National Institute for Health and Clinical Excellence

Referral for Suspected Cancer
Scope Consultation Table
3rd – 30th April 2012

Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
SH	Pancreatic Cancer Action	2	1.1	As per above- short title suggestion: *Recognising cancer: symptoms, investigations and management*	We have changed the short title of the guideline to 'Suspected cancer' in line with NICE style..
SH	British Association of Dermatologists (BAD)	1		Suspected cancer: recognition and management of suspected cancer in children, young people and adults. The use of 'management' in the title infers treatment and care of the patient. Referral Management guidelines for suspected cancer (all age groups) would be more appropriate as this is all encompassing and aligns itself to the terminology and process for how patients are diagnosed and the levels of care as set out in the NICE IOG. Alternatively we suggest the title, Suspected cancer: recognition of suspected cancer in children, young people and adults (all age groups).	We consider that the word 'management' encompasses more than just treatment – including investigation and safety netting. Therefore we have retained it in the title.
SH	British Association of Dermatologists (BAD)	2		Suspected cancer: recognition and management. Same comments as above	We consider that the word 'management' encompasses more than just treatment – including investigation and safety netting. Therefore we have retained it in the title.
SH	British Association of Dermatologists (BAD)	3		**Groups that will be covered** a) Children (from birth to 15 years), young adults (aged 16–24 years) and adults (aged 25 years and over) presenting to primary care with signs or symptoms of suspected cancer .	Thank you for your comment
SH	British Association of	4		**Subgroups that are identified as needing specific consideration will be considered during development but may include:**	

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	Dermatologists (BAD)			• older people This is an important group for skin cancer as they present the largest age group with skin cancer. Their care can be more complex and they have higher morbidity rates from skin cancer. This is set to increase with aging population and people living longer. Access to a dermatology specialist input is required due to the complexity of care. • people with cognitive impairment • people with multiple morbidities Dermatology patients receiving phototherapy treatments, immunosuppressants, biologics or transplant patients are at risk of getting skin cancer. This is an important group that will see their GPs who may not be aware of this risk and to monitor the patients as part of routine care when they visit their GP. • people from lower socioeconomic groups	Thank you for your comment. We agree. We note your comment. However raising awareness of skin cancer for these groups of patients and screening are outside the scope of the guideline.
SH	Cancer Research UK	1	1	We recommend the current title is amended to 'Suspecting cancer: recognition and management when suspecting cancer in children, young people and adults.' The current title suggests that cancer has already been suspected whereas the guideline is an active aid to identifying cancer and successfully referring for diagnosis and treatment. Changing the title would give the guideline a sense of vigour and energy.	We accept that in some patients a diagnosis of cancer is not even considered as a possibility early on. However the educational aspects of this guideline should help to address this without a need to change the title.
SH	Sarcoma UK	1	1.	The proposed guideline title is appropriate. We believe it is clear and unequivocal if a bit long.	Thank you for your comment.
SH	Oesophageal Patients Association	1	1.1 3.2b	'*Referral for Suspected Cancer'* is a sensible title, notwithstanding that it is often about common symptoms where the index of suspicion may need to be refined to allow specialist investigation to take place more frequently than at present. If GPs did actually *suspect* cancer, they would not doubt refer the patients for specialist investigation accordingly.	We have changed the short title of the guideline to 'Suspected cancer' in line with NICE style, not 'Referral for suspected cancer'
SH	Association of	1	1.1	Suspected cancer: recognition and management – The term	We consider that the word 'management'

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	Breast Surgery			management is misleading as it suggests management of the cancer. Suggest recognition and diagnosis	encompasses more than just treatment – including investigation and safety netting. We have changed the short title of the guideline to 'Suspected cancer' in line with NICE style.
SH	The Prostate Cancer Charity	2	3.1	Prostate cancer Prostate cancer is the most common cancer in men in the UK. Each year 37,000 men are diagnosed and 10,000 men die from the disease. 250,000 men in the UK are living with and beyond prostate cancer.[i] Prostate cancer mainly affects men over 50 and risk increases with age. Men are two and a half times more likely to develop prostate cancer if their father or brother has had it. African Caribbean men are also three times more likely to develop prostate cancer than white men of the same age. Prostate cancers can grow slowly or very quickly. Prostate cancers are slow-growing and may never cause any symptoms or problems in a man's lifetime. However, a significant number of men will have a prostate cancer that is more aggressive or 'high risk.' These need treatment to help prevent or delay spread outside the prostate gland. Treatment is not curative if these cancers are diagnosed at the advanced stage. Detecting these prostate cancers earlier may lead to fewer deaths the current 10,000 men who die from prostate cancer each year. Early prostate cancers often do not have any signs or symptoms. Lower urinary tract symptoms (LUTS) are common in older men. LUTS are likely to be caused by benign prostate disease, however if they are due to prostate cancer it has often reached an advanced and incurable stage[ii]. It is therefore important for GPs to be aware of groups at high risk of prostate cancer and the tests which are available, as set out in the Prostate Cancer Risk Management Programme (PCRMP) guidelines[iii]. These guidelines should be cross-	Thank you for this information. The GDG will cross reference the NICE guideline on prostate cancer where appropriate.

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				referenced in the "referral for Suspected Cancer" guidance.	
SH	Eli Lilly and Company Limited	1	3.1. Epidemiology	• Some tumours may be difficult to diagnose based on symptoms only, due to which patients are diagnosed only at an advanced stage. For such tumours, the guideline needs to specify an acceptable referral rate in order to drive a change in clinical practice towards early diagnosis. • Patients in the early stages of some cancers are often asymptomatic. Therefore a symptom based approach may not identify this cohort of patients. For example, in lung cancer, the patient with haemoptysis and weight loss is more likely to present at an advanced stage. Early diagnosis should aim to pick up the patient with a solitary peripheral nodule which may be relatively asymptomatic. To this end, the guideline needs to consider recommending strategies for identification of early disease for 'at risk' populations, incorporating diagnostic recommendations. • To reflect the difficulties in picking up early stage disease, a lower accuracy of referral rate should be acceptable for tumours in which majority of patients are picked up in the metastatic setting,	Where the evidence permits us to make recommendations on referral rates, we will do so. The scope of the guideline includes only patients who present to primary care with signs and symptoms suggestive of cancer. Screening of high risk groups is beyond the scope of this NICE clinical guideline. Other strategies will need to be used in addition to this guideline to ensure earlier diagnosis. Where the evidence permits us to make recommendations on referral rates, we will do so.
SH	Oesophageal Patients Association	2	3.1 c	Some types of cancer may develop more quickly than others; and may be more easily diagnosed than others.	We agree.
SH	University of Nottingham	1	3.2	We strongly support the concept of a symptoms based approach to risk assessment for suspected cancer in primary care. Conceptually this more closely approximates the diagnostic process and so it more likely to fit within usual work flows in primary care.	Thank you
SH	University of Nottingham	2	3.2	Since the NICE review was completed in February 2011, there have been a series of publications which have assessed risk of cancer among patients with symptoms. The papers are listed below and cover 6 cancers – lung, gastro-oesophageal, pancreatic, colorectal, ovarian and renal tract cancer. The resulting algorithms are collectively known as the QCancer scores and have been designed for use in primary care - within the consultation with symptomatic	Many thanks for bringing this to our attention.

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				patients and also 'in batch mode' to identify at risk patients who might have not been investigated (ie safety netting). All the algorithms have been through scientific peer review and have also been validated by Oxford University on a separate dataset. There is a simple to use web calculator which implements all 6 algorithms http://www.qcancer.org/all-in-one/ . The calculator takes account of symptom as well as age, sex, co-morbidities, smoking status to give an absolute measure of risk that the patient has an as yet undiagnosed cancer. The calculator can be updated to take account of new knowledge, changes in data quality, and updates to national guidelines. 1. Hippisley-Cox J, Coupland C. Identifying patients with suspected lung cancer in primary care: derivation and validation of an algorithm. *Br J Gen Pract* 2011;61(592):e715-23. 2. Hippisley-Cox J, Coupland C. Identifying patients with suspected gastro-oesophageal cancer in primary care: derivation and validation of an algorithm. *Br J Gen Pract* 2011;61(592):e707-14. 3. Hippisley-Cox J, Coupland C. Identifying patients with suspected pancreatic cancer in primary care: derivation and validation of an algorithm. *British Journal of General Practice* 2012;62(594):e38-e45. 4. Hippisley-Cox J, Coupland C. Identifying patients with suspected colorectal cancer in primary care: derivation and validation of an algorithm. *British Journal of General Practice* 2012;62(594):e29-e37. 5. Hippisley-Cox J, Coupland C. Identifying women with suspected ovarian cancer in primary care: derivation and validation of algorithm. *BMJ* 2012;344. 6. Hippisley-Cox J, Coupland C. Identifying patients with suspected renal tract cancer in primary care: derivation and validation of an algorithm. *British Journal of General Practice* 2012;62(597):e251-e60.	

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				Competing interest: JHC is the lead author of the above work and also director of clinrisk Ltd which has developed open and closed source software too implement the algorithms in the NHS.	
SH	University of Nottingham	3	3.2	Section e. we think it's very important to have robust objective measures of cancer risk to help prioritise patients for further investigations and scans. It can also be reassuring for patients who are actually at low risk.	Section 3.2.e is background text and these bullet points were taken from the NAEDI website. This list is not meant to be exhaustive.
SH	Sarcoma UK	2	3.2	We welcome this debate, and we agree with the approach outlined. The work of NAEDI, although still at an early stage, is highly promising and the 'target' of 10,000 lives saved looks very challenging but realistic. It must be said that the timetable for this Guidance means it will appear late with regard to the target timeline and may not contribute significantly but hopefully its impact will be lasting. We particularly welcome the comments in paras g) and h) which we believe could make a significant difference to achieving earlier diagnosis and access to curative treatment for many sarcoma patients. This would, of course, be subject to the indicative symptoms relevant to sarcoma being among those considered and included for referral.	Thank you. Whilst it is not possible to amend the timelines we will ensure close collaboration with the NAEDI initiative. Thank you for your comments. We agree.
E SH	The Prostate Cancer Charity	3	3.2	Prostate Cancer and NAEDI. Currently, very little is being done to improve men's awareness of prostate cancer and the tests available to them. The National Awareness and Early Diagnosis Initiative (NAEDI) does not currently address prostate cancer awareness but has the potential to do so in the future. Therefore, as the updated clinical guideline makes reference to NAEDI, the Charity believes it is important this guideline update considers this issue in relation to men who may have prostate cancer. Many men with prostate cancer do not present with symptoms. It is therefore vital that primary care professionals are aware of men who	Raising awareness of prostate cancer and screening are outside the scope of the guideline. The urological section of CG27 will be updated. Where the evidence permits,

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				are more at risk of developing prostate cancer – such as African Caribbean men and those who have a family history of the disease. There should be an opportunity to discuss their potential risk and offer tests if necessary, such as PSA and a Digital Rectum Examination (DRE).	recommendations will be made on specific sub-groups of patients.
SH	The Prostate Cancer Charity	4	3.2	Diagnosis and PSA test The PSA test, a simple blood test that can help diagnose problems that might be prostate cancer, is currently the best tool we have to identify a man's risk of having the disease. The PSA test is not currently recommended for use in a national screening programme because there are both advantages and disadvantages of having the test. Screening has been found to reduce the number of deaths from prostate cancer. However, it can also lead to significant levels of over-treatment.[iv] As we currently do not have a test that can differentiate between the harmless and aggressive forms of prostate cancer, screening would cause many men to receive treatment that they would not need and as a result may experience significant side effects, such as erectile dysfunction and incontinence. All men are entitled to receive a PSA test on the NHS. However, it is Government policy that before having a PSA test men should consider the advantages and disadvantages of having the test and make an informed decision about whether having it is right for them.[v] To make an informed decision men need balanced information about the PSA test and must have the opportunity to discuss this information with a health professional. The Prostate Cancer Risk Management Programme (PCRMP) seeks to provide GPs with this information so that they can share it with men concerned about the disease. However, the PCRMP has not been implemented effectively. A survey conducted by the Charity found that two thirds of GPs were unaware of the PCRMP.[vi] This is despite efforts by the Department of Health to promote and disseminate a revised resource pack to GPs about the programme between July	We agree. However screening is outside the scope of this guideline. Thank you for this information

