MACMILLAN CANCER SUPPORT

SCOTTISH PRIMARY CARE CANCER GROUP

Healthcare Improvement Scotland

NHS SCOTLAND 70 YEARS #nhsscot70

# Scottish Referral Guidelines for Suspected Cancer

January 2019

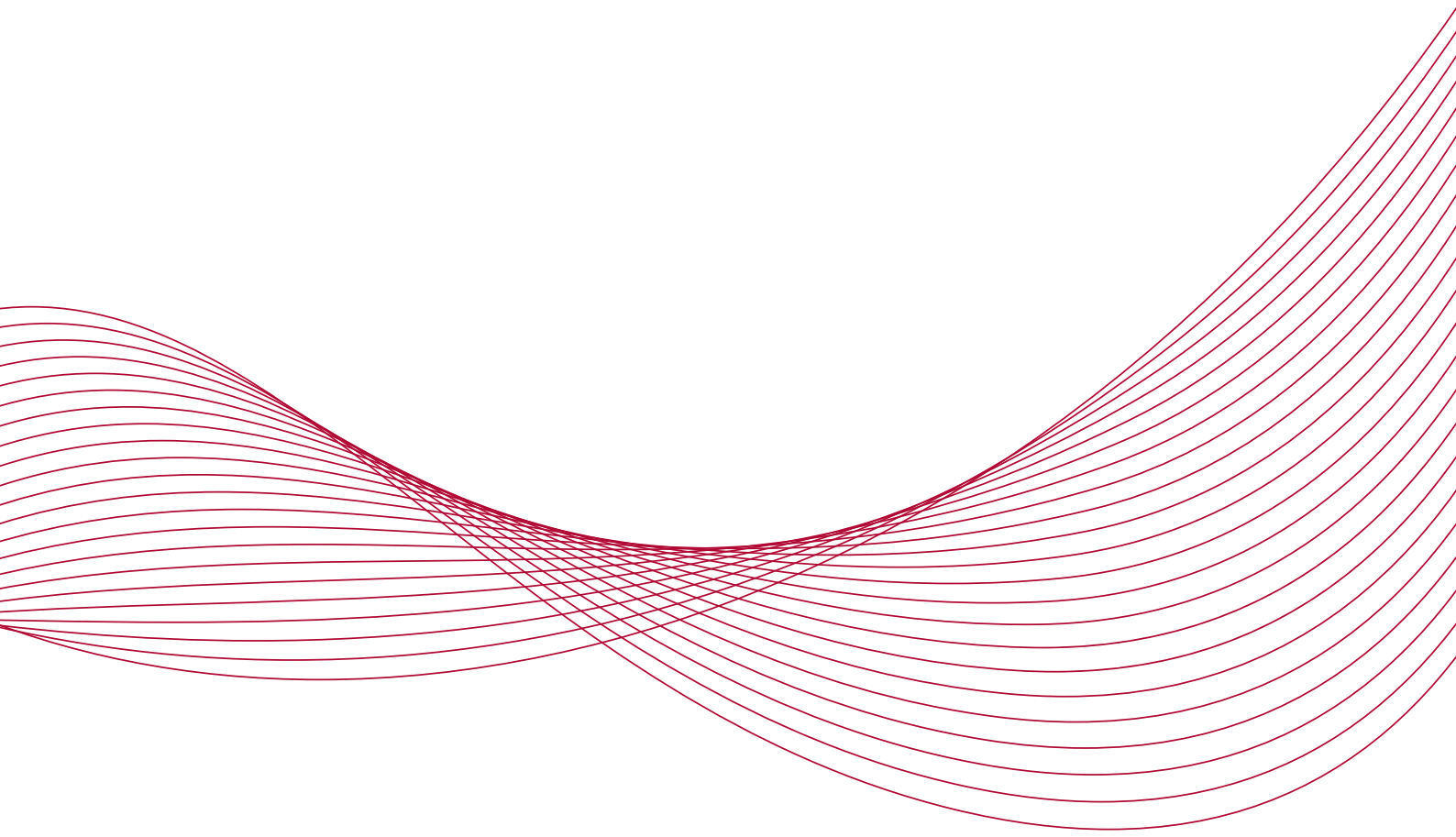
First published October 2013. Updated May and August 2014. Refreshed 2018



Healthier Scotland
Scottish Government

# CONTENTS

# 1 INTRODUCTION



## 1.1 BACKGROUND

Although cancer is a common condition with 31,331 new cases being diagnosed in 2016 in Scotland (excluding non-melanoma skin cancers), an individual general practitioner (GP) practice is likely to see only about 35 new cases per annum. The average number of new cases per annum of individual cancer types for a GP practice with a list size of 5,881 patients is shown in Table 1. A GP practice is likely to see on average four or five new cases per annum of people with each of the most common cancers (lung, breast and colorectal) and only approximately one new cancer of the bladder, kidney and oesophagus. An individual GP might see only one new cancer in a child under 15 years in a 35 year career (one every seven or eight years in an average sized GP practice) and yet a GP will see children with symptoms and signs that could conceivably be cancer every single week.

**Table 1: Ten most common cancers in Scotland in 2016[1]**

| Cancer | ICD-10 code | Total new cases per annum | No. cases per 5,881 population per annum |
|---|---|---|---|
| Trachea, bronchus and lung | C33-C34 | 5,045 | 5.49 |
| Breast | C50 | 4,636 | 5.04 |
| Colorectal | C18-C20 | 3,700 | 4.03 |
| Prostate | C61 | 3,167 | 3.45 |
| Malignant melanoma of skin | C43 | 1,383 | 1.5 |
| Head and neck | C00-C14, C30-C32 | 1,240 | 1.35 |
| Non-Hodgkin's lymphoma | C82-C85 | 1,022 | 1.11 |
| Kidney | C64-C65 | 980 | 1.07 |
| Bladder | C67 | 870 | 0.95 |
| Oesophagus | C15 | 858 | 0.93 |

The task for the clinician is to differentiate between people whose symptoms may be due to cancer and the much larger number of people with similar symptoms arising from other causes. For certain symptoms, it may be entirely appropriate for a clinician to wait to see if it resolves. Persistence or worsening of the symptom may alert the clinician to the possibility of cancer. Wherever possible these factors have been taken into account in the development of these guidelines.

1 Based on total Scottish population of 5,404,700 as at 30 June 2016: National Records of Scotland mid 2016 population estimates Scotland, Scottish Cancer Registry, Information Services Division (ISD), April 2018, GP Workforce & Practise Populations

Cancer remains a national clinical priority for the Scottish Government and NHSScotland. The Scottish Government's Cancer Strategy 'Beating Cancer: Ambition and Action'[2] was launched in March 2016. This strategy and accompanying £100 million commitment, serves as a blueprint for the future of cancer services in Scotland, improving the prevention, detection, diagnosis, treatment and aftercare of those affected by the disease.

Increasing early diagnosis of cancer can reduce premature deaths from cancer and subsequently have a positive effect on overall life expectancy. One of the objectives of the Scottish Government Detect Cancer Early Programme is to work with clinicians and the wider primary care team to promote referral or investigation at the earliest reasonable opportunity for people who may be showing a suspicion of cancer, while making the most efficient use of NHS resources and avoiding an adverse impact on access to services.

## 1.2 PURPOSE

The Scottish Referral Guidelines for Suspected Cancer were first published in 2002 and subsequently revised in 2007 and 2014. The recommendations here supersede those in previous guidelines.

The guidelines should help GPs, the wider primary care team, other clinicians, patients and carers to identify those people who are most likely to have cancer and who therefore require urgent assessment by a specialist. Equally, it is hoped that the guidelines will help clinicians to identify people who are unlikely to have cancer and who may appropriately be managed in a primary care setting or who may require non-urgent referral to a specialist.

## 1.3 DEVELOPMENT OF THE 2014 GUIDELINES

A multidisciplinary steering group was convened in 2012 to produce a relevant, evidence-based, clinically useful and user-friendly document for clinicians in primary care. The methodology and scope of the guidelines is detailed in **Appendix 1**.

## 1.4 GUIDELINE REFRESH 2019

The Scottish Primary Care Cancer Group reviewed the 2014 guidelines in 2018 and identified changes that were required as a result of new evidence and guidelines. It was therefore decided to undertake a further update. Healthcare Improvement Scotland identified evidence published since the original guidelines. Of particular note was the publication of NICE guideline NG12 Suspected cancer: recognition and referral (June 2015 updated July 2017) which uses a risk threshold value of 3% positive predictive value of finding cancer for any specific presenting symptoms or signs. As with NICE, we have included exceptions to the 3% PPV threshold, in particular, for children's cancer.[3]

2 Beating Cancer: Ambition and Action **https://www.gov.scot/publications/beating-cancer-ambition-action/**

3 NICE Guideline [NG12] Suspected cancer: recognition and referral (June 2015 last updated July 2017) **https://www.nice.org.uk/guidance/ng12**

A steering group was established to oversee the update process, under the chairmanship of Dr Peter Hutchison (membership in **Appendix 2**). Members of the previous tumour specific groups were asked to participate in the revision of the guidelines. Where the previous members were unable to do so, they were asked to recommend specialists to be involved. Membership of the groups was ratified by the steering group. Subgroups were convened for the various cancers where the evidence suggested that recommendations should change. Where the evidence did not support the need for a full update, views were sought from the original members of the individual tumour subgroups. Epidemiological data were updated throughout the guidelines.

A dissemination group (membership in **Appendix 3**) was established to oversee the implementation of the guidelines.

The updated guidelines were submitted for peer review across clinical, third sector and patient representative networks in Scotland and the steering group considered and responded to each comment received.

## 1.5 FORMAT OF THE GUIDELINES

There is not complete uniformity in the layout of the guidelines as members of specific subgroups advised slightly different formats that reflect the distinct nature of symptoms and patterns of disease. However, for each tumour group the guidelines include information on key points about the pattern of the relevant cancer and guidelines for referral.

## 1.6 REFERRAL TIMELINES

The referral timelines used in the guidelines include:

- **urgent suspicion of cancer:** Patients referred via the urgent suspected cancer pathway should receive first treatment within 62 days of receipt of referral. These referrals will be prioritised and tracked.
- **emergency referral:** to be seen on the same day
- **urgent** (not suspected cancer): not tracked or counted in the target for cancer referrals – not used in these guidelines
- **routine:** all other referrals, and
- **primary care management**

All staff involved in the referral process should be aware of the difference and importance of using these terms. In particular, labelling an urgent referral as being for suspected cancer ensures that these cases can be specifically identified, tracked and audited under the Scottish Government target.

## 1.7 REFERRAL PATHWAYS

NHS boards have well-established urgent suspicion of cancer referral pathways to facilitate prompt diagnosis of cancer. These pathways function particularly well in cases where symptoms and signs are suspicious of a specific tumour type. However, for people with vague symptoms (such as unexplained weight loss and fatigue) there is potential for delay in reaching a diagnosis. To minimise this risk, direct access to imaging for primary care practitioners enables the differential diagnosis to be narrowed and referral to the appropriate secondary care specialty to be made, thereby reducing delays. The availability of such access to imaging varies across the NHS boards.

## 1.8 DISSEMINATION OF THE GUIDELINES

The guidelines will be widely disseminated in a variety of formats to all clinicians to whom someone may first present with symptoms of possible cancer including GPs, Advanced Nurse Practitioners and other nursing staff, pharmacists, dentists, optometrists, NHS24, paramedics and A&E departments. They will also be brought to the attention of secondary care clinicians of all grades in order to encourage equity of access to investigation and to facilitate interdepartmental referrals.

The current guidelines are available at **http://www.cancerreferral.scot.nhs.uk/** and a desktop Quick Reference Guide has been developed by the Scottish Primary Care Cancer Group which has been used as the basis for an App for use on mobile devices.

