Referral guidelines for suspected cancer
Consultation with stakeholders on the draft scope: comments received and responses made to them by the Institute in collaboration with the NCC-PC

The National Institute for Clinical Excellence has commissioned the National Collaborating Centre for Primary Care (NCCPC) to develop a clinical guideline on referral guidelines for suspected cancer for use in the NHS in England and Wales. The draft scope was subject to four weeks' consultation (2-30 September 2002) with stakeholders. This document contains the comments submitted by stakeholders during the consultation period and the responses made to them by the Institute in collaboration with the NCC-PC.

Only stakeholders who responded to the consultation are listed here. For a complete of stakeholders registered for this guideline, please see the NICE website – link attached - http://www.nice.org.uk/cat.asp?c=33928
<table>
<thead>
<tr>
<th>Company</th>
<th>Comments</th>
<th>Response</th>
</tr>
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<tbody>
<tr>
<td>AstraZeneca UK Ltd</td>
<td>Regarding the above clinical guidelines from NICE, we have received and reviewed the draft scope. The scope appears to be comprehensive in its coverage of the different cancers and as is already highlighted in the document, AstraZeneca would concur that time to referral for the different cancers is key regarding the treatment of these diseases. AstraZeneca UK therefore have no further comments regarding the scope. We look forward to working with the developers of this particular guideline in the near future.</td>
<td>Noted</td>
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<tr>
<td>Bournemouth PCT</td>
<td>Thank you for the opportunity for commenting on your draft proposals for the referral guideline document. I presume that you are planning to create standard care pathways for patients with suspected cancer so that the standard of care is the same from the Isles of Scilly to Northumbria. Two issues come to mind. We already have some excellent &quot;Guidelines for urgent referral of patients with suspected cancer&quot; which I hope most GPs and secondary care doctors follow but I do know that locally it is still the minority of cases that are actually referred via the &quot;Centralised Urgent fax&quot; system set up in all of our local Acute Hospitals, which requires patients to be referred within 24 hours. Patients are still referred urgently but are being done so in the more traditional way of the GP faxing or telephoning Consultants directly, by-passing the audited system. This allows mistakes to occur and occasionally still some patients with worrying symptoms are being referred &quot;routinely&quot;. How can you address this? Secondly if you are going to set out a standard set of investigations etc for referring doctors to do prior to referral then you must make sure that all GPs have the same access to investigation services. I am aware that different hospitals allow GPs to do different investigations. Some places will let GPs organise CT scans and contrast radiography but locally even though I can organise a barium enema I cannot obtain a CT scan or MRI scan without referring the patient. I have no direct access. Also even if GPs can refer for investigations how can you control the waiting times for these? It takes 3-4 weeks for me to obtain an ultrasound scan on a patient and then the report may take another 7-10 days to arrive in the surgery. This makes a mockery of the &quot;Urgent&quot; cancer referral system. If it takes a GP so long to do the</td>
<td>This comment is concerned with local organisational or administrative systems. Detailed consideration of these issues is outside the scope since local circumstances will vary. The guideline will address initial investigations, and will take note of these points, including the issue of access to investigations.</td>
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investigations then you can see why many GPs then think that to HAVE to make the referral within 24 hours of having made the decision to refer is just an extra administrative hurdle which GPs have to jump over.

If the care pathways are to be successful then ALL acute hospitals must be able to provide the same standard of care. The same investigations MUST be available to all GPs wherever they practise and that if the investigations are being done, due to the patient having a suspected cancer, they must be available quickly.

I feel that the hospital infrastructure must be improved either before or at least at the same time as the guidelines are written.

Breakthrough Breast Cancer

Please find below the response from Breakthrough Breast Cancer regarding draft scope on the referral guideline for suspected cancer.

Breakthrough Breast Cancer is a charity committed to fighting breast cancer through research and awareness, in order to obtain our vision - a future free from the fear of breast cancer. Breakthrough has established the first dedicated breast cancer research centre in the UK, in partnership with the Institute of Cancer Research, which opened in 1999.

We welcome the timely development of this guideline. Breakthrough has a number of concerns about the current referral process for suspected breast cancer, which we feel need be addressed.

With specific reference to this guideline we feel very strongly that the guideline has to also consider the impact of delay on quality of life with regards to increased anxiety as well as survival. The significance of the number cancer related deaths mean that cancer is a very real fear for people in this country. A survey carried out by Breakthrough Breast Cancer last year revealed that breast cancer is the number one health concern for women in the UK. This can mean that the period of delay between visiting a GP and seeing a specialist is an extremely stressful time for any individual and should be kept to a minimum, regardless of the potential outcome.

