# Metastatic malignant disease of unknown primary origin overview

NICE Pathways bring together everything NICE says on a topic in an interactive flowchart. NICE Pathways are interactive and designed to be used online.

They are updated regularly as new NICE guidance is published. To view the latest version of this NICE Pathway see:

http://pathways.nice.org.uk/pathways/metastatic-malignant-disease-of-unknown-primary-origin
NICE Pathway last updated: 10 July 2018

This document contains a single flowchart and uses numbering to link the boxes to the associated recommendations.


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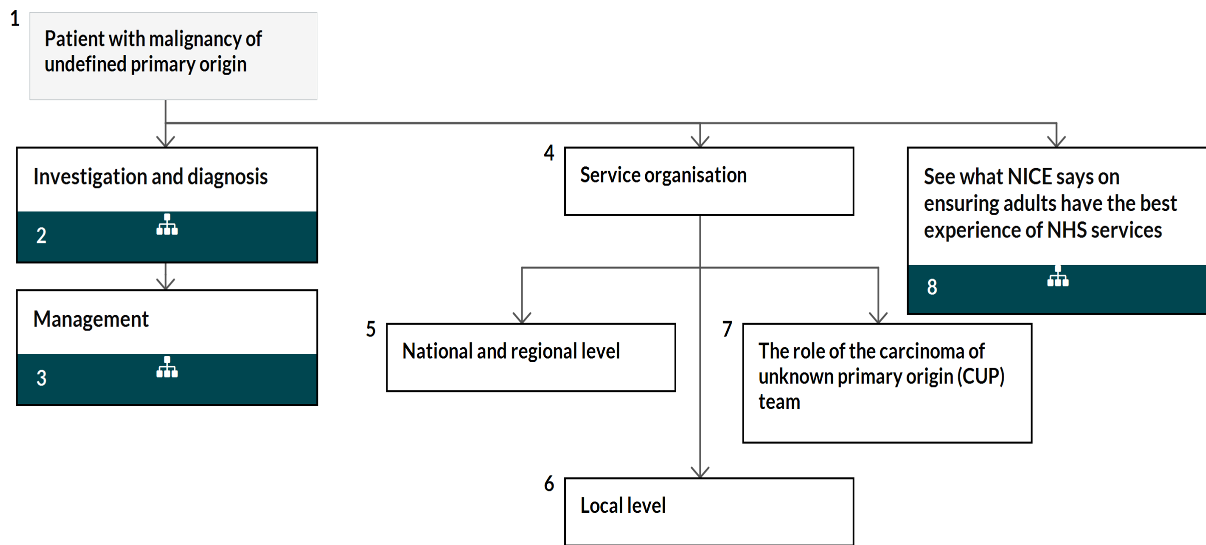



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## 1 Patient with malignancy of undefined primary origin

No additional information

## 2 Investigation and diagnosis

See Metastatic malignant disease of unknown primary origin / Investigating and diagnosing metastatic malignant disease of unknown primary origin

## 3 Management

See Metastatic malignant disease of unknown primary origin / Managing metastatic malignant disease of unknown primary origin

## 4 Service organisation

NICE has published a cancer service guideline on improving supportive and palliative care for adults with cancer.

## 5 National and regional level

CUP network MDTs[1] should be set up to:

- review the treatment and care of patients with confirmed CUP, or those with MUO or provisional CUP and complex diagnostic or treatment issues
- carry out established specialist MDT responsibilities.

Every cancer network should set up a network site-specific group to define and oversee policies for managing CUP. The group should:

- ensure that CUP teams are properly set up (for more information about the CUP team, see the role of the carcinoma of unknown primary origin (CUP) team [See page 5])
- ensure the local care pathway for CUP is in line with this guidance
- be aware of the variety of routes by which newly diagnosed patients present
- advise the cancer network on CUP-related matters, recognising that there is often limited experience of CUP


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[1] Local arrangements for accessing a specialist CUP MDT may vary.


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- maintain a network-wide audit of the incidence and timely management of CUP and patient outcomes
- arrange regular group meetings to report patient outcomes and review the local care pathway.

For MUO and CUP:

- data and coding definitions should be developed and used in routine statistics
- a minimum data set should be agreed nationally, collected by clinicians and reviewed at network level
- a national audit should be set up based on the agreed minimum data set
- the National Cancer Intelligence Network should analyse current epidemiology data and the use of the NHS by MUO and CUP patients.

