .....	<b>3</b>
<b>Summary of Modules</b> .....	<b>4</b>
<b>Module One: Screening for cancer</b> .....	<b>5</b>
<b>Module Two: Prompt recognition and early referral</b> .....	<b>9</b>
<b>Module Three: Access to appointments and advice</b> .....	<b>13</b>
<b>Module Four: Cancer Care Reviews</b> .....	<b>17</b>
<b>Module Five: Late effects of cancer and consequences of treatment</b> .....	<b>21</b>
<b>Module Six: Anticipatory Care Planning and sharing of information</b> .....	<b>26</b>

# Introduction

**General practice has never been under so much pressure. The population in Scotland is ageing and people are living longer with complex disease. Most people over the age of 60 will have more than one chronic long-term medical condition and the numbers of people living into their 80s and 90s has never been higher.**

At the same time, the UK has a depleted GP workforce. GPs are retiring and leaving faster than they can be replaced and junior doctors are choosing not to commit to a career in general practice in the same numbers as before. The shape and structure of general practice is likely to look very different in the future, with a greater skill mix and extended roles within nursing and other allied health professions.

The Quality and Outcomes Framework (QOF) of the General Medical Services (GMS) contract was removed in April 2016; however, there will always be a need for GP practices to focus on quality and outcomes. With an ageing population comes an increasing incidence and prevalence of cancer. It is important GP practices are encouraged to improve the quality of care that people with cancer receive.

This toolkit contains suggestions of how the quality of cancer care can be improved. By using case studies, reflective practice, data collection and analysis, practitioners will explore the following:

- How the practice supports informed uptake into the national screening programmes
- What can be done to ensure prompt recognition and early detection of cancer
- Whether access to appointments within the practice might have an impact on people with cancer
- The quality of Cancer Care Reviews that are undertaken within the practice
- The longer term impact of cancer and cancer treatment on an individual
- The use and quality of Anticipatory Care Planning (ACP) and the Key Information Summary (KIS) for those living with cancer and those at a palliative stage in their disease

It is expected the whole GP practice multidisciplinary team will become engaged with this toolkit and that learning will be shared through the Practice Quality Lead with the wider GP cluster.

## Policy Context

**Every year, around 30,000 people in Scotland are diagnosed with cancer<sup>1</sup>. The recently published cancer strategy 'Beating Cancer: ambition and action' predicts this figure will reach 40,000 per year by 2027, and that over 40% of people in Scotland will be diagnosed with cancer during their lifetime.**

The strategy highlights that one-year survival rates have increased from 48% to 66% in men and from 58% to 69% in women. While this is good news for people with cancer, the strategy points out these increased survival rates mean more people will be accessing specialist and primary care services. The ageing population also means they are likely to have multiple conditions and complex health needs<sup>2</sup>.

The national clinical strategy acknowledges effective primary care can significantly improve outcomes for patients and deliver the most cost-effective healthcare system<sup>3</sup>. The national clinical strategy also highlights the need for increased training, both for GPs and the wider community multidisciplinary team. This is vital if we are to achieve the aim of refocusing GPs' activity towards complex care and system-wide quality improvement, with wider members of the team becoming more involved in some activities previously undertaken by GPs<sup>3</sup>.

Both the cancer strategy and the national clinical strategy recognise the unacceptable level of health inequalities in Scotland. The cancer incidence is 30% to 50% higher for people living in deprived areas. The cancer strategy commits to building on the work of the Detect Cancer Early<sup>6</sup> (DCE) programme to reduce health inequalities, improving support for people living with and beyond cancer and radically improving patient experience and quality of life<sup>2</sup>.

### Scotland Prevalence Projections from Maddams, Utley and Møller



Maddams J, Utley M, Møller H. *Projections of cancer prevalence in the United Kingdom, 2010-2040. British Journal of Cancer* 2012; 107: 1195-1202. Macmillan analysis based on extrapolation of 2010 and 2020 projections that the number of people living with cancer will hit an estimated 2.5 million in 2015 in the UK. The Scotland share of the UK total is taken from Maddams J., *Thames Cancer Registry*, personal communication. See also Maddams J, et al. *Cancer prevalence in the United Kingdom: estimates for 2008. British Journal of Cancer* 2009; 101: 541-547.