Link to Website: **http://www.cancerreferral.scot.nhs.uk**

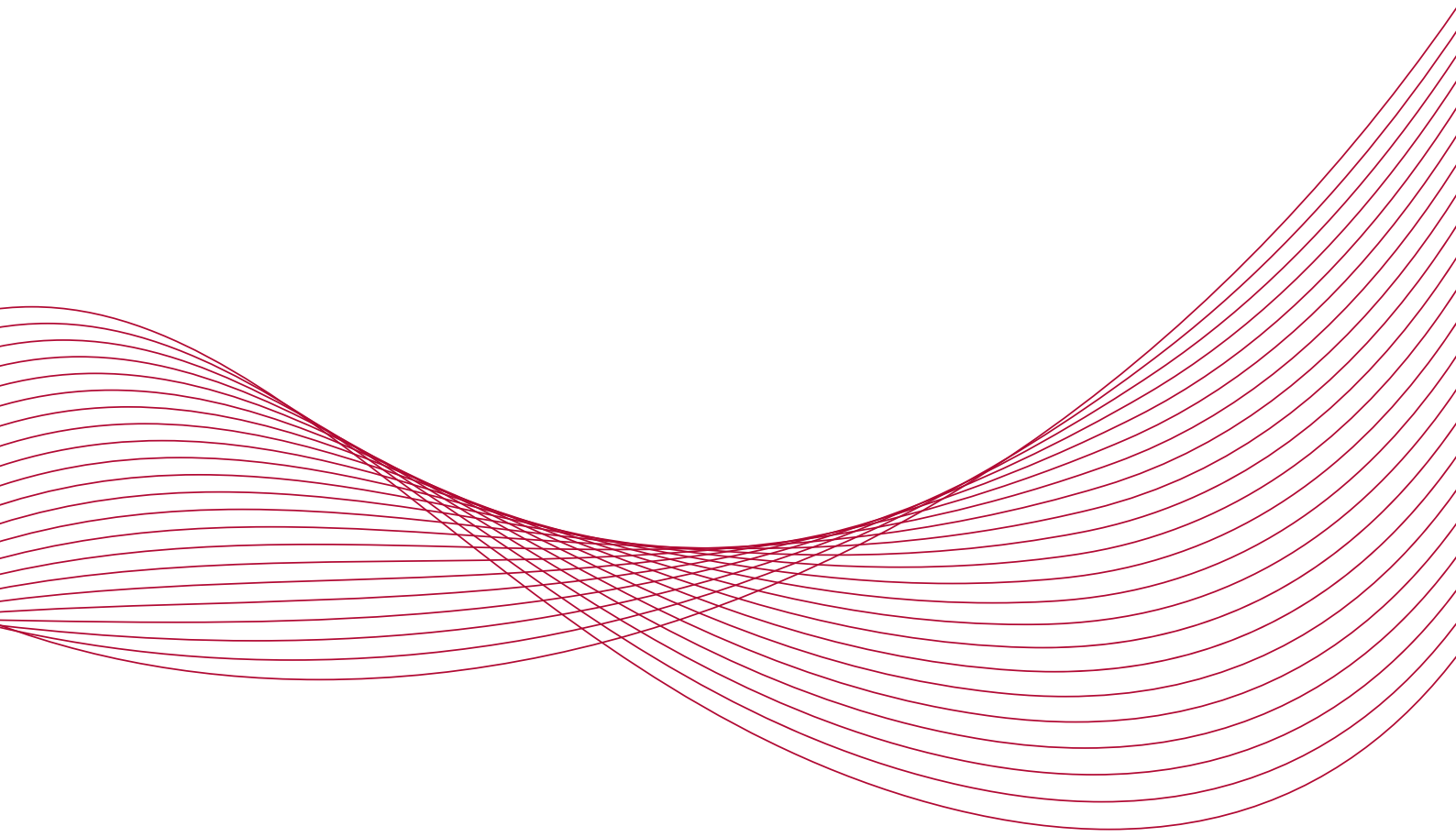
Link to both the Apple App store: **https://itunes.apple.com/gb/app/cancer-referral-guidelines-quick-reference-guide/id1049728177?mt=8**

and to the Android App store: **https://play.google.com/store/apps/details?id=com.scet.cancercareguidelines**

## 1.9 AUDIT AND REVIEW OF THE GUIDELINES

Audit and monitoring of the guidelines in practice should generate a valuable amount of new information which will be used to revise the guidelines in the future. It is strongly recommended that the Regional Cancer Networks undertake prospective audit of the guidelines.

# 2 COMMON ISSUES FOR CANCER REFERRALS



## 2.1 PATIENT ISSUES

### 2.1.1 Patients' and carers' needs

All healthcare professionals should be sensitive to the needs of patients, carers and relatives when cancer is suspected. Realistic Medicine[4] is the Scottish Government's initiative to put the person at the centre of decision-making and encourages a personalised approach to their care. Good communication is key and five questions to be considered by all involved can help lead to informed decision-making:

- Is this action really needed?
- What are the benefits and risks?
- What are the possible side effects?
- Are there alternative options?
- And, importantly, what would happen if we did nothing?

**Good practice includes:**

- Being sensitive to the person's wishes to be involved in decisions about their care
- Providing understandable information at a level appropriate to the person's wishes to be informed
- Being aware of, and offering to provide access to, sources of information in various formats
- Using the word "cancer" as a reason for investigation or referral unless there is serious concern about causing unwarranted distress
- Providing information about any referral to other services in format(s) most suitable for the person, including how long they might have to wait, who they are likely to see, and what is likely to happen to them
- Considering carefully the need for emotional and physical support while awaiting an appointment with a specialist and, where appropriate, providing a key contact
- Considering any carers' needs for support and information, taking issues of confidentiality into consideration
- Taking the individual's particular circumstances into account, for example age, family, work and culture
- Recognising that there are occasions when intrusive intervention is not in a person's best interests. There should be full discussion about alternative approaches, including with relevant others if a person lacks capacity, complying with the Adults with Incapacity (Scotland) Act 2000
- Maintaining a high standard of communication skills, including, for example, in the process of breaking bad news

4 Practising Realistic Medicine **https://www.gov.scot/publications/summary-practising-realistic-medicine/**

### 2.1.2 Demographic factors

Deprivation affects the incidence of and mortality associated with cancers. It also impacts on the ability of people to access healthcare services. It is essential that any consultation or other opportunity where a person from a deprived area presents with symptoms suggestive of possible cancer is used to full advantage. Some cancers occur more frequently in certain communities, e.g. the lifetime risk of prostate cancer in black men is twice that of all men combined.

### 2.1.3 Comorbidity

The increasing number of people with long-term conditions and co-morbidity pose major clinical challenges and affect both the incidence of and mortality from cancer. Chronic disease management programmes afford an opportunity to identify symptoms suggestive of possible cancer.

### 2.1.4 Safety netting

It is not always appropriate for a clinician to refer someone immediately with new symptoms or signs which could be cancer (for example, one week of diarrhoea or a sore throat for 10 days) and an initial 'watch and wait' strategy may be appropriate. It is also important for clinicians to provide a 'safety net' and ensure people know what symptoms to monitor and when to return if their condition does not improve or change. In some cases, however people may be unwilling to watch and wait due to high levels of anxiety. In such cases, the referring clinician should ensure that this is detailed in the referral documentation.

**Note that in children, repeat presentations (three or more times) of any symptoms which do not appear to be resolving or following an expected pattern should be considered for referral for a second opinion, taking into account parental/carer and child concerns.**

### 2.1.5 Follow up

It is good practice for the referrer to consider ways of supporting the person to attend investigations, consultations or reviews and addressing any concerns they may have about their referral. For example, a leaflet such as Cancer Research UK's "Your Urgent Referral Explained"[5] can be given to them at the time of referral. Other similar resources are available. Systems should be in place to ensure people are not lost to follow up.

5 Cancer Research UK: Your Urgent Referral Explained **https://publications.cancerresearchuk.org/categories/your-urgent-referral**

## 2.2 REFERRAL PROCESS

### 2.2.1 Use of the Guidelines

The guidelines are designed for use in any primary care setting, by any member of the clinical team. Local arrangements should be in place in each NHS board area for advanced nurse practitioners and other nursing staff, pharmacists, dentists, optometrists, NHS24, paramedics and others to ensure rapid referral is arranged. This may be by direct referral (with simultaneous notification of the GP) or by making arrangements for the person to see their GP urgently, clearly notifying the concern about suspected cancer.

The guidelines will also be brought to the attention of secondary care clinicians of all grades in order to encourage equity of access to investigation and to facilitate interdepartmental referrals.

### 2.2.2 Purpose of referral

The 'urgent suspicion of cancer' referral pathway is designed to allow the rapid assessment and investigation of a person to determine the cause of their symptoms. For people whose presenting symptoms persist, it is not acceptable to simply exclude cancer without providing an assessment of the likely underlying cause. This may involve individual hospital specialties making internal referrals to their colleagues to help determine the nature and cause of the presenting symptoms. These internal referrals should be undertaken with the minimum of delay and with good communication to both the patient and referring clinician. Where diagnostic tests are undertaken, the clinician requesting the test has a responsibility for acting on the result and ensuring that the patient receives this.

NHS boards may wish to consider to which diagnostic services primary care clinicians should have direct open access. In these situations the clinician would be responsible for communicating the result to the patient and arranging any subsequent follow up.

### 2.2.3 Clinical decision support tools and structured documentation/proformas for referral

To achieve consistency, clinical decision support systems and structured proformas for referral can be helpful for use in all clinical settings. Scottish Care Information (SCI) Gateway provides the means for electronic referrals incorporating structured proformas, but clinical decision support systems vary across NHSScotland.

### 2.2.4 Downgrading of urgent suspected cancer referrals

On rare occasions it may be acceptable for the receiving hospital specialty to downgrade an urgent suspicion of cancer referral to urgent or routine. This should never occur without notifying the referring GP practice timeously. The clinician should have the opportunity to explain why an urgent suspected cancer referral was requested. Vital information may have been omitted from the referral or may have become available since the referral was made. It is essential that the person is kept informed about any change in referral priority.

### 2.2.5 Feedback where no cancer is found

The referring clinician should receive timely feedback on the outcomes for all people with an urgent suspicion of cancer referral. Where negative results are found, and concerns still exist, the specialist should consider direct onward referral to another specialty. Information about inappropriate referrals should be fed back to the referring clinician detailing why it was felt to be inappropriate and suggesting an alternative course of action.

### 2.2.6 Opportunity for health promotion

Suspicion of cancer, whether warranting referral or not, is an opportunity to consider health promotion such as smoking cessation, alcohol, diet, obesity, exercise and engaging with national screening and immunisation programmes. People should be informed that 4 in 10 cancers are preventable[6], and that addressing risk factors can help reduce their overall cancer risk.