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				2009 and March 2010. As a high PSA result may indicate suspected cancer, we believe this needs to be referenced in these referral guidelines, with a link to the PCRMP guidelines. As most GPs are not aware of the PCRMP, they may look instead to these guidelines for information on next steps following an abnormal PSA test result. It is therefore important to ensure that they are directed to the correct guidance. It would be even better if the PCRMP guidance was summarised here, for ease of use.	The evidence review for this guideline is likely to take account of the evidence used to support the PCRMP guidance.
SH	Eli Lilly and Company Limited	2	3.2. Current practice	• Para e) refers to DoH initiative on early diagnosis of cancer. This guideline should cross-reference the Lung Cancer Quality Standard and the NHS Outcomes Framework (early diagnosis measure).	We have included a list of relevant Quality Standards under section 5.
	Target Ovarian Cancer	1	3.2b	Target Ovarian Cancer welcomes the approach to list by symptoms rather than by cancer type. However that list should then reflect all symptoms currently listed in guidance on cancer.	We intend to limit ourselves to the common symptoms that are likely to be suggestive of a diagnosis of cancer. In discussing these symptoms we will include other secondary symptoms which might make up a symptom cluster.
SH	The Royal College of Radiologists	3	Section 3.2b	'The symptoms of cancer are very common in primary care and almost always are due to non-cancer diagnoses'. This statement is very broad ranging and may not be true in some cases eg abdominal or pelvic mass; we suggest replacing this with '…are *usually* due to non-cancer diagnoses'.	We have made this change
SH	The Royal College of Radiologists	4	Section 3.2b	This section suggests that the current guideline has been unsuccessful because it is structured around cancer type rather than symptoms and signs. Feedback from GPs indicates that many find the current guidelines valuable, particularly the referral algorithms. Successful sections of the current guidelines should be retained. There is a danger that basing the new guidelines on symptom groups may increase complexity and make the guidelines less user friendly.	It is not our intention to eliminate the structure around cancer type – rather to give primacy to signs and symptoms. We anticipate considerable overlap between the symptom and site structures.
SH	Oesophageal Patients Association	3	3.2 c	Another reason for late diagnosis may be the GP gatekeeper function within the NHS; in other countries GPs may have an ethos of readier referral for specialist examination. So additional diagnostic	Thank you for your comments, we agree.

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				assistance may well be helpful.	
SH	Breakthrough Breast Cancer	1	3.2 f)	Breakthrough Breast Cancer supports the approach to tie in the work of The National Awareness and Early Diagnosis Initiative (NAEDI) with this NICE clinical guideline to ensure consistent messaging to both GPs and the public, and help to prompt early diagnosis.	Thank you for your comment, we agree.
SH	Lymphoma Association	1	3.2.f	We fully support the move to a symptom-based approach for the updated guideline, which is likely to be particularly beneficial for lymphoma where there may be any number of different presenting symptoms.	It is not our intention to eliminate the structure around cancer type – rather to give primacy to signs and symptoms. We anticipate considerable overlap between the symptom and site structures.
SH	Breakthrough Breast Cancer	2	3.2 g)	We welcome the change in the structure of the referral guidelines to focus on symptom clusters rather than individual conditions. This will better reflect how patients present in primary care and how a primary care practitioner may approach the information.	It is not our intention to eliminate the structure around cancer type – rather to give primacy to signs and symptoms. We anticipate considerable overlap between the symptom and site structures..
SH	Breakthrough Breast Cancer	3	3.2 g)	More explanation is needed regarding what is meant by the term 'safety netting'. Does this refer to similar work being undertaken by the National Cancer Action Team? If so, consideration of how this might apply in Wales and Northern Ireland will be needed. Reference: - http://www.ncat.nhs.uk/our-work/diagnosing-cancer-earlier/gps-and-primary-care It is positive that advice will be provided on what to do when evidence for referral is unclear but it is essential that this section of the guideline is very carefully considered to avoid any delays in diagnosing some possible cancer cases. We will be keen to read the further detail on this section as the guidelines are developed to best understand the potential implications for patients presenting with any signs and symptoms of breast cancer. It is vital that all primary care practitioners have the necessary information to be confident in knowing when, and when not, to refer.	Safety netting in the context of this guideline indicates advice on follow up for patients who do not meet the criteria for immediate referral and are therefore either having testing in primary care or a watch and wait policy. It incorporates two elements (i) ensuring good practice protocols for management of results and (ii) a framework for follow up of undiagnosed patients. We will explain the term safety netting in the final guideline. Although we will work collaboratively with the NAEDI initiative which applies only to England, we are producing an evidence based guideline which will be relevant to practitioners in England and Wales. NICE clinical guidelines are also reviewed locally for their applicability to Northern Ireland (see

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					www.dhsspsni.gov.uk)
SH	Cancer Research UK	2	3.2.g	Consideration and caution needs to be given regarding the use of symptom clusters for all types of cancer and patients. While there is no doubt that symptom clusters can be highly informative, their use should not be at the expense of identifying lone symptoms when these are associated with a relatively high risk of cancer or, when taken in conjunction with risk factors, such as smoking status/history, are associated with a relatively high risk of cancer and warrant further investigation. The guideline will need to ensure that all symptoms included in the current guideline are covered in the revised guideline in some form because there are some cancers where stand alone symptoms can be significant. Information about risk factors, where there are implications for risk of cancer, or risk of advanced diagnosis, should be included in the guideline and used to inform recommendations for management.	The guideline will include both lone symptoms and symptom clusters. We appreciate cancer is more common in certain groups but our focus is on identifying cancer in any patient with a suspicious symptom. We intend to limit ourselves to the common symptoms that are likely to be presenting ones of cancer. In discussing these symptoms we will include other secondary symptoms which might make up a symptom cluster. The scope of the guideline includes only patients who present to primary care with signs and symptoms suggestive of cancer. Screening of high risk groups is beyond the scope of this NICE clinical guideline. Other strategies will need to be used in addition to the guideline to ensure earlier diagnosis.
SH	Cancer Research UK	3	3.2.g	We would welcome further information about the evidence which will be used to develop safety netting practices and follow up plans to develop safety netting mechanisms.	Until we have searched and appraised the evidence we do not know what this will be.
SH	Lymphoma Association	2	3.2.g and h	We agree with the clustering of symptoms. This is extremely important for lymphoma as individual symptoms are often non-specific and when taken in isolation may seem insignificant, whereas in combination they should lead to a suspicion of lymphoma.	Thank you for your comments, we agree.
SH	Cancer Research UK	4	4	We would welcome further information about the structure and format of the guideline particularly with respect to how advice relating to	We agree that the guideline needs to be easy to use. We will endeavour to

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				different patient groups (for example teenagers and young adults) will be presented. Consideration should be given to ensuring the guideline is as easy to use as possible.	structure it in such a way to achieve this aim.
SH	Children's Brain Tumour Research Centre, University of Nottingham	1	4.1	We fully support the recommendation to review the needs of children, young people and older adults separately.	Thank you.
SH	Royal College of Paediatrics and Child Health	5	4.1	We fully support the recommendation to review the needs of children, young people and older adults separately.	Thank you.
SH	Teenage Cancer Trust	3	4.1.1	As we've detailed above we very much welcome the specific naming of the teenage and young adult group. In the scoping document this age group is referred to as 'young adults', we would recommend that the terminology 'teenagers and young adults (TYA)' is used as this is the terminology recognised in cancer care practice.	The three divisions in the scope match the divisions used in paediatric oncology. The literature uses these divisions, so using different groupings would create problems for searching and appraising the evidence. We acknowledge that the presentations do differ, but do not believe that they change abruptly in moving from one age to another.
SH	The Prostate Cancer Charity	6	4.1.1	The Charity notes that subgroups will be identified during the guideline development. However, it is essential that those who are at greater risk of prostate cancer are covered in this section. African Caribbean men are three times more likely to develop prostate cancer than white men of the same age in the UK.[vii] Men who have father or brother has been diagnosed with prostate cancer are two and a half times more likely to develop prostate cancer.	We appreciate cancer is more common in certain groups and this will be clarified in the introduction to the guideline. However our focus is on identifying cancer in any patient with a suspicious symptom. If the evidence suggests that certain symptoms are more common in particular subgroups this will be reflected in the guideline.
SH	The Rarer Cancers Foundation	1	4.1.1.	Our comments are as follows- people from particularly rural and/or isolated parts of the Country should be identified as needing specific consideration – their ability to access primary care is often restricted because of poor public transport, they are often elderly and from lower socioeconomic groups	We agree. The list of potential sub groups is not exhaustive and accessing services for people living in remote areas may be identified by the GDG during guideline development.

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SH	The Rarer Cancers Foundation	2	4.1.1.	Our comments are as follows – we hear that people who have been previously diagnosed with cancer are often " lost to the system" following discharge. The RCF would like to see a robust system to ensure people who represent with symptoms of suspected recurrence or metastatic disease from a previously treated cancer, are given specific consideration whether this is within or outwith surveillance or follow-up from the initial diagnosis.	This group of patients have been explicitly excluded from the scope of this update (see section 4.3.2.b) as they were excluded from the scope of CG27. Recommendations on recurrence or metastases would be better placed in site specific cancer guidance. Patients with a second primary are covered by this guideline.
SH	The Rarer Cancers Foundation	3	4.1.1.	Our comments are as follows - There needs to be a proper support and assistance programme in place for anyone undergoing a referral for suspected cancer. This is particularly relevant to those who are ultimately diagnosed with a rarer cancer for whom it may be several weeks before a definitive diagnosis is made. These patients may undergo a series of tests/scans at different hospital sites and many rarer cancer patients report they feel they are being passed from pillar to post even if the actuality is very different.	We think this is encompassed within 4.3.1.f
SH	Eli Lilly and Company Limited	3	4.1.1. Groups that will be covered	• The patient groups 'older' and 'patients with multiple morbidities' need to be defined more clearly.	The definition will depend on the evidence that is found relating to these sub-groups.
SH	Guy Francis Bone Cancer Research Fund	1	4.1.1 a)	Would suggest that Children should be from birth to 10 years (as the major childhood cancer Leukemia is virtually unknown after 10 years old). Then Teenagers & Young Adults from 11 years to 24 years (as this specifically identifies the number 1 TYA cancer – Primary Bone Sarcoma – in a separate category which should aid GP & other HCPs in early diagnosis if a cluster of seemingly unrelated signs are detected in this age range. Brain tumours – the 2nd. most common cancer in both Children & TYA – remain highlighted. Adults should be in 2 categories – firstly, 25 - 65 years; secondly Over 65.	We have retained these standard age groupings whilst recognising that the epidemiology and evidence does not always match them.
SH	Samantha Dickson Brain Tumour Trust	2	4.1.1a and 4.1.2	We feel that this NICE guidance should cover two non-primary care settings. Firstly, the situation where a patient with suspected cancer presents at A&E. Based on the NCIN 'Routes to diagnosis' project, 23% of all	The remit of the guideline is the recognition and management of suspected cancer in primary care. The guideline may still be of value in other healthcare settings – particularly seeing

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				cancers, and 58% of brain tumours are diagnosed via this route. This is a significant proportion of the population diagnosed, and we feel that inclusion of this group within this scope is important. Secondly, children with suspected cancer are often assessed by a paediatrician. Brain tumours are the second-most common cancer in children. Our view is that this professional group also should be included within the scope of this guideline.	unselected patients – such as those mentioned.
SH	Guy Francis Bone Cancer Research Fund	2	4.1.1 b)	If the Adult category suggestion above is divided into 2 groups, then there is no need for an "older people" subgroup.	The definition will depend on the evidence that is found relating to these sub-groups.
SH	Breakthrough Breast Cancer	4	4.1.1 b)	Consideration of older people as a subgroup in the guideline is welcome as the risk of breast cancer increases with age - for most women getting older is their biggest risk factor for breast cancer. However, surveys have repeatedly shown that older women are often unaware of their increased risk of developing breast cancer, and they tend not to be aware of non-lump signs and symptoms of breast cancer. It is therefore important that primary care practitioners are particularly alert to potential signs or symptoms in older patients as they are more likely to delay seeking help with breast cancer symptoms than younger women. References: - Linsell L, Forbes LJL, Kapari M, Burgess C, Omar L, Tucker L and Ramirez AJ. A randomised controlled trial of an intervention to promote early presentation of breast cancer in older women: effect on breast cancer awareness. *British Journal of Cancer*. 2009; 101 Suppl 2: S40-48 - Linsell L, Burgess CC and Ramirez AJ. Breast cancer awareness among older women. *British Journal of Cancer*. 2008; 99: 1221–1225 - Moser K, Patnick J, Beral V. Do women know that the risk of breast cancer increases with age?. *British Journal of General Practice*. 2007; 57: 404-406	We agree. Thank you for your comments and providing us with this very useful data which we will pass on to the Guideline Development Group
SH	Breakthrough Breast Cancer	5	4.1.1 b)	It is important to highlight that while breast cancer is uncommon in women under the age of 40, it does still occur. Recent research has shown that younger women with cancer symptoms are more likely to	We agree. Thank you for your comment. This guideline applies to all women regardless of age and we acknowledge