Consequences of cancer and its treatment is another area of focus in the new cancer strategy. In Scotland, there are an estimated 30 to 35 cancer survivors for every 1,000 people. Eight or more of these people may be experiencing significant consequences of their cancer and its treatment. The wider psychological impact of a cancer diagnosis is also recognised. Social, financial and relationship issues can all impact on recovery. The cancer strategy highlights that more needs to be done to improve quality of life for people with cancer<sup>2</sup>. The Transforming Care After Treatment<sup>4</sup> (TCAT) programme is already taking forward a range of initiatives to support people with cancer, and the new strategic framework for action on palliative and end-of-life care<sup>5</sup> aims to ensure that people have the support they need as they near the end of their lives.

The first Cancer Patient Experience Survey (CPES)<sup>7</sup> in Scotland has shown that, although overall perceptions of care are generally very high, there are significant gaps in the number of patients being given a care plan and in the numbers who received information on how to get financial help and benefits. In addition, only 28% of patients were aware they could take a family member with them to appointments. The survey also found those with a care plan responded more positively to all 50 questions across the survey. It is anticipated that the CPES will be repeated on a regular basis<sup>3</sup>.

<sup>1</sup>**Scottish government cancer statistics** <http://www.gov.scot/Topics/Health/Services/Cancer>

<sup>2</sup>**Beating cancer: ambition and action** <http://www.gov.scot/Resource/0049/00496709.pdf>

<sup>3</sup>**National clinical strategy** <http://www.gov.scot/Resource/0049/00494144.pdf>

<sup>4</sup>**Transforming Care After Treatment (TCAT) programme** <http://www.gov.scot/Topics/Health/Services/Cancer/TCAT>

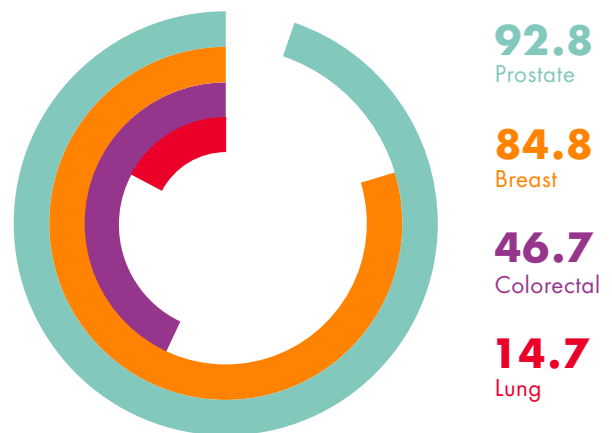
<sup>5</sup>**Strategic Framework for Action on Palliative and End of Life Care**

<http://www.gov.scot/Topics/Health/Quality-Improvement-Performance/peolc/SFA>

<sup>6</sup>**Detect Cancer Early programme** <http://www.gov.scot/Topics/Health/Services/Cancer/Detect-Cancer-Early>

<sup>7</sup>**Cancer Patient Experience Survey** <http://www.gov.scot/Publications/2016/06/3957>

Cancer prevalence rates per 10,000 people (Source ISD, 2013)



Adjusted from source of Scottish Cancer Registry, ISD rate per 100,000 for 2013  
Data extracted: March 2015

## Commitment

Many of the modules within this toolkit will complement and support existing quality improvement work undertaken at practice and cluster level. However, as the toolkit goes further than the quality initiatives expected from clusters, GP practices are invited to apply for funding from Macmillan Cancer Support to undertake the modules within this toolkit. The funding is designed to help facilitate protected time for the practice team to examine and consider their current ways of working.

