NHS
Liverpool University Hospitals
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Patient information

Prognostication

A Guide to a Prognostic Biopsy

St Paul's Eye Unit

Your consultant has offered you the option of having a biopsy of your eye tumour (Uveal Melanoma). This is called a prognostic biopsy.

You can decide whether to have a prognostic biopsy or not.

This guide explains what the prognostic biopsy is for, what will happen and aims to help you to decide whether you want it or not.

This leaflet is in two parts; part one provides information about the test, what it's for and what this means for you in the future.

Where you see an asterisk* supplementary information is provided in pages seven to ten.

In part two we will provide information to support you in making the decision whether to have the test or not.

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Part 1

What is a prognostication?

Most cancers start in one part of the body. Unfortunately, cancer cells can spread to other parts of the body, this is called secondary cancer or metastasis. The most common site for uveal melanoma to spread is the liver.

If you have the type of tumour that spreads to the liver it can be difficult to treat. Prognostication simply means that we try to find out how likely this is to happen to you.

It is based on a number of factors, including particular features of your uveal melanoma (e.g. size and location within the eye and if there are changes in the chromosomes). These factors as well as your age are taken into consideration, in order to estimate your personal risk for cancer spread.

How does prognostication work?

To perform the prognostic test, we need to test your cancer in a specialist laboratory. To do this we surgically remove a small portion of the cancer. This is called a biopsy.

When would the prognostic biopsy be taken?*

This depends on the treatment that you have and where the tumour is in your eye.

Your consultant will discuss with you when it can be taken.

What can prognostication tell me?

We can estimate how likely it is that the cancer will spread to your liver in the next ten years. This is usually a very accurate estimate. The risk can be high, medium or low.

Please understand that no test is 100 % accurate, and this is not a diagnostic test i.e. patients with a low risk can still develop cancer in the liver.

What is it like to have a biopsy?

You can have the biopsy awake under a ‘local anaesthetic’ or be under ‘general anaesthetic’ and the biopsy will be taken while you are anaesthetised. Your specialist nurse will be able to give you more information. For patients having their eye removed the biopsy sample will be taken from the eye after it has been removed.

Are there any risks involved in having the biopsy?

For patients who retain the eye there is an exceptionally small risk of the cancer cells spreading within the eye and also on the surface of the eye. Our data analysis shows, the biopsy does not increase the risk of the tumour spreading to other parts of the body. Other risks include, bleeding, infection and damage to the retina which in a small percentage of cases can lead to reduction in vision.

Can the biopsy testing fail?

Sometimes it is not possible to carry out the prognostic test on the biopsy. This may occur for several reasons, but is usually because we were unable to take a large enough piece of the cancer. Biopsy testing fails about once in fifteen times. In this case, your consultant will look at the other features of your tumour that can predict cancer spread - e.g. its size and position and make an estimation regarding metastatic risk. This will not be as accurate as the full prognostic test which includes more detailed features of the tumour cells.

How long do I have to wait for my results?

Results to confirm whether your tumour is a melanoma (type of cancer) takes seven to ten working days. Results for the more detailed prognostic test can take between four to six weeks.

Occasionally, and in exceptional cases it can take longer if further tests are needed. We understand that waiting for the test results is a difficult time.

If you have any questions or concerns while you are waiting for the results please contact the specialist nurses on the following telephone number.
Tel: 0151 706 3976
Text phone number: 18001 