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				experience repeated GP appointments before being referred for specialist diagnosis and therefore attention must be paid to the possibility of breast cancer in younger women, especially in those with a family history of the disease. Reference: - Lyratzopoulos G, Neal RD, Barbiere JM, Rubin GP, Abel GA. Variation in number of general practitioner consultations before hospital referral for cancer: findings from the 2010 National Cancer Patient Experience Survey in England. *The Lancet Oncology*, Volume 13, Issue 4, Pages 353 - 365, April 2012	breast cancer is uncommon in women under the age of 40. The GDG will review the evidence and if specific subgroups is identified will draft recommendations accordingly.
SH	Breakthrough Breast Cancer	6	4.1.1 b)	Breakthrough Breast Cancer wishes to add an additional sub-group to the list for special consideration: people with a family history of cancer. This is particularly pertinent in breast cancer as of all women who develop breast cancer, about 1 in 5 has a significant family history of the disease. If there is a history of breast cancer, or some other cancers (especially ovarian cancer), this may increase the patient's risk of developing breast cancer, and at a younger age. It does not mean that they will definitely get the disease. Primary care practitioners should be aware of the relevance of a family history of cancer.	A guideline is currently in development on familial breast cancer. We appreciate cancer is more common in certain groups and this will be clarified in the introduction to the guideline. However our focus is on identifying cancer in any patient with a suspicious symptom. If the evidence suggests that certain symptoms are more common in particular subgroups this will be reflected in the guideline.
SH	Breakthrough Breast Cancer	7	4.1.1 b)	It should also be noted that attention to the possibility of breast cancer in male patients should be considered. While the condition is rare in men (around 300 men are diagnosed with breast cancer every year in the UK), cases do occur and primary care practitioners should be made aware of this.	Thank you for your comments. We agree and they are included in the scope of this guideline.
SH	The Royal College of Radiologists	5	Section 4.1.1(b)	We suggest that the subgroup for 'older people' needs to be defined. The population who do not have English as a first language is another group that at are at high risk for delayed referral and should also be considered for inclusion.	The definition will depend on the evidence that is found relating to these sub-groups. This list is not exhaustive. If the evidence review highlights any particular groups, the Guideline Development Group will make recommendations accordingly.
SH	Ovarian Cancer	1	4.1.1 b)	We welcome that different subgroups have been identified as needing	The recommendations from the ovarian

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	Action			specific consideration, but would like to direct NICE's attention to a recent paper by Dr Georgios Lyratzopoulos The Lancet Oncology, Volume 13, Issue 4, Pages 353 - 365, April 2012 doi:10.1016/S1470-2045(12)70041-4 The paper showed that for 'rarer' cancers including ovarian cancer ethnicity, age, and gender do impact on delays in diagnosis at primary healthcare level. The ethnic variation was concentrated in older groups across rarer cancers. Therefore, we would like to see certain ethnic groups who are disproportionately affected by delayed diagnosis included on your list of those requiring specific attention. Some ovarian cancers are hereditary and, and so people with a family history of cancers where there is a known hereditary link should also be included as a sub-group. (N.B. researchers currently think around 40% of ovarian cancers are hereditary, instead of the previous figure of 10%. Knowledge is developing around which cancers are thought to have a hereditary link with ovarian cancer. BRCA1 and BRCA2 gene mutations are already well-known for making women prone to breast cancer and ovarian cancer.)	guideline will not be updated, they will be incorporated into this guideline. Many thanks for this information which we will forward to the Guideline Development Group. We appreciate cancer is more common in certain groups and this will be clarified in the introduction to the guideline. However our focus is on identifying cancer in any patient with a suspicious symptom. If the evidence suggests that certain symptoms are more common in particular subgroups this will be reflected in the guideline.
SH	Samantha Dickson Brain Tumour Trust	3	4.1.1b	Our view is that young adults with suspected cancer are a group which is poorly served when it comes to referral for suspected cancer. One study has shown that 59% of teenagers with brain tumours visited their GP four or more times with symptoms before they were referred. Young people are typically inexperienced users of the healthcare system. They may lack confidence in attending their GP and in expressing their health concerns clearly. During adolescence, we are aware of brain tumour patients whose symptoms are attributed to exam stress or puberty. We feel that health care professionals should give particular attention to young people presenting with signs and symptoms that could indicate cancer, and that they warrant inclusion as a group requiring specific consideration for the purposes of these	We agree. This is why we have specified the younger age groups in the populations covered by this guideline

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				guidelines.	
SH	The Royal College of Radiologists	6	Section 4.1.2a	The scope excludes 'people who have been referred to secondary care for specialist management'. However, under the current system, it is recognised that some patients may be discharged from secondary care following HSC referral without complete clinical evaluation and investigation and without symptoms having been explained eg a patient with upper GI symptoms and weight loss who undergoes endoscopy only. This is a significant factor in delayed diagnosis of cancer in a proportion of patients and we are concerned that this group may not be considered in the new guidelines. Similarly, 'people who present for the first time outside of the primary care setting' are not included. In some patients the lines of responsibility for referral are unclear eg those patients who have attended A&E but not required admission, and this is a further important cause of delayed diagnosis. It is a concern that communication and referral pathways between primary and secondary care are not being considered for these groups.	Our symptom based guideline may suggest more than one possible cancer site for certain symptoms. Therefore the GP will need to be alert to consider a second or third possibility in such a scenario. The remit of the guideline is the recognition and management of suspected cancer in primary care. The guideline may still be of value in other healthcare settings – particularly seeing unselected patients – such as those mentioned.
SH	Sarcoma UK	3	4.1.2 b)	We accept that patients presenting outside the primary setting should not be included in this Guidance. However a high proportion of patients first present through A&E, often after numerous visits to a GP. The relationship between such presentation and GP performance must be considered by the Guidance Development Group and they should be free to make recommendations which might impact on future GP performance (eg recommending formal feedback to GPs).	The remit of the guideline is the recognition and management of suspected cancer in primary care. The guideline may still be of value in other healthcare settings – particularly seeing unselected patients – such as those mentioned.
SH	Children's Brain Tumour Research Centre, University of Nottingham	2	4.2	The guideline will also be useful to clinicians in secondary care when pts present with symptoms outside their area of expertise e.g. a diabetologist seeing a pt with symptoms of prostate cancer. This should be highlighted in the revised guideline.	The remit of the guideline is the recognition and management of suspected cancer in primary care. The guideline may still be of value in other healthcare settings – particularly seeing unselected patients – such as those mentioned.
SH	Teenage Cancer	4	4.2	It would be useful to include school nursing/health services and	The remit of the guideline is the

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	Trust			secondary education health services/clinics.	recognition and management of suspected cancer in primary care. The guideline may still be of value in other healthcare settings – particularly seeing unselected patients
SH	Breakthrough Breast Cancer	8	4.2	It is good to see the inclusion of community pharmacies highlighted in the list of healthcare settings as they have an important role to play in raising awareness of cancer signs and symptoms and encouraging customers to go to their GP to get any signs/symptoms checked out. While it has previously been felt that pharmacists have been under-used in promoting cancer awareness, it is encouraging that a number of pilot projects have been undertaken, and others that are ongoing, successfully using pharmacies to raise awareness of the signs and symptoms of cancer. In addition, pharmacists are keen to be more involved and The Royal Pharmaceutical Society supports campaigns to promote the role of pharmacists in the early detection of cancer. References: - Pharmacist Davan Eustace, a member of the NAEDI steering group, commenting in the NAEDI Newsletter. Jul 2008 - NAEDI Newsletter. Feb 2012 - Central Office for Information. Evaluation of the Bowel Cancer Awareness Pilot in the South West and East of England: 31 January to 18 March 2011. Mar 2012 - http://www.rpharms.com/public-health/cancer-awareness.asp	Thank you for this information.
SH	Royal College of Paediatrics and Child Health	4	4.2	The guideline will also be useful to clinicians in secondary care when pts present with symptoms outside their area of expertise e.g. a diabetologist seeing a pt with symptoms of prostate cancer. This should be highlighted in the revised guideline	The remit of the guideline is the recognition and management of suspected cancer in primary care. The guideline may still be of value in other healthcare settings – particularly seeing unselected patients – such as those mentioned.
SH	Guy Francis Bone Cancer Research Fund	3	4.2 a)	Would suggest the examples are broadened as first presentation may not be to a GP but to an A & E Department or Drop-In Centre where the HCP will not know the patients' medical history.	The remit of the guideline is the recognition and management of suspected cancer in primary care. The

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					guideline may still be of value in other healthcare settings – particularly seeing unselected patients.
SH	University of Nottingham	4	4.3.1	The assessment of risk associated with symptoms must take account of age and sex.	We agree.
SH	University of Nottingham	5	4.3.1	The symptom list needs to include some additional symptoms - Appetite loss is an independent predictor of a number of cancers. This in addition to weight loss and after adjustment for age, sex, past history and other symptoms. For example appetite loss is associated with an increased risk of colorectal cancer in women (adjusted hazard ratio 2.43, 95% CI 1.70 to 3.47) and men (adjusted hazard ratio 2.15,95% CI 1.53 to 3.03). It is also associated with increased risk of pancreatic cancer, lung cancer, gastro-oesophageal cancer, renal cancer, ovarian cancer. We recommend it is included in the list of symptoms. - Haematemesis is an independent predictor of upper GI cancer (see ref 2 listed above). The adjusted hazard ratio for haematemesis at the mean age for women is 25.2 (adj HR 14.4 to 44.2). For men the adj HR is 7.62 (608 to 9.55) - Heartburn/indigestion is also an independent predictor (a) gastro-oesophageal cancer as well as (b) pancreatic cancer. - Change in bowel habit is an independent predictor of colorectal cancer in men (adjusted hazard ratio 2.25, 95% CI 1.47 to 3.46) Some of the symptoms above (and those listed in the consultation document) have strong age interactions which means they have a bigger effect at younger ages generally. Its also important for face validity that the important of symptoms in taken in context of the patient's smoking status and also their age. This is what the www.qcancer.org tools have been designed to do.	Thank you for your suggested additional symptoms. Section 4.3.1 lists symptoms recognised as frequently occurring in patients with cancer presenting to primary care. We have added appetite loss, haematemesis, heartburn/dyspepsia, bony and soft-tissue masses to this list. If our searches utilising these symptoms in primary care, uncover any important omissions, these will be included in the guideline.
SH	Barnsley Hospital NHS Foundation Trust	1	4.3.1	If there is to be a 'watch and wait' surveillance of low patients with low risk symptoms what qualifies as 'low risk'? And for how long should this surveillance be conducted?	We will need to search and appraise the evidence on this issue before we are able to make recommendations

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SH	Pancreatic Cancer UK	2	4.3.1	(Clinical issues that will be covered) We appreciate that for many cancers there will be separate guidelines relating to family history. However, we wondered whether there does need to be some reference to family history in the guideline relating to cancers, like pancreatic cancer, where there is no formal family history guidance?	We appreciate cancer is more common in certain groups and this will be clarified in the introduction to the guideline. However our focus is on identifying cancer in any patient with a suspicious symptom. If the evidence suggests that certain symptoms are more common in particular subgroups this will be reflected in the guideline.
SH	Bowel Cancer UK	1	4.3.1	Bowel Cancer UK supports the move towards guidance structured around signs and symptoms. We agree with the view that the previous guidance, organised around tumour site, required the user to think firstly in terms of cancer to recognise that the guidelines were relevant. Many bowel cancer patients, particularly people under the age of 50, are initially incorrectly diagnosed as the signs and symptoms of bowel cancer can also be indicative of other conditions. Bowel Cancer UK wants to see this change - we want to see bowel cancer ruled first, not last. We believe that a move to guidance based on signs and symptoms will help achieve this.	Thank you.
SH	The Prostate Cancer Charity	5	4.3.1	The Charity believes two important signs and symptoms are missing from those outlined in the scoping document. Erectile dysfunction and lower back pain can indicate the possibility of prostate cancer. Therefore we would urge these two possible symptoms are added to the list.	Section 4.3.1d lists symptoms recognised as frequently occurring in patients with cancer presenting to primary care. If our searches utilising these symptoms in primary care, uncover any important omissions, these will be included in the guideline.
SH	The Royal College of General Practitioners	4	4.3.1	There are some important predictors missing from section 4.3.1. For example, they appetite loss, heartburn/dyspepsia, haematemesis, change in bowel habit	Thank you for your suggested additional symptoms. Section 4.3.1 lists symptoms recognised as frequently occurring in patients with cancer presenting to primary care. We have added appetite loss, haematemesis,