Each practice will nominate a GP, who will link with Macmillan and lead the activities within the toolkit. This GP will ensure any learning from the modules is shared with others in the practice. They are also strongly encouraged to discuss issues within their cluster.

Successful GP practices will be asked to choose three of the six modules and should complete them over a one-year period. Practices can select one module each from Modules One or Two, Modules Three or Four, and Modules Five or Six, ensuring a broad focus across the cancer pathway. There will be a short e-learning resource to accompany some of the modules. GP practices will be expected to submit a short report at the end of the year highlighting their key learning points and to participate in evaluation.

## Summary of Modules

**Module One:**  
**Screening for cancer**

**Module Two:**  
**Prompt recognition and early referral**

**Module Three:**  
**Access to appointments and advice**

**Module Four:**  
**Cancer Care Reviews**

**Module Five:**  
**Late effects of cancer and consequences of treatment**

**Module Six:**  
**Anticipatory Care Planning and sharing of information**

# Module One: Screening for cancer

## Introduction:

Participating in the national population cancer screening programmes is one of the best ways to detect cancer early. There are well-established and successful population screening programmes for breast, bowel and cervical cancer. The latter plays an active part in preventing cancer in the first place. Breast and bowel screening both have a significant role in identifying cancer at an early stage, which improves the chances of survival.

This module is designed to help practices become more aware of the screening programmes and understand the risks and benefits involved from participation. It also offers the opportunity to increase patient uptake through informed consent. Practices may be able to obtain up-to-date screening data from their health board screening co-ordinator regarding their own GP practice and cluster. There is also national and health board data available at [Information Services Division \(ISD\)](#).

## Module Questions:

### A Background information, data collection and analysis

- 1 From the most recent data available to your practice, what percentage of eligible women registered in your practice have attended for breast screening?
  
- 2 From the most recent data available to your practice, what percentage of eligible people registered at your practice have completed the bowel screening test?
  
- 3 What percentage of eligible women registered in your practice are up to date with their cervical smears?
  
- 4 From the information available to you, how does your practice compare to others in your NHS Board and what is your practice performance like compared to the national average?
  
- 5 Describe your practice policy for identifying screening programme non-responders.
  - a) Breast non-responders









# Module Two: Prompt recognition and early referral

## Introduction:

When cancer is diagnosed at an early stage, treatment options and chances of a full recovery are greater. Five-year survival rates from cancer in Scotland are lower than the rest of the UK and most other European countries. This difference occurs mostly in the first year after diagnosis, suggesting advanced stage at disease presentation could be a contributing factor.

This module encourages practices to look at patients who have been recently diagnosed with cancer and consider if the diagnosis could have been made earlier.

## Module Questions:

### A Background information, data collection and analysis

- 1 For your practice population, look back on your data, or gather data prospectively for six months if you do not already do so, and identify the proportion of patients diagnosed with cancer:
  - who were referred urgently with a suspicion of cancer
  
  - who presented as an emergency
- 2 Look at your recent referrals on [SCI Gateway](#). Of the last 10 patients referred urgently with a suspicion of cancer and for whom a final diagnosis has been reached, which (if any) were diagnosed with cancer and which were diagnosed with the cancer type indicated in the referral?

### 3 How are referral guidelines for cancer displayed and used in your practice?

## B Reflective practice

GPs are sometimes criticised for their referral behaviour, particularly when a diagnosis of cancer is involved. It can be a difficult task to achieve the fine balance between over-referring and causing anxiety in patients, overwhelming the system with unnecessary referrals for investigations or specialist opinion and ensuring, amongst the array of presentations seen, that the worrying symptoms and signs are recognised and acted upon.

Use the following questions to facilitate a discussion within your practice about your suspected cancer referrals.

- 1 Take a fresh look at the [Scottish Referral Guidelines for Suspected Cancer](#) on the Healthcare Improvement Scotland website.

Write down any learning points from reviewing the guidelines.

- 2 How aware are you about the 'at risk' groups? Look at the suspected cancer referral guidelines and consider the groups of people most at risk of particular cancers. What learning have you gained?