Likewise, when considering the need for urgent referral it is essential the guideline examines the evidence for how many non-urgent referrals are ultimately diagnosed as cancer. As stated above, the impact this delay has on increased anxiety as well as survival has to be considered.

With regard to breast cancer, evidence shows that around one third of
women who ultimately are diagnosed as having breast cancer were referred non-urgently (S Thrush, G Sayer, D Scott-Coombes and J.V.Roberts (2002) Grading referrals to specialist breast unit may be ineffective, BMJ, 324; 1279). There is evidence that GPs are not following referral guidelines as rigorously as they could be. However, asking GPs to distinguish between urgent and non-urgent for different types of cancers, is essentially asking them to make a pre-diagnosis which they are not qualified to do.

Thank you for allowing us to comment and we hope that due consideration is taken to the issues that we have raised.

<table>
<thead>
<tr>
<th>Breast Cancer Care</th>
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| I enclose comments from Breast Cancer Care on the draft scope for referral guidelines for suspected cancers Thank you for inviting us to comment and contribute to the development of these on these guidelines. Breast Cancer Care is the leading provider of breast cancer information and support across the UK. We are committed to providing accessible, high-quality services for everyone affected by breast cancer. All our services are free and include a helpline, nurse specialists, website, publications, and practical and emotional support. In terms of local services we provide volunteer led peer support, prosthesis fittings and educational programmes.

The nature of our work at Breast Cancer Care means that we are in constant contact with people affected by breast cancer through the services we provide and our volunteer network. This means we are in an excellent position to represent the views and opinions of people affected by breast cancer.

Breast Cancer Care is very interested in the development of effective and robust referral guidelines for suspected cancer for two main reasons. Firstly, early detection of breast cancer and fast access to treatment can lead to better treatment outcomes. We are therefore interested in any work that will ensure individuals suspected of having breast cancer are referred for diagnosis as soon as possible and that individuals are not misdiagnosed. Secondly, through our work we have become very aware of the anxiety and stress individuals experience when they suspect they have breast cancer. We would like to ensure that the referral process helps to minimise this stress and anxiety.

We look forward to continuing to work with you on this project.

**Comments from Breast Cancer Care**

We hope the recommendations in the guideline will lead to a reduction in the numbers of cases referred non-urgently.
Section 4.1.1.a) Groups and categories that will be covered

- We are interested to know whether the guidelines will include information on the risk of different cancers for different ethnic groups as well as age groups.

- Breast Cancer Care believes the referral guidelines should include recognition of the fact that different ethnic or age groups might have particular difficulties in discussing possible symptoms of cancer with a health professional. The guidelines should include advice on this issue.

Section 4.1.1.d) The guideline will address the information needs of patients who are referred for suspected cancer

- Breast Cancer Care believes information given to patients at the time of referral should stress that they can return to their GP if they have any concerns in between the time of referral and their appointment. This is especially important in the case of non-urgent referrals because patients can be waiting up to 12 weeks for an appointment. Individuals in this group should be informed that they can return to their GP if they notice any further changes or symptoms while waiting for their appointment.

Section 4.2 d) The guideline will also be relevant to the work, but will not cover the practice, of those working in: accident and emergency departments, walk-in centres, NHS Direct, voluntary sector

- Breast Cancer Care believes if the guideline is relevant to the work of accident and emergency departments, walk-in centres, NHS Direct, and the voluntary sector it should also cover their working practice. Each of these organisations could potentially be the first point of contact with the health system for individuals with cancer. It is important that clear procedures are in place in these settings for handling suspected cancer, in particular to ensure people not ‘fall through the net’. Walk-in centres may increase in importance as providers of primary care and some individuals may begin to rely on these centres rather than have a regular GP, it is therefore essential that they have robust referral procedures.

Section 4.3) Clinical Management

We agree that walk-in centres and other providers should have robust referral procedures. The guideline will provide clinical recommendations that will be relevant to clinicians in these services, although will not provide a service framework, or stipulate operational or administrative procedures for such providers.
- Although diagnosis itself is not covered in the guideline, we feel it is important that the guideline includes the procedure for informing the referring GP or health professional about the results of the diagnosis. The individual may wish to return to the referring health professional to discuss their diagnosis or seek advice and it is therefore important that the health professional is well informed in order to communicate effectively with the person about the next steps.