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					heartburn/dyspepsia, bony and soft-tissue masses to this list. If our searches utilising these symptoms in primary care, uncover any important omissions, these will be included in the guideline.
SH	Breakthrough Breast Cancer	9	4.3.1	We welcome the change in the structure of the referral guidelines to focus on symptom clusters rather than individual conditions. This will better reflect how patients present in primary care and how a primary care practitioner may approach the information.	Thank you.
SH	North Trent Cancer Network (NTCN)	4	4.3.1	The focus on symptoms is forward thinking	Thank you.
SH	British Association of Dermatologists (BAD)	5	4.3.1	**Areas from the original guideline that will be updated** • The initial investigations that contribute to the assessment of patients prior to, or in association with, referral for suspected cancer, where clinical responsibility is retained by primary care. The original guidance provides information and criteria of when to refer. Existing NICE guidance for skin cancer already contains information on diagnosis etc of skin cancer. The referral guidance needs to be a short and easy guide to reflect these requirements and reflect the level of clinician who can treat skin cancer patients and in the appropriate settings such as a GP with Specialist Interest or a dermatologist providing clinics in primary care/community. **D) Signs and symptoms that indicate the possibility of a cancer Diagnosis:** This list does not indicate symptoms for skin cancer on pages 5 and 6 **Areas not in the original guideline that will be included in the**	The guidance you refer to is current NICE service guidance. These issues are outside the scope of this update. Section 4.3.1d lists symptoms recognised as frequently occurring in patients with cancer presenting to primary care. If our searches utilising these symptoms in primary care, uncover any important omissions, these will be included in the guideline. This is already covered by the NICE

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				update Follow-up plans (including 'safety-netting') for patients whose care is managed in primary care without referral for definitive investigation. GPs firstly need to be trained to carry out this activity and have better skin lesion recognition skill to achieve these proposed requirements. Follow up plans also have to be in line with monitoring requirements for patients diagnosed and treated for skin cancer.	service guidance on skin cancer. This guideline will provide a framework for follow up of undiagnosed patients. It does not cover follow-up of patients diagnosed with a particular cancer.
SH	Eli Lilly and Company Limited	4	4.3.1. Key clinical issues that will be covered	• Any change in symptoms could also be a potential sign of cancer. It is not clear how this aspect will be addressed in the guideline. A change in patient reported quality of life should also be addressed.	These issues will be discussed with the Guideline Development Group when agreeing the clinical questions (PICO). Health related quality of life will be included as an outcome for relevant clinical questions
SH	Airedale NHS Foundation Trust	1	4.3.1 (c)	It will be very important for the GDG to consider referral arrangements for patients whose presentation does not point to a particular primary site and who therefore cannot meet the criteria for referral to a specific clinic. The concept of a specialist "suspected malignancy of undetermined origin" clinic raises fears of cancer specialists being required to conduct a "general medicine" clinic.	We agree that some patients, especially those with non-specific symptoms, such as weight loss, may have a number of different cancers as a possible cause. This is one reason for giving primacy to symptoms. We will advise on the likeliest site of the suspected cancer and this will then allow the GP to make an appropriate referral
SH	Ovarian Cancer Action	2	4.3.1 c)	We particularly welcome this proposed update to the Guideline, as speed of diagnosis is particularly important in cases of ovarian cancer (90% of women diagnosed at stage 1 will survive 5 years). If patients present with any of the symptoms and signs and the pattern identified in the *NICE Guideline on the Recognition and Initial Management of Ovarian Cancer* they should receive a CA125 blood test immediately. If serum CA125 is 35 IU/ml or greater, **or if serum levels are rising**, the patient should be referred for a trans-vaginal ultrasound using the fast-track (2-wait) referral system. If the patient's CA125 serum is	Thank you for this information. As stated in section 5.1.2, recommendations on this issue from GC122 (Ovarian Cancer) will be incorporated into this update.

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				normal or not rising, but her symptoms persist over the next 4 weeks she should be referred for a trans-vaginal ultrasound using the fast-track referral system. This is because 10% of ovarian cancers do not affect the CA125 level of a patient and patients may slip through the net undiagnosed. The patient should be referred for further investigation urgently if the trans-vaginal ultrasound indicates ovarian cancer. (N.B. World thought-leaders in ovarian cancer research identified at the HHMT summit 2011 that a rising CA125 serum can indicate ovarian cancer, even if the serum levels are lower than 35 IU/ml – therefore it is vital that clinicians note rising scales and take immediate action.)	
SH	Pancreatic Cancer Action	4	4.3.1 (d)	Family history of cancer needs to be included	We appreciate cancer is more common in certain groups and this will be clarified in the introduction to the guideline. However our focus is on identifying cancer in any patient with a suspicious symptom. If the evidence suggests that certain symptoms are more common in particular subgroups this will be reflected in the guideline.
SH	Bowel Cancer UK	2	4.3.1 (d)	We particularly welcome the inclusion of abdominal pain, fatigue and rectal bleeding within the scope of the review. These are all signs and symptoms of bowel cancer if they persist for longer than three weeks. We would be keen to see the revised guideline reflect the length of time signs and symptoms persist for, as well as the signs and symptoms themselves.	We will need to search and appraise the evidence on this issue before we are able to make recommendations
SH	Pancreatic Cancer Action	3	4.3.1 (d)	Symptoms need including: • Back pain (upper middle back) for example is a presentation in pancreas Ca in the tail of the pancreas • Persistent dyspepsia (especially if not responding to prescribed medication such as PPIs)	Thank you for your suggested additional symptoms. Section 4.3.1 lists symptoms recognised as frequently occurring in patients with cancer presenting to primary care. We have added appetite loss, haematemesis, heartburn/dyspepsia, bony and soft-tissue masses to this list. If our searches utilising these symptoms in primary care,

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					uncover any important omissions, these will be included in the guideline.
SH	Airedale NHS Foundation Trust	2	4.3.1 (d)	This list of symptoms, each with a very low positive predictive value for malignancy, which includes vary generic symptoms such as weight loss, reinforces comment (1) above.	We agree that the PPV for individual symptoms is low, but we intend to look at clusters of symptoms and other factors which increase the likelihood of specific cancers.
SH	Oesophageal Patients Association	4	4.3.1 d	Additions to this list of symptoms should include: a history of persistent heartburn or water brash, particularly at night; persistent hiccups; persistent dyspepsia	Section 4.3.1d lists symptoms recognised as frequently occurring in patients with cancer presenting to primary care. If our searches utilising these symptoms in primary care, uncover any important omissions, these will be included in the guideline.
SH	Sarcoma UK	4	4.3.1 d)	This listing should specifically include 'soft issue lumps on limbs'. These are quite distinct in presentation from bony lumps (and bone pain) associated with primary bone tumours. Approximately 50% of soft tissue sarcomas are found on limbs. Some are cutaneous but these are a minority. Most are painless. Many tumours are deep (eg in the thigh), they can grow extremely quickly (eg from 2cm to 6cm in three weeks in a recent case), and the average tumour size resected has been reported as 10cm. We would be happy to work with our professional colleagues of the British Sarcoma Group to develop a short paper from a clinical and patient perspective to brief the GDG.	Section 4.3.1d lists symptoms recognised as frequently occurring in patients with cancer presenting to primary care. If our searches utilising these symptoms in primary care, uncover any important omissions, these will be included in the guideline.
SH	Teenage Cancer Trust	5	4.3.1 d)	There are additional signs and symptoms seen commonly in the TYA group which should be added: • Bleeding (general i.e. nosebleeds) and bruising (seen in TYA leukaemia) • General swelling/lumps seen in soft tissue sarcoma/bone tumours • Night sweats • Pruritus	Section 4.3.1d lists symptoms recognised as frequently occurring in patients with cancer presenting to primary care. If our searches utilising these symptoms in primary care, uncover any important omissions, these will be included in the guideline.
SH	Guy Francis Bone Cancer Research Fund	4	4.3.1 d)	Suggested additional signs & symptoms: Lump or swelling at the end of a long bone. Increasing pain, particularly at night.	Section 4.3.1d lists symptoms recognised as frequently occurring in patients with cancer presenting to

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				Gradual weight loss at a time of life when the body is still growing and there should be gradual weight gain. Inexplicable loss of energy or tiredness.	primary care. If our searches utilising these symptoms in primary care, uncover any important omissions, these will be included in the guideline.
SH	Breakthrough Breast Cancer	10	4.3.1 d)	We are concerned that the 'breast signs and symptoms' in the symptoms list are not explicitly listed as separate signs and symptoms in the guideline. There are many different signs and symptoms and while there is generally high awareness of a breast lump as a possible breast cancer indicator, awareness of non-lump symptoms is lower, and can lead to delays in presentation. Reference: - U Macleod, E D Mitchell, C Burgess, S Macdonald and A J Ramirez, (2009) Risk factors for delayed presentation and referral of symptomatic cancer: evidence for common cancers, Br J Cancer 101: S92-S101 - Breakthrough Breast Cancer (2011) Quantitative survey carried out online amongst amongst YouGov Plc panel 13th – 15th July 2011, 1024 women 18+, GB representative. Regarding breast cancer symptoms that may occur away from the breast area, an additional symptom should be added to the list in the guideline: 'axillary lump or swelling'. Axillary lump or swelling can occur in the absence of clinical breast abnormality and is a symptom of possible breast cancer that should indicate referral. Reference: - Willett AM, Michell MJ, Lee MJR. (Eds) Best practice diagnostic guidelines for patients presenting with breast symptoms. Nov 2010. In addition, breast cancer that has spread to lymph nodes may result in swelling above or below the collar bone. This symptom may be an indicator for referral. (N.B. this symptom may also be present in other types of cancer therefore should be included in the symptoms list.) References: - http://www.nhs.uk/Conditions/Cancer-of-the-breast--female/Pages/keymessages.aspx	We will need to search and appraise the evidence before we can determine which particular breast signs and symptoms need to be covered in the recommendations. We have listed "breast signs and symptoms" in section 4.3.1.d to enable us to do this.