## C Significant Event Analysis (SEA)

Consider the following for a patient who has recently been diagnosed with cancer:

- Date of diagnosis
- Reflection on how the person presented
- Diagnosis
- What went well caring for this patient/family?
- What could have been done better?
- What learning/educational needs have been identified?
- What issues require further action?

Either complete the SEA in the box below or submit a separate SEA on the [Royal College of General Practitioners \(RCGP\) template](#).

### Further reading / Useful resources

**Detect Cancer Early programme** <http://www.gov.scot/Topics/Health/Services/Cancer/Detect-Cancer-Early>

**Scottish Referral Guidelines for suspected cancer**

[http://www.healthcareimprovementscotland.org/our\\_work/cancer\\_care\\_improvement/programme\\_resources/scottish\\_referral\\_guidelines.aspx](http://www.healthcareimprovementscotland.org/our_work/cancer_care_improvement/programme_resources/scottish_referral_guidelines.aspx)

**Macmillan Ten Top Tips: multiple or vague symptoms**

[http://www.macmillan.org.uk/documents/aboutus/health\\_professionals/primarycare/10toptips/10toptipsvaguesymptoms.pdf](http://www.macmillan.org.uk/documents/aboutus/health_professionals/primarycare/10toptips/10toptipsvaguesymptoms.pdf)

**SCI (Scottish Care Information) Gateway** [http://www.sci.scot.nhs.uk/products/gateway/gateway\\_prod\\_overview.htm](http://www.sci.scot.nhs.uk/products/gateway/gateway_prod_overview.htm)

**Royal College of General Practitioners SEA templates**

<http://www.rcgp.org.uk/clinical-and-research/our-programmes/quality-improvement/significant-event-audit.aspx>

## Module Three: Access to appointments and advice

### Introduction:

Access to healthcare is one of the priorities that GP clusters are being asked to consider. Access to Primary Care is important across the cancer pathway. Both the National Awareness and Early Diagnosis Initiative (NAEDI) and the [Detect Cancer Early \(DCE\)](#) project have highlighted different barriers which contribute to late diagnosis of cancer. Some of these relate to the ability to obtain an appointment with an appropriate health care professional. There are also important access requirements for patients with cancer who have emergencies such as neutropenic sepsis or malignant spinal cord compression.

This module encourages GP clusters to consider access from a cancer patient's perspective. A typical patient journey with cancer is listed below, from first noticing symptoms, through to diagnosis, treatment and complications of treatment. At each stage in the journey the GP practice should consider how easy it would be for this patient to get an appointment with an appropriate healthcare professional in the practice.

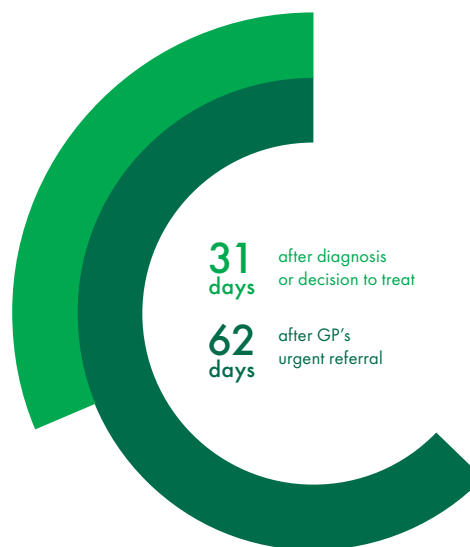
### Module Questions:

Annie is 58, has mild learning difficulties and has noticed some blood in her stool. This is the third time it has happened, but she has put off seeing the doctor as she hoped it would settle on its own. She phones your receptionist to ask for an appointment. She is keen to get an appointment before 9am or after 5pm as she volunteers a few miles away in a local shop and relies on a work colleague for transport.