### 2.2.7 General points about suspected cancer

- Cancer often presents with vague symptoms that do not help identify which pathway of investigation to follow. In particular, ovarian and pancreatic cancer often present very late so, in unwell people with nothing other than malaise and significant unexplained weight loss, most NHS Boards have pathways in place for Primary Care access to CT chest, abdomen and pelvis as first investigation
- Recent evidence has identified thrombocytosis as a strong risk marker for malignancy, in particular lung, endometrial, gastric, oesophageal and colorectal cancer (acronym "LEGO-C"). With a cancer incidence of 11.6% and 6.2% in males and females respectively, these figures well exceed the 3% threshold to warrant investigation[7]
- Metastatic disease is commonly the first presentation of a new cancer. The possibility of an underlying primary cancer should be considered especially with symptoms and signs suggesting lung, liver, bone or brain cancer. For example, bone metastases are commonly due to prostate, breast and lung cancer. Metastatic disease should be borne in mind when anybody with a previous history of cancer presents with new symptoms
- Tumour markers have a limited place in the decision to refer for suspected cancer: only PSA for prostate cancer in men, CA125 for ovarian cancer in women, and serum and urine paraproteins for myeloma should be routinely used in Primary Care[8]

6 Statistics on Preventable Cancers **https://www.cancerresearchuk.org/health-professional/cancer-statistics/risk/preventable-cancers**

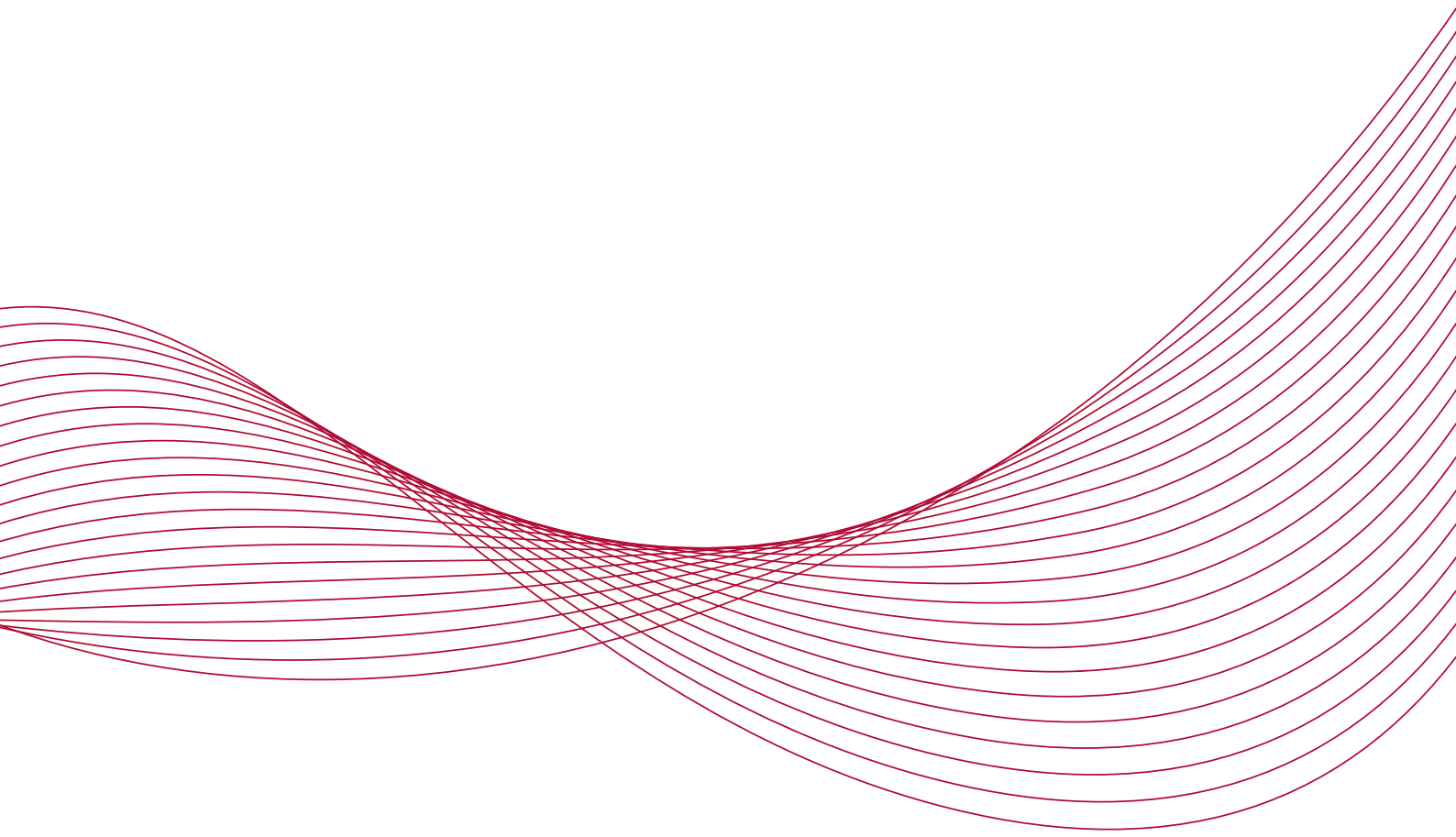
7 Clinical relevance of thrombocytosis in primary care: Br J Gen Pract 2017; 67 (659): e405-e413. DOI: **https://doi.org/10.3399/bjgp17X691109**

8 Cancer Working Group of the Scottish Clinical Biochemistry Managed Diagnostic Network **https://www.clinicalbiochemistry.scot.nhs.uk/working-groups/cancer/**

- It is good practice to include general fitness or performance status in the referral (e.g. ECOG/WHO scale) in order to facilitate discussion about the most appropriate pathway

| Grade | ECOG/WHO Performance Status |
|---|---|
| 0 | Fully active, able to carry on all pre-disease performance without restriction |
| 1 | Restricted in physically strenuous activity but ambulatory and able to carry work of a light or sedentary nature, e.g., light house work, office work |
| 2 | Ambulatory and capable of all self-care but unable to carry out any work activities; up and about more than 50% of waking hours |
| 3 | Capable of only limited self-care; confined to bed or chair more than 50% of waking hours |
| 4 | Completely disabled; cannot carry on any self-care; totally confined to bed or chair |
| 5 | Dead |

# 3 REFERRAL GUIDELINES



## 3.1 LUNG CANCER

More than 90% of people with lung cancer are symptomatic at the time of diagnosis. Many symptoms of lung cancer (particularly cough and fatigue), however, are common presentations in primary care, often associated with chronic diseases such as gastric reflux or chronic obstructive pulmonary disease. It is therefore important that changes in symptoms are identified and acted upon.

Chest X-ray findings are abnormal in over 96% of symptomatic people with lung cancer. In most cases where lung cancer is suspected, it is appropriate to arrange an urgent chest X-ray before urgent referral to a chest physician. However, a normal chest X-ray does not exclude a diagnosis of lung cancer. If the chest X-ray is normal but there is a high suspicion of lung cancer, people should be offered urgent suspicion of cancer referral to a respiratory physician.

In people with a history of asbestos exposure, mesothelioma, as well as lung cancer, should be considered. Approximately 80 to 90% of people with mesothelioma will have a history of occupational or close contact exposure. More common presentations include chest pain, dyspnoea and unexplained systemic symptoms.

### Urgent suspicion of cancer chest X-ray (CXR)

- Any unexplained haemoptysis
- Unexplained and persistent (more than three weeks)
  - change in cough or new cough
  - dyspnoea
  - chest/shoulder pain
  - loss of appetite
  - weight loss
  - chest signs
  - hoarseness (if no other symptoms present to suggest lung cancer refer via Head & Neck pathway)
  - fatigue in a smoker aged **over 40 years**
- New or not previously documented finger clubbing
- Persistent or recurrent chest infection
- Cervical and/or persistent supraclavicular lymphadenopathy*
- Thrombocytosis where symptoms and signs do not suggest other specific cancer**
- Any person who has consolidation on chest X-ray should have further imaging no more than six weeks later to confirm resolution

* if CXR normal, refer via Head and Neck pathway

** if CXR normal, consider alternative diagnosis including other cancers

## Urgent suspicion of cancer referral

- Any unexplained symptoms or signs detailed on previous page persisting for longer than six weeks, despite a normal chest X-ray (other than isolated thrombocytosis or cervical and/or persistent supraclavicular lymphadenopathy)
- Chest X-ray suggestive/suspicious of lung cancer (including pleural effusion, pleural mass and slowly resolving consolidation)
- Persistent haemoptysis in smokers/ex-smokers **over 40 years of age**

## Good practice points

- There should be a locally agreed pathway for radiology to notify the respiratory team of an abnormal chest X-ray suggestive of cancer
- It is good practice for the referrer to consider taking bloods, including full blood count and an **assessment of renal function if not done in preceding three months, in order to expedite further imaging**
- In people with features, suggestive of cancer including suspected metastatic disease, but no other signs to suggest the primary source, consider CT chest, abdomen and pelvis in accordance with local guidelines about the investigation of an unknown primary cancer

## 3.2 BREAST CANCER

It is estimated that between 0.35% and 0.6% of all GP consultations in Scotland are for breast symptoms. Many of these will be for young women, whereas the biggest risk factor, after gender, is increasing age, with more than 80% of breast cancers occurring in women over the age of 50.

Breast cancer accounts for 30% of cancers in women and around 4,500 people are diagnosed with breast cancer in Scotland each year; approximately 25 of these are men. In cases of gender reassignment, care must be taken to provide sensitive and clinically appropriate care depending on individual circumstances and taking into account any hormone therapy involved.

Guidance about referral to regional genetics centres (see **Appendix 5**) for those with a family history of breast cancer is available.[9]

9 HIS Familial Breast Cancer Report **www.healthcareimprovementscotland.org/our_work/cancer_care_improvement/programme_resources/familial_breast_cancer_report.aspx**

| | Urgent suspicion of cancer referral | Routine referral | Primary care management - issue relevant advice leaflet (if available) |
|---|---|---|---|
| **Lump** | • Any new discrete lump in patients 30 years and over<br>• New asymmetrical nodularity that persists at review after two to three weeks (in patients over 35 years)<br>• Unilateral isolated axillary lymph node in women persisting at review after two to three weeks<br>• Recurrent lump at the site of a previously aspirated cyst | • Any new discrete lump in patients under 30 years with no other suspicious features<br>• New asymmetrical nodularity that persists at review after two to three weeks (in patients under 35 years) | • Women with longstanding tender lumpy breasts and no focal lesion<br>• Tender developing breasts in adolescents |
| **Nipple Symptoms** | • Visibly bloodstained discharge<br>• New unilateral nipple retraction<br>• Nipple eczema if unresponsive to moderately potent topical steroids after a minimum of two weeks | • Persistent unilateral spontaneous discharge sufficient to stain outer clothes | • Transient nipple discharge which is not bloodstained<br>• Check prolactin levels in persistent bilateral discharge<br>• Longstanding nipple retraction<br>• Nipple eczema if eczema present elsewhere |
| **Skin changes** | • Skin tethering<br>• Fixation<br>• Ulceration<br>• Peau d'orange | | • Obvious simple skin lesions such as epidermoid (sebaceous) cysts |

| | Urgent suspicion of cancer referral | Routine referral | Primary care management - issue relevant advice leaflet (if available) |
|---|---|---|---|
| **Abscess/ infection** | • Mastitis or breast inflammation which does not settle or recurs after one course of antibiotics | | • Abscess or inflammation – try one course of antibiotics as per local guidelines<br>• Any acute abscess requires immediate discussion with secondary care |
| **Breast pain** | | • Unilateral pain persisting over three months in post-menopausal women<br>• Intractable pain that interferes with the person's lifestyle or sleep | • Women with moderate degrees of breast pain and no discrete palpable lesion |
| **Gynaecomastia** | | • Exceptional aesthetics referral to plastic surgery pathway if appropriate (i.e. NOT to the breast service)<br>• Exclude or treat any endocrine cause prior to referral | • Examine and exclude abnormalities such as lymphadenopathy or evidence of endocrine condition with blood tests as per local guidelines<br>• Review to exclude drug causes |
| **Breast implants** | | • If appropriate, refer to the service that first inserted the implant (usually plastic surgery) | • Reassurance is often appropriate if symptoms relate to the implant alone and not to underlying breast tissue |

## 3.3 LOWER GASTROINTESTINAL CANCER

Lower gastrointestinal symptoms are common presentations in primary care. Rectal bleeding is estimated to affect 14,000 per 100,000 population each year. There are large differences in the predictive value of rectal bleeding for cancer according to its association with other symptoms and signs and the age of the person.

Different management strategies should be adopted according to cancer risk, so that those people with transient low-risk symptoms caused by benign disease avoid unnecessary investigation.

The risk of colorectal cancer is increased if there is a past history of ulcerative colitis, colorectal polyps or cancer, or if there is a family history of colorectal cancer or Lynch syndrome. Guidance for referral to regional genetics centres (see **Appendix 5**) for those with such a family history is available in SIGN 126.[10]

In people with ulcerative colitis, a plan for follow up should be agreed in line with current national guidelines.