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				- http://www.royalmarsden.nhs.uk/cancer-information/prevention-surveillance/pages/breast-awareness.aspx - http://cancerhelp.cancerresearchuk.org/type/breast-cancer/secondary/about/symptoms-of-secondary-breast-cancer#nodes The following symptoms should all be included in the list in the guidelines to aid primary care practitioners in the signs and symptoms to look out for (listed alphabetically): • Axillary lump/swelling • Axillary pain • Breast lump or lumpy area • Breast pain • Breast size or shape – change • Breast skin colour – e.g. red, inflamed • Breast skin texture – e.g. dimpling, puckering • Breast tissue thickening - change • Chest lump • Collar bone area lump/swelling • Nipple appearance – e.g. inverted, change in direction or shape • Nipple discharge • Nipple and surrounding area rash or crusting	
SH	Ovarian Cancer Action	3	4.3.1 d)	'Increased urinary urgency and/or frequency'; 'feeling full (early satiety) and/or loss of appetite'; and 'back-ache' should be added to this list of symptoms in line with the *NICE Guideline on the Recognition and Initial Management of Ovarian Cancer* and the NAEDI key messages on ovarian cancer symptoms.	As stated in section 5.1.2, recommendations on this issue from GC122 (Ovarian Cancer) will be incorporated into this update. Therefore these symptoms have not been added to the list
SH	Lymphoma Association	3	4.3.1.d	The main presenting symptoms associated with lymphoma are included except: • persistent itch • excessive sweating/fevers (especially at night). We believe these symptoms should be included in the list.	Section 4.3.1d lists symptoms recognised as frequently occurring in patients with cancer presenting to primary care. If our searches utilising these symptoms in primary care, uncover

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					any important omissions, these will be included in the guideline.
SH	Target Ovarian Cancer	2	4.3.1d	The list of symptoms should include those that are cited in the latest guidance on ovarian cancer 'the recognition and initial management of ovarian cancer' CG122. Currently the following are not included in your draft list: a reference to bloating (CG122 describes this as – persistent abdominal distension (some women refer to this as bloating). A woman would never use the term persistent abdominal distension, and when they say 'bloating' GPs can take it to mean intermittent bloating without checking what the woman means. Also loss of appetite and early satiety are not included in the list, but are in CG122.	As stated in section 5.1.2, recommendations on this issue from GC122 (Ovarian Cancer) will be incorporated into this update. Therefore these symptoms have not been added to the list
SH	Samantha Dickson Brain Tumour Trust	4	4.3.1d	Brain and CNS signs and symptoms that could be added to this list include: -symptoms of raised intracranial pressure -behaviour change -loss of fine motor skills -head tilt or wry neck -reduced consciousness. The Group are encouraged to review the signs and symptoms of brain tumours in children described in detail on the website for 'HeadSmart: be brain tumour aware', which is aimed at both parents and health professionals: www.headsmart.org.uk	Section 4.3.1d lists symptoms recognised as frequently occurring in patients with cancer presenting to primary care. If our searches utilising these symptoms in primary care, uncover any important omissions, these will be included in the guideline.
SH	The Royal College of Radiologists	7	Section 4.3.1(d)	Signs and Symptoms - although epigastric pain is listed, indigestion-type symptoms are not specifically mentioned and they are a very common symptom indicating an oesophageal or gastric primary. Similarly, reflux and heartburn might be included although they all cover the same sort of symptom group.	Thank you for your suggested additional symptoms. Section 4.3.1 lists symptoms recognised as frequently occurring in patients with cancer presenting to primary care. We have added appetite loss, haematemesis, heartburn/dyspepsia, bony and soft-tissue masses to this list. If our searches utilising these symptoms in primary care, uncover any important omissions, these will be included in the guideline

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SH	Cardiff and Vale University Health Board	1	4.3.1 d) and e)	Over a number of departmental audits over the last 4-5 years, the previous NICE Guidelines for the referral of suspected haematological cancers have performed consistently inferiorly to our own departmental guidelines in terms of rates of picking up new haematological cancers from the community. On multiple occasions, what turned out to be new cancers would NOT have been referred by GPs to the hospital if only the NICE guidelines had been followed. We feel that greater detail / scope is required in the guidelines, especially for abnormal haematological tests which should prompt urgent suspected cancer referral. In particular: Unexplained white cell count >50 Leucoerythroblastic blood film Lymphocytosis >20 (or lesser lymphocytosis in association with blood cytopenias, splenomegaly, progressive lymphadenopathy) Lymphadenopathy for less than 6 weeks (but associated with B symptoms, hepatosplenomegaly, rapid nodal increase, hypercalcaemia, blood cytopenias) Paraprotein with accompanying features to suggest haematological malignancy (hypercalcaemia, unexplained renal impairmenrt, urinary BJPs, bone pain, pathological fracture, X-ray lesions suggestive of myeloma, anaemia, blood cytopenia, hyperviscosity, splenomegaly, lymphocytosis, lymphadenopathy)	Thank you for your comments. The NICE guidance is intended to be used in conjunction with clinical skills and experience. The list of symptoms in 4.3.1.d includes most of the symptoms produced by haematological malignancies. The Abnormal blood tests in 4.3.1.e are those which can commonly result when the tests are performed for reasons where there is no suspicion of malignancy and the GP has to interpret a risk of malignancy. Your suggested test results either indicate suspicion of cancer as a reason for the test or are so abnormal that the clinical hospital specialists would have added a comment about cancer for the GP.
SH	Airedale NHS Foundation Trust	3	4.3.1 (e)	Tumour markers should be included in this list in that clinicians will need guidance about avoiding their use as well as using them.	The use of tumour markers in primary care was not prioritised for inclusion in the scope.
SH	Sarcoma UK	5	4.3.1 e)	We welcome the inclusion of anaemia which is an indicative symptom for gastrointestinal stromal tumour (GIST). This is a tumour where diagnosis is frequently delayed, with consequent greater risk of metastasis and the resulting provision of high cost treatment by the NHS. Delayed diagnosis has huge cost implications.	Thank you for your comment.
SH	Teenage Cancer Trust	6	4.3.1 e)	The list should add: • leukocytosis	Section 4.3.1e lists abnormal results recognised as frequently occurring in patients with cancer presenting to

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					primary care. If our searches utilising these abnormal results in primary care, uncover any important omissions, these will be included in the guideline.
SH	Bowel Cancer UK	3	4.3.1 (f)	Having access to accurate and easy to understand information during a referral for suspected cancer is crucial for a patient. The National Cancer Experience Survey 2010 revealed that nearly a quarter of patients with bowel cancer said that they were given conflicting information at some point during their patient pathway. We therefore welcome the inclusion of patient information needs within the scope of the review.	We agree. Thank you for this information.
SH	Guy Francis Bone Cancer Research Fund	5	4.3.1. f)	Add to information needs – Parents/Carers of Patients who are referred or monitored.	We have added carers.
SH	Pancreatic Cancer Action	5	4.3.1 (g)	Safety-netting is essential for these patients and strong guidance on follow-up for patients with vague symptoms (such as dyspepsia) persisting and not responding to prescribed medication is needed. Attention to family history of cancer crucial. Guidance should also highlight the need to monitor patients who repeat attend with the same symptom, those rare/never attenders who suddenly become repeat attenders with symptoms and those (especially with clusters of symptoms) who need an increased strength of analgesia to manage pain	Safety netting in the context of this guideline indicates advice on follow up for patients who do not meet the criteria for immediate referral and are therefore either having testing in primary care or a watch and wait policy. It incorporates two elements (i) ensuring good practice protocols for management of results and (ii) a framework for follow up of undiagnosed patients.
SH	Pancreatic Cancer Action	6	4.3.1 (g)	What is not included in current guidelines and should be included are diagnostic algorithms for individual cancers such as pancreatic cancer where there is none currently.	The guideline will make recommendations on which signs and symptoms prompt a referral to secondary care. A diagnostic algorithm, which could be developed as part of a guideline on the diagnosis and management of pancreatic cancer,is therefore outside the scope of this guideline.
SH	Airedale NHS	4	4.3.1 (g)	Guidance on safety netting will fulfil a major need.	We agree.

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	Foundation Trust				
SH	North Trent Cancer Network (NTCN)	5	4.3.1 (g)	Information about follow up in primary care (for patients not referred) is also welcome	Thank you.
SH	Sarcoma UK	6	4.3.1 g)	We would draw the GDG's attention to the use of risk analysis tools (eg nomograms) which have been developed to inform secondary/tertiary follow-up of some cancer patients. We believe there is a value in such tools for supporting community based follow-up of those patients whose active monitoring is the responsibility of primary care providers.	This guideline will provide a framework for follow up of undiagnosed patients. It does not cover follow-up of patients diagnosed with a particular cancer.
SH	Pancreatic Cancer UK	3	4.3.1 g)	We agree follow-up plans, including safety netting, should be included in the updated guideline. In relation to pancreatic cancer, we have a particularly strong view that follow-up should take into account repeated consultations for same symptoms – but also where there are repeated consultations with different symptoms differ that could be generally related. We would also propose that patterns of patient consultations be taken into account. For example, for patients that may have an increased number of consultations over a period of time – which is not in keeping with their previous consultation record.	Safety netting in the context of this guideline indicates advice on follow up for patients who do not meet the criteria for immediate referral and are therefore either having testing in primary care or a watch and wait policy. It incorporates two elements (i) ensuring good practice protocols for management of results and (ii) a framework for follow up of undiagnosed patients.
SH	Breakthrough Breast Cancer	11	4.3.1 g)	We welcome that follow-up plans for those managed in primary care will be included in the updated guideline as it is essential to consider how to manage potential patient anxiety, provide clear information to those who may need monitoring and those who may be safely reassured, and sign-post to further information and support where needed.	Thank you.
SH	Breakthrough Breast Cancer	12	4.3.1 g)	It is unclear what is meant by the term 'safety netting'. It is positive that advice will be provided on what to do when evidence for referral is unclear but it is essential that this section of the guideline is very carefully considered to avoid potential delays in diagnosing some possible cancer cases. We will be keen to read the further detail on this section as the guidelines are developed to best understand the potential implications for patients presenting with any signs and symptoms of breast cancer. It is vital that all primary care	Safety netting in the context of this guideline indicates advice on follow up for patients who do not meet the criteria for immediate referral and are therefore either having testing in primary care or a watch and wait policy. It incorporates two elements (i) ensuring good practice protocols for management of results and

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				practitioners have the necessary information to be confident in knowing when, and when not, to refer.	(ii) a framework for follow up of undiagnosed patients.
SH	Children's Brain Tumour Research Centre, University of Nottingham	3	4.3.1g	We think some advice on safety-netting should be included for children and young people. Children may not be brought for review even if symptoms persist and there may be a greater risk of these with certain social and demographic factors that should be highlighted. Young adults may be less good at actively seeking further review if symptoms persist and a more pro-active approach then is used in older adults may be required.	Children and young people are included in 4.3.1.g
SH	Royal College of Paediatrics and Child Health	6	4.3.1g	We think some advice on safety-netting should be included for children and young people. Children may not be brought for review even if symptoms persist and there may be a greater risk of these with certain social and demographic factors that should be highlighted. Young adults may be less good at actively seeking further review if symptoms persist and a more pro-active approach then is used in older adults may be required.	Children and young people are included in 4.3.1.g
SH	Breakthrough Breast Cancer	13	4.3.1 h)	The Scope indicates that it is not intended to update recommendations 1.2.5 – 1.2.12 (regarding the diagnostic process) in the original guideline. It may be helpful to expand recommendation 1.2.10. This recommendation currently reads: *'The primary healthcare professional should include all appropriate information in referral correspondence, including whether the referral is urgent or non-urgent.'* It is possible that primary care practitioners and secondary care practitioners have different interpretations as to what 'appropriate information' comprises. To ensure all pertinent information is included in referral correspondence it might be helpful to expand upon what is meant by 'appropriate information'.	We believe that this is an issue for local implementation and would not benefit from updating. Most secondary care providers have well developed systems for 2 week wait cancer referrals that require the referrer to complete an agreed pro forma that is often submitted electronically. If the information provided is substandard this can be dealt with through local negotiation.
SH	The Rarer Cancers Foundation	4	4.3.2 (b)	Our comments are as follows – We do not believe this group of patients should be outside the scope of this guidance. Our membership of rarer cancer patients and carers tell us that people who have been previously diagnosed with cancer often feel "lost to the system". The RCF would like to see a robust system to ensure	This group of patients have been explicitly excluded from the scope of this update (see section 4.3.2.b) as they were excluded from the scope of CG27. Recommendations on recurrence or

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				people who represent with symptoms of suspected recurrence or metastatic disease, from a previously treated cancer are given specific consideration, whether this is within or outwith the period for surveillance or follow up from the initial diagnosis.	metastases would be better placed in site-specific cancer guidance. However the recommendations in this guideline may still be of value to patients presenting with a symptom of recurrence.
SH	Guy Francis Bone Cancer Research Fund	6	4.3.2 b)	We are concerned that this might lead to a delay or even misdiagnosis of a second cancer at a later date in the patient's life. For example, a 1-6 year old child with Retinoblastoma developing Osteosarcoma in their teenage/young adult years.	This will not exclude diagnosis of a second primary cancer
SH	Children's Brain Tumour Research Centre, University of Nottingham	4	4.4	These outcomes are excellent - truly relevant to patient care and experience. Is there going to be advice as to how the data should be collected to evaluate these outcomes. NCIN currently does not mandate data collection on presentation to primary care with cancer symptoms. Will QOL data be collected directly from the patients - if so how? So far the DoH seems to have been reluctant to collect this vital information - a mandate from NICE to do this would provide support for this essential data	The guideline can make research recommendations after the evidence has been appraised. We will not be collecting QOL direct from patients - this data will be extracted from the evidence if it is reported
SH	Barnsley Hospital NHS Foundation Trust	2	4.4	How do we ensure pathways do not become fragmented i.e diagnostics undertaken by one provider with treatment decisions undertaken by another provider? For the purpose of waiting times reporting if patients are to undergo a programme of 'in-practice' investigations or surveillance when does the clock start ticking?	The scope doesn't include events after referral to hospital for diagnosis and treatment. We are proposing measuring the time from first symptom in primary care to diagnosis. Section 4.4 lists outcomes that will be looked for in the literature review. They are not intended to be outcomes that we hope to achieve through implementation of the guideline.
SH	Sarcoma UK	7	4.4	Would suggest the addition of e) to reflect positive and improving performance in the Cancer Patient Experience Survey conducted by the National Cancer Action Team (NCAT).	Section 4.4 lists outcomes that will be looked for in the literature review. They are not intended to be outcomes that we hope to achieve through implementation of the guideline.
SH	Pancreatic Cancer UK	4	4.4	(Main outcomes) We propose that the proportion of people diagnosed without advanced (or secondary) cancer should be considered as a main outcome of the guidance.	This is not intended to be an exhaustive list of outcomes. The Guideline Development Group will agree outcomes