- 1 How long is it likely to take for her to get an appointment with any doctor at these times?
- 2 Annie has built a trusting relationship with a particular doctor in the practice. As she is embarrassed about her symptoms she would prefer to see this doctor. How long might she wait for an appointment if she asks to see 'her own' doctor?
- 3 Is there anything your practice could do or offer to enable people like Annie to access help in these situations?

Annie attends for her appointment and has an abdominal and rectal examination and some blood tests (FBC, CRP, U+E, LFTs). She is asked to make a further appointment the following week to discuss the results and the next steps. However, she calls reception three days later and is told the blood tests are all normal. She therefore chooses not to waste the doctor's time with another appointment.

### Maximum waiting times before starting treatment



- 4 What safety nets are in place to ensure Annie is followed up and referred for further investigation if she does not return?

Annie is contacted and makes a further appointment. She is still having occasional rectal bleeding and so the doctor explains the need to refer Annie to the hospital for a colonoscopy to check for any serious problems such as cancer. Annie appears upset and is confused by all the information that is being given to her.

- 5 Discuss with colleagues and list the additional support which could be given to Annie at this time. Where would you access appropriate patient information explaining invasive procedures such as colonoscopy?

Annie has a colonoscopy and biopsies which show a colorectal cancer. Your GP practice receives notification of this from the hospital.

- 6 Do you have a system to contact patients after a significant diagnosis such as cancer? How does this work? Could it be improved?

Annie is treated with chemotherapy. She is told about the risk of neutropenic sepsis and is given written information about this. However she does not fully understand what she was told and misplaces the leaflet. She has now developed a sore throat with a high fever and so calls the GP practice for an appointment.





12 How does this work?

13 Could it be improved?

Two years after Annie completes her chemotherapy, the practice receives a letter from the oncology department to say she has not attended the last two appointments which were sent to her.

14 Describe the policy the practice has for following up on hospital DNAs and whether there is anything else which you think you could / should be doing.

15 What learning or actions from this module can be shared with other GP practices within your cluster?

### Further reading / useful resources

**Detect Cancer Early programme** <http://www.gov.scot/Topics/Health/Services/Cancer/Detect-Cancer-Early>

**Example of a generic patient pathway (see page 4 of report: Innovation to implementation: stratified pathways of care for people living with or beyond cancer, NHS Improvement 2013)** <http://www.ncsi.org.uk/wp-content/uploads/howtoguide.pdf>





- 8 Find out from the other Practice Quality Leads within your cluster the process they use to ensure high quality Cancer Care Reviews are undertaken. Write down any learning points below.

## **C Significant event analysis**

- 1 Identify five people who were diagnosed with cancer approximately one year ago. Look at their notes and reflect upon the support offered to them by the practice. Was a formal Cancer Care Review undertaken?

- 2 What could be improved?

- 3 Look at a small selection (3 to 6) of Cancer Care Reviews undertaken by different professionals within your GP practice in the last year. Identify one or two of these Cancer Care Reviews which you think were undertaken well and consider the elements which made this so. Discuss and share the learning from this exercise with other GPs and nurses in the practice.

## Further reading / useful resources

**Transforming Care After Treatment (TCAT) programme** <http://www.gov.scot/Topics/Health/Services/Cancer/TCAT>

**Carrying out an effective Cancer Care Review**

[http://www.rcgp.org.uk/~/\\_/media/Files/CIRC/Toolkits-2015/CoC/Macmillan-Effective-Cancer-Care-Reviews.ashx](http://www.rcgp.org.uk/~/_/media/Files/CIRC/Toolkits-2015/CoC/Macmillan-Effective-Cancer-Care-Reviews.ashx)

**Macmillan guide to benefits and financial help for people affected by cancer**

<http://be.macmillan.org.uk/Downloads/CancerInformation/FinancialSupport/MAC4026HWTCCe1320150501.pdf>

**UK Chief Medical Officers, Physical activity benefits for adults and older adults**

<https://www.gov.uk/government/publications/uk-physical-activity-guidelines>

**The importance of physical activity: a concise evidence review**

<http://www.macmillan.org.uk/documents/aboutus/commissioners/physicalactivityevidencereview.pdf>