**An abdominal and rectal examination plus blood tests to assess renal function (in case of triage straight to CT colonography), liver function tests and to exclude anaemia and thrombocytosis should be performed on all people with symptoms suggestive of colorectal cancer. There is emerging evidence that thrombocytosis is a risk marker for underlying cancer, including colorectal, and this can facilitate appropriate triage in secondary care. A negative rectal examination, or a recent negative bowel screening test, should not rule out the need to refer. The carcinoembryonic antigen test should not be used as a screening tool.**

Quantitative faecal immunochemical testing (qFIT) is being used for symptomatic patients in pilot projects in many NHS Boards. In some it is used by secondary care as a triage tool to determine most appropriate initial investigation and in others by primary care to help decide on the need for referral. **Each pilot has its own referral guidance which must be used where available.** In all pilots these referrals and their outcomes will be formally audited in order to determine the most appropriate use of the test. Ultimately it is expected that a nationally agreed system for using qFIT to support the investigation of gastrointestinal disease will be implemented. This is likely to radically change our approach to the referral process. This guideline will be further reviewed at that point.

10 SIGN 126 - Diagnosis and management of colorectal cancer **http://www.sign.ac.uk/sign-126-diagnosis-and-management-of-colorectal-cancer.html**

## Urgent suspicion of cancer referral - high risk features

| | |
|---|---|
| **Bleeding** | • Repeated rectal bleeding without an obvious anal cause<br>• Any blood mixed with the stool |
| **Bowel habit** | • Persistent (more than four weeks) change in bowel habit especially to looser stools - not simple constipation |
| **Mass** | • Unexplained abdominal mass<br>• Palpable ano-rectal mass |
| **Pain** | • Abdominal pain with weight loss (also consider upper GI cancer) |
| **Iron deficiency anaemia** | • **Unexplained iron deficiency** anaemia |

## Good practice points

- Consider the possibility of ovarian cancer as per gynaecological cancers guideline
- An abdominal palpation should be undertaken, CA125 blood serum level measured and urgent pelvic ultrasound scan carried out in:
  - any woman over 50 years who has experienced new symptoms within the last 12 months that suggest irritable bowel syndrome, or
  - women (especially those over 50 years) with one or more unexplained and recurrent symptoms (most days) of:
    - abdominal distension or persistent bloating
    - feeling full quickly or difficulty eating
    - loss of appetite
    - pelvic or abdominal pain
    - increased urinary urgency and/or frequency
    - change in bowel habit

- Low risk features:
  - transient symptoms (less than four weeks)
  - patients under 40 years in absence of high risk features
- Watch and wait (four weeks):
  - Assessment and review
  - Consider bowel diary
  - Appropriate information, counselling and agreed plan for review with GP
  - Refer if symptoms persist or recur

## 3.4 OESOPHAGO-GASTRIC, HEPATOBILIARY AND PANCREATIC CANCERS

Approximately 2,900 people are diagnosed with a primary oesophago-gastric, hepatobiliary or pancreatic cancer in Scotland every year[11] and these often present late with consequent poor outcomes, early signs being notoriously vague.

Combinations of symptoms and signs increase the likelihood of cancer, as does increasing age.

The risk of developing an oesophago-gastric cancer is higher in people of East Asian origin. Other risk factors for upper GI cancers (including hepatobiliary and pancreatic) are smoking, alcohol, obesity and family history.

Investigation of oesophago-gastric cancers commonly starts with upper GI endoscopy, whereas the investigation of hepatobiliary and pancreatic cancer starts with CT imaging. If either of these initial investigations is negative, the responsible clinician should consider further investigation prior to discharge back to the original referrer.

An abdominal examination and appropriate blood tests (for example, testing for anaemia, thrombocytosis, renal function, LFTs and HbA1c) should be performed. These can facilitate triage in secondary care. Note that thrombocytosis can be a non-specific risk marker for underlying malignancy.

All people with high risk features should be referred to a team specialising in the management of oesophago-gastric, hepatobiliary or pancreatic cancers, depending on local arrangements.

11 Cancer Incidence Report In Scotland (2016) **https://www.isdscotland.org/Health-Topics/Cancer/Publications/2018-04-24/2018-04-24-Cancer-Incidence-Report.pdf?51368349791**

## Urgent suspicion of cancer referral

- **Dysphagia** (interference of the swallowing mechanism that occurs within five seconds of the swallowing process) or **unexplained odynophagia** (pain on swallowing) at any age
- Unexplained **weight loss**, particularly >55 years, combined with one or more of the following features:
  - new or worsening upper abdominal pain or discomfort
  - unexplained iron deficiency anaemia
  - reflux symptoms
  - dyspepsia resistant to treatment
  - vomiting
- New vomiting persisting for more than two weeks

## Good practice points

Consider routine referral for people presenting with new upper gastrointestinal pain or discomfort combined with any of the following risk factors:

- family history of oesophago-gastric cancer in a first-degree relative
- Barrett's oesophagus
- pernicious anaemia
- previous gastric surgery
- achalasia (dysfunction of the oesophageal muscle)
- known dysplasia, atrophic gastritis or intestinal metaplasia

## Primary care management

Dyspepsia without accompanying symptoms or risk factors should be managed according to **local or national guidelines**

## Hepatobiliary and pancreatic cancer

### Urgent suspicion of cancer referral

- Painless obstructive jaundice
- Unexplained weight loss, particularly >55 years, combined with one or more of the following features:
  - upper abdominal or epigastric mass
  - new onset diabetes
  - any suspicious abnormality, in the hepatobiliary tract, found on imaging (such as biliary dilatation or pancreatic/liver lesion)
  - new onset, unexplained back pain (consider other cancer causes including myeloma or malignant spinal cord compression)
  - ongoing GI symptoms despite negative endoscopic investigations

### Good practice points

- Consider seeking advice in people presenting with new onset GI symptoms with known chronic liver disease

Symptoms and signs of oesophago-gastric and hepatobiliary and pancreatic cancers overlap to a large extent. This table summarises examples of symptoms and signs that can be associated with the different cancers – they are **NOT** by themselves necessarily reasons to refer.

| Associated symptoms/signs | Pancreas, liver and gall bladder cancer | Oesophago-gastric cancer |
|---|---|---|
| Dysphagia | | ✔ |
| Iron deficiency anaemia | | ✔ |
| Haematemesis | | ✔ |
| Reflux symptoms | | ✔ |
| Vomiting (>two weeks) | ✔ | ✔ |
| Upper abdominal pain | ✔ | ✔ |
| Unexplained weight loss | ✔ | ✔ |
| Upper abdominal mass | ✔ | ✔ |
| Post-prandial pain | ✔ | ✔ |
| Early satiety (feeling full up after a small amount of food) | ✔ | ✔ |
| Unexplained obstructive jaundice | ✔ | |
| Unexplained back pain | ✔ | |
| Late onset diabetes | ✔ | |
| New onset irritable bowel syndrome over age 40 | ✔ | |
| Steatorrhoea or malabsorption | ✔ | |

## 3.5 UROLOGICAL CANCERS

### Prostate cancer

Prostate cancer is the most common cancer in males in Scotland, with approximately 3,100 new cases diagnosed every year. Risk increases with age and approximately 99% of cases are diagnosed in men aged over 50 years. Risk of prostate cancer is increased if a first degree relative has had prostate cancer or if there is a family history of BRCA associated breast or ovarian cancer. The presence of a BRCA mutation increases risk substantially, in particular for early or aggressive disease in BRCA2 mutation. In the UK, the lifetime risk of prostate cancer in black men (1 in 4) is double that of all men combined (1 in 8).

Men presenting with **unexplained** possible symptoms and signs suggestive of prostate cancer such as changes to urinary patterns, erectile dysfunction, unexplained visible haematuria, lower back pain, bone pain or weight loss should have a digital rectal examination and a prostate specific antigen (PSA) test with counselling.[12] A PSA test may be raised within three days of ejaculation or six weeks of a proven UTI, catheterisation or other invasive procedure, such as prostate biopsy. 5 alpha reductase inhibitors such as finasteride may reduce the PSA level. It should be noted that the majority of men with prostate cancer have no symptoms at all.

### Bladder and kidney cancer

Visible haematuria is the most common presenting symptom for both bladder and kidney cancer. Other presenting features include loin pain, renal masses, non-visible haematuria, anaemia, weight loss and pyrexia. Both cancers are uncommon, with around 800 new bladder and 950 new kidney cancers each year. There is evidence of an association between bladder cancer and a raised white cell count on a blood test in people aged over 60.

### Testicular and penile cancer

Although scrotal swellings are a common presentation in primary care, testicular cancer is relatively rare, with around 200 new cases per annum, of which approximately 72% are in men between 15 and 45 years. Solid swellings affecting the body of the testis have a high probability (> 50%) of being due to cancer. Because of the potential for rapid progression of testicular cancers, specialist services should consider triaging referrals in order to expedite such cases. Cancer of the penis is rare, with around 60 new cases each year in Scotland, but its incidence is rising. Sexually transmitted disease should be excluded and referred only if a lesion persists after treatment.

All people presenting with symptoms or signs suggestive of urological cancer should be referred to a team specialising in the management of urological cancer, depending on local arrangements.

12 Prostate Cancer Risk Management Programme – Summary Card **http://www.gov.scot/Topics/Health/Services/Cancer/Risk-Management/Prostate-Cancer-Summary-Card**

## Urgent suspicion of cancer referral

### Prostate Cancer

- Evidence from digital rectal examination of a hard, irregular prostate
- Elevated or rising age-specific Prostate Specific Antigen (PSA). Rough guide to normal PSA levels (ng/ml):
  - Less than 60 years < 3
  - Aged 60-69 years < 4
  - Aged 70-79 years < 5

These figures are a pragmatic aid based on clinical consensus. The principles of Realistic Medicine should be applied when considering referral and, in older men, routine or no referral may be appropriate for PSA levels of:

- Aged 80-85 years > 10
- Aged 86 years and over > 20

### Bladder and kidney cancer

- Aged 45 and over and have:
  - **unexplained** visible haematuria without urinary tract infection, or
  - visible haematuria that persists or recurs after successful treatment of urinary tract infection
- Age 60 and over and have unexplained non-visible haematuria and either dysuria or a raised white cell count on a blood test
- Abdominal mass identified clinically or on imaging that is thought to arise from the urinary tract

### Testicular and penile cancer

- Non painful enlargement or change in shape or texture of the body of the testis
- Suspicious scrotal mass found on imaging
- Men considered to have epididymo-orchitis or orchitis which is not responding to treatment
- Any non-healing lesion on the penis or painful phimosis

## Routine referral

- Elevated age-specific PSA where **urgent referral will not affect outcome due to age or comorbidity**
- Asymptomatic persistent non-visible haematuria without obvious cause
- Unexplained visible haematuria < 45 years of age
- Patients over 40 who present with recurrent UTI associated with any haematuria

## 3.6 SKIN CANCERS

Approximately 12,000 people are diagnosed every year with non-melanoma skin cancer in Scotland, of which around 3,000 are squamous cell carcinomas (SCC). In addition around 1,200 malignant melanoma are registered per annum. The incidence of both melanoma and non melanoma skin cancer is rising.

Risk factors for all skin cancer types include excessive sunlight exposure, sun bed use, fair skin and susceptibility to sunburn. For melanoma, a large number of benign melanocytic naevi and family history are risk factors. For SCC, multiple small actinic keratoses, high levels of previous UV-A photochemotherapy and immuno-suppression are also risk factors. People with multiple atypical naevi and a strong family history may have an increased risk of developing skin cancer. Skin cancers are very infrequent in people with dark skin and in children under 15 years.

Guides for assessment include the 7-point checklist and the ABCD (Asymmetry, Border irregular, Colour irregular, Diameter increasing) checklist. Some melanomas will have no major features.

The dermatoscope is a useful tool for trained clinicians screening pigmented lesions as it can increase diagnostic accuracy.

People presenting with a skin lesion suggestive of cancer should normally be referred to a dermatologist, depending on local arrangements.

