

Cancer of Unknown Primary

A series of Patient Decision Aids for patients, their families and carers

Cancer of Unknown Primary

These Decision Aids have been written for patients and their families and carers. They have been given to you because you, or someone you care for, has been told that they may have a Cancer of Unknown Primary (CUP).

It's likely that you will be given a great deal of information and you may have to make a number of decisions. These Decision Aids are designed to help you to make the best decisions for you. They will not replace discussions that you will be able to have with doctors, nurses, or loved ones but they may help.

The Decision Aids are designed to be used together with the Macmillan Cancer Support leaflet called Understanding Cancer of Unknown Primary. We will make reference to things where the booklet can give more explanation. The booklet is available at cancer centres and can be found online at:

www.macmillan.org.uk/information-and-support

Contents

Some definitions	4
Diagnosing CUP – a flowchart	7
Decisions about having standard tests	10
Decisions about having genetic tests	12
Decisions about taking part in research	17
Decisions about having systemic treatment	21
Decisions about Supportive or Palliative Care	28
PDA development group	29

General

Cancer of Unknown Primary

This is a type of cancer where doctors have not been able to work out where it started. Where a cancer starts in the body is called the primary site. Sometimes it is not possible to identify this site.

- Malignancy of Undefined primary Origin (MUO) – it is likely that a patient has a cancer which has spread but the type of cancer is not known at this stage.
- Provisional Cancer of Unknown Primary – Initial tests (including a biopsy) have confirmed the presence of cancer which has spread, but the primary cancer remains unclear. Further tests may be suggested
- Confirmed Cancer of Unknown Primary – Despite further tests the primary site remains unknown and a CUP diagnosis is confirmed.

Metastasis (plural is Metastases)

This is when a cancer has spread to another part of the body away from where it started (the primary site). In most cases once a cancer has spread like this (or metastasised) it can no longer be cured. Sometimes metastases are called secondaries.

Prognosis

This is a prediction made by a doctor about what the future might hold for the patient. It is very difficult to be accurate.

Recurrence

This is when a cancer comes back after a period of time when it could not be found (i.e. after a period of complete remission – see below). It may come back in the same place or somewhere else in the body.

Remission

This is when a cancer stops growing and its effects on the body reduce. It does not mean necessarily that a person is cured.

Response to treatment

This is when a cancer gets smaller, stays the same or gets bigger. It is usually assessed with scans.

People you might meet

Oncologist

A doctor who has had special training in the treatment of cancer – a cancer expert

Cancer Specialist Nurses

There can be different terms used for these nurses – Cancer of Unknown Primary Clinical Nurse Specialist or Advanced Nurse Practitioner. They are highly trained nurses who are able to support and advise patients and families.

Palliative Care Specialists (Supportive Care Specialists)

They are highly trained doctors and nurses who can help patients and families facing potentially serious illnesses. They either work in hospital or outside hospital where they can visit people at home. In some parts of the country Specialist Palliative Care Nurses are called Macmillan Nurses.

Tests you might have

Biopsy

This is when a doctor carries out a procedure to remove a small sample of tissue from a person's body so that it can be analysed to work out what is wrong with them. This can be done with a local or general anaesthetic.

CT scan

CT stands for Computed Tomography – this is a series of X-rays taken by a machine which puts them together to produce images of what is going on in someone's body in 3 dimensions.

Endoscopy

This is a flexible camera which is used to look for illnesses like cancer. It can be placed in different parts of the body depending on where the doctor wants to look (e.g. gullet, rectum, lung, bladder)

Gene Expression Based Profiling

These are optional tests carried out on biopsies of cancer to look for targets for treatment. These tests are not normally available on the NHS and need to be paid for by patients if they choose to have them done.

MRI Scan

MRI stands for Magnetic Resonance Imaging - a type of scan that uses strong magnetic fields to produce images of what is going on in someone's body in 3 dimensions.

PET Scan

PET stands for Positron Emission Tomography - this is a scan which uses low dose radiation to look for active cancer cells in the body.

Ultrasound Scan

This is a type of scan which uses sound waves to produce images of what is going on in someone's body.

Treatments you might have

Biological (or targeted) therapy

A treatment given by mouth or injection which tries to control cancer growth by targeting an important genetic change in cancer cells

Chemotherapy

A treatment which uses drugs to try and destroy cancer cells. It can be given by mouth (e.g. tablets) or through a vein by a drip.

Immunotherapy

A treatment which tries to help a patient's body fight a cancer through boosting a patient's immune system

Palliative Care (Supportive Care)

This is help for people and families who are facing potentially serious illnesses like cancer. Its aim is to help with whatever problems people have and, in particular, with symptoms and worry. People can have Supportive / Palliative Care whether they are having anti-cancer treatment or not.