**Delivering physical activity advice** [http://www.rcgp.org.uk/~/\\_/media/B8AA8DB227DA468A953770DA03920AD0.ashx](http://www.rcgp.org.uk/~/_/media/B8AA8DB227DA468A953770DA03920AD0.ashx)

**Holistic Needs Assessment template** [http://www.rcgp.org.uk/~/\\_/media/Files/CIRC/Toolkits-2015/CoC/Macmillan-Concerns-checklist.ashx](http://www.rcgp.org.uk/~/_/media/Files/CIRC/Toolkits-2015/CoC/Macmillan-Concerns-checklist.ashx)

**British Medical Journal e-learning module: supporting people with cancer in primary care**

[http://learning.bmj.com/learning/module-intro/cancer\\_support\\_primary\\_care.html?locale=en\\_GB&moduleId=10042332](http://learning.bmj.com/learning/module-intro/cancer_support_primary_care.html?locale=en_GB&moduleId=10042332)

**What is a Holistic Needs Assessment?**

<http://www.macmillan.org.uk/aboutus/healthandsocialcareprofessionals/macmillansprogrammesandservices/recoverypackage/holisticneedsassessment.aspx>

# Module Five: Late effects of cancer and consequences of treatment

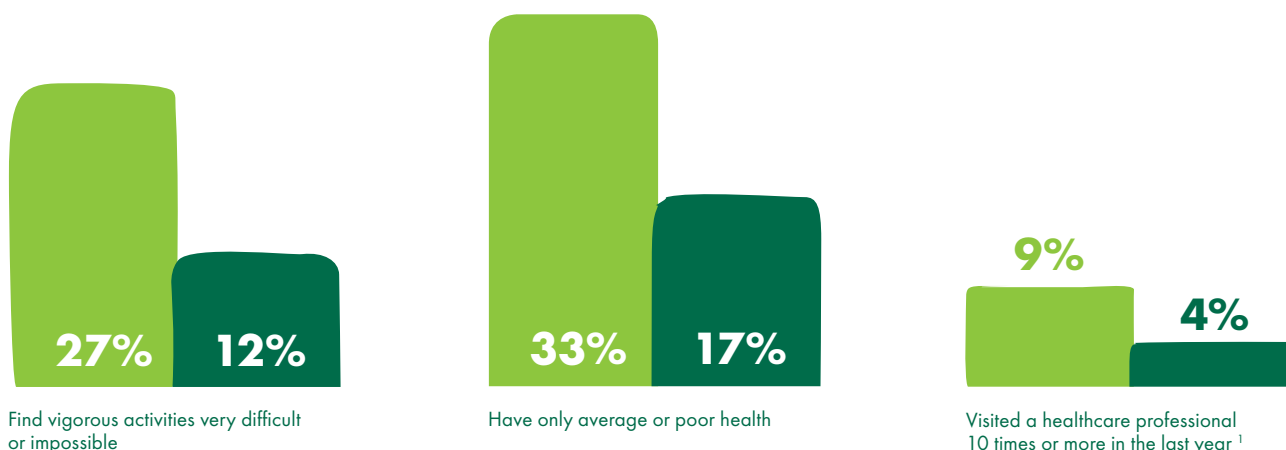
## Introduction:

Cancer treatment is often invasive and can have both short and longer term consequences, some of which may arise years after treatment was administered. Consequences of treatment can include physical and psychological effects, such as chronic fatigue, sexual difficulties, mental health problems, pain, urinary and gastrointestinal problems and lymphoedema.

Failure to identify and manage these distressing problems effectively can compromise survival, recovery and quality of life for the patient and their carers.

## Comparison of people living with cancer and healthy people

Research suggests people who have had cancer and do not have any other chronic conditions are more likely to experience health problems than those without cancer.