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					for each clinical question.
SH	Pancreatic Cancer Action	7	4.4	If we are to improve the number of people surviving cancer in the UK, it is essential that one of the outcomes must be the stage at which cancer has been diagnosed. If no staging information (TNM etc) is available (sometimes it's not) then a simple metric of early (operable/treatable with curative intent) or advanced should be used.	This is not intended to be an exhaustive list of outcomes. The Guideline Development Group will agree outcomes for each clinical question.
SH	Samantha Dickson Brain Tumour Trust	5	4.4	Other outcome measures that could be considered: -One year survival rates – given that this is a measure commonly used to assess how UK diagnosis standards compare with those in other countries. -Assessment of patient experience of diagnosis, via the DH Cancer Patient Experience Survey.	This is not intended to be an exhaustive list of outcomes. The Guideline Development Group will agree outcomes for each clinical question.
SH	Royal College of Paediatrics and Child Health	2	4.4	These outcomes are excellent - truly relevant to patient care and experience. Is there going to be advice as to how the data should be collected to evaluate these outcomes. NCIN currently does not mandate data collection on presentation to primary care with cancer symptoms. Will QOL data be collected directly from the patients - if so how? So far the DoH seems to have been reluctant to collect this vital information - a mandate from NICE to do this would provide support for this essential data	The guideline can make research recommendations after the evidence has been appraised. We will not be collecting QOL direct from patients - this data will be extracted from the evidence if it is reported
SH	The Rarer Cancers Foundation	5	4.4.	Our comments are as follows – We would like to see a outcomes measurement related to increased patient satisfaction and patient confidence in the effectiveness of the referral for suspected cancer process. This could be recorded via patient experience surveys	Section 4.4 lists outcomes that will be looked for in the literature review. They are not intended to be outcomes that we hope to achieve through implementation of the guideline.
SH	Breakthrough Breast Cancer	14	4.4 a)	For breast cancer, the main outcome proposed regarding the proportion of people diagnosed via the two week wait referral system applies to different systems in England, and Wales and Northern Ireland where this clinical guideline will also be applicable. In England, all patients referred with *breast symptoms, even if cancer is not suspected,* should be seen within two weeks of referral. While in Wales there is no maximum waiting time target for referral, the National Standards state: *Initially efforts have been directed to ensure that patients referred urgently with suspected cancer are offered an appointment with a member of the MDT within 10 working days*. The	Section 4.4 lists outcomes that will be looked for in the literature review. They are not intended to be outcomes that we hope to achieve through implementation of the guideline. Audit criteria will be produced to support the recommendations within the guideline.

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				Welsh strategy for the management of breast cancer is currently being updated. In Northern Ireland all *urgent breast cancer* referrals should be seen within 14 days. Greater clarity regarding this outcome in the NICE guideline is needed for breast cancer. In England the outcome measure will have less meaning for evaluating referral practices as the vast majority of people referred with breast symptoms will be seen via the two week referral system. References: - Department of Health. Cancer Reform Strategy. Dec 2007 - Welsh Assembly Government. National Standards for Breast Cancer Services 2005. Jan 2005 - http://www.dhsspsni.gov.uk/priorities-for-action-2010-11.pdf A main outcome measure that would be very useful to capture would be the proportion of people whose cancer is diagnosed at stages 1 and 2 versus those diagnosed at stages 3 and 4. This would provide consistency with the measure proposed in the Department of Health's Public Health Outcomes Framework. It should also be noted that Wales may be developing 'health gain' targets for cancer beyond 2012 which may also be of relevance to the update of this guideline. Reference: - Department of Health. Improving outcomes and supporting transparency: Part 1: A public health outcomes framework for England, 2013-2016. Jan 2012 - http://wales.gov.uk/topics/health/research/research/gain/?lang=en	
SH	Pancreatic Cancer Action	8	4.4 (b)	Also include here the number of actual visits the patient has made to the GP as well as the time interval.	This is not intended to be an exhaustive list of outcomes. The Guideline Development Group will agree outcomes for each clinical question.
SH	Breakthrough Breast Cancer	15	4.4 b)	The measure of the interval between first symptom presentation in primary care and eventual cancer diagnosis is useful although we would welcome further information on how the interval will be accurately measured.	This is an outcome that will be looked for in the literature review; we feel the current definition is adequate.
SH	Breakthrough Breast Cancer	16	4.4 d)	Further detail about the measurement of health-related quality of life as an outcome measure is needed. At what point will this be	Section 4.4 lists outcomes that will be looked for in the literature review. The

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				measured (e.g. during primary care monitoring, after referral, after diagnosis, after treatment and if so, how long after treatment), and will all patients who present with symptoms be measured (i.e. those who are referred and those who are monitored in primary care)? It is essential to ensure that any measures of health-related quality of life are meaningful in different scenarios. We would also be interested to read how health-related quality of life will be measured and determined to better understand potential implications for people presenting with signs and symptoms of breast cancer.	Guideline Development Group will agree detailed parameters when agreeing each clinical question. Quality of life will be reported where available, further detail of quality of life reported will feature in the guideline.
SH	Children's Brain Tumour Research Centre, University of Nottingham	5	4.5	When calculatingly the economic costs for children it is important to also consider the economic costs to the parents and carers and also potential lost revenue from adult life if a late diagnosis leads to a child developing a life-altering disability e.g. blindness with brain tumours.	Thank you for this information
SH	Guy Francis Bone Cancer Research Fund	7	4.5	This should include a recognition of "special circumstances", for example the observations set out in the NICE document - "Osteosarcoma - mifamurtide: discounting of health benefits in special circumstances - 07 September 2011".	This is standard text and we are not able to change it.
SH	Royal College of Paediatrics and Child Health	3	4.5	When calculatingly the economic costs for children it is important to also consider the economic costs to the parents and carers and also potential lost revenue from adult life if a late diagnosis leads to a child developing a life-altering disability e.g. blindness with brain tumours.	Thank you for this information
SH	Eli Lilly and Company Limited	5	4.5. Economic aspects	• Since the guideline will be looking at the cost-effectiveness of care processes leading to and including referral, the likely impact of cost considerations on the frequency of initial diagnostic testing, reassessment in primary care or frequency of immediate, urgent or non-urgent referrals should be taken into account. • Particularly for tumour types where symptoms are often a late feature of presentation and because the actual incidence per practice is low, recommendations need to be made around use of diagnostics and appropriate referral rates. Otherwise there is a risk that primary care is discouraged from referring/investigating on the basis of cost.	Thank you for your comments. Cost-effectiveness issues will be discussed by the Guideline Development Group when deciding which topics to prioritise for health economic evaluation.

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				The potential negative impact of any cost measures on best clinical practice should also be considered. This is especially relevant in terms of the new commissioning structure.	
SH	Oesophageal Patients Association	5	5.1.1	The changing epidemiology of Upper GI cancer should lead to a review of Section 1.4, page 17 in relation to the inclusion of a history of persistent heartburn as a symptom; and for relaxation of the age criterion so that patients under 55 years should be referred for endoscopy in greater numbers than at present. The following come from Wall CM, Charlett A, Caygill CPJ et al *Are newly diagnosed columnar-lined oesophagus patients getting younger?* European J Gastroenterol & Hepatol 2009, 29; 1127-31, from the 2009 National Statistics and from UKBOR data: 1. 27% of Barrett's patients are < age 55 at diagnosis. 2. This age at diagnosis is getting progressively younger. 3. In males(the predominant sufferers of adenocarcinoma) almost 12% are age < 55 at diagnosis 4. There is increasing anecdotal evidence, particularly among our own group, of OAC occurring in the 30s and 40s. In email discussion with Julia Hippisley-Cox, Julia states "I agree that work does support the inclusion of heartburn and indigestion as predictors for gastro-oesophageal cancer. We actually found that heartburn was association with more than twice the risk of gastro-oesophageal cancer in women and more than three times the risk in men. The risks associated with indigestion were four times and six times higher than those for patients without either indigestion or heartburn. " *Predictive effect of heartburn and indigestion and risk of upper gastro-intestinal malignancy* in British Journal of General Practice, March 2012.	Thank you for providing these data. The Guideline Development Group will examine all the relevant, available evidence when drafting their recommendations. Heartburn/dyspepsia have been added to section 4.3.1.d. The Guideline Development Group will examine all the relevant, available evidence when drafting their recommendations.
SH	Target Ovarian Cancer	3	5.1.3	We welcome the fact that CG122 as defined will be incorporated	Thank you.

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SH	British Association of Dermatologists (BAD)	6	GDG	The recruitment of this group seems to be largely made up of GPs. Given there is no requirement for GPs to undertaken any undergraduate or postgraduate training in dermatology and particularly skin lesion recognition this is of some concern. An accredited GP with a specialist interest in dermatology and skin cancer recommended to ensure adequate expertise is engaged. Skin cancer is the commonest cancer in the UK and is increasing, with more deaths from this than other cancers such as cervical cancer.	The Guideline Development Group will seek specialist advice if and when required.
SH	British Association of Oral and Maxillofacial Surgeons (BAOMS)	1	General	BAHNO – British Association of Head and Neck Oncologists are not listed in the contributor's listings. Professor Woodwards represented both BAOMS and BAHNO at the meeting on 19 March 2012. Please add BAHNO to the list.	We have passed this comment on to NICE so that they are added to the Stakeholder list.
SH	NHS Direct	1	General	NHS Direct welcome the guideline and have no comments on its content.	Thank you.
SH	Sarcoma UK	8	General	There has been recent publication in Lancet Oncology of analysis from the 2010 Cancer Patient Experience Survey conducted by NCAT. The paper covers the difficulty of diagnosis of some rarer cancers, although sarcoma has not been covered in this study because of some coding problems associated with being such a small group. It has been indicated that sarcoma comes into the harder to diagnose group identified in the paper. Following this paper the authors are developing a 'measure of diagnostic difficulty' based on three or more GP consultations before hospital referral. Sarcoma will be within this group, whether for younger patients with bone tumours or adult patients with all kinds of soft tissue tumour. We would recommend that the authors are consulted by the Guidance Development Group. *Variation in number of general practitioner consultations before hospital referral for cancer: findings from the 2010 National Cancer Patient Experience Survey in Englan.d Georgios Lyratzopoulos,*	Thank you for this information

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				Richard D Neal, Josephine M Barbiere, Gregory P Rubin, Gary A Abel: University of Cambridge: The Lancet Oncology, Volume 13, Issue 4, Pages 353 --- 365, April 2012	
SH	Sarcoma UK	9	General	We have one major concern. Our own surveys among patients suggest that the knowledge and actions of the consultant who takes the first GP referral are as critical to early diagnosis as the actions of the GP. Although the numbers are smaller than for delays caused by GPs dismissal of symptoms, inappropriate diagnostic approaches and inappropriate surgery (known internationally in the sarcoma community as a whoops! procedure) remain relatively common for sarcoma patients who are not referred along a sarcoma pathway. The role of the GP's inappropriate referral in these cases is usually forgotten amid recriminations about a consultant's failure. We would like to see a process in place so that GPs receive feedback on their referral performance. Where inappropriate decisions, particularly with rarer cancers, are made we believe that these should be publicised (anonymised) to all GPs in an area (eg by the Clinical Commissioning Group to all member practices) so that they are all aware and can learn from the experience.	We agree this is an important issue. However the decision to provide feedback to GPs on inappropriate referrals will need to be made locally. Recommendations on this issue cannot be made in the guideline.
SH	Sarcoma UK	10	General	A continuing specific area of concern is around retroperitoneal sarcomas. We believe that here is an important general lesson about rarer cancers. These tumours usually grow painlessly and with only minor discomfort for many months. When symptoms appear they are often vague and non-specific. Imaging is the certain way of identifying these tumours in the first instance, and is often the only diagnostic tool required. We recognise that with the proposed approach for this Guidance capturing vagueness and improving levels of suspicion among GPs should be enhanced. However we would welcome clear reminders to primary care practitioners that where patients do not respond to treatment based on vague symptoms, or where doubt persists about a preliminary diagnosis, it is important to consider a differential diagnosis which uses different diagnostic approaches. In recent years the largest sarcoma removed weighed 25kgs. The patient had been unsuccessfully treated for obesity for over three years – the key word here is unsuccessfully. There had been no	We accept rarer cancers pose a particular diagnostic challenge for GPs. The GDG will appraise the relevant evidence and hope to include general advice about persistence of symptoms and other factors relevant to rare cancers.