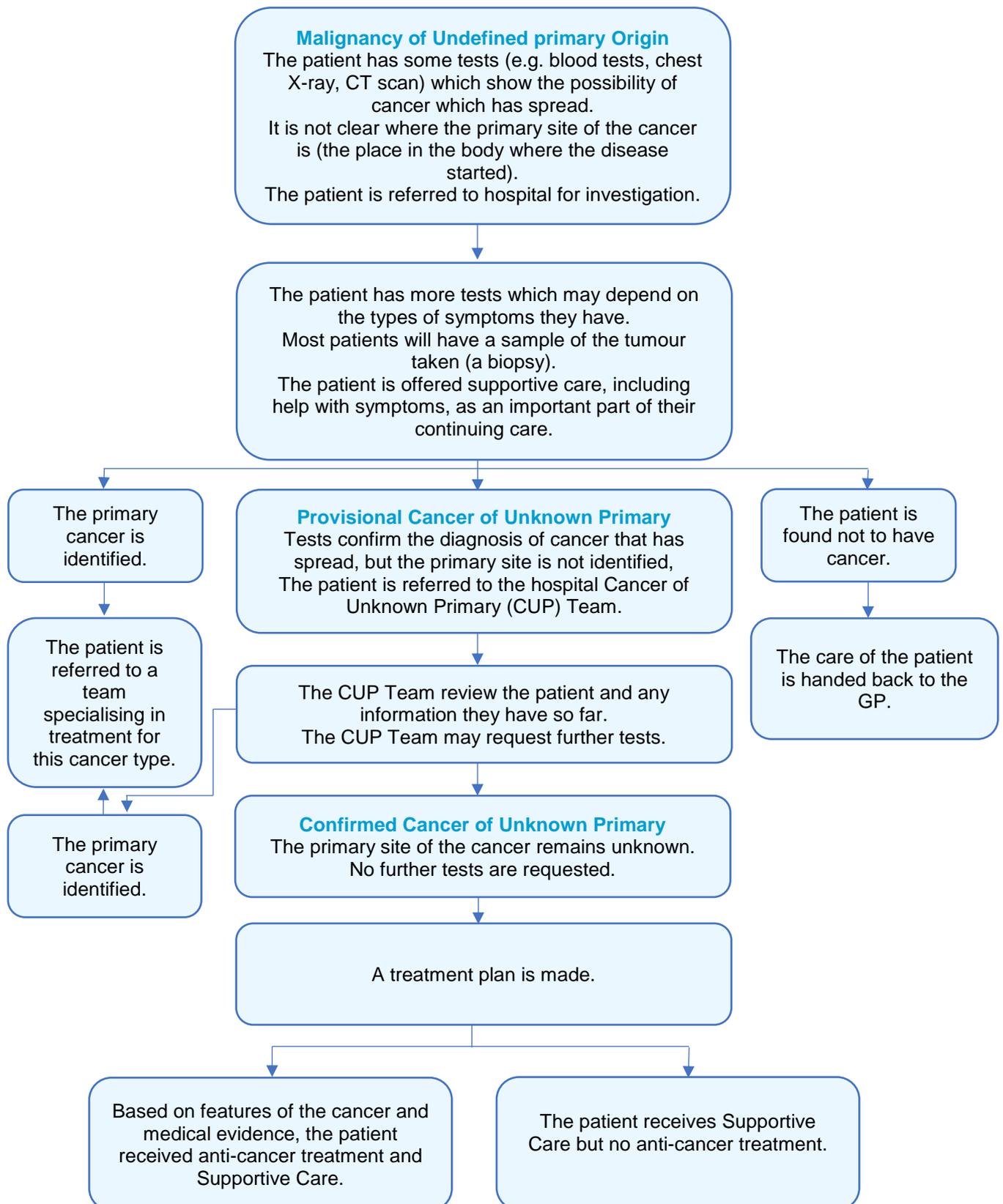
Radiotherapy

This is a treatment which uses X-rays to try to destroy cancer cells. Radiotherapy is given at Cancer Centres in one-off doses or courses using special X-ray machines.

Systemic Anti-Cancer Therapy

This is treatment to target a cancer that includes biological therapy, chemotherapy and immunotherapy.

Diagnosing CUP



Decisions about having Standard Tests

This Patient Decision Aid is to help you make the right decision about having more tests. The decision aid may also be used to help inform families and carers. Your medical team will assist you in making decisions about your treatment and it is important that you understand the options available.

