Unknown primary cancer: scope consultation 21 January – 18 February 2008

Organisation	Section No	Comments	Response
3 Counties Cancer Network Palliative Care Lead	Section No	This organisation was approached but did not respond	Response
Clinicians Group		This organisation was approached but did not respond	
Addenbrookes Hospital, Cambridge University Hospital		This organisation was approached but did not respond	
NHS Trust			
Afiya Trust		This organisation was approached but did not respond	
Arden Cancer Network		This organisation was approached but did not respond	
Association for Clinical Biochemistry		This organisation was approached but did not respond	
Association for Palliative Medicine of Great Britain and		This organisation was approached but did not respond	
Ireland		5 11 1	
Association of the British Pharmaceuticals Industry		This organisation was approached but did not respond	
(ABPI)			
Barnsley Hospital NHS Foundation Trust		This organisation was approached but did not respond	
BASO ~ The Association for Cancer Surgery		This organisation was approached but did not respond	
Bedfordshire PCT		This organisation was approached but did not respond	
Birmingham cancer network		This organisation was approached but did not respond	
Boehringer Ingelheim Ltd		This organisation was approached but did not respond	
Bolton Council		This organisation was approached but did not respond	
Bournemouth and Poole PCT		This organisation was approached but did not respond	
Breakthrough Breast Cancer		This organisation was approached but did not respond	
British Association of Otolaryngologists Head & Neck		This organisation was approached but did not respond	
Surgeons			
British Association for Counselling and Psychotherapy		This organisation was approached but did not respond	
British Dietetic Association		This organisation was approached but did not respond	
British National Formulary (BNF)		This organisation was approached but did not respond	
British Nuclear Medicine Society		This organisation was approached but did not respond	
British Thoracic Society		This organisation was approached but did not respond	
Calderdale PCT		This organisation was approached but did not respond	The selection for a second state in
Cancer of Unknown Primary (CUP) Foundation	4.3 (a)	Add	Thank you for your comment. This is
		genetic profiling	already covered by the heading molecular techniques (section 4.3.a).
Cancer Research UK		This organisation was approached but did not respond	
Cancer Services Collaborative		This organisation was approached but did not respond	
Cancerbackup		This organisation was approached but did not respond	
Commission for Social Care Inspection		This organisation was approached but did not respond	
Connecting for Health		This organisation was approached but did not respond	
5			

Department of Health

Department of Health, Social Security and Public Safety of Northern Ireland Derby-Burton Cancer Network Derbyshire Mental Health Services NHS Trust

GE Healthcare				
Get A-Head Charitable Trust				
Health Commission Wales				
Healthcare Commission				
Heart of England NHS Foundation Trust				
Humber and Yorkshire Coast Cancer Network				
Imaging Equipment Limited				
Imperial College Healthcare NHS Trust				

Institute of Biomedical Science Kirklees PCT Leeds PCT Marie Curie Cancer Care Medicines and Healthcare Products Regulatory Agency (MHRA) Mouth Cancer Foundation National Cancer Network Clinical Directors Group

General

3

This organisation responded and said that they had no comments to make This organisation was approached but did not respond This organisation was approached but did not respond

Desirability of clinical trials in the UK to explore new diagnostic classifiers, new chemotherapeutic standards and best targeted therapy approaches This organisation was approached but did not respond

This organisation was approached but did not respond This organisation was approached but did not respond

This organisation was approached but did not respond This organisation was approached but did not respond This organisation was approached but did not respond This organisation was approached but did not respond

This organisation was approached but did not respond If the Guideline is to make a significant improvement to the care and outcomes of patients with cancer with an unknown primary, the guideline will not only need to be able to make recommendations about the clinical management of these patients but also needs to be able to make recommendations about the structural and organisational arrangements within the NHS for this group of patients. Such considerations should include the formation of a multidisciplinary team (MDT) to lead on the management of these patients and the relationship between this and other anatomical site specific MDTs.

There is currently no agreement about how the care for

Thank you for your comment. NICE expects us to make appropriate research recommendations.

Thank you for your comment. The remit for this topic has been altered to include service delivery issues where appropriate.