### Urgent suspicion of cancer referral

Lesions on any part of the body which have one or more of the following features:

- Change in colour, size or shape in an existing mole
- Moles with **A**symmetry, **B**order irregularity, **C**olour irregularity, **D**iameter increasing or >6mm
- New growing nodule with or without pigment
- Persistent (more than four weeks) ulceration, bleeding or oozing
- Persistent (more than four weeks) surrounding inflammation or altered sensation
- New or changing pigmented line in a nail or unexplained lesion in a nail
- Slow growing, non-healing or keratinising lesions with induration (thickened base)
- Any melanoma or invasive SCC or high risk BCC diagnosed from biopsy
- Any unexplained skin lesion in an immuno-suppressed patient
- BCC invading potentially dangerous areas, for example peri-ocular, auditory meatus or any major vessel or nerve

## Good practice points

- Lesions which are suspicious for melanoma should not be removed in primary care. All excised skin specimens should be sent for pathological examination
- Lesions suspicious of basal cell carcinomas (BCC) may not require urgent referral, except those invading potentially dangerous areas
- Referrals should be accompanied by an accurate description of the lesion (including size, pain and tenderness) and photos if possible, subject to clinical governance arrangements, to permit appropriate triage

## 3.7 GYNAECOLOGICAL CANCERS

### Ovarian cancer

Over 90% of women with ovarian cancer are over the age of 40 years on diagnosis. Among women in Scotland with no family history the lifetime risk of developing ovarian cancer is estimated to be 1 in 59. Approximately 610 new cases of ovarian cancer are diagnosed in Scotland every year. Ovarian cancers are usually diagnosed late and approximately 30% of cases have a palpable pelvic mass. Symptoms are often non-specific abdominal symptoms but are characterised by their persistency and frequency.

Family history (both maternal and paternal) of breast or ovarian cancer can be used to identify women who have a higher risk of developing ovarian cancer. Guidance for referral to regional genetic centres (**Appendix 5**) for those with a family history is available within SIGN guideline 135 Management of epithelial ovarian cancer[13].

### Endometrial cancer

Most people (95%) with endometrial cancer present with postmenopausal bleeding. This cancer is uncommon in premenopausal women (< 5%). Approximately 690 new cases are diagnosed in Scotland each year. Risk factors for endometrial cancer include: tamoxifen, obesity, age over 45 years, nulliparity, family history of colon or endometrial cancer and exposure to unopposed oestrogens. A higher suspicion of risk should be used in these women. **Note that thrombocytosis is a risk marker for underlying malignancy including endometrial cancer.**

### Cervical cancer

Cervical cancer affects all adult age groups, with 50% of cases occurring between the ages of 30 and 50 years. The incidence of cervical cancer in Scotland is around 12.3 per 100,000 population and its estimated lifetime risk around 1 in 106.

The majority of cases (80%) are diagnosed on speculum examination and up to 40% are screen detected. Typical symptoms include vaginal discharge, postmenopausal bleeding, postcoital bleeding and persistent intermenstrual bleeding. A cytology test is not required before referral, and a previous negative result is not a reason to delay referral.

13 SIGN 135 Management of epithelial ovarian cancer **https://www.sign.ac.uk/sign-135-management-of-epithelial-ovarian-cancer.html**

### Vulval cancer

Most cases of vulval cancer occur in women over 65 years and 90% of patients have a visible tumour on clinical examination. Patients usually present with bleeding, discomfort, itch or a burning sensation. There are about 106 new cases of vulval cancer diagnosed every year in Scotland.

### Vaginal cancer

Vaginal cancer is rare and comprises less than 1% of gynaecological cancers. It is most commonly diagnosed in women above 60 years and is rare in women less than 40 years. Approximately 25 new cases of vaginal cancer are diagnosed in Scotland every year.

## Urgent suspicion of cancer referral

| | |
|---|---|
| **Ovarian cancer** | • Abnormal ultrasound scan and/or CA125 level<br>• Ascites and/or ultrasound-confirmed pelvic or abdominal mass (that is not obviously uterine fibroids, gastrointestinal or urological in origin) |
| **Endometrial cancer** | • Any woman on hormone replacement therapy (HRT), presenting with persistent or unexplained postmenopausal bleeding, after cessation of HRT for four weeks<br>• Unscheduled vaginal bleeding in a patient taking tamoxifen<br>• Postmenopausal bleeding<br>• Persistent intermenstrual bleeding, especially with other risk factors despite a normal pelvic examination<br>• A woman presenting with a palpable abdominal or pelvic mass on examination that is not obviously uterine fibroids, gastrointestinal or urological in origin should be referred urgently for ultrasound scan and, if significant concern, simultaneously to a specialist. Awaiting results of the ultrasound scan should not delay referral |
| **Cervical cancer** | • Any woman with clinical features (vaginal discharge, postmenopausal, postcoital or persistent intermenstrual bleeding) and abnormality suggestive of cervical cancer on examination of the cervix |
| **Vulval cancer** | • Any unexplained vulval lump found on examination<br>• Vulval bleeding due to ulceration |
| **Vaginal cancer** | • Any suspicious abnormality of the vagina on speculum examination |

## Good practice points

An abdominal palpation should be undertaken, CA125 blood serum level measured and urgent pelvic ultrasound scan carried out in:

- any woman over 50 years who has experienced new symptoms within the last 12 months that suggest irritable bowel syndrome, or
- women (especially those over 50 years) with one or more unexplained and recurrent symptoms (most days) of:
  - abdominal distension or persistent bloating
  - feeling full quickly or difficulty eating
  - loss of appetite
  - pelvic or abdominal pain
  - increased urinary urgency and/or frequency
  - change in bowel habit

A full pelvic examination, including speculum examination of the cervix, should be carried out in women presenting with:

- significant alterations in their menstrual cycle
- intermenstrual bleeding
- postcoital bleeding
- postmenopausal bleeding
- vaginal discharge, or
- pelvic pain

A vulval examination should be carried out for any woman presenting with any vulval symptom.

**If there is significant concern, awaiting the results of any investigation should not delay referral.**

## Primary care management

- Symptoms (as above) persisting or worsening for any woman who has a normal CA125 with normal ultrasound, assess for other clinical causes and investigate as appropriate or refer to appropriate secondary care services, depending on local arrangements
- Women presenting with vulval symptoms of pruritus or pain should be examined prior to initiation of any treatment and follow up should also include examination until symptoms are resolved or a diagnosis is confirmed
- Refer urgently or routinely, if symptoms persist, depending on the symptoms and the degree of concern about cancer

## 3.8 HAEMATOLOGICAL CANCERS

Haematological cancers can present with a variety of symptoms. A combination of symptoms and signs, often non-specific, may suggest haematological cancer and warrant further examination, investigation and possible referral.

### Leukaemia (acute and chronic)

Approximately 690 people are diagnosed with leukaemia in Scotland each year. Although all ages can be affected, around 70% of cases occur in people aged over 60 years. Symptoms and/or signs of bone marrow failure such as fatigue, pallor, bruising, bleeding and infections can occur. Fatigue and vulnerability to infection can result from most types of haematological cancer but are particularly severe in acute leukaemia. Some leukaemias may present with lymphadenopathy and/or hepatosplenomegaly. The most common form of leukaemia in adults is chronic lymphocytic leukaemia (CLL), which is often an indolent disease and an incidental finding.

### Non-Hodgkin's lymphoma

Approximately 1,000 new cases of non-Hodgkin's lymphoma are diagnosed in Scotland each year. Although all ages can be affected, around 75% of cases occur in people aged over 60 years. Common symptoms or signs at presentation include fatigue, weight loss, night sweats, lymphadenopathy and hepatosplenomegaly.

### Hodgkin's lymphoma

Approximately 160 new cases of Hodgkin's lymphoma are diagnosed in Scotland each year, with 40% of cases occurring in people under the age of 40 years. Clinical features at presentation are similar to those for non-Hodgkin's lymphoma, but 95% of people present with lymph gland involvement.

### Myeloma

Approximately 430 new myeloma cases are diagnosed in Scotland each year. About 84% of cases occur in people aged over 60 years. Clinical features at presentation include bone pain, symptoms of anaemia, renal impairment, and symptoms of hypercalcaemia (such as polyuria and polydipsia).

The presence of an isolated paraprotein or monoclonal gammopathy of unknown significance (MGUS) is not a cancer, and is a common incidental finding in the elderly (10% over 85 years). 12% of people with MGUS, however, will develop myeloma or related disease within 10 years. All patients with MGUS should therefore be monitored to detect progression in paraprotein level. Some people with a paraprotein are at more risk of developing myeloma than others, and this can often be predicted from results. Discussion with a haematologist is therefore encouraged if in any doubt.

**For people presenting with these non-specific symptoms, the clinician should always consider checking human immunodeficiency virus (HIV) status along with other routine investigations.**

Routine tests and investigations should be repeated at least once if a person's condition remains unexplained. If myeloma is suspected, urine as well as serum electrophoresis should be performed.

Arrangements for biopsy of persistent abnormal lymph glands vary locally.

Note that thrombocytosis is a non-specific risk marker for underlying malignancy, especially lung, endometrial, gastric, oesophageal and colorectal cancers (LEGO-C).

All people presenting with symptoms or signs suggesting haematological cancer should be referred to a team specialising in the management of haematological cancer, depending on local arrangements.

## Urgent suspicion of cancer referral

- Blood count / film reported as suggestive of acute leukaemia or chronic myeloid leukaemia*
- Lymphadenopathy (>2cm) persisting for six weeks or increasing in size or generalised (HIV status should always be checked if generalised)
- Hepatosplenomegaly in the absence of known liver disease
- Bone pain associated with a paraprotein and/or anaemia
- Bone X-rays reported as being suggestive of myeloma
- The following clinical features may also merit urgent referral:
  - fatigue
  - night sweats
  - weight loss
  - itching
  - bruising
  - recurrent infections
  - bone pain
  - polyuria and polydipsia (hypercalcaemia)

*will normally be identified in the laboratory and communicated to the clinician for management to be agreed.

## Primary care management

- CLL in an older person should be discussed with a local haematologist but many cases do not require detailed haematological review
- Asymptomatic monoclonal gammopathy may be followed up in primary care depending on local arrangements – consider discussion with a haematologist if any concern

## 3.9 HEAD AND NECK CANCERS

The incidence of head and neck cancer is increasing; around 1,200 people are diagnosed with a head and neck cancer each year in Scotland and around 240 with thyroid cancers. The incidence of oropharyngeal cancer is increasing in the younger population, and appears to be associated with human papilloma virus (HPV) infection.

Risk factors for head and neck cancers (excluding thyroid) include: social deprivation; smoking; HPV; alcohol; drugs (especially opioids and cannabis); poor diet; tobacco chewing habits (including betel, gutkha and pan); and older age. The risk of developing nasopharyngeal cancer is higher in people of Chinese origin and a higher index of suspicion should be used in these people.

If any uncertainty about the significance of an abnormality in the mouth, a dentist's opinion should be sought in the first instance. There should be systems in place for urgent suspicion of cancer referral pathways for dentists.

All people with features suspicious of malignancy should be referred to a team specialising in the management of head, neck or thyroid cancers, depending on local arrangements.

**With the changing pattern of disease, age, non-smoking or non-drinking status should not be a barrier to referral.**

### Emergency (same day) referral

- Stridor

### Urgent suspicion of cancer referral

**Head and neck cancer**

- Persistent unexplained head and neck lumps for >three weeks
- Unexplained ulceration or unexplained swelling/induration of the oral mucosa persisting for >three weeks
- All unexplained red or mixed red and white patches of the oral mucosa persisting for >three weeks
- Persistent (not intermittent) hoarseness lasting for >three weeks. If other symptoms are present to suggest suspicion of lung cancer, refer via lung cancer guideline
- Persistent pain in the throat or pain on swallowing lasting for >three weeks

**Thyroid Cancer**

- Solitary nodule increasing in size
- Thyroid swelling age 16 and under
- Thyroid swelling with one or more of the following risk factors:
  - neck irradiation
  - family history of endocrine tumour
  - unexplained hoarseness
  - cervical lymphadenopathy

## 3.10 BRAIN AND CENTRAL NERVOUS SYSTEM CANCERS

Approximately 1,000 people in Scotland are diagnosed with primary tumours (malignant and non-malignant) of the brain and CNS, each year. Approximately 41% of these cases are malignant brain cancer (excluding meninges, cranial nerves, pituitary gland, craniopharyngeal duct, and pineal gland), of which more than 80% occur in people over the age of 40 years. However, metastatic cancer commonly involves the brain and presents with similar features.