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				imaging.	
SH	Teenage Cancer Trust	1	General	Teenagers and young adults with cancer are at particular risk of delayed diagnosis. Teenage Cancer Trust has surveyed hundreds of young people with cancer about their diagnosis experience; 1 in 4 told us that they had to visit their GP four times or more before their cancer symptoms were recognised and referred for diagnosis. This self-reporting has been confirmed in recent research by Lyratzopoulos, G. et al, which shows that young people with cancer were more likely than other age groups to have three or more pre-referral consultations before being referred for diagnosis. (ref: Variation in number of general practitioner consultations before hospital referral for cancer: findings from the 2010 National Cancer Patient Experience Survey in England, 2012, Lancet Oncology) Furthermore, the RCGP's national audit of cancer diagnosis (2011) found that young people diagnosed with cancer have some of the lowest rates of GP practice presentation and are a group with the highest emergency admissions and unknown stage of diagnosis. It is clear that there are a range of difficulties in the diagnosis of cancer in teenagers and young adults. Better recognition of the signs and symptoms of cancer in young people could really help to address this. Fern, L. et al's research helps to identify key cancer alert symptoms in young people. In the analysis of GP records for these alert symptoms they found that only 4% of GP presentations by young people were for these alert symptoms. This makes the case for more recognition of these cancer alert symptoms, and the rarity of these symptoms suggests that they should stand out to GPs when presented. (ref: How frequently do young people with potential cancer symptoms	Thank you

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				present in primary care?, 2011) Teenage Cancer Trust believes that more needs to be done to raise awareness of teenage and young adult cancers with GPs, other healthcare professionals and the public. This guidance should help to increase awareness and achieve earlier diagnosis, and through specifying the teenage and young adult age group it has the potential to achieve improvements needed for this age group.	
SH	Guy Francis Bone Cancer Research Fund	8	General	Whilst we fully support the revision of NICE Clinical Guideline 27, we should like to also address how best to present the Guideline in such a way that, say, a GP can quickly recognise a single sign as part of a cluster of single signs which could be indicative of symptoms of a cancer. We understand that a leading University is investigating the development of an Apps as an electronic "prompt" for downloading onto GPs computers. We would suggest that this may be a cost effective route to speedier correct and unduly delayed diagnosis and/or referral.	Implementation tools will be developed to support users of the guideline to implement the recommendations. We will pass these suggestions on to the NICE implementation team
SH	The Royal College of Radiologists	1	General	Recognition of the importance of radiology in the investigation of suspected cancer by the inclusion of a radiologist on the guideline development group is welcomed. Whilst these guidelines are clearly focused in primary care and strong GP input is key to their development, the balance of the GDG between primary and secondary care could perhaps be improved by the inclusion of a secondary care physician (eg gastroenterologist or chest physician).	We will have two secondary care physicians on the GDG.
SH	The Royal College of Radiologists	2	General	Whilst it is recognized that these guidelines are focused upon the symptoms and signs of cancer in primary care, the efficiency of the referral pathway to secondary case is inexorably linked to the optimal management of these patients. It is suggested that the updated guidelines should consider inefficiencies in the current system. An area of particular concern for radiologists is patients who have undergone imaging in primary care or by secondary providers and a statement that 'malignancy cannot be excluded' has been included in the imaging report. Many patients are then inappropriately referred through the HSC pathway or for advanced imaging. Whilst this is partially a matter of poor quality control, it does also highlight	We agree that timely and accurate reporting of imaging is good clinical practice. We will advise on when it is appropriate to request radiological opinion, but will not ask the GP to request cancer exclusion.

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				inefficiencies in communication which should be considered in the guidelines. Optimising the quality of and communicating the results of imaging investigations are also issues for patients with suspected cancer undergoing investigation in primary care (section 4.3.1b).	
SH	The Prostate Cancer Charity	1	General	The Prostate Cancer Charity is the UK's leading charity working with people affected by prostate cancer. We fund research, provide support and information, and campaign to improve the lives of people affected by prostate cancer. The Charity is committed to ensuring that the voice of people affected by prostate cancer is at the heart of all we do.[viii] The Prostate Cancer Charity welcomes the opportunity to comment on the scoping document for suspected cancer: recognition and management.	Thank you.
SH	The Prostate Cancer Charity	7	General	Delay in NICE quality standard for prostate cancer The Charity is concerned that the decision last year by NICE to delay the development of a quality standard for prostate cancer will have a significant impact on the care that men receive. Key aspects of the quality standard for prostate cancer relate to the referral and diagnostic process. Currently, it looks highly unlikely that a quality standard for prostate cancer will produced until Autumn 2014. Therefore, the Charity is currently developing its own standards of quality care in consultation with those affected by prostate cancer.	The decision from NICE to separate the quality standard from the guideline came about following the experience of developing quality standards for a broad range of topics over the past 24 months, including two pilots where quality standards were developed in conjunction with relevant guidance. NICE is much clearer about the difference between guidelines/guidance and quality standards and this has led to the decision that we need a different approach to developing a clinical guideline/guidance from a quality standard, albeit very much using the expertise of topic experts in a particular subject area. It can be challenging for GDGs to position a quality standard across the breadth of the whole pathway of care, including the outcomes

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					frameworks in health, social care and public health. NICE appreciates your input into the development of the clinical guideline and we hope that you will provide that same level of input when the NICE prostate quality standards are developed.
SH	Central South Coast Cancer Network	1	General	The guidance doesn't seem to specifically mention shoulder pain as a possible presenting symptom for lung cancer	Thank you for your suggested additional symptoms. Section 4.3.1 lists symptoms recognised as frequently occurring in patients with cancer presenting to primary care. We have added appetite loss, haematemesis, heartburn/dyspepsia, bony and soft-tissue masses to this list. If our searches utilising these symptoms in primary care, uncover any important omissions, these will be included in the guideline
SH	British Dental Association	1	General	The British Dental Association welcomes a partial update of this guideline. The inclusion of new evidence relating to signs and symptoms as well as initial investigation will be beneficial and could work towards increasing the accuracy and speed of the referral process as well as lessening the variation in guideline implementation. Mouth cancer incidence has been increasing over the last decade. This increase is not being met by an increase in survival rate which itself is related to early detection. For these reasons The Association would like to draw attention to common signs of mouth cancer that have not been included in the scope document: • a growth or swelling which has been present for more than about two weeks • a white or red patch in the mouth.	Thank you. Section 4.3.1d lists symptoms recognised as frequently occurring in patients with cancer presenting to primary care. If our searches utilising these symptoms in primary care, uncover any important omissions, these will be included in the guideline.

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				While we understand the list provided is not exhaustive we believe that the importance of their inclusions warrants their mention.	
SH	The Royal College of General Practitioners	1	General	I think a symptom based approach is an excellent way forward	Thank you.
SH	The Royal College of General Practitioners	2	General	Any risk assessment tool must account for age and sex, smoking, co-morbidities and also symptom clusters. A good example is http://www.qcancer.org/all-in-one/ which we developed in Nottingham	Thank you for this information.
SH	The Royal College of General Practitioners	3	General	There have been a range of papers on cancer risk assessment which we have published in the RCGP journal in the last 6 months which should be considered by the committee (see 5)	Thank you for this information. The GDG will examine all the relevant, available evidence when drafting their recommendations.
SH	The Royal College of General Practitioners	5	See 3.	1. Hippisley-Cox J, Coupland C. Identifying patients with suspected lung cancer in primary care: derivation and validation of an algorithm. *Br J Gen Pract* 2011;61(592):e715-23. 2. Hippisley-Cox J, Coupland C. Identifying patients with suspected gastro-oesophageal cancer in primary care: derivation and validation of an algorithm. *Br J Gen Pract* 2011;61(592):e707-14. 3. Hippisley-Cox J, Coupland C. Identifying patients with suspected pancreatic cancer in primary care: derivation and validation of an algorithm. *British Journal of General Practice* 2012;62(594):e38-e45. 4. Hippisley-Cox J, Coupland C. Identifying patients with suspected colorectal cancer in primary care: derivation and validation of an algorithm. *British Journal of General Practice* 2012;62(594):e29-e37. 5. Hippisley-Cox J, Coupland C. Identifying women with suspected ovarian cancer in primary care: derivation and validation of algorithm. *BMJ* 2012;344. 6. Hippisley-Cox J, Coupland C. Identifying patients with suspected renal tract cancer in primary care: derivation and validation of	Thank you for this information.

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				an algorithm. *British Journal of General Practice* 2012;62(597):e251-e60.	
SH	The Royal College of General Practitioners	6	General	Agree that a symptom based assessment tool for primary care is important. Professor Hippisley-Cox has mentioned her symptom based tools in a separate submission through the RCGP. We are also aware of other important tools such as the Hamilton risk assessment tool which is going through evaluation. The scope should cover the range of tools that might be on offer to primary care.	Thank you. These issues will be discussed with the GDG when agreeing the clinical questions (PICO).
SH	The Royal College of General Practitioners	7	General	Also agree with symptoms that should be included such as appetite loss, heartburn/dyspepsia, haematemesis, change in bowel habit	Thank you for your suggested additional symptoms. Section 4.3.1 lists symptoms recognised as frequently occurring in patients with cancer presenting to primary care. We have added appetite loss, haematemesis, heartburn/dyspepsia, bony and soft-tissue masses to this list. If our searches utilising these symptoms in primary care, uncover any important omissions, these will be included in the guideline
SH	Royal College of Paediatrics and Child Health	1	General	Please find attached copies of articles which may be of help – 2 attachments UK Guidelines for management of bone Brit Journal Gen Practice_paper (RCPC	Thank you for this information.
SH	The Royal College of Nursing	1	General	The Royal College of Nursing welcomes proposals to update this guideline. It is timely. The draft scope seems comprehensive.	Thank you.
SH	Gorlin Syndrome Group	1	General	The new title appears to be representative of the areas covered by the scope.	Thank you.
SH	Gorlin Syndrome Group	2	General	The guidance is clear, concise and adequately describes the referral process for suspected cancer. On this occasion we have nothing further to add.	Thank you.
SH	Cancer Research UK	5	General	We would recommend that this guideline is considered in the context of the range of other guidelines/frameworks recently published or in	The GDG will examine all the relevant, available evidence when drafting their

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				development, such as the NHS Outcomes and NHS Commissioning Frameworks and Quality Standards relating to cancer. It is important that where there is crossover, the messages for commissioners and clinicians are consistent and robust.	recommendations.
SH	Cancer Research UK	6	General	The revised guideline needs to consider and include relevant information contained in the Department of Health's guidance on direct access to diagnostic tests for cancer which was published in April 2012. This guidance includes best practice referral pathways for general practitioners in four priority areas for diagnostics for improving earlier diagnosis of cancer: • Non-obstetric ultrasound: to support diagnosis of ovarian cancer • Chest X-ray: to support diagnosis of lung cancer • Flexible-sigmoidoscopy: to support the diagnosis of colorectal cancer • Brain MRI: to support diagnosis of brain cancer http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_133510	The GDG will examine all the relevant, available evidence when drafting their recommendations.
SH	Cancer Research UK	7	General	We recommend that discussion and thought about the format and dissemination of the final guideline should take place at this stage to ensure that it is drafted and published in the most appropriate way for the largest number of GPs to use and follow.	We agree that the guideline needs to be easy to use. We will endeavour to structure it in such a way to achieve this aim. The format and dissemination of the final guideline will be discussed with the Editorial and Implementation teams at NICE
SH	The Rarer Cancers Foundation	6	General	Our comments are as follows – Where within this process is it appropriate to look at the impact of management referral systems on the ability of GP practices to refer individual patients for diagnostic tests?	We will not be looking at management referral systems. We will be making recommendations on when to refer and when to investigate
SH	North Trent Cancer Network (NTCN)	1	General	No problem with this document	Thank you.
SH	North Trent Cancer Network	2	General	This guideline update is welcome	Thank you.

