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## **PRESS RELEASE**

# **NICE guideline set to transform cancer care for thousands of patients**

From today (26 July), specialist cancer teams will be tasked with improving the care and treatment of patients whose cancer has spread to other parts of the body from an unknown primary location. The re-organisation of cancer services for this group of patients is one of a raft of measures being recommended by the National Institute for Health and Clinical Excellence (NICE) to tackle the current inequality in care these patients often receive compared with people who have a site-specific type of cancer such as breast, lung or prostate.

This guideline has received the support of the National Cancer Peer Review Programme in England, which is studying the recommendations to develop a number of peer review measures. These are 'quality measures' that hospitals are required to follow and are assessed against with the aim of improving care for cancer patients and their families.

**Professor Peter Littlejohns, NICE Clinical and Public Health Director, said:** "We are pleased that the National Cancer Peer Review Programme in England is taking note of our guideline and looking to use it to improve services. This type of cancer is known as metastatic malignant disease of unknown primary origin or more commonly, cancer of unknown primary. It is very much a neglected cancer – patients generally have a poor prognosis and little is known about which types of treatment work best for them. They also tend to miss out on medical and other benefits that are given to patients with a specific type of cancer because of a lack of information, understanding and specialised services.

“It is important that patients with this form of cancer receive the same level of care that other cancer patients experience. This guideline seeks to provide a consistent, national approach to the diagnosis and management of this condition.”

It is thought over 10,000 people each year are diagnosed with cancer of unknown primary (CUP) in England and Wales but many do not receive the same level of care as other cancer patients. This new guideline aims to help the NHS provide effective and tailored care for patients with CUP. Central to this is the development of specialised teams at local, regional and national level, specifically:

- All hospitals with a cancer centre or unit should establish specialist CUP teams to support and manage the care of patients with this diagnosis. This team will be responsible for guiding patients' care until they are referred to a consultant with expertise in a particular type of cancer, referred for palliative care alone, or are finally diagnosed with confirmed CUP.
- Specialist CUP Multi Disciplinary Teams should be set up at Network level to review the treatment and care of patients with confirmed CUP, or with complex diagnostic issues.
- Every cancer network should establish a group responsible for managing all stages of CUP.

**Dr Andrew Fowell, Guideline Development Group (GDG) Chair and a Macmillan Consultant in Palliative Medicine at Eryri Hospital, North Wales, said:** “Just as specialised teams help care for patients with a site-specific cancer such as breast, prostate, bowel or liver, the same needs to exist for those with CUP. These teams can provide great support for cancer patients and better one-on-one care.

“We expect some oncologists to become CUP specialists, alongside their more conventional site-specific activities. They will be supported by CUP Nurse Specialists, Palliative Care physicians, and other core diagnostic staff. These teams should be supported by their hospitals to ensure they are given sufficient time in their job plans for this specialist role and any training that may be needed.”

**Dr David Brooks, GDG member and Macmillan Consultant in Palliative Medicine at Chesterfield Royal Hospital, helped to establish a specialist CUP team earlier this year. He said:** “Our Unknown Primary Team consists of existing members of the Upper GI Cancer and Palliative Care teams. We see one or two patients per week in a Cancer Unit that covers a population of just over 300,000 so the workload is not onerous. It is early days but we are already seeing benefits in both providing early supportive and palliative care, more effective targeting of

investigations to confirm treatable disease and, in those who are not fit for treatment, stopping inappropriate tests and re-focusing care towards arranging appropriate support and palliation to enable the patient to get home.”

The guideline sets out ways in which patients’ experiences should be improved, particularly through the creation of these local CUP teams, including:

- Inpatients should be seen by a dedicated member of the CUP team by the end of the next working day after referral. Outpatients should be seen within two weeks.
- Patients should be given access to an identified CUP specialist nurse or key worker when this type of cancer is diagnosed.
- Decision aids should be developed to help patients and their carers make informed decisions about continuing diagnostic investigations and using anti-cancer treatment after CUP has been diagnosed.

**Janie Thomas, who lives in Kidderminster and has CUP, helped to develop this**

**guideline and said:** “Most patients leave the hospital, having seen their oncologist for the first or second time, knowing that they have cancer of the breast, lung, bowel or other specific part of the body. They can seek advice in readily available pamphlets, plough through information on the internet or even contact one of the many groups specialising in a particular type of cancer. I couldn’t do that. Not knowing where the cancer had come from was difficult to cope with; where do you turn for help, support and advice? How can you make decisions about your care and treatment when there’s no information available?”

“I’m very glad to have played a part in developing this guideline and to have helped give a voice to those cancer patients whose tumours have spread from an unknown part of their body. CUP patients deserve the same level of care, treatment and support as those with specific cancers.”

The guideline also contains advice for those involved in the diagnosis and care of a patient with CUP, such as oncologists, pathologists and nurses. These recommendations include:

- Take account of prognostic factors, in particular performance status, presence of liver metastases, lactate dehydrogenase levels and serum albumin, when making decisions about further diagnostic tests and treatment.
- Explain to patients and carers if further investigations will not alter treatment options and provide appropriate emotional and psychological support.

- Offer patients with CUP the opportunity to enter clinical trials.
- If chemotherapy is given outside clinical trials, take into account the clinical and pathological characteristics of the tumour, the toxicity profile of the drugs, their ease of administration and response rate when choosing which treatment to use.