## 6 Local level

Every hospital cancer centre or unit should:

- set up a CUP team
- ensure patients have access to the CUP team when MUO is diagnosed
- assign a specialist nurse or key worker to patients with MUO or CUP
- upgrade patients to the cancer waiting times pathway when MUO is suspected or first diagnosed
- ensure services are set up for rapid and appropriate investigation in line with this guidance
- ensure staff are appropriately trained.

For more information about the CUP team, see the role of the carcinoma of unknown primary origin (CUP) team [See page 5].

## 7 The role of the carcinoma of unknown primary origin (CUP) team

The CUP team should:

- include an oncologist, a palliative care physician and a CUP specialist nurse or key worker (see below) as a minimum
- have administrative support
- have sufficient designated time in their job plans for their role
- have a named lead clinician (see below)


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- after referral, assess MUO inpatients by the end of the next working day and outpatients within 2 weeks
- write a management plan for each patient including investigations, symptom control, access to psychological support and information
- actively review the outcome of all investigations with a nominated pathologist and radiologist as appropriate
- be involved in the patient's care until they are:
  - referred to a site-specialist consultant **or**
  - referred for palliative care alone **or**
  - diagnosed with a non-malignant condition
- continue managing the patient's care if confirmed CUP is diagnosed.

**Role of the CUP specialist nurse or key worker**

The CUP specialist nurse or key worker should:

- take a major role in coordinating the patient's care in line with this guidance
- liaise with the patient's GP and other community support services
- ensure that patients and carers can get information, advice and support about diagnosis, treatment, palliative care and spiritual and psychosocial concerns
- meet the patient soon after referral and keep in close contact regularly by mutual agreement
- be an advocate for the patient at CUP team meetings.

**Role of the named lead clinician**

The named lead clinician should:

- take managerial responsibility for the CUP service in the cancer centre or unit
- ensure there is a clinical system for the appropriate care of MUO and CUP patients
- ensure each patient has an identified CUP specialist nurse or key worker (see above)
- ensure there is cover for all members of the CUP team during absence
- ensure senior clinical input is available to inform decision-making and treat patients
- ensure there is a single point of contact for the patient to access the CUP team
- implement the care pathway and help educate other healthcare professionals in diagnosing and managing MUO and CUP
- ensure timely and effective communication between healthcare professionals caring for patients with MUO or CUP, including primary and palliative care


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- represent the cancer centre or unit at the CUP network site-specific group and CUP network MDT[1]
- contribute to regular local and network audits of the management of MUO or CUP.

## 8 See what NICE says on ensuring adults have the best experience of NHS services

See patient experience in adult NHS services

[1] Local arrangements for accessing a specialist CUP MDT may vary.


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## Glossary

### Confirmed CUP

confirmed carcinoma of unknown primary origin is metastatic epithelial or neuro-endocrine malignancy identified on the basis of final histology, with no primary site detected despite a selected initial screen of investigations, specialist review and further specialised investigations as appropriate

### CUP

carcinoma of unknown primary origin

### MDT

multidisciplinary team

### MUO

malignancy of undefined primary origin is metastatic malignancy identified on the basis of a limited number of tests, without an obvious primary site, before comprehensive investigation

### provisional CUP

metastatic epithelial or neuro-endocrine malignancy identified on the basis of histology or cytology, with no primary site detected despite a selected initial screen of investigations, before specialist review and possible further specialised investigations

## Sources

Metastatic malignant disease of unknown primary origin in adults: diagnosis and management (2010) NICE guideline CG104


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## Your responsibility

### Guidelines

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals and practitioners are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or the people using their service. It is not mandatory to apply the recommendations, and the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian.

Local commissioners and providers of healthcare have a responsibility to enable the guideline to be applied when individual professionals and people using services wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with complying with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.

### Technology appraisals

The recommendations in this interactive flowchart represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, health professionals are expected to take these recommendations fully into account, alongside the individual needs, preferences and values of their patients. The application of the recommendations in this interactive flowchart is at the discretion of health professionals and their individual patients and do not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or their carer or guardian.

Commissioners and/or providers have a responsibility to provide the funding required to enable the recommendations to be applied when individual health professionals and their patients wish to use it, in accordance with the NHS Constitution. They should do so in light of their duties to


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have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.

### Medical technologies guidance, diagnostics guidance and interventional procedures guidance

The recommendations in this interactive flowchart represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, healthcare professionals are expected to take these recommendations fully into account. However, the interactive flowchart does not override the individual responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or guardian or carer.

Commissioners and/or providers have a responsibility to implement the recommendations, in their local context, in light of their duties to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity, and foster good relations. Nothing in this interactive flowchart should be interpreted in a way that would be inconsistent with compliance with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.


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