You have been told that you may have cancer that has spread but where it started (the primary site) and the type of cancer has not yet been identified. Doctors refer to this as Malignancy of Undefined primary Origin (MUO). A biopsy is usually needed to confirm that you do have cancer and to try and identify the primary site. Sometimes a biopsy will confirm cancer but will not identify the primary site. This is because the cancer cells have lost their unique features when they have spread and their genetic origin cannot be identified under the microscope. A diagnosis of cancer without an identified primary site is called Cancer of Unknown Primary or CUP.

Extra tests may be needed to:

- Try and identify the primary site
- Get information on genetic abnormalities within cancer cells which could be targets for drug treatments

These tests may include blood tests, more scans, endoscopy examinations and more biopsies. Once the diagnosis of cancer is confirmed, further tests are usually only done if treatment is being considered AND the results of these tests will influence the type of treatment.

Some patients may decide not to have anticancer treatment and therefore further tests may not be required.

It may help to look back at the CUP Diagnostic Flowchart as you read this section. The main options are:

- **No further tests.** After a consultation with a doctor you have been told that you probably have cancer which has spread. More tests are needed in order to confirm this diagnosis, discover what type of cancer you have, and gain further information that might help the choice of cancer treatment. You may decide that you do not wish to have a biopsy. You may decide that you do not wish to have cancer treatment such as chemotherapy and, once the diagnosis is confirmed, you do not wish to have further tests to help guide treatment choices.
- **Further tests recommended by your Oncologist.** Before your Oncologist can offer you treatment, they need as much information as possible about the likely primary site of the cancer and any genetic targets for treatment. Your Oncologist may recommend further tests. Such tests may include an endoscopy, other types of scanning such as a PET scan and sometimes another biopsy. If a primary site is still not identified, these tests may help your Oncologist to choose the cancer treatment which is most likely to help you. Many new cancer treatments target specific genetic changes in cancers which

can be identified by special laboratory tests. Your first biopsy may be enough to perform these tests but sometimes a further biopsy may need to be taken from your tumour.

At any time, you can decide not to have the tests which are being recommended.

Some thoughts people may have when considering the options may include:

- *I've been told I may have cancer of unknown primary (CUP) and it is probably not curable. The doctors know I have cancer which has spread but cannot say where it started and so I need to have more tests including scans and maybe another biopsy. Even if the primary is not found, these results may still help my Oncologist to choose the best treatment for me.*
- *I am not sure I want cancer treatment that might give me side effects and only modest benefit. So maybe I do not need to have these tests.*
- *My Oncologist said that to treat the cancer they need more information from more tests. If CUP is confirmed it may be treatable. This treatment might help my symptoms and help me to live longer. My Oncologist cannot say how much longer. I will agree to further tests to hopefully answer some of these questions.*

The right decision for you may change over time. As your illness, or your circumstances change, you may think differently. Remember that you might find it helpful to talk to your CUP Specialist Nurse.

Further reading: www.macmillan.org.uk/information-and-support

Decision Aid about having Standard Tests

Your Oncologist has told you that you have CUP. You are being offered tests to help your Oncologist to choose the best treatment for you.

Below is information about the choices. The table lets you compare similarities and differences between the options, side-by-side.

If I choose to have further tests	If I choose NOT to have further tests
<p>Further tests may help your Oncologist to decide what treatment to give you. A cure is often not possible but the right treatment might lead to better chances that the cancer is controlled and you may live longer.</p> <p>You may have further tests but they only give limited new information to your Oncologist.</p> <p>Sometimes test results might mean that certain types of cancer may be excluded and this helps to narrow down the treatment options.</p> <p>Your tests may show that you have a specific primary cancer which leads to a different treatment for you. Or it may lead to a wider choice of treatments being available to you.</p> <p>Very rarely, further tests may show that the cancer is of a type which can be cured.</p> <p>Further tests may mean you spend more time in hospital and may introduce some delay in starting treatment as you wait for results.</p> <p>You will still be able to have Supportive and Palliative Care.</p>	<p>If you decide not to have further tests your Oncologist may not know which is the best cancer treatment for you.</p> <p>Your Oncologist will offer you treatment based on the evidence that they have already and this treatment may start sooner.</p> <p>If you do not wish to have cancer treatment, further tests may be unnecessary and you will save yourself time, the inconvenience of coming to hospital, as well as discomfort or complications that may result from having these tests.</p> <p>You could spend less time in hospital.</p> <p>You will still be able to have Supportive and Palliative Care.</p>

How do you feel about the options available to you?

You can use the table to help you think about how important the issues are to you.