The anatomical location of CNS tumours influences symptoms that include physical, cognitive and psychological components.

Brain tumours are the commonest cause of cancer related death in children and people under 40 years. People with brain tumours typically present with progressive neurological deficit (such as progressive weakness, sensory loss, dysphasia, ataxia), developing over days to weeks. Other signs and symptoms include: seizure disorder; headache with evidence of raised intracranial pressure (such as vomiting and papilloedema); and cognitive or behavioural changes. An adult presenting with new onset seizure disorder of any type has a probability of 2-6% of having a brain tumour, whereas new onset status epilepticus is associated with a probability of 10% or more. A person presenting with chronic daily headache without features of raised intracranial pressure has a very low probability of having a brain tumour.

Spinal cord tumours often cause neurological symptoms including back and neck pain, numbness, and tingling and weakness in the arms or legs. Tumours in the lower part of the spinal cord may cause loss of control of the bladder and bowel. Please refer to the guideline on Malignant Spinal Cord Compression for further guidance.

### Emergency (same day) referral

| | |
|---|---|
| **Headache** | • Patients with headache and/or vomiting with papilloedema |

### Urgent suspicion of cancer referral

| | |
|---|---|
| **Neurological deficit** | • Progressive neurological deficit (including personality, cognitive or behavioural change) in the absence of previously diagnosed or suspected alternative disorders (such as multiple sclerosis or dementia) |
| **Seizure** | • Any new seizure<br>• Seizures which change in character such as post–ictal deficit, headache, increased frequency, etc. |

## Good practice points

- Consider urgent investigation/referral for people with non-migrainous headaches of recent onset, when accompanied by 'red flag' features suggestive of raised intra cranial pressure (for example: woken by headache; vomiting; drowsiness), progressive neurological deficit or new seizure disorder
- All NHS Boards have pathways for investigation of headaches which should include Primary Care direct access to imaging
- If any uncertainty about the presence of papilloedema, the person should be urgently referred to an optometrist for assessment. If there are red-flags suspicious of cancer as detailed above, a simultaneous urgent suspicion of cancer referral to secondary care should be made. If papilloedema is confirmed, the optometrist should refer directly to secondary care
- An urgent, suspicion of cancer pathway should exist in all NHS Boards for optometrists to refer directly to secondary care for people with optic discs suspicious of papilloedema

## 3.11 SARCOMAS AND BONE CANCERS

### Soft tissue sarcomas

Approximately 140 people are diagnosed with soft tissue sarcomas in Scotland each year. Around 90% are diagnosed in people aged 40 years or older and almost 60% in people over the age of 65. These tumours are frequently missed or only referred after repeat presentations.

In adults, soft tissue masses that are superficial, painless, less than 5cm and static in size are unlikely to be malignant.

### Primary bone cancer

Approximately 50 people in Scotland are diagnosed with cancer of the bone every year.

### Osteosarcoma

Osteosarcoma is the most common type of primary bone cancer. It can occur at any age, but is most commonly found in teenagers and young adults. Osteosarcoma typically presents with persistent localised bone pain. The most common sites are around the knee joint and upper arm.

### Ewing's sarcoma

The incidence of Ewing's sarcoma peaks at 10–15 years of age, and rarely occurs under the age of five, or over the age of 30. Arising in any bone, the most commonly affected sites are the pelvis, lower limb bones and chest wall. The predominant symptoms are persistent pain and swelling of the affected area. Ewing's sarcoma is frequently misdiagnosed as osteomyelitis.

### Chondrosarcoma

Chondrosarcoma is most often found in adults over the age of 40 years and is rare under the age of 20. The most common sites involved are the pelvis, femur, and shoulder girdle. Clinical presentation is usually a bony mass with pain often as a late feature.

## Urgent suspicion of cancer referral (soft tissue sarcoma)

A soft tissue mass with one or more of the following characteristics:

- size > 5cm
- increasing in size
- deep to fascia, fixed or immobile
- recurrence after previous excision
- regional lymph node enlargement

## Investigation for suspected bone cancer

An X-ray of the appropriate area should be requested on patients who have:

- unexplained bone pain or tenderness, which is:
  - persistent
  - increasing
  - non-mechanical
  - nocturnal or at rest

If X-ray is suggestive of bone tumour, refer as urgent suspicion of cancer to sarcoma service.

## Good practice points

- Sarcomas of the long bones are usually excluded by normal X-ray but further investigation may be required for spine, pelvis, ribs or scapula
- If symptoms persist but X-ray is normal, repeat X-ray (following discussions with radiologist) and consider referral
- Suspected spontaneous or low impact fracture should raise suspicion of underlying malignancy

## 3.12 CHILDREN, TEENAGERS AND YOUNG ADULT CANCERS

While cancer in children, teenagers and young adults (CTYA) is rare, it is a significant cause of mortality and morbidity and early detection is important. Approximately 120 children aged less than 15 years, and 180 young persons aged between 15 and 24 years, are diagnosed with cancer in Scotland each year. The youngest age group (0-4 years) accounts for 48% of all childhood cancers. The distribution of cancers in teenagers and young adults is different from that in both young children and adults. The two most commonly occurring cancers in childhood are leukaemia (acute lymphoblastic leukaemia) and central nervous system (mostly brain) tumours. The two most commonly occurring cancers in male teenagers and young adults are lymphoma and testicular cancer, and malignant melanoma and lymphoma in females in this age group.

No risk factor or familial susceptibility can be identified in most cases. However, genetic susceptibility is apparent in some cases with associated conditions (such as Down syndrome, familial adenomatous polyposis coli, neurofibromatosis, aniridia and Li Fraumeni syndrome). The absence of a family history should not delay further investigations.

Cancers in children, teenagers and young adults are frequently diagnosed late due to the non-specific nature of many of the symptoms. A useful resource for parents is the awareness card identifying warning symptoms and signs of childhood cancer produced by the Grace Kelly Ladybird Trust[14].

Many of the cancer specific guidelines in this document are relevant to all ages e.g. melanoma, brain & CNS, sarcoma, etc. Some conditions specific to this age group need special mention:

| | |
|---|---|
| **Lymphomas** | • *Hodgkin's lymphoma:* approximately 30 new cases are diagnosed in children and young adults less than 24 years, in Scotland every year. Approximately 83% of these cases are aged between 15 and 24 years. Hodgkin's lymphoma rarely occurs under the age of five. Its natural history may be long (months), and about a third of patients have systemic symptoms.<br>• *Non-Hodgkin's lymphoma:* approximately 20 new cases are diagnosed in children and young adults less than 24 years, in Scotland every year. Approximately 70% of these cases are aged between 15 and 24 years. Non-Hodgkin's lymphoma has a more rapid progression of symptoms than Hodgkin's lymphoma. |
| **Leukaemia** | • Approximately 55 new cases are diagnosed in children and young adults less than 24 years in Scotland every year (about 70% are aged under 15 and about 38% under five). This accounts for about 8% of people diagnosed with leukaemia, every year. |

14 Grace Kelly Ladybird **https://www.gracekellyladybird.co.uk/knowthesigns**

| | |
|---|---|
| **Neuroblastoma** | • The majority of children present with abdominal distension (with or without a palpable mass) and symptoms of bone marrow failure. Infants under one year of age may have localised abdominal or thoracic masses; very young infants, less than six months old, may have massive hepatomegaly and skin lesions. |
| **Brain tumours** | • Brain tumours remain one of the most common causes of cancer-related death in children and people under 40 years. Approximately two fifths of deaths among children age less than 15 dying from cancer are due to CNS tumours.<br>• Headsmart[15] is an online resource which presents evidence based detailed guidance in different age groups. |
| **Wilms' tumour (nephroblastoma)** | • Common presenting features include unexplained visible haematuria, or unilateral abdominal mass, with or without pain, in a well-child. |
| **Bone tumours** | • Osteosarcoma: can occur at any age although approximately 60% present in the second decade of life. Most common sites are femur, tibia and humerus.<br>• Ewing's sarcoma: peak incidence is between 10 and 15 years. Ewing's sarcoma rarely occurs under the age of five years or over the age of 30 years. Most commonly affected sites are the pelvis, femur, tibia, fibula, rib and humerus.<br>• Sarcomas of the long bones are usually excluded by normal X-ray but further investigation may be required for spine, pelvis, ribs or scapula. |
| **Retinoblastoma** | • Common symptoms of retinoblastoma include white or absent pupillary red reflex and squint.<br>• There is a family history in approximately 15% of cases. |
| **Gonadal tumours** | • Testicular cancer is one of the most common cancers in male teenagers and young adults.<br>• Testicular or other scrotal masses can be difficult to differentiate – any non transilluminable mass associated with the testis is significant.<br>• Ovarian tumours can be associated with precocious puberty. |

## General recommendations

- **Consider referral** for any patient with repeat presentations (three or more times) of any symptoms which do not appear to be resolving or following an expected pattern, taking into account parental or carer and patient concern
- In a child where symptoms and signs do not clearly fit with these guidelines, but nevertheless lead to concern about excluding cancer, the referrer should consider discussing the case with a senior paediatric colleague at their earliest convenience

15 Headsmart **https://www.headsmart.org.uk/**

## Specific recommendations

### Urgent suspicion of cancer referral

- Unexplained petechiae or purpura is always an indication for emergency referral
- Unexplained fatigue, persistent pallor, failure to thrive or weight loss
- Any new persistent unexplained pain, particularly back pain or nocturnal pain
- Unexplained abdominal mass or distension
- Unexplained visible haematuria

| | |
|---|---|
| **Bone pain, especially if:** | • diffuse or involves the back<br>• persistently localised at any site<br>• nocturnal pain<br>• limping<br>• requiring analgesia, or<br>• limiting activity |
| **Lymphadenopathy, if:** | • non tender, firm/hard and greater than 2cms in maximum diameter<br>• progressively enlarging<br>• associated with other signs of general ill health, fever or weight loss<br>• involves axillary nodes (no local infection or dermatitis) or any supraclavicular lymphadenopathy |
| **Headache, if increasing in severity or frequency and:** | • worse in the morning or causing early wakening, or<br>• associated with vomiting or any new neurological signs |
| **Any new neurological signs, signs (such as weakness, loss of balance, etc.) especially if:** | • associated with behavioural change or deterioration in normal daily or school performance |
| **Other possible signs of brain tumours:** | • increasing head circumference<br>• failure of fontanelle closure<br>• abnormal head position such as wry neck, head tilt or stiff neck |

| | |
|---|---|
| **Soft tissue mass, if:** | • shows rapid or progressive growth<br>• size greater than 2cm maximum diameter<br>• deep to fascia, fixed or immobile, regardless of size<br>• recurrence after previous excision of sarcoma<br>• associated with regional lymph node enlargement |
| **Eyes:** | • any new squint, if associated with headache or other neurological signs (otherwise consider optometrist and ophthalmology assessment)<br>• change in pupillary red reflex to absent or white |

### Primary care management

- X-ray if there is unexplained bone pain of:
  - increasing severity
  - persistent
  - tender
  - non-mechanical bone pain particularly if disturbing rest or sleep
- If symptoms persist but X-ray is normal, repeat X-ray (after discussion with a radiologist) and consider referral, especially if the patient presents three or more times
- Spontaneous or minor trauma fracture should raise suspicion of bone cancer

## 3.13 MALIGNANT SPINAL CORD COMPRESSION

The true incidence of malignant spinal cord compression (MSCC) and epidural disease is unknown. Approximately 5-10% of patients with cancer develop metastatic spinal cord compression. The majority of patients diagnosed with MSCC have an established diagnosis of cancer, but for some (10-20%), MSCC is the presenting feature of malignancy. Many people with cancer are at risk of MSCC but particularly those with lung, breast, prostate cancer or multiple myeloma, which account for approximately 60% of cases of MSCC.