■ = People who have had cancer    ■ = People who have not had cancer

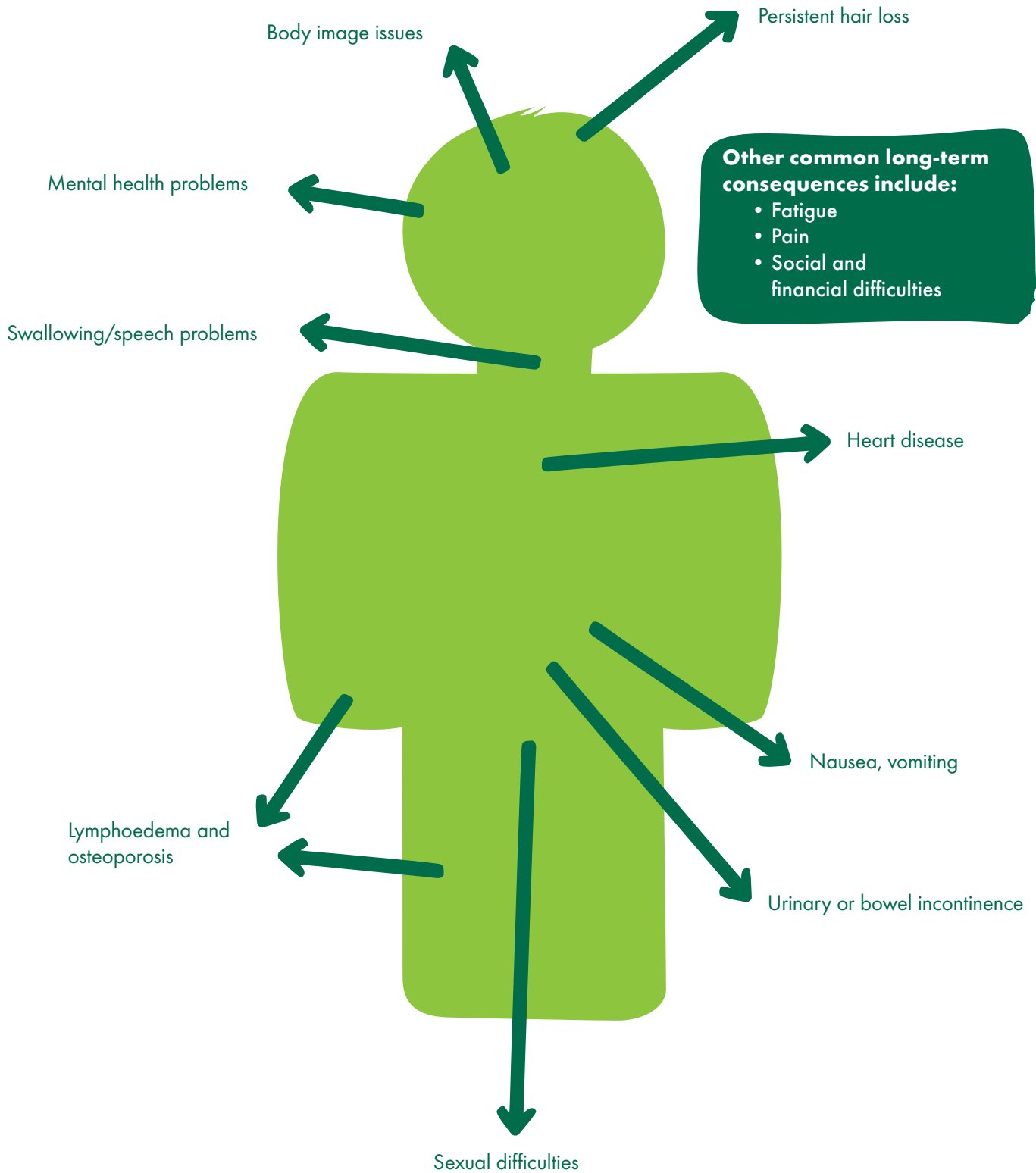
For more information on the long-term consequences of cancer and its treatment visit [bit.ly/mcs197](https://bit.ly/mcs197)

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Macmillan Cancer Support, registered charity in England and Wales (261017), Scotland (SC039907) and the Isle of Man (604). MAC14381\_INFO3

<sup>1</sup> Based on data reviewed as part of Macmillan Cancer Support (2013) *Throwing light on the consequences of cancer and its treatment*. Elliott J, Fallows A, Staetsky L, Smith PWF, Foster CL, Maher EJ and Corner J. 2011. The health and well-being of cancer survivors in the UK: findings from a population-based survey. *British Journal of Cancer* 105, S11-S20.