Option	How do I rate this option?				
	Strongly Agree	Agree	Neither Agree or Disagree	Disagree	Strongly Disagree
The most important thing to me is to have a treatment that gives me the best chance of a longer life. I accept that I will need further tests in order to achieve this.					
I want a treatment that gives me the best chance of controlling my cancer, regardless of the bother or discomfort of more tests, if this gives my Oncologist as much information as he/she needs.					
Avoiding the discomfort of additional tests is very important to me.					
I don't want to spend time in hospital having tests.					
I would rather start treatment quickly based on my Oncologist's previous experience of treating cancer patients rather than spend more time waiting for test results and worrying that my cancer is spreading.					

Decisions about having Genetic Tests

(Gene expression-based profiling)

This Patient Decision Aid is for people who have been given a diagnosis of Cancer of Unknown Primary (CUP) following some tests. Its aim is to help you decide whether to have extra tests carried out. These tests look at genes contained within your cancer. Usually, these tests are not paid for by the National Health Service (NHS). Sometimes they could be paid for if you are taking part in a research study OR your Oncologist can make a special case to the NHS. Otherwise, you will have to pay for them.

Gene expression-based profiling, sometimes called molecular profiling, may help work out where the cancer started OR possible targets your Oncologist can attack with drugs. A tissue sample of your cancer, taken in a biopsy, is sent to a laboratory for study. It is possible that the doctors may be able to use part of a biopsy you have already had. Sometimes, another biopsy will be needed.

Genetic testing is a very rapidly changing area of science and it is worth getting more information and discussing it with your Oncologist.

More information on the tests and their cost is available on the CUP Foundation website: www.cupfoundjo.org/diagnosis/tests.

The main options are:

- **No genetic test.** The standard tests carried out so far have established a diagnosis of CUP and they will give your Oncologist information to help plan treatment.
- **A genetic test.** This may add to the information about your cancer and help your Oncologist choose the best treatment.

Some thoughts people may have when considering the options might include:

- *If further information will help my oncologist and perhaps direct my treatment more precisely I'm willing to pay (several thousand pounds) for this.*
- *I don't want another biopsy but if there is enough tissue left from my original biopsy I would like to give this a try.*
- *I don't want to risk any delay and I am happy for my oncologist to use his experience and judgment based on the standard tests.*

This decision aid aims to help you make the right decision for you now. If you opt for gene expression-based profiling it is likely to be of the greatest benefit as early as possible in your treatment pathway.

The right decision for you may change over time. This decision aid aims to help you make the right decision for you now, but you may wish to change your mind as your illness or your life changes. If you choose to have gene expression-based profiling it will probably help your treatment most if you have it done early in your treatment.

Decision Aid about whether to have Genetic Tests

(Gene expression-based profiling)

Your Oncologist has told you that you have CUP. You may be able to have more tests on your cancer which could help your Oncologist choose the best anti-cancer treatment for you.

Shown below is information about each of the different options. The table lets you compare similarities and differences between the options, side-by-side.

	Standard tests only	An additional genetic test
What is it?	These are the tests needed to make a diagnosis of CUP according to current national guidelines. These tests are done on the NHS.	Genetic tests may provide additional information which helps narrow down the identification of the cancer's primary site. The tests may also suggest ways of treating the cancer using some newer drugs.
Is this considered standard care?	Yes. There is research backing-up the way that CUP is currently diagnosed and treated in the NHS.	There are different practices in different countries. In the UK, genetic tests in CUP are still the subject of research. Some tests are available and patients can pay to have them done.
Do I need a biopsy?	If you are well enough for treatment, this has probably been done already as part of your standard tests.	If there is enough tissue left from your original biopsy there will be no need for a further biopsy – some of the original tissue will be used. If all of the material from the biopsy has already been used you may need to have another one. If your genetic tests are not funded by the NHS you may need to pay for this second biopsy.
Will this delay my treatment?	Your standard tests may involve some delay but they should give your Oncologist enough information for your treatment to be chosen.	Having an additional genetic test after your standard tests (especially if this needs another biopsy), may delay your treatment.
What are the potential advantages and disadvantages?	You can start any treatment offered quickly. You will not have to consider paying for a test. Standard tests will not show whether your cancer has genetic targets for new drugs.	The tests may give your Oncologist information which helps them to choose a better treatment for you. Waiting for more tests and results may delay your treatment starting OR if your treatment has started

<p>What are the potential advantages and disadvantages – continued from previous page</p>		<p>the results may suggest that the treatment is changed.</p> <p>The test may fail to find any useful targets for treatment in which case you will continue on 'standard' treatments.</p> <p>The tests may not be funded by the NHS so you may need to pay for them.</p> <p>The test results may suggest drug options that are not funded by the NHS so you may need to pay for them.</p>
--	--	---

How do you feel about the options available to you?