- In terms of the urgent/ non-urgent classification of referrals the guidelines should consider the effect on the individual of being labelled urgent or non-urgent. If the patient is aware they are being referred urgently this may lead to increased anxiety and the guidelines should cover effective communication with the individual to help them cope with the anxiety of waiting for an appointment and diagnosis.

- At Breast Cancer Care we are concerned about the urgent /non-urgent classification of patients because research has shown that a significant proportion of women who are found to have breast cancer have been labelled as non-urgent by their GP. An AUDIT carried out by the British Association of Surgical Oncology found that some individuals have had to wait 12 weeks for an appointment as a result of being classified as non-urgent. During the process of drawing up these guidelines the system of classifying patients as urgent referrals should be thoroughly reviewed to ensure it is more effective in the future at identifying urgent and non-urgent referrals.

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<table>
<thead>
<tr>
<th>British Association of Dermatologists, The</th>
<th>Thank you for the opportunity to comment on this scope.</th>
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<td></td>
<td>Whilst we are in agreement with the overall need for referral guidelines, we have doubts about the need for further guidance on skin cancer referral for those tumours already covered by the 2-week referral process – in the case of skin cancers, melanoma and squamous cell carcinoma of the skin.</td>
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<td></td>
<td>The British Association of Dermatologists has an active Therapy and Guidelines group: this group is responsible for the development and assessment of guidelines used by our members. It would be the ideal vehicle for discussion of any proposed referral guidelines within the field of Dermatology. Previous NICE referral guidelines (acne, eczema) were developed with minimal input from our organisation, and we would wish to avoid this for skin cancer.</td>
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We agree that the referring health professional needs full and timely information. Detailed recommendations on this issue would substantially extend the scope of the guideline, and therefore it will only be considered in general terms.

We agree the guideline should address information and support needs.

The classification of urgent and not-urgent referrals will be reviewed.
We anticipate, although this is not clear from the scope document, that there will be separate guidance for each type of cancer, not just between specialities, but between different types of cancer within a speciality grouping: thus the referral guidelines for a basal cell skin cancer must be different from those for a suspected malignant melanoma, for example.

It is often the case that guidance on referral is followed by an increase in the numbers of patients referred. Referral guidelines are unlikely to improve the diagnostic ability of GPs, and current referral practices lead us to believe that any diagnostic difficulty results in referral, often inappropriately through the two-week referral system. Dermatology services around the country are already stretched beyond their limits, not least by artificial access targets imposed across the whole range of outpatient referral. Accurate diagnosis can only be provided through a predominantly consultant delivered or at least consultant led service. Will NICE be considering the implications of referral guidelines for the clinical services concerned, and will funding for additional consultant posts be attached to the guidance? If not, either targets for skin cancer will be unachievable, or patients with inflammatory skin disease will be severely disadvantaged.

Patient information is valuable if the information is relevant and appropriate. Since the patient’s diagnosis will be unknown at the time of referral, and only between 1 in 25 and 1 in 100 of those referred actually has a skin cancer, what information will be provided that will not produce unnecessary anxiety in the bulk of patients who do not have skin cancer? Many patients currently referred are unaware that they will attend a skin cancer-screening clinic, and are very anxious when they discover the fact. They are also disappointed when their benign skin lesion is not removed on their attendance at hospital. Information that dispels anxieties and explains the purpose of the clinic visit is already used by many Dermatology departments, but standardisation would be valuable.

It is difficult to imagine advice on management between referral and diagnosis that could be meaningful. Until a diagnosis is made, symptomatic treatment is all that is possible: such advice would not normally form part of a referral guideline.

We agree.

We hope that the guideline will lead to improved diagnostic accuracy, although we note the comment about potential impact on numbers of referrals. NICE guidelines consider cost-effectiveness, and we hope the recommendations of the guideline development group would be taken into account by those planning services.

A patient told they are being referred does require some information, for example on why the referral is necessary. The guideline will consider what information is required. Information needs will be influenced by the type of cancer in question.

Clinical management of the cancer may not be appropriate, but other aspects of primary care patient management should be considered, for example responses to patients’ requests for additional information.