## Examples of long-term consequences of cancer and its treatment



For more information on the long-term consequences of cancer and its treatment visit [bit.ly/mcs197](https://bit.ly/mcs197)

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## Module Questions:

### A Background information, data collection and analysis

- 1 From your practice cancer register calculate how many patients were diagnosed:
  - Within the last year
  
  - Within the last two years
  
  - Within the last five years
  
  - More than ten years ago
- 2 Calculate roughly what proportion of patients on your practice cancer register regularly attend the surgery with symptoms or signs related to their cancer.
- 3 Write down an estimate for the proportion of older people who are currently living with a diagnosis of cancer and then check how close you are: [http://www.macmillan.org.uk/documents/aboutus/research/researchandevaluationreports/peoplelivingwithcancer\(generalsurvivorship\).pdf](http://www.macmillan.org.uk/documents/aboutus/research/researchandevaluationreports/peoplelivingwithcancer(generalsurvivorship).pdf)
- 4 Spend a few minutes familiarising yourself with the [National Cancer Survivorship initiative](#) (NCSI) website and the [Transforming Cancer After Treatment programme](#). Note any key learning points.



- 4 What kind of information would be useful for you to have in an end-of-treatment summary letter from an oncologist that would give you more confidence in managing a patient who has been treated for cancer and for whom discharge from long-term hospital follow-up is planned?

## Further reading / Useful resources

**Transforming Care After Treatment (TCAT) programme** <http://www.gov.scot/Topics/Health/Services/Cancer/TCAT>

**Consequences of cancer toolkit** <http://www.rcgp.org.uk/clinical-and-research/toolkits/consequences-of-cancer-toolkit.aspx>

**National Cancer Survivorship initiative (NCSI)** [www.ncsi.org.uk](http://www.ncsi.org.uk)

**A practical guide for carers, by carers**

<https://be.macmillan.org.uk/Downloads/CancerInformation/InfoForCarers/MAC5767LookingaftersomeonewithcancerE05P0620150722-metadata.pdf>

**People living with cancer**

<http://www.macmillan.org.uk/documents/aboutus/research/researchandevaluationreports/peoplelivingwithcancer%28generalsurvivorship%29.pdf>



- 3 From your GP practice cancer register, calculate the proportion of people who have a KIS.
  
- 4 Ask the other Practice Quality Leads within your cluster what systems they use to ensure the KIS is kept up to date. Write any learning below.

## **B Reflective Practice**

- 1 Examine 10 KISs your practice has developed for people with cancer and calculate:
  - What proportion contained information about preferred care choices such as place of care or resuscitation?
  
  - What proportion contained information about potential health problems related to the cancer with a suggested management plan for these?
  
- 2 Arrange a meeting within your practice, or with Practice Quality Leads from your cluster, to review the quality of information within this sample of KISs.

Choose two or three which you consider to be of higher than average quality and discuss and write down what aspects made these higher quality.

- 3 Write down how you will share the learning from this module with any other members of the team who were not involved in the discussions.

### **Further reading / useful resources**

**Transforming Care After Treatment (TCAT) programme** <http://www.gov.scot/Topics/Health/Services/Cancer/TCAT>

**Key Information Summary** <http://www.scimp.scot.nhs.uk/key-information-summary/>

**Anticipatory Care Planning** <http://www.jitscotland.org.uk/wp-content/uploads/2015/01/Final-A5-Anticipatory-Care-booklet-v6.pdf>

**Resource last updated August 2016**