General

National Patient Safety Agency (NPSA) National Public Health Service - Wales NHS Direct **NHS Plus** NHS Quality Improvement Scotland North East London Cancer Network North Tees PCT North Yorkshire and York PCT Nucletron UK Ltd **PERIGON Healthcare Ltd** PRIMIS+ Robert Jones & Agnes Hunt Orthopaedic Hospital NHS Trust - British Bone and Soft Tissue Tumour Panel **Roche Diagnostics Royal Brompton & Harefield NHS Trust Royal College of General Practitioners Royal College of Midwives** Royal College of Nursing

Royal College of Paediatrics and Child Health Royal College of Pathologists

these patients should be organised. The current arrangements are very variable and may be somewhat ad hoc. It means that this group of patients, who in spite of their complex diagnostic and management problems, may be managed by anatomical site specific MDTs or are managed outside of the current MDT system. Recommending not only what pathway they should be following but which professionals should be responsible for managing that pathway would be likely to bring about much greater improvements in care than recommendations about the clinical aspects alone. This organisation was approached but did not respond This organisation was approached but did not respond

This organisation was approached but did not respond This organisation was approached but did not respond This organisation was approached but did not respond This organisation was approached but did not respond The draft scope is comprehensive. The RCN would welcome national guideline which would help healthcare professionals improve the process of investigation of patients with metastatic malignancy disease from undiagnosed primary cancer and help define optimal treatment and care for patients who have no primary cancer identified.

This organisation was approached but did not respond This organisation was approached but did not respond Thank you for your comment.

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Royal College of Physicians of London Royal College of Radiologists Royal Society of Medicine SACAR Sandwell PCT Sarcoma UK Scottish Intercollegiate Guidelines Network (SIGN) Sheffield PCT Sheffield Teaching Hospitals NHS Foundation Trust Siemens Medical Solutions Diagnostics Skin Care Campaign Social Care Institute for Excellence (SCIE)	General	The draft document for scope of guidance appears comprehensive. No specific comments at this point This organisation was approached but did not respond This organisation was approached but did not respond	Thank you for your comment.
Society and College of Radiographers	3a	The absence of guidelines for Health Care Professionals to provide appropriate supportive care and referral for this group of patients during all stages of their pathway. (Linked to poor patient access to information and support facilities).	Thank you for your comment.
Society and College of Radiographers	3c	In addition to guidelines for care, clarification of appropriate referral pathways to multidisciplinary teams and Allied Health Professionals for this heterogeneous subset of patients would improve efficiency of care.	Thank you for your comment. The remit for this topic has been altered to include service delivery issues where appropriate.
Society and College of Radiographers	3d	Could this section include identification of appropriate supportive and psychosocial care for this subset of patients?	Thank you for your comment. We will include supportive and psychosocial care in sections 3.d and 4.3.
Society and College of Radiographers	4.1	Consideration of performance status with regard to appropriate diagnostic procedures and treatments.	Thank you for your comment. Our recommendations will take into account all relevant clinical factors including performance status and this is implicitly referred to in section 4.3.c.
Society and College of Radiographers	4.3 a	Nasendoscopes for diagnosing the primary site of disease.	Thank you for your comment. We will include referral to all endoscopy techniques in section 4.3.a
Society and College of Radiographers	4.3	The use of radiotherapy to treat the local site of the metastasis and/or including possible sites of the primary tumour based on presentation of the metastasis, the histopathology of the metastasis and imaging.	Thank you for your comment. We will include reference to locoregional therapy in section 4.3.d which will cover radiotherapy.
South East Wales Cancer Network		This organisation was approached but did not respond	

Sussex Cancer Network	4.3	The equivalent heading in the scope re MSCC is <i>Clinical</i> management (including service delivery where
		appropriate) and we will definitely be making
		recommendations on structure in relation to service
		delivery eg need for MD working, though not a formal
		team as IOGs, availability of MRI etc.
		While we recognise and appreciate the difference
		between IOGs and Clinical guidelines, the development
		group are likely to need to make some
		recommendations on the structure of a service for
		unknown primary management, given the lack of any
		such system at present, and the fact that there will
		never be a relevant IOG.
Thames Valley Cancer Network		This organisation was approached but did not respond
University Hospital Birmingham NHS Foundation Trust		This organisation was approached but did not respond
University of North Tees and Hartlepool NHS Trust		This organisation was approached but did not respond
Welsh Assembly Government		This organisation was approached but did not respond
Welsh Scientific Advisory Committee (WSAC)		This organisation was approached but did not respond
West & East & North Hertfordshire PCTs		This organisation was approached but did not respond
Wiltshire PCT		This organisation was approached but did not respond
Wyeth Pharmaceuticals		This organisation was approached but did not respond
York Hospital NHS Trust		This organisation was approached but did not respond
Yorkshire and the Humber Specialised Commissioning		This organisation was approached but did not respond
Group		

Thank you for your comment. The remit for this topic has been altered to include service delivery issues where appropriate.