The guideline will cover the suggestive symptoms and signs, and the scope has been
some form of investigation. Although para 4.1.1c may cover this, the term 'investigation' does not usually cover symptomotology and clinical features I feel that such a guideline for referral should include signs and symptoms of the individual cancers which should lead to a suspicion of cancer and subsequent referral and/or investigation amended to clarify this point. The guideline will consider the principal individual cancers in each of the 12 sites indicated in the scope.

| British Dental Association | The BDA would like to be sure that oral cancer is included in the scope of this project. We assume that it is covered by head and neck cancers. A significant number of suspected oral cancers are identified in general dental practice. We agree that oral cancers should be included by head and neck cancers. |
| British Medical Association | Thank you for sending us the draft scope on referral guidelines for suspected cancers and inviting us to comment on its development. As a stakeholder, the British Medical Association would like to put forward the following comments. Clinical Management - Paragraph 4.3.a The BMA considers that reference to the diagnosis of suspected cancer as “usually undertaken in specialist care after referral” misleading, and the subsequent exclusion of ‘diagnosis’ from the scope erroneous. Diagnosis is usually undertaken locally in the District General Hospital, for example by GPs requesting ultrasound scans, enemas or barium meals, in order to diagnose the suspected cancer. Further to this, the preparation of the patient, for example by the completion of CT scans, before moving on to a specialist or tertiary centre for treatment, is also fulfilled within the DGH. The need for urgent referral is therefore often discovered during this diagnostic phase. The BMA strongly believes that the scope of the guideline should reflect the early stages covering diagnosis. The investigation patterns of GPs availability to access radiology and endoscopy services should, in particular, be considered. The features that lead to a doctor suspecting a patient has cancer will vary from patient to patient, and the level of certainty will vary. The guideline will not cover investigation until a definitive diagnosis is reached, but only until referral should be made. Consideration of all the diagnostic tests indicated in each of the 12 groups of cancers being considered would represent a major expansion of the scope. If 2 or 3 cancers were being considered, this might be possible, but not with 12. The guideline may include recommendations that advise increased access for GPs to some diagnostic procedures. |
There is a growing body of psychological and clinical evidence that patients become extremely anxious during the initial process of referral. Many go to their GPs already anxious about their symptoms and this anxiety is reinforced by referral to a specialist service. The patient is often unsupported during the waiting time between initial referral, consultation and diagnosis.

There is also evidence that the manner in which patients are advised that they are being referred with a suspected cancer can have a significant impact on their level of anxiety.

The following recommendations are therefore made for inclusion:

**PAGE 3
SECTION RE WHAT THE GUIDELINES WILL ADDRESS**

“The guidelines will address the communications skills training needs of those who are involved in the referral of patients with suspected cancer”

The guidelines will address the psychological needs of patients who are referred for suspected cancer.”

“The guidelines will address the support needs of patients who are referred for suspected cancer”

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4.3

The monitoring of patients, including their psychological needs, after referral but before the first specialist assessment will be considered in the guidelines.

<table>
<thead>
<tr>
<th>BUPA</th>
<th>The feedback from BUPA on this is that it looks good and helpful, and that we have no specific comments.</th>
<th>Noted</th>
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<tbody>
<tr>
<td>Chartered Society of Physiotherapy</td>
<td>This response is set out using terms and numbering derived from the draft scope for the guideline.</td>
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Response

We welcome the proposed scope for the guideline, and have only a few suggestions to make.

4.1 Population

4.1.1 (c)
This should include such questions that therapists may ask prior to physiotherapy, for example, manipulation of the spine (see the Royal College of General Practitioners’ Low back pain guidelines, 1999), use of electrotherapy.

4.2 Healthcare setting

(a) This refers to the healthcare professionals as opposed to the Healthcare Setting, so perhaps needs a slight amendment.

(b) and (c)
This should include hospital outpatient physiotherapy departments, GP practice-based, and community physiotherapists e.g. a patient may be referred for treatment of low back pain, but the results of asking the mandatory screening questions may signify potential malignant cord compression.

Similarly it may the physiotherapist who, on assessment of an adolescent with lower limb pain, recognises the signs or symptoms of an undiagnosed sarcoma.

Chelsea & Westminster Healthcare NHS Trust

Here are the comments of Chelsea and Westminster Hospital on the Scope for the Review of Referral guidelines for suspected cancer

Page 3
"children's tumours" can be interpreted as solid tumours only. Wording should make clear that children's haematological malignancies are also included.

We agree.
The strength of the evidence for the referral guidelines needs stating and an estimation of their sensitivity and specificity. This will enable providers to make informed decisions on how much resource to allocate to routine or urgent cases. For some tumours the proportion of cancers diagnosed from urgent GP referrals is low. It is inappropriate to favour urgent referrals based on weak evidence over other, better supported, practices. Finally guidelines need to have the facility for clinical discretion built into them.