About 90% of patients are over 50 years of age and nearly all MSCC patients have pain, usually severe spinal nerve root pain (80%) with or without local back pain. The site of pain and the site of compression do not always correlate and X-rays and bone scans may be misleading. MSCC is usually diagnosed late, by which timely treatment may well be ineffective – once paraplegia develops it is usually irreversible. MSCC should be dealt with as an oncological emergency.

**A normal neurological examination does not preclude epidural disease or evolving MSCC.**

**The definitive method of investigation is MRI of the whole spine.**

**All patients with bone metastasis, or considered by their clinician to be at high risk of developing MSCC, should be given written guidance on early symptoms with advice to contact a health care professional promptly. This information should also be sent to the GP.**

**Written information on early symptoms should also be given to patients following treatment for MSCC.**

All Scottish cancer networks have developed locally agreed MSCC pathways. More information is available via the Scottish Palliative Care Guidelines website.[16]

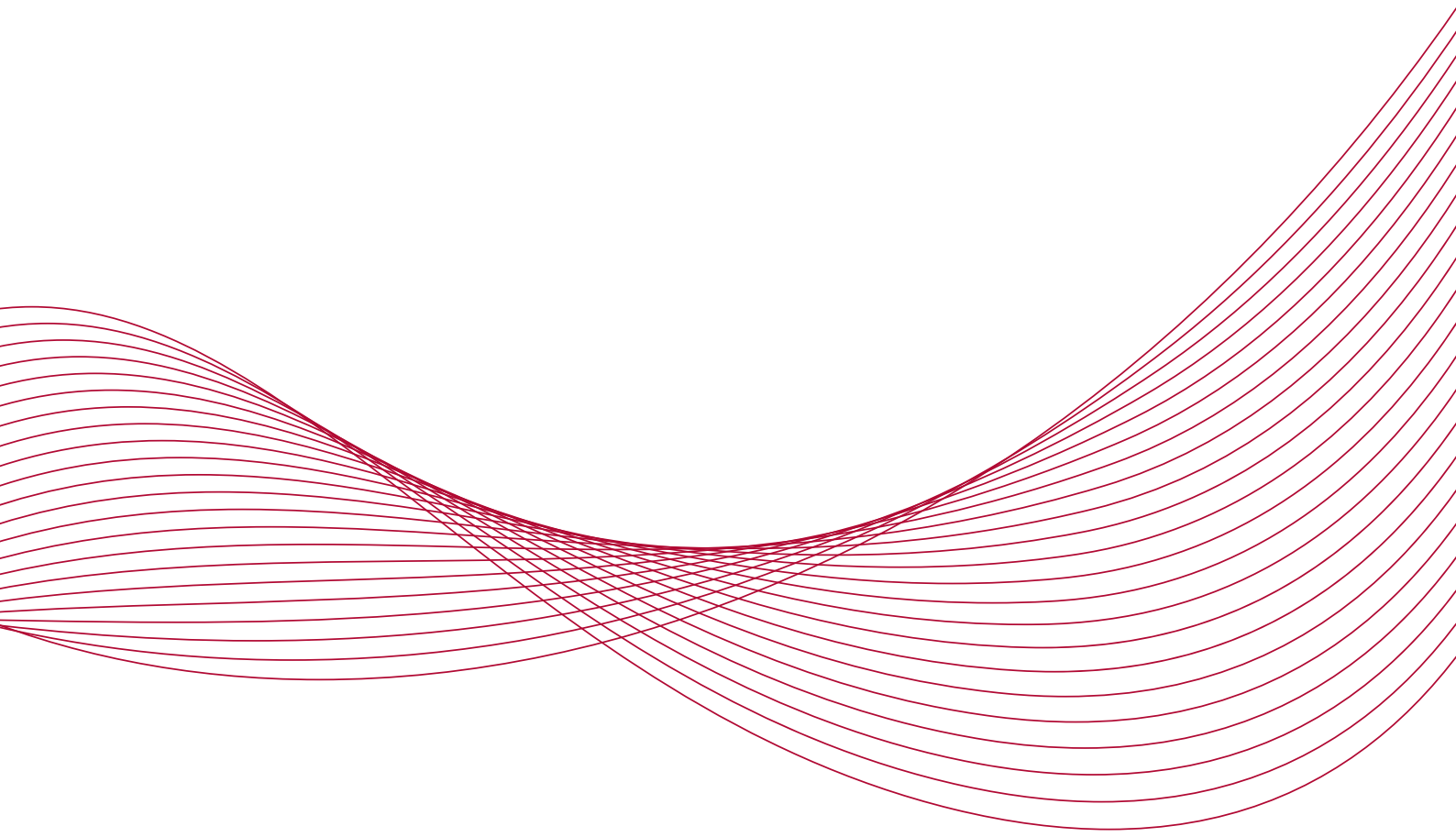
## Urgent suspicion of cancer referral for patients with known cancer (particularly prostate, breast, lung or multiple myeloma)

People with a history of cancer and any of the following symptoms:

- significant localised back pain, especially thoracic
- severe, progressive pain or poor response to medication
- spinal pain aggravated by straining (for example, at stool, or coughing or sneezing)
- nocturnal spinal pain, especially if preventing sleep
- radicular pain (for example, round chest, down front or back of thighs)
- limb weakness or difficulty in walking
- sensory loss (including perineal or saddle paraesthesia)
- bladder or bowel dysfunction

16 Scottish Palliative Care Guidelines **https://www.palliativecareguidelines.scot.nhs.uk/guidelines/palliative-emergencies/malignant-spinal-cord-compression.aspx**

# APPENDICES



## APPENDIX 1: METHODOLOGY USED – 2014 VERSION

The steering group agreed that the starting point for the revision process would be the existing referral guidelines, enhanced by a review of evidence-based recommendations for referral from across the world. These recommendations were identified from a search of the websites for a number of guideline-producing organisations in June 2012. This was supplemented with a search for relevant guidelines in Medline and Embase. The search was updated in January 2013 to ensure that all relevant guidelines were identified. Only guidelines published in English were considered.

All the guidelines identified by the search were appraised for methodological quality using the Appraisal of Guidelines for Research and Evaluation II (AGREEII) instrument. AGREEII is a validated tool used for the assessment of clinical practice guidelines. It consists of 23 items organised into six quality domains that cover separate dimensions of guideline quality. Each guideline is assigned an overall quality rating and a decision regarding whether the guideline would be recommended for practice is also made. Each item is rated on a 7-point scale (1=strongly disagree to 7=strongly agree). An overall summary of recommendations and quality rating for each guideline was compiled into evidence tables which are available at **www.healthcareimprovementscotland.org**.

The groups identified, reviewed and systematically considered differences in recommendations emerging from the guidelines, in the light of their clinical and practical experience as well as their expert knowledge of the literature, while taking account of the Scottish context. Where Scottish Intercollegiate Guidelines Network (SIGN) guidelines are in place or are being revised, effort was made to ensure consistency between these guidelines and the related SIGN guideline.

## APPENDIX 2: MEMBERSHIP OF GUIDELINE STEERING GROUP 2018

| | |
|---|---|
| **Peter Hutchison** | Chair, retired General Practitioner, NHS Dumfries & Galloway |
| **Hugh Brown** | General Practitioner, NHS Ayrshire & Arran, Chair of The Scottish Primary Care Cancer Group |
| **Sara Twaddle** | Director of Evidence, Healthcare Improvement Scotland |
| **Nicola Barnstaple** | Programme Director, Cancer Access Team, Scottish Government |
| **Val Doherty** | Clinical Advisor, Cancer Access Team, Scottish Government |
| **Andrew Grierson** | Project Manager, Cancer Access Team, Scottish Government, NHS National Services Scotland |
| **Lorraine Sloan** | Strategic Partnership Manager, Scotland, Macmillan Cancer Support |

## APPENDIX 3: MEMBERSHIP OF THE GUIDELINE DISSEMINATION GROUP

| | |
|---|---|
| **Peter Hutchison** | Chair, retired General Practitioner, NHS Dumfries & Galloway |
| **Hugh Brown** | General Practitioner, NHS Ayrshire & Arran. Chair of The Scottish Primary Care Cancer Group |
| **Sara Twaddle** | Director of Evidence, Healthcare Improvement Scotland |
| **Diane Primrose** | Programme Manager, Cancer Access Team, Scottish Government |
| **Andrew Grierson** | Project Manager, Cancer Access Team, Scottish Government, NHS National Services Scotland |
| **Lorraine Sloan** | Strategic Partnership Manager, Scotland, Macmillan Cancer Support |
| **Cara Taylor** | Macmillan Cancer Nurse Consultant, NHS Tayside |
| **Paul Baughan** | General Practitioner, NHS Forth Valley, Health Improvement Scotland Clinical Lead Palliative and End of Life Care, Macmillan General Practitioner Advisor (Scotland) |
| **Lorna Porteous** | General Practitioner Lead for Cancer and Palliative Care in Lothian, Macmillan General Practitioner Advisor (Scotland) |
| **Marion O'Neill** | Regional Manager, Scotland and Northern Ireland, Cancer Research UK |
| **Douglas Rigg** | General Practitioner, NHS Greater Glasgow & Clyde |
| **Adam Osprey** | Policy & Development Pharmacist, Community Pharmacy Scotland |
| **Meiling Denney** | Assistant Director of Postgraduate General Practitioner Education, NHS Education for Scotland & Sigi Joseph, General Practitioner, NHS Lothian |

# APPENDIX 4: MEMBERSHIP OF GUIDELINE SUB GROUPS

## Urology Sub Group 2018

| | |
|---|---|
| **Peter Hutchison** | Chair, retired General Practitioner, NHS Dumfries & Galloway |
| **Hugh Brown** | Vice Chair, General Practitioner, NHS Ayrshire & Arran. Chair of Scottish Primary Care Cancer Group |
| **Andrew Grierson** | Project Manager, Cancer Access Team, Scottish Government, NHS National Services Scotland |
| **Lorraine Sloan** | Strategic Partnership Manager, Scotland, Macmillan Cancer Support |
| **Alex Laird** | Consultant Urologist, NHS Lothian |
| **Seamus Teahan** | WoSCAN Lead Clinician Cancer and Urological Surgeon, NHS Forth Valley |
| **Adam Gaines** | Director, Prostate Scotland |

## Children, Teenagers and Young Adults Sub Group 2018

| | |
|---|---|
| **Peter Hutchison** | Chair, retired General Practitioner, NHS Dumfries & Galloway |
| **Hugh Brown** | Vice Chair, General Practitioner, NHS Ayrshire & Arran. Chair of Scottish Primary Care Cancer Group |
| **Andrew Grierson** | Project Manager, Cancer Access Team, Scottish Government, NHS National Services Scotland |
| **Lorraine Sloan** | Strategic Partnership Manager, Scotland, Macmillan Cancer Support |
| **Pam Neilson** | Founding Member and Campaigner, Glow Gold Childhood Cancer Campaign |
| **Pat Hayes** | Campaigner, Glow Gold Childhood Cancer Campaign |
| **Emma Barron** | Parent Rep, Glow Gold Childhood Cancer Campaign |
| **Juliette Murray** | Consultant Breast Surgeon, NHS Lanarkshire |
| **Kirsty Kilpatrick** | FY2, NHS Ayrshire & Arran |
| **Katy Marshall** | FY2, NHS Ayrshire & Arran |
| **Hamish Wallace** | Professor of Paediatric Oncology, University of Edinburgh & Royal Hospital for Sick Children |