You can use the table to help you think about how important the issues are to you.

Option	How do I rate this option?				
	Strongly Agree	Agree	Neither Agree or Disagree	Disagree	Strongly Disagree
The most important thing to me is to have treatment that controls my cancer and gives me the best chance of a longer life.					
I want doctors to have as much information as possible about my cancer to help control my cancer even if this is going to cost me money.					
I want to start treatment quickly based on my Oncologist's experience and the standard test results.					
I don't want to spend time and money on a new test for which there is limited evidence.					
I do not wish to have drug treatment for my cancer and so do not need more tests. I wish to focus on my quality of life and control of my symptoms for as long as possible.					

Decisions about taking part in Research

This Patient Decision Aid is to help you decide whether you want to take part in research.

It may be that your doctor has suggested that you take part in a research study; or you may want to ask the team looking after you about some research that you can take part in.

The research may involve new drugs or perhaps tests on your cancer to try and identify targets your Oncologist can attack with drugs.

- Undertaking research is the best way to find out the effectiveness and safety of new diagnostic approaches and medical treatments. The treatments that are used today are based on previous research.
- You may feel concerned about taking part in research. It is important to know that research projects must be approved by expert independent committees to make sure high standards are maintained and that the patient's safety is protected.
- You will always be given an information leaflet. This should clearly outline the possible advantages and disadvantages of taking part. You should also be given time to think about your decision and you may find it helpful to discuss it with your family and/or GP.
- Deciding not to take part in research will never affect the way you are treated by staff.

The main options are:

- Taking part in research. As well as possibly benefiting future patients, there can be benefits to you from taking part in research studies; but this is not guaranteed. People taking part in research studies will be monitored closely during and after the study and you can decide to withdraw from the study at any time without giving a reason.
- Not taking part in research. The current standard treatment would be offered to those deciding not to take part in the research. Some people feel more secure having a treatment that is 'tried and tested'.

Possible benefits of taking part in Research:

- Access to new treatments that are not otherwise available
- A new treatment may be more effective than the current standard treatment
- Research staff will closely monitor and support you
- Results from the research may help future individuals

Possible disadvantages to taking part in Research:

- You may have to make more frequent visits to hospital and need more tests
- A new treatment may not be more effective than the current standard treatment
- A new treatment may give you side effects

Some thoughts people may have when considering taking part in research may include:

- *I'm overwhelmed with everything - I just want to get on with standard treatment without delay.*
- *Although research may not benefit me personally I'd like to help future patients with Cancer of Unknown Primary.*
- *I've been offered the chance to take part in a research study which involves several additional visits to hospital. I wish to avoid any additional hospital visits.*
- *Any new diagnostic test that has the potential to explain more about my cancer has to be a good thing.*
- *I've had enough tests - I really do not want any more.*
- *I have been given a chance to take part in a study where a new treatment is being compared with the current standard treatment. I would like to have a chance of trying the new treatment.*

The right decision for you may change over time. If you choose to take part in research and then change your mind and wish to withdraw from the study, this is fine. If you do not take part in a research study offered to you now, there may be other opportunities to participate in research in the future. This decision aid aims to help you make the right decision for you now, but you may wish to change your mind as your illness or your life changes.

Further reading: www.macmillan.org.uk/information-and-support.

Decision Aid about whether to take part in research or not

Your Oncologist has told you that you have Cancer of Unknown Primary (CUP). You are being offered the opportunity to take part in a research study and you may be unsure whether you wish to do so. Shown below is information about each of the different options. The table lets you compare similarities and differences between the options, side-by-side.

	Taking part in research	Not taking part in research
What are the benefits?	You will have more detailed monitoring because you are taking part in scientific research. You may have access to new drugs which you would not get otherwise.	You will have current standard treatment which has been established for longer and its effects are well known by the doctors treating you.
What are the disadvantages?	You may need to have more tests which may cause a delay in starting treatment. You may be required to attend hospital more frequently.	You will not be able to receive the new drugs which are being tested in the trial.
Effects on my treatment visits?	Your visits may be longer. You may be looked after by a different team in a different area from patients not taking part in research.	The time it takes to have your treatment may be longer or shorter than an experimental treatment.
How will it affect the way I am treated by my Oncology team?	You may have more frequent contact with the Oncology and Research team.	Deciding not to take part in a trial will never affect the way you are treated by staff.
Effect on my quality of life?	New treatments may have more or fewer side-effects depending on the specific treatment offered.	Current standard treatment may have more or fewer side-effects compared to a new treatment.