On a general note, the practice or prioritising some patients over others is also at odds with The philosophy of the Cancer Services Collaborative, who would see this as a "carve out".

We will do our best to indicate the likelihood of cancer when certain signs and symptoms are present, but the available evidence may be inadequate for this purpose. We agree that clinical discretion must be retained.

We plan to base the recommendations of the guideline on the best available evidence.

Department of Health

Thank you for the opportunity to comment on the draft scope. This letter reflects the views of the Department of Health and the Welsh Assembly Government.

1. Could you consider whether it would be possible to clarify to the reader that this guidance is an update of a previously published document?

**Background**

2. We believe that it could be useful in this section to make specific reference to:

a) DH and Welsh Assembly Government policies on urgent referral for patients with suspected cancer (i.e. the 2 week policy in England and the equivalent for Wales);

b) The Referral Guidelines for Suspected Cancer published by DH in March 2000;

c) The NHS Cancer Plan commitment that the Referral Guidelines should be reviewed by NICE;

d) The need to take account of further information from audits and research studies that have become available over the past 2-3 years.

Agreed.

Agreed.

Agreed.

Agreed.
Clinical need for the guideline

3. Would it be possible to include in this section some comment on the poor survival rates (not the same as mortality rates) in the UK. The evidence for this comes from the EUROCARE project, which also shows that patients in the UK tend to have more advanced disease at the time of diagnosis/treatment than their European counterparts.

4. We believe it would be helpful for you to consult the relevant experts in primary and secondary care who were members of the steering group for the Referral Guidelines published in 2000. You might wish to indicate your intention to do so, if this is the case, in the scope document.

5. ONS have recently published 1999 incidence figures for England. If you would wish to update this section the figures can be accessed at: www.statistics.gov.uk/statbase/ssdataset.asp?vlnk=4505&More=Y

Section 4.1.1 - Groups & Categories that will be covered

6. Would it be possible for you to consider making the following changes:-

4.1.1. (b) brain tumours we believe should read "brain/central nervous system tumours"

4.1.1 (c) we believe this should be amended to read "......in association with, urgent referral for suspected cancer"

4.1.1. (e) we believe this should be amended to read "...to help health care professionals appropriately identify patients needing urgent referral for suspected cancer."

Section 6 - References

7. Please would you consider adding the following reference "NHS Executive (April 2000) Referral Guidelines for Suspected Cancer"

Agreed

8. Please would you consider the following clinical question within this

Agreed
"Should a woman who presents with mastitis symptoms who is not lactating and does not respond to antibiotic treatment after 5 days be referred immediately to a breast specialist for biopsy?"

This question results from a letter Hazel Blears, the Parliamentary Under Secretary of State for Public Health, received from a lady diagnosed with inflammatory breast cancer. The lady suggested that this condition is often misdiagnosed for mastitis which results in a delay in receiving appropriate treatment. She asked that "GP Surgery protocols included a mandate" about referring women to a specialist if they have mastitis, are not lactating and do not respond to antibiotics in 5 days. Ms Blears offered to raise this with you.

9. We would like to alert you at this early stage to work which we believe should form part of the evidence base considered for the review of the referral guidelines. The Department is currently commissioning a systematic review of cancer waiting times audits. Some of these audits will have focused on waiting times and cancer detection rates amongst those urgently and routinely referred, others will provide data on the characteristics of patients referred (e.g. age, symptoms). The review should be available by April 2003.

10. We would also like to bring your attention to the following documents currently informing Welsh Assembly Government policy :-

b) CSCG has also issued (1999) guidelines for the referral of patients with breast problems.
c) The NHS Breast Screening Programme and the Cancer Research Campaign also issued guidance in 1999.

Gorlin Syndrome Group

A comprehensive piece of work but would comment on the following areas:

Section 4.2 Healthcare setting - No provision for vulnerable groups, i.e. homeless, drug users, people not registered with a Doctor or accessing primary care. How do these vulnerable groups access services?

Reference to the access and provision of treatment - consideration needs to be given to inequitable delays, travel/costs to specialist centres.

We agree people in these groups should not be excluded. The guidelines should be helpful to those caring for them. Thank you for raising this important point.
difficulties experienced by disabled. Consideration also needs to be given to the provision of care and treatment for rare, long-term medical conditions, particularly in terms of review and follow-up treatment.