## Head and Neck Sub Group 2018

| | |
|---|---|
| **Peter Hutchison** | Chair, retired General Practitioner, NHS Dumfries & Galloway |
| **Hugh Brown** | Vice Chair, General Practitioner, NHS Ayrshire & Arran. Chair of Scottish Primary Care Cancer Group |
| **Andrew Grierson** | Project Manager, Cancer Access Team, Scottish Government, NHS National Services Scotland |
| **Catriona Douglas** | Ear, Nose and Throat Surgeon, NHS Greater Glasgow & Clyde |
| **Craig Wales** | Consultant Oral Maxillofacial Surgeon, NHS Greater Glasgow & Clyde |
| **Guy Vernham** | Consultant Head and Neck Surgeon, NHS Lothian |
| **Jennifer Montgomery** | Ear, Nose and Throat Surgeon, NHS Greater Glasgow & Clyde |

## Brain and Central Nervous System Sub Group 2018

| | |
|---|---|
| **Peter Hutchison** | Chair, retired General Practitioner, NHS Dumfries & Galloway |
| **Hugh Brown** | Vice Chair, General Practitioner, NHS Ayrshire & Arran. Chair of Scottish Primary Care Cancer Group |
| **Andrew Grierson** | Project Manager, Cancer Access Team, Scottish Government, NHS National Services Scotland |
| **Lorraine Sloan** | Strategic Partnership Manager, Scotland, Macmillan Cancer Support |
| **Lindsay Campbell** | Managed Clinical Network (MCN) Manager, West of Scotland Cancer Network (WoSCAN) |
| **Imran Liaquat** | Consultant Neurosurgeon, NHS Lothian |
| **Val Doherty** | Clinical Advisor, Cancer Access Team, Scottish Government |
| **Cameron Miller** | Head of Policy & Public Affairs, Brain Tumour Charity |
| **Sara Twaddle** | Head of Evidence & Technologies, Director of Scottish Intercollegiate Guidelines Network (SIGN), Healthcare Improvement Scotland |
| **Jenny Bennison** | General Practitioner, NHS Lothian, Vice Chair of Scottish Intercollegiate Guidelines Network (SIGN) |

## Lung Sub Group 2018

| | |
|---|---|
| **Peter Hutchison** | Chair, retired General Practitioner, NHS Dumfries & Galloway |
| **Hugh Brown** | Vice Chair, General Practitioner, NHS Ayrshire & Arran. Chair of Scottish Primary Care Cancer Group |
| **Lorraine Sloan** | Strategic Partnership Manager, Scotland, Macmillan Cancer Support |
| **John Maclay** | Consultant Physician, Respiratory Medicine, NHS Greater Glasgow & Clyde |
| **Joris van der Horst** | Consultant Respiratory Physician, NHS Greater Glasgow & Clyde |
| **Douglas Rigg** | General Practitioner, NHS Greater Glasgow & Clyde |
| **Lorraine Dallas** | Director of Information and Support, The Roy Castle Lung Cancer Foundation |
| **Luke Daines** | Academic General Practitioner |
| **Julie Mencnarowski** | Clinical Nurse Specialist, NHS Lothian |
| **Mohammed Asif** | Consultant Cardiothoracic Surgeon, NHS Greater Glasgow & Clyde |
| **Davanand Sharma** | Consultant Respiratory Physician, NHS Greater Glasgow & Clyde |

## Breast Sub Group 2018

| | |
|---|---|
| **Peter Hutchison** | Chair, retired General Practitioner, NHS Dumfries & Galloway |
| **Hugh Brown** | Vice Chair, General Practitioner, NHS Ayrshire & Arran. Chair of Scottish Primary Care Cancer Group |
| **Lorraine Sloan** | Strategic Partnership Manager, Scotland, Macmillan Cancer Support |
| **Elizabeth Smyth** | Consultant Breast Surgeon, NHS Grampian |
| **Lawrence Cowan** | National Manager (Scotland), Breast Cancer Now |
| **Juliette Murray** | Consultant Breast Surgeon, NHS Lanarkshire |
| **Laura Wilkinson** | Consultant Radiologist, NHS Greater Glasgow & Clyde |
| **Mike McKirdy** | Consultant Breast Surgeon, NHS Greater Glasgow & Clyde |
| **Julie Doughty** | Consultant Breast Surgeon, NHS Greater Glasgow & Clyde |
| **Alastair McMurray** | FY2, NHS Greater Glasgow & Clyde |
| **Katy Marshall** | FY2, NHS Ayrshire & Arran |

## Lower GI Sub Group 2018

| | |
|---|---|
| **Peter Hutchison** | Chair, retired General Practitioner, NHS Dumfries & Galloway |
| **Hugh Brown** | Vice Chair, General Practitioner, NHS Ayrshire & Arran. Chair of Scottish Primary Care Cancer Group |
| **Andrew Grierson** | Project Manager, Cancer Access Team, Scottish Government, NHS National Services Scotland |
| **Lorraine Sloan** | Strategic Partnership Manager, Scotland, Macmillan Cancer Support |
| **Graeme Wilson** | Consultant Colorectal Surgeon, NHS Lothian |
| **Claire Donaghy** | Head of Scotland, Bowel Cancer UK |
| **Craig Mowat** | Consultant Gastroenterologist, NHS Tayside |
| **Sandra Melville** | Lead Pharmacist, Royal Pharmaceutical Society |
| **Angus MacDonald** | Consultant Colorectal Surgeon, NHS Lanarkshire |
| **Jack Winter** | Consultant Gastroenterologist, NHS Greater Glasgow & Clyde |
| **Rob Boulton-Jones** | Consultant Gastroenterologist, NHS Greater Glasgow & Clyde |
| **Louise Gorman** | General Practitioner, NHS Forth Valley |
| **David Linden** | Retired General Practitioner and Clinical Advisor, Cancer Access Team, Scottish Government |

## Upper GI Sub Group 2018

| | |
|---|---|
| **Peter Hutchison** | Chair, retired General Practitioner, NHS Dumfries & Galloway |
| **Hugh Brown** | Vice Chair, General Practitioner, NHS Ayrshire & Arran. Chair of Scottish Primary Care Cancer Group |
| **Andrew Grierson** | Project Manager, Cancer Access Team, Scottish Government, NHS National Services Scotland |
| **Lorraine Sloan** | Strategic Partnership Manager, Scotland, Macmillan Cancer Support |
| **Lindsay Campbell** | Managed Clinical Network (MCN), WoSCAN |
| **Alasdair Macmillan** | Consultant Gastrointestinal Surgeon, NHS Lothian |
| **Ross Carter** | Pancreatic Surgeon, NHS Greater Glasgow & Clyde |

| | |
|---|---|
| **Sami Shimi** | NOSCAN Clinical Lead, NHS Tayside |
| **Colin Mckay** | Clinical Director for Surgery, NHS Greater Glasgow & Clyde |
| **Andrew Crumley** | Consultant General and Upper GI Surgeon, NHS Forth Valley |
| **Jack Winter** | Consultant Gastroenterologist, NHS Greater Glasgow & Clyde |
| **Rob Boulton-Jones** | Consultant Gastroenterologist, NHS Greater Glasgow & Clyde |
| **Catherine Pollock** | Consultant Gastroenterologist, NHS Fife |
| **Jane Moir** | Nurse Endoscopist, NHS Ayrshire & Arran |
| **Fiona Brown** | Development Manager, Pancreatic Cancer Scotland |
| **Suzy Mercer** | Development Consultant, Pancreatic Cancer Scotland |
| **Mairi Handy** | Development Officer, Pancreatic Cancer Scotland |
| **Nik White** | Head, Pancreatic Cancer UK |
| **Neil Pryde** | Macmillan Lead Cancer GP, and Cancer Strategy Lead, Specialty Doctor, Palliative Care, NHS Fife |
| **Hamish McRitchie** | Consultant Radiologist and Clinical Lead for NRTP, NHS Borders |
| **Lorna Porteous** | General Practitioner Lead for Cancer and Palliative Care in Lothian, Macmillan General Practitioner Advisor (Scotland) |
| **Jenny Bennison** | General Practitioner, NHS Lothian, Vice Chair of Scottish Intercollegiate Guidelines Network (SIGN) |
| **Ben Hall** | GP Vocational Trainee |

## APPENDIX 5: REGIONAL GENETICS CENTRES

Advice about referral pathways to clinical genetics is available from each of the Regional Genetics Centres:

- **Glasgow:** www.nhsggc.org.uk/about-us/professional-support-sites/west-of-scotland-genetic-services/clinical-genetics/
- **Edinburgh:** www.nhslothian.scot.nhs.uk/Services/A-Z/ClinicalGeneticsService/Pages/default.aspx
- **Dundee:** www.nhstayside.scot.nhs.uk/OurServicesA-Z/Genetics/index.htm
- **Aberdeen:** www.nhsgrampian.org/medicalgenetics/

## APPENDIX 6: EQUALITY AND DIVERSITY

The Scottish Government and Healthcare Improvement Scotland are committed to equality and diversity in respect of the nine equality groups defined by age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion, sex, and sexual orientation.

The guidelines development process has been assessed and the guidelines are expected to have a positive impact on certain age groups (depending on the tumour type) and more deprived populations in Scotland. The completed equality and diversity checklist is available on **www.healthcareimprovementscotland.org**.

## APPENDIX 7: KEY REFERENCES


- **Cancer Incidence in Scotland 2016** https://www.isdscotland.org/Health-Topics/Cancer/Publications/2018-04-24/2018-04-24-Cancer-Incidence-Report.pdf?51368349791
- **Scottish Cancer Registry, Information Services Division (ISD), April 2018 (based on total Scottish population of 5,404,700 as at 30 June 2016)** http://www.isdscotland.org/Health-Topics/General-Practice/Workforce-and-Practice-Populations/
- **National Records of Scotland mid 2016 population estimates Scotland** https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/population/population-estimates/mid-year-population-estimates/mid-2016
- **Beating Cancer: Ambition and Action** https://www.gov.scot/publications/beating-cancer-ambition-action/
- **Practising Realistic Medicine** https://www.gov.scot/publications/summary-practising-realistic-medicine/
- **NICE Guideline [NG12] Suspected cancer: recognition and referral (June 2015 last updated July 2017)** https://www.nice.org.uk/guidance/ng12
- **Cancer Research UK: Your Urgent Referral** https://publications.cancerresearchuk.org/categories/your-urgent-referral
- **Familial Breast Cancer Report** www.healthcareimprovementscotland.org/our_work/cancer_care_improvement/programme_resources/familial_breast_cancer_report.aspx
- **Diagnosis and Management of Colorectal Cancer** http://www.sign.ac.uk/sign-126-diagnosis-and-management-of-colorectal-cancer.html
- **Prostate Cancer Risk Management Programme – Summary Card** http://www.gov.scot/Topics/Health/Services/Cancer/Risk-Management/Prostate-Cancer-Summary-Card
- **Management of epithelial ovarian cancer** https://www.sign.ac.uk/sign-135-management-of-epithelial-ovarian-cancer.html
- **Headsmart – The Brain Tumour Charity, Children's Brain Tumour Research Centre and the Royal College of Paediatrics and Child Health** https://www.headsmart.org.uk/
- **Grace Kelly Ladybird Trust** https://www.gracekellyladybird.co.uk/ https://www.gracekellyladybird.co.uk/knowthesigns
- **Cancer Working Group of the Scottish Clinical Biochemistry Managed Diagnostic Network** http://www.mcns.scot.nhs.uk/scbmdn/wp-content/uploads/sites/10/2018/09/Tumour-Marker-bookmark-NHS-download.pdf
- **Statistics on preventable cancers** https://www.cancerresearchuk.org/health-professional/cancer-statistics/risk/preventable-cancers
- **Clinical relevance of thrombocytosis in primary care:** Br J Gen Pract 2017; 67 (659): e405-e413. DOI: https://doi.org/10.3399/bjgp17X691109




This publication is available at **www.gov.scot**

Any enquiries regarding this publication should be sent to us at
The Scottish Government
St Andrew's House
Edinburgh
EH1 3DG

ISBN: 978-1-78781-516-2 (web only)

Published by The Scottish Government, January 2019

Produced for The Scottish Government by APS Group Scotland, 21 Tennant Street, Edinburgh EH6 5NA
PPDAS520066 (01/19)