How do you feel about the options available to you?

You can use the table to help you think about how important the issues are to you.

Option	How do I rate this option?				
	Strongly Agree	Agree	Neither Agree or Disagree	Disagree	Strongly Disagree
The most important thing to me is to have a treatment that gives me the best chance of a longer life. I will take part in research if this improves my chances.					
I would like to take part in a study of a new diagnostic test or a new drug even though it is uncertain how well it will work.					
Receiving a new treatment in a study gives me more hope as scientists are learning more about cancer and treatments are improving all the time. I am willing to take part in research.					
I am worried that the trial treatment may not work and I will have wasted time taking part when I could have had the current standard treatment. I feel more secure having a treatment that is "tried and tested".					
The additional tests required by a study may delay me starting treatment for my condition and I don't want any delay.					

Decisions about having Systemic Treatment

(Systemic Treatment, or Systemic Anti-Cancer Therapy, refer to chemotherapy, biological or targeted therapy and immunotherapy)

This Patient Decision Aid is to help you decide what treatment, or combination of treatments, is suitable to treat your Cancer of Unknown Primary (CUP). This decision aid is for people who have been diagnosed with CUP. This means that tests have been completed and the oncologist is considering a course of drug treatment to try to control the growth of your cancer and reduce its effects on your health.

CUP is a type of cancer where doctors have not been able to work out where it started in the body. At present, there may be treatments to help you but CUP cannot be cured.

The main options for treatment are:

- **Supportive and Palliative Care.** This means having treatments to help symptoms and improve quality of life. These treatments will not influence the growth of the cancer and may not lead to longer life. The treatments include pain killers, medication to increase appetite, blood transfusions, and removing fluid that has collected in parts of the body such as the chest or abdomen.
- **Systemic Treatment.** This is drug treatment given to try to control the growth of the cancer and possibly make it smaller by killing some of the cancer cells. Systemic treatment cannot cure your cancer completely but may lead to a remission where the cancer shrinks and remains stable for a while.
- **Systemic Treatment and Supportive and Palliative Care together.** People can have these at the same time.

There are several reasons why you may not receive systemic treatment:

- the oncologist does not think it will help
- you do not want it
- you are not well enough to be able to tolerate potential side-effects

You may choose not to have systemic treatment because you have decided that the possible benefits you might get from it do not justify the inconvenience, time spent visiting hospital and possible side-effects. Many people are concerned about the side effects of systemic treatment and how these can impact on their day-to-day lives. Please discuss any worries with your oncologist or a member of the CUP team, for example your Clinical Nurse Specialist. There are treatments which can help you cope with side-effects to lessen their impact on your day-to-day life.

Possible benefits from systemic treatment:

- you may live longer
- your symptoms may improve
- you may feel better so that you have a better quality of life

Possible disadvantages of systemic treatment:

- the treatment may not work well so that you do not live any longer
- you have side-effects from the treatment which decrease your quality of life

- you have to spend more time in hospital for appointments or treatment of side effects
- occasionally there can be severe side-effects from treatment which may shorten your life

Some thoughts people may have when considering the options might include:

- *I've decided to attempt a course of chemotherapy to see if this will reverse the growth of my cancer and improve my symptoms. I hope to feel better but I accept that while I am on chemotherapy, I may experience side effects which will affect how I feel.*
- *I want to have the treatment that gives me the best chance of surviving longest with CUP. I understand there is no guarantee that my treatment will work but my progress will be monitored. I know that I can stop my treatment at any time.*
- *I don't want systemic treatment. I am worried about possible side-effects and I have been told that treatment may not work or may only prolong my life by only a few months. I am not sure this is worth the effort and I have decided to choose Supportive and Palliative Care only.*

The right decision for you may change over time. This decision aid aims to help you make the right decision for you now, but you may wish to change your mind as your illness or your life changes.

Further reading: www.macmillan.org.uk/information-and-support.

Decision Aid about whether to have Systemic Treatment or not

Your oncologist has told you that you have CUP. You are being offered systemic treatment - drugs that fight cancer. Systemic treatment may consist of chemotherapy, biological therapies, hormonal therapies or immunotherapy. You may be unsure whether you wish to have this treatment.

Shown below is information about each of the different options. The table lets you compare similarities and differences between the options, side-by-side.

How do you feel about the options available to you?

You can use the table to help you think about how important the issues are to you.