<table>
<thead>
<tr>
<th>Macmillan Cancer Relief</th>
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<tbody>
<tr>
<td>Thank you for your invitation to comment on the draft scope for the Referral Guidelines for Suspected Cancers. Macmillan Cancer Relief is pleased to be invited to comment on the scope for the guidelines and we would like to make the following points:</td>
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<tr>
<td>• It is essential that these processes are clear and transparent.</td>
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<td>• It is essential that users are fully involved at all stages in the process, that adequate notice is given to patient groups to allow for sufficient time for their involvement and their own consultation processes, and that they are appropriately supported and reimbursed to allow them to be fully involved.</td>
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<td>• In this respect we would ask that NICE allows sufficient time for us to consult with users and postholders on any draft proposals. Four weeks is not enough time to allow genuine consultation with key stakeholder groups.</td>
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<tr>
<td>In respect of the draft scope, we would like to make the following comments:</td>
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<td>• Overall, we believe the scope of the proposed guidelines to be adequate.</td>
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<td>• Users should be fully involved in developing the guidelines, not only the consultation process. They should be invited to participate in any steering groups and working groups set up to aid this process. The draft guidelines should also be tested out with service users prior to full implementation.</td>
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<td>• It would be helpful to consider the needs of the family of those who are referred. It would also be helpful for the guidelines to address areas for patient self-management and cancer awareness.</td>
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<tr>
<td>• The guidelines must also address the need for information and support for patients and their families.</td>
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<td>• Paragraph 4.1.1 c): We suggest that the proposal to identify those</td>
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<tr>
<td>Users groups have been invited to make nominations to the guideline development group.</td>
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<td>We agree. Methods of increasing cancer awareness would be a major addition to the guideline, and the additional work involved would make guideline development difficult.</td>
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<tr>
<td>Agreed.</td>
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<td>User group representatives will</td>
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investigations which could take place prior to referral could be tested out with service users.

- **Paragraph 4.1.1 d):** This should read: "The guideline will address the information and support needs of patients who are referred for suspected cancer". Information alone is not enough, and must be accompanied by appropriate support mechanisms, such as notifying people about voluntary organisations' helplines, local cancer self-help and support groups etc. A suspected cancer diagnosis is potentially very frightening, and people may need support while they are waiting for the outcome.

- **Paragraph 4.2 a):** This paragraph should include not only care, but also information and support, reflecting our opinion set out in the previous bullet point. The guidance should describe the role of primary care in referral, as opposed to the role of diagnosis, which is the remit of the hospital doctor.

It should be noted, however, that people do not access treatment through primary care only, and the routes to referral may come from, for example, medical wards, maternity clinics, mental health clinics etc. The guidelines must apply equally to these other areas.

- **Paragraph 4.2 d):** We do not understand why the nature of practice at walk-in centres have been excluded from the guidelines.

We thought it might be helpful if we referred you to a letter on this subject which we submitted in response to the initial consultation on the guidelines in 1999. A copy of this is attached for your information.

Finally, we look forward to being involved in consultation on the revised guidelines themselves.

| Macmillan Cancer Relief (2) | The scope of the guideline suggests that it is not considering tests after referral. However, it might be argued that one of the major differences between UK and Europe is accessibility to diagnostic tests (endoscopy, radiology, ultrasound). It has been suggested that the lack of primary care access to such tests is one of the key problems in relation to early diagnosis of cancer. It is suggested, therefore, that there might be a case for either including diagnostic tests in the guideline or ensuring that there is a guideline being prepared on diagnostic pathways." | The inclusion of diagnostic tests would make the scope to large that completion of the guideline would be almost impossible. Access to tests indicated in investigation leading to referral decisions will be included. |
National Kidney Research Fund, The

With reference to the above Guideline, as a stakeholder in the process the Fund's comment on the draft Scope document is that this document appears fine, and uncontroversial; essentially it can be summarised as NICE are going to re-look at the cancer referral guidelines. It remains to be seen whether the actual Guidelines will be so uncontroversial.

Prostate Cancer Charity, The

We have three points that we would like to make for the draft scope.

1. In section 4.1 Population
   4.1.1 d) The Guideline will address the information AND SUPPORT needs of patients who are referred for suspected cancer.

   We add AND SUPPORT because it is important to look after people who are referred for suspected cancer, but who never actually step over the threshold and become cancer patients, though they may live with the prospect of cancer for some considerable time, in the presence of ambiguous clinical results. I think especially of men with elevated PSAs which may indicate prostate cancer who have repeated biopsies over months and years, and men with PIN which may or may not be a marker for subsequent prostate cancer, women with recurrent breast lumps and also women who need repeated attention for cervical abnormalities.