**Dr Richard Osborne, GDG lead clinician and Consultant in Medical Oncology, Dorset Cancer Centre, said:** “There was a real need to examine the entire care pathway for CUP because currently, the management of this condition varies across the country. It’s important that patients receive the same level of high-quality care that other cancer patients benefit from, no matter where they may live. This guideline will provide a sound basis for healthcare professionals to ensure patients are informed and their care is centred around their needs and wishes. The guideline also calls for more research to further our understanding of the disease and help ensure patients receive the most effective treatments available.”

NICE has produced a podcast to help explain the guideline’s key recommendations and the thinking behind them, as well as other tools to help healthcare professionals implement the guideline and a booklet for patients and carers. All materials are available from the [NICE podcasts](#) page.

**Ends**

### **Notes for editors**

- The NICE guideline on the diagnosis and management of metastatic malignant disease of unknown primary origin, including a version for patients and carers and corresponding implementation tools, are available from the NICE website at; [www.nice.org.uk/CG104](http://www.nice.org.uk/CG104).
- This guideline has been developed by the National Collaborating Centre for Cancer (NCC-C)
- Metastatic malignant disease of unknown primary origin is also known as Cancer of Unknown Primary or Carcinoma of Unknown Primary. For the purposes of the guideline, this type of disease is categorised in three stages;
  - ***Malignancy of undefined primary origin (MUO):*** Metastatic malignancy identified on the basis of a limited number of tests, without an obvious primary site, before comprehensive investigation.
  - ***Provisional carcinoma of unknown primary (provisional CUP):*** Metastatic epithelial or neuroendocrine malignancy identified on the basis of histology/cytology, with no primary site detected despite a selected initial set of investigations, before specialist review and possible further specialised investigations.
  - ***Confirmed carcinoma of unknown primary (confirmed CUP):*** Metastatic epithelial or neuroendocrine malignancy identified on the basis of final histology, with no primary site detected despite a

selected initial set of investigations, specialist review, and further specialised investigations as appropriate.

- Currently, the clinical management of CUP varies widely across England and Wales. Some of the problems in current clinical practice, as identified in the guideline, include:
  - No referral guidelines for suspected CUP and no system to rapidly identify patients to ensure early specialist involvement
  - Uncertainty about appropriate diagnostic tests, including the use of new technologies, and optimal treatment
  - Lack of both an overall organisational structure and a team structure to ensure high-quality care
  - Insufficient specialist oncology expertise and dedicated key workers or specialist nurses.
  - Lack of support and information for patients

### **Key recommendations on the establishment of specialist CUP teams:**

- Every hospital with a cancer centre or unit should establish a carcinoma of unknown primary (CUP) team, and ensure that patients have access to the team when malignancy of undefined primary origin (MUO) is diagnosed. The team should:
  - consist of an oncologist, a palliative care physician and a CUP specialist nurse or key worker as a minimum
  - have administrative support and sufficient designated time in their job plans for this specialist role and
  - have a named lead clinician.
- Every hospital with a cancer centre or unit should assign a CUP specialist nurse or key worker to patients diagnosed with MUO or CUP. The CUP specialist nurse or key worker should:
  - take a major role in coordinating the patient's care in line with this guideline
  - liaise with the patient's GP and other community support services
  - ensure that the patient and their carers can get information, advice and support about diagnosis, treatment, palliative care, spiritual and psychosocial concerns
  - meet with the patient in the early stages of the pathway and keep in close contact with the patient regularly by mutual agreement and
  - be an advocate for the patient at CUP team meetings.
- Refer outpatients with MUO to the CUP team immediately using the rapid referral pathway for cancer, so that all patients are assessed within 2 weeks of referral. A member of the CUP team should assess inpatients with MUO by the end of the next working day after referral. The CUP team should take responsibility for ensuring that a management plan exists which includes:
  - appropriate investigations
  - symptom control
  - access to psychological support and
  - providing information.
- A CUP network multidisciplinary team (MDT) should be set up to review the treatment and care of patients with confirmed CUP, or with MUO or provisional CUP and complex diagnostic or treatment issues. This team should carry out established specialist MDT responsibilities.

- Every cancer network should establish a network site-specific group to define and oversee policies for managing CUP. The group should:
  - ensure that every CUP team in the network is properly set up
  - ensure that the local care pathway for diagnosing and managing CUP is in line with this guideline
  - be aware of the variety of routes by which newly diagnosed patients present
  - advise the cancer network on all matters related to CUP, recognising that many healthcare professionals have limited experience of CUP
  - maintain a network-wide audit of the incidence of CUP, its timely management, and patient outcomes
  - arrange and hold regular meetings for the group to report patient outcomes and review the local care pathway.

## **About NICE**

1. The National Institute for Health and Clinical Excellence (NICE) is the independent organisation responsible for providing national guidance on the promotion of good health and the prevention and treatment of ill health.
2. NICE produces guidance in three areas of health:
  - **public health** – guidance on the promotion of good health and the prevention of ill health for those working in the NHS, local authorities and the wider public and voluntary sector
  - **health technologies** – guidance on the use of new and existing medicines, treatments, procedures and medical technologies within the NHS
  - **clinical practice** – guidance on the appropriate treatment and care of people with specific diseases and conditions within the NHS.