	Systemic treatment in addition to Supportive and Palliative Care	Supportive and Palliative Care only
What is it?	Systemic treatment means drugs given to try to slow or shrink your cancer by killing cancer cells.	Supportive and Palliative Care includes all treatments to help the symptoms of cancer or cancer treatments, such as drugs for pain, sickness or fatigue.
Effect on my symptoms	Systemic treatment is intended to improve symptoms by shrinking your cancer or stopping it growing. If the cancer stops growing or even shrinks this usually helps to reduce the symptoms from cancer.	Supportive and Palliative Care is to help control your symptoms.
Effect on growth and further spread of my cancer	Systemic treatment may temporarily stop the cancer growing and may cause it to shrink. The treatment may delay spread to other parts of the body.	Supportive and Palliative Care will not affect the growth of the cancer or prevent further spread.
Effect on length of life	Systemic treatment can sometimes help people with cancer, including those with CUP, to live longer but every individual's response is different.	Supportive and Palliative Care has been shown to help people with some types of cancer to live longer. There is no evidence that Supportive and Palliative Care will help CUP patients to live longer.
Side-effects or complications of treatment	Systemic treatment may cause side-effects which can be severe and possibly life-threatening. Your oncologist may need to pause or stop your treatment altogether. Side-effects are often manageable but may take time to get better.	Supportive and Palliative Care treatments are intended to help symptoms and do not usually cause severe side-effects. However, all drugs can have unwanted effects.

<p>Effect on my quality of life</p>	<p>Quality of life may improve if cancer symptoms improve, BUT side-effects of treatment may reduce quality of life.</p>	<p>Supportive and Palliative Care aims to improve your quality of life by helping control symptoms. How successful this will be varying from person to person.</p>
<p>Where will I have my treatment?</p>	<p>Systemic treatment is usually given in hospital in the outpatient department or day unit. If you have bad side-effects you may need to be admitted to hospital.</p> <p>Some drug treatments can be taken at home as tablets.</p>	<p>People having Supportive and Palliative Care usually have this at home. You might be seen as an out-patient in a hospital or hospice. Admission to hospital might occasionally be needed to manage difficult symptoms.</p>
<p>Who will be involved in my care alongside my GP and District Nurse?</p>	<p>The Hospital Oncology Team. The Supportive and Palliative Care Team could help you and your family too.</p>	<p>The Supportive and Palliative Care team.</p>

How do you feel about the options available to you?

You can use the table to help you think about how important issues are to you.

Option	How do I rate this option?				
	Strongly Agree	Agree	Neither Agree or Disagree	Disagree	Strongly Disagree
I would like a treatment that gives me the best chance of a longer life					
I want the best quality of life in the time I have left. I don't want to have to cope with the side effects of systemic treatment for what might just be a slightly longer life					
Avoiding side-effects is very important to me					
I want to spend as little time in hospital as possible					
I do not want the treatment to affect my life in general					
I want to avoid showing signs that I am having cancer treatment					

Decisions about referral to Supportive or Palliative Care

This Patient Decision Aid is to help you decide whether you want to be referred to a Palliative Care specialist.

In some areas Palliative Care might be called Supportive Care (or Supportive and Palliative Care) but we will refer to this as Palliative Care in this Patient Decision Aid. In some parts of the country Palliative Care Nurses are called Macmillan Nurses.

Being told you have cancer is life changing. The 'unknown' nature of a Cancer of Unknown Primary (CUP) diagnosis can add to the stress and worry that many cancer patients experience in addition to physical symptoms. Palliative Care specialists are an important part of the CUP team and work side by side with the Oncology team to provide support and symptom management as patients undergo treatment.

Some people believe that Palliative Care is just for people who are extremely ill. This isn't true; an early referral to Palliative Care could help improve your quality of life by supporting you at all stages of your illness. Palliative Care Nurses can offer advice about managing symptoms and also support you and your family emotionally with any worries you may have. They work alongside the Oncology team, GPs and District Nurses who you can still see. This support can be provided in your home, in hospital or at a hospice.

If you have not been referred to a Palliative Care specialist you can ask to be put in touch with one for extra support.

The main options are:

- **Palliative Care from a specialist.** This means having treatments to help symptoms and improve quality of life. These treatments will not influence the growth of the cancer and may not lead to longer life. Such treatments include pain killers, medication to improve appetite, blood transfusions, and removing fluid that is collecting in parts of the body such as the chest or abdomen.
- **Not receiving Palliative Care from a specialist.** The Oncology Team, GP and District Nurses can support you and your family.