2 In section 4.2 Healthcare setting

   4.2 a) Can you insert something here about referral to the right kind of expert centre, one with sufficient throughput to be considered 'expert'? In the guidelines for management of Urological cancers there is a recommendation that surgeons who do fewer than five radical prostatectomies per year hand over patients to more appropriately experienced colleagues. This point can be made more robust by giving the Primary Care teams the knowledge to enable them to refer appropriately away from 'dabblers' to experts. I imagine this is an issue for other tumour groups where the place of the general surgeon in cancer surgery may not be the best option available.

3 In section 4.3 Clinical Management

   4.3 b) There may be a clinical question to answer here.

   Many men who have prostate cancer do not have their physical health endangered by delays in referral because of the nature of the cancer. This is...
a separate issue from their mental health, of course. There may be good reason on this ground alone to complete referral for an expert assessment asap. Even so, it is possible that rushing some patients through referral is counter productive as it may give the impression that a possible cancer is inevitably life threatening in the near future. On the other hand it may be exactly the right thing to do. Perhaps there needs to be some investigation of methods of discovering patient preference in this matter.

<table>
<thead>
<tr>
<th>Roche Products Limited</th>
<th>Just to confirm that on this occasion we will not be making any comments on the referral guidelines.</th>
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</table>
| Royal College of General Practitioners | Thank you for giving the Royal College of General Practitioners the opportunity to comment on the draft scope in respect of the above guideline. Our comments are as follows:

1. In section 4.4.1 a list of cancers is provided that will be covered by the guideline. Additional requirements for work to should be undertaken in relation to (a) non-specific features of malignant disease and (b) stage-specific diagnosis.

2. Greater clarity is needed in relation to the patient population at which the guideline is targeted (section 4.2). Insufficient consideration of this issue in both the assembly of the evidence and the application of that evidence could seriously undermine the work. |
| Royal College of Nursing | Thank you for updating the Royal College of Nursing on the progress of this guideline and for the opportunity to comment on the draft scope. The scope was sent to members of the RCN Cancer Nurses Society and the Paediatric Form, whose comments are as follows:

Specific comments

4.1. Population

4.1.1. Members were concerned that some cancers were listed and not others (including renal and hepatic cancers). Rather than refer to ‘children’s urological cancers include renal cancers. We agree that...
tumours’ as this would exclude leukaemias (which account for a third of the paediatric client group), the term ‘cancers in children and young people’ is considered more appropriate.

4.1.1. d) Attention should be paid to the work being done on patient information needs by the University of Oxford, Division of Public Health and Primary Care, Institute of Health Sciences, especially the DISCERN tool (details can be obtained at [http://www.discern.org.uk](http://www.discern.org.uk)). This project is funded by the NHS Executive R & D Programme.

4.1.1. e) Would interventions intended to help healthcare professionals minimise delay in suspecting cancer cover issues such as educational development/requirement of those working within primary care? This is an important issue, especially for those working in neuro-oncology where patients are often wrongly diagnosed for months because of the rarity of CNS tumours and for those working in paediatrics where often a child’s mother will seek GP consultation prior to referral for secondary care.

### Audit support within the guideline

The guideline should also cover a means of audit to evaluate the best method of communication/referral between PHCT and tertiary centres. In the case of neuro-oncology, this should also cover waiting times to see a neurologist (from referral by GPs).

### Other clinical questions

Two questions were raised by members:

- How do you alter the system when delay occurs?
- Who should have responsibility for monitoring referrals?

### General comments

1. RCN members consulted would welcome clarification of how this guideline will differ from site-specific guidelines which have been produced.

2. Will the guideline incorporate/reflect other Department of Health documentation, for example, Manual of Cancer Standards (2000) and the NHS 2002 draft ‘Protocol Governing the use of Cancer Waiting Times Database’?

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children’s cancers should include leukaemias.

Thank you for this information.

Education/development would be included.

The detailed specification of an audit would be outside the scope of the audit.

These are service management issues, and will not be directly addressed in the guideline.

We will ensure communication with other relevant guideline groups.