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	(NTCN)				
SH	North Trent Cancer Network (NTCN)	3	General	More emphasis should be put on identifying patients with features of early disease (e.g. cough/ haemoptysis) rather than those with advanced disease that will usually come very quickly to attention through their being unwell	Our focus is on identifying cancer in any patient with a suspicious symptom. We consider that equal weight should be given to all symptoms, regardless of whether they are early or advanced.
SH	Pancreatic Cancer UK	1	General (Proposed guideline title)	We agree that the former title is not appropriate. However, we are concerned that the proposed new title lacks a sense of purpose and action. We are also concerned that the title may not be obvious to those who may need to "search" for the guidelines. Perhaps something more along the lines of - *suspected cancer in primary care settings: guidelines for recognition, management and investigation* – would provide those working in primary care better insight into the purpose of the guideline	We have retained the current title. We consider that the word management encompasses more than just treatment – including investigation and safety netting.
SH	Pancreatic Cancer Action	1	Guideline Title	Agree the title needed improving. We feel the emphasis should be on recognising the disease to facilitate earlier diagnosis. Also feel it unnecessary to differentiate between age groups in the title as they are all covered. Perhaps a little tweak could be as follows: "*Recognising cancer: symptoms, investigations and management of suspected cancer in the UK population"*	We have retained the current title. We consider that the word management encompasses more than just treatment – including investigation and safety netting.
SH	Teenage Cancer Trust	2	Title	We welcome the change to the title as it more accurately reflects the purpose of the guidance. We welcome the inclusion of 'children, young people and adults' in the title.	Thank you.
SH	Samantha Dickson Brain Tumour Trust	1	Title	"Suspected cancer: recognition and management of suspected cancer in children, young people and adults" We consider this an improvement to the originally proposed title 'Referral for suspected cancer' which did not adequately reflect that a diagnosis pathway also include the timely diagnostic assessment(s) and providing the outcome to the patient.	Thank you.

These organisations were approached but did not respond:

A Little Wish
Abbott GmbH & Co KG
Alder Hey Children's NHS Foundation Trust
All Wales Dietetic Advisory Committee
Aneurin Bevan Health Board
Anglesey Local Health Board
Anglia cancer network
Arden Cancer Network
Association of Anaesthetists of Great Britain and Ireland
Association of Breast Surgery
Association of British Insurers
Association of British Neurologists
Association of Clinical Pathologists
Association of Coloproctology of Great Britain and Ireland
Association of Surgeons of Great Britain and Ireland
Association of Upper Gastrointestinal Surgeons of Great Britain and Ireland
Astrazeneca UK Ltd
Bard Limited
Barrett’s Oesophagus Campaign
Baxter Healthcare
Bayer HealthCare
Beating Bowel Cancer
BME cancer.communities
Bolton Hospitals NHS Trust
Bradford and Airedale Primary Care Trust
Bradford District Care Trust
Breast Cancer Campaign

Breast Cancer Care
Bristol and Avon Chinese Women's Group
British and Irish Orthoptic Society
British Association of Oral Surgeons
British Association of Surgical Oncology
British Association of Urological Surgeons
British Committee for Standards in Haematology
British Dietetic Association
British Gynaecological Cancer Society
British Heart Foundation
British Liver Trust
British Lung Foundation
British Medical Association
British Medical Journal
British National Formulary
British Nuclear Medicine Society
British Paediatric Neurology Association
British Psychological Society
British Psychosocial Oncology Society
British Society for Colposcopy and Cervical Pathology
British Society of Paediatric Radiology
British Society of Gastroenterology
British Society of Haematology
British Thoracic Society
British Thyroid Foundation
BUPA Foundation
C. R. Bard, Inc.

Cambridge University Hospitals NHS Foundation Trust
Camden Link
Cancer Black Care
Cancer of Unknown Primary
Cancer Services Collaborative Primary Care Lead
Cancer Services Co-ordinating Group
Cancer Voices
Cancer52
Caper Research Unit
Care Quality Commission (CQC)
Central & North West London NHS Foundation Trust
Central Manchester and Manchester Children's Hospital NHS Trust
Chartered Society of Physiotherapy
Chronic Lymphocytic Leukaemia Support Association
City Hospitals Sunderland NHS Foundation Trust
CLIC Sargent
Cochrane Oral Health Group
Community District Nurses Association
ConvaTec Ltd
Cwm Taf Health Board
Department for Communities and Local Government
Department of Health, Social Services and Public Safety - Northern Ireland
Dorset Primary Care Trust
Dudley PACT Patient Advisory Cancer Team
Eisai Ltd
Equalities National Council
Faculty of Dental Surgery

Faculty of Public Health
Fibroid Network Charity
GE Healthcare
General Practice and Primary Care
George Eliot Hospital NHS Trust
GIST Support UK
GlaxoSmithKline
Gloucestershire LINk
Great Western Hospitals NHS Foundation Trust
Greater Manchester and Cheshire Cancer Network
Greater Midlands Cancer Network
Guerbet Laboratories Ltd
Health Protection Agency
Health Quality Improvement Partnership
Healthcare Improvement Scotland
Help Adolescents With Cancer
Hertfordshire Partnership NHS Trust
Hindu Council UK
Hull and East Yorkshire Hospitals NHS Trust
Humberside Oesophageal Support Group
Imaging Equipment Ltd
Impact of Neutropenia in Chemotherapy European study group
Imperial College Healthcare NHS Trust
Independent Healthcare Advisory Services
International Brain Tumour Alliance
James Whale Fund for Kidney Cancer
KCARE

Kidney Cancer Support Network
Kidney Cancer UK
Lancashire Care NHS Foundation Trust
Lancashire Teaching Hospitals NHS Trust
Leeds Teaching Hospitals NHS Trust
Leicestershire County and Rutland Primary Care Trust
Leukaemia & Lymphoma Research
Leukaemia Society
Leukemia Research Fund
Lilly UK
Link Pharmaceuticals
Liverpool Primary Care Trust
London Cancer
Luton and Dunstable Hospital NHS Trust
Macmillan Cancer Support
Maidstone and Tunbridge Wells NHS Trust
Medicines and Healthcare products Regulatory Agency
Medway NHS Foundation Trust
Merseyside & Cheshire Cancer Network
Mid Staffordshire NHS Foundation Trust
Ministry of Defence
Mole Clinic Ltd, The
Mouth Cancer Foundation
Musculoskeletal Association of Chartered Physiotherapists
Myeloma UK
National Alliance of Childhood Cancer Patient Organisations
National Cancer Action Team

National Cancer Intelligence Network
National Cancer Network Clinical Directors Group
National Cancer Research Institute
National Institute for Health Research Health Technology Assessment Programme
National Kidney Research Foundation
National Patient Safety Agency
National Public Health Service for Wales
National Radiotherapy Implementation Group
National Treatment Agency for Substance Misuse
NET Patient Foundation
Newham Primary Care Trust
NHS Clinical Knowledge Summaries
NHS Connecting for Health
NHS Milton Keynes
NHS National Cancer Screening Programmes
NHS Norfolk Primary Care Trust
NHS Plus
NHS Sheffield
NHS South Birmingham
NHS Trafford
NHS Wandsworth
NHS Warwickshire Primary Care Trust
North East Lincolnshire Care Trust Plus
North East London Cancer Network
North of England Cancer Network
North Staffordshire Cancer Service User Forum
North Yorkshire & York Primary Care Trust

Northern Ireland Cancer Network
Nottingham City Hospital
Nottinghamshire Healthcare NHS Trust
Novartis Pharmaceuticals
Oldham Primary Care Trust
Ovacome
Oxfordshire Primary Care Trust
Pan Birmingham Cancer Network
PERIGON Healthcare Ltd
Peterborough and Stamford Hospitals NHS Foundation Trust
Pfizer
Pharmametrics GmbH
POhWER
Primary Care Respiratory Society UK
Pseudomyxoma Survivor
Public Health Wales NHS Trust
QResearch
Queen Elizabeth Hospital
Queen's Medical Centre Nottingham University Hospitals NHS Trust
Roche Diagnostics
Roche Products
Rotherham Primary Care Trust
Roy Castle Lung Cancer Foundation
Royal Berkshire NHS Foundation Trust
Royal Brompton Hospital & Harefield NHS Trust
Royal College of Anaesthetists
Royal College of General Practitioners in Wales

Royal College of Midwives
Royal College of Obstetricians and Gynaecologists
Royal College of Ophthalmologists
Royal College of Paediatrics and Child Health , Gastroenetrology, Hepatology and Nutrition
Royal College of Pathologists
Royal College of Physicians
Royal College of Psychiatrists
Royal College of Speech & Language Therapists
Royal College of Surgeons of Edinburgh
Royal College of Surgeons of England
Royal National Institute of Blind People
Royal National Orthopaedic Hospital NHS Trust
Royal Pharmaceutical Society
Royal Society of Medicine
Royal Surrey County Hospital NHS Trust
Royal United Hospital Bath NHS Trust
Royal West Sussex NHS Trust
Sarcoma Information Services Ltd.
Schering Health Care Ltd
School of Health and Population Sciences
Scottish Intercollegiate Guidelines Network
Sheffield Teaching Hospitals NHS Foundation Trust
Skin Care Campaign
SNDRi
Social Care Institute for Excellence
Society and College of Radiographers
Society for Cardiothoracic Surgery of Great Britain and Ireland

Society of British Neurological Surgeons
South Asian Health Foundation
South Staffordshire Primary Care Trust
South Wales Cancer Network
Step4Ward Adult Mental Health
Sue Ryder Care
Sussex Cancer Network
Swindon and Marlborough NHS Trust
Tameside Hospital NHS Foundation Trust
Teenagers and Young Adults with Cancer
Tenovus Cancer Information Centre
Thames Valley Cancer Network
The Anthony Pilcher Bone Cancer Trust
The Association for Clinical Biochemistry
The British In Vitro Diagnostics Association
The Hepatitis C Trust
The National LGB&T Partnership
The Neurofibromatosis Association
The Princess Alexandra Hospital NHS Trust
The Rotherham NHS Foundation Trust
The University of Glamorgan
The Walton Centre for Neurology and Neurosurgery

UCL Partners
UK Childhood Leukaemia Working Party
UK Children's Cancer Study Group
UK Clinical Pharmacy Association
University College London Hospital NHS Foundation Trust

Welsh Cancer Services Coordinating Group
Welsh Government
Welsh Scientific Advisory Committee
Western Cheshire Primary Care Trust
Westminster Local Involvement Network
Wirral University Teaching Hospital NHS Foundation Trust
Women's Health Concern
York Hospitals NHS Foundation Trust

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[i] Prostate Cancer – UK incidence statistics. Cancer Research UK http://info.cancerresearchuk.org/cancerstats/types/prostate/incidence/#trends
[ii] Prostate Cancer Risk Management Programme http://www.cancerscreening.nhs.uk/prostate/prostate-booklet-text.pdf

[iii] ibid
[iv] Schroder F, et al. Screening and prostate-cancer mortality in a randomised European Study. *The New England Journal of Medicine*. 2009. 360: 1320–8.

[v] Prostate Cancer Risk Management Programme (PCRMP) http://www.cancerscreening.nhs.uk/prostate/about-pcrm.html
[vi] Kantar Health conducted web based interviews on behalf of The Prostate cancer Charity with 505 GPs from across the UK drawn from TNS healthcare professional panels in February 2011.

[vii] Johns LE, Houlston RS. A systematic review and meta-analysis of familial prostate cancer risk. BJU International. 2003;91:789-794.

[viii] Transforming the future for prostate cancer: The Prostate Cancer Charity's 2020 goals and 2008-2014 strategy. The Prostate Cancer Charity 2008. Available at: http://www.prostate-cancer.org.uk/about-us/what-we-do/our-strategy