Possible benefits from Palliative Care from a specialist:

- Better control of symptoms from your cancer, or anti-cancer treatment, and better quality of life
- Better support for you and your family
- The opportunity to talk about the future and make plans

Possible disadvantages of Palliative Care from a specialist:

- You will have to meet another healthcare professional when you may feel you have seen enough already
- You don't want to go to a hospice or another hospital department to talk to someone about Palliative Care
- You don't want to talk about the future right now.

The decisions patients may make include:

- *I've been told that I am not fit enough for chemotherapy. I want to see a Palliative Care Specialist to help me with my symptoms and help me to plan for the future.*
- *I've decided to meet a Palliative Care Nurse who will come and see me at home. They can give me advice about getting my pain better and how I can cope with the side-effects I'm getting from chemotherapy. They can also support my family so we can face my cancer together.*
- *I was offered a Palliative Care Nurse but I see enough doctors and nurses and I don't think I need to see anyone else. It might be something I consider in the future.*

The right decision for you may change over time. This decision aid aims to help you make the right decision for you now, but you may wish to change your mind as your illness, or your life, changes.

Further reading: www.macmillan.org.uk/information-and-support.

Decision Aid about referral to Supportive or Palliative Care

Your Oncologist, GP or District Nurse has suggested that you see a Palliative Care specialist. This could be in your home, in the hospital or hospice. People sometimes think that Palliative Care specialists only support people when they are very ill, but Palliative Care can help people all the way through their illnesses from the time they are diagnosed, working alongside other treatments.

Below is information about each of the different options. The table lets you compare similarities and differences between the options, side-by-side.

	Seeing a Palliative Care Specialist	Not seeing a Palliative Care Specialist
What is it?	Help for patients and families who are facing potentially serious illnesses like cancer. Its aim is to help with whatever problems people have and, in particular, with symptoms and worry. People can have Palliative Care whether they are having anti-cancer treatment or not.	I will get support from the Oncology Team, GP and District Nurses.
Support early in my illness	Meeting a Palliative Care specialist when I have just been diagnosed can provide early help with symptoms and support me all through my illness.	I already have enough people involved in my care. I do not feel that I need to meet the Palliative Care team at this point but know that I can ask for their help later.
Effect on my symptoms	Palliative Care specialists focus on controlling symptoms and may have ideas and treatments which can help you.	Symptoms may not be as well controlled.
Effect on length of life	In some cancers combining Palliative Care from the start with chemotherapy has been shown to prolong life when compared to chemotherapy alone. There may be benefits in terms of life expectancy from earlier Palliative Care input in CUP.	For someone not having chemotherapy it is not known whether seeing a Palliative Care specialist has an effect on life expectancy.
Planning for the future	I might find it helpful to talk to an expert about how I can be helped in the future. There may be a time when I want to talk to them about where / how I want to be cared for as my illness progresses.	I don't want to have these conversations at the moment. When I do I can ask.

Support for family	I think my family would find it helpful to talk to someone.	My family are happy with the care I am receiving from the Oncology Team and my GP. I worry that bringing in a Palliative Care specialist now will make them think I am going to die soon or that things are worse than they seem.
---------------------------	---	---

How do you feel about the options available to you?

You can use the table to help you think about how important the issues are to you.

Option	How do I rate this option?				
	Strongly Agree	Agree	Neither Agree or Disagree	Disagree	Strongly Disagree
I see enough healthcare professionals. I don't want to see any new people.					
I want to see a Palliative Care doctor to get as much help and advice as possible about my symptoms and how to cope with side effects of treatment.					
I'd like my family to see a Palliative Care Nurse to talk about how my illness is affecting them.					
I don't want to go to the hospice to see anyone. I thought hospices were there to help people who are dying. I am still well and intend to fight my cancer to the full.					
I want to talk to someone about how I am going to be cared for when I am very ill.					

Development Group

Dr Paul Perkins (Chair)

Consultant in Palliative Medicine, Sue Ryder Leckhampton Court Hospice and Gloucestershire Hospitals NHS Foundation Trust

Jo Cheetham

Acute Oncology Advanced Nurse Practitioner, Gloucestershire Oncology Centre

Dr David Farrugia

Consultant Medical Oncologist, Gloucestershire Hospitals NHS Foundation Trust

Anne Parkinson

Research Nurse, Sue Ryder Leckhampton Court Hospice

Jan Rose

Patient Representative

Dr John Symons

Patient Representative and Director, Cancer of Unknown Primary (CUP) Foundation – Jo's friends

Diana Wheatley

Patient Representative

This document was produced in February 2019 as a pilot. Comments, and suggestions for improvement, are welcome and may be sent to:

director@cupfoundjo.org