Yes
| Royal College of Obstetricians & Gynaecologists | This is to confirm that the RCOG is content with the scope. However, we would add that it is important that investigations which are relevant prior to referral by GPs are considered, for example, ultrasound for suspected ovarian tumours. | Thank you for raising this point. |
| Royal College of Paediatrics and Child Health | The Royal College of Paediatrics and Child Health is pleased to respond to the scoping document for this guideline. Although the rationale for the guideline is delays in referral for adult malignancies, the inclusion of children's malignancies is welcome. These are largely sarcomas, with a pattern of rapid progression that warrants extremely rapid referral and assessment.  

The term 'tumours' used in the scoping document (paragraph 3b) covers benign as well as malignant tumours, and should be replaced by the word 'malignancies'. Adolescents' malignancies should not be forgotten, and perhaps the category should read 'children's and adolescents' malignancies'.  

Additionally (paragraph 3b), there are a number of different childhood malignancies, and although there may be reasons for delay in referral that are common to them all, there are also different individual factors influencing the speed of referral. It is unclear whether there will be an attempt to consider each of the main childhood malignancies separately, as for adults.  

The scope excludes secondary care after referral (paragraph 4.2b). However, the management of children's malignancies is largely provided through tertiary services. Delays in referral to these children's oncology departments may occur following referral to surgical services in secondary care. Similarly, some children may reach the oncology service through Accident and Emergency departments. They are frequently referred via District General Hospital paediatric departments. The scope therefore needs reviewing in the light of the different patient pathway for children. In paragraph 4.2d, the guideline may also be relevant to the work of community pharmacists as they will see patients who may be self medicating for something which requires referral. | Thank you for this point. |
| Royal College of Radiologists | Thank you for giving us the opportunity to comment on the above document. | Noted |
As indicated in paragraph 4(b) this document defines exactly what the proposed guideline will and will not examine and what the guideline developers would consider. It is therefore by definition a somewhat general introduction, with very little justifying objective comment.

The list of cancers in 4.1.1(b) appears to be comprehensive and the population appropriate. It also indicates that the guideline will only address the initial investigations prior to referral.

A letter regarding your draft document has also been sent to [NICE].

Did this raise different points and if so should it be included here?

Royal Pharmaceutical Society of Great Britain

This is to advise that the Royal Pharmaceutical Society of Great Britain has no comment to make on the above consultation.

Society of British Neurological Surgeons

1. The term “Brain tumour” as indicated in the Scope document would include benign brain tumours such as acoustic schwannomas and meningiomas. These are invariably slow growing tumours and would not naturally fall within the remit of a guideline for suspected cancers. Likewise, some intrinsic brain tumours (e.g. gliomas) while technically cancerous may also be extremely slow growing and may not require the same referral process as other forms of cancer. In common with all neoplasm of the central nervous system those primarily originating within the brain or spinal cord rarely if ever spread outside the central nervous system and their biological behaviour is unlike those of cancers elsewhere in the body. Conversely, metastases to the brain from cancers originating elsewhere are common and often present as the first manifestation of a malignant disease. Thus referral guidelines for suspected cancer of the brain should be confined to those with a suspected primary malignant tumour (e.g. malignant glioma) or secondary (i.e. metastatic) malignant tumour and not include other forms of brain tumour where a calibrated referral could not be justified.

2. The Scope document should include malignant tumours involving the spinal cord and neuraxis.

3. The Scope should deal with the following specific areas:
   - Clinical indicators to suspect cancer of the brain/spine.
   - Indications for imaging of the brain/spine when cancer is suspected.
   - Guidance regarding professionals who should have access to such imaging.

Thank you for this point. The guideline scope will be amended accordingly.

Agreed.

These issues will be dealt with in the context of suspecting cancer and deciding on referral.
4. Time scale for out patient appointment/admission to neurosurgical unit when Cancer is suspected or diagnosis confirmed. The SBNS has in conjunction with the Regional Specialist Commissioning Groups recently produced a document “Standards for Patients Requiring Neurosurgical Care”. In Part 2, Section A2 the advice from the SBNS is that for patients who are diagnosed with primary intracranial/spinal malignant tumour facilities will be available to allow an initial expert assessment within 2 weeks and admission for investigation and any necessary treatment within 6 weeks from referral. For patients with benign intracranial/spinal tumour expert assessment should be available within 4 weeks and admission for treatment within 3 months. The Society feels it is appropriate to bring this document to your attention and as such an electronic version is attached with this letter. A hard copy version can be obtained from The Royal College of Surgeons of England.

5. The guidance to patients should include information regarding support services available.

Thank you for mentioning the Standards for Patients Requiring Neurosurgical care.

We agree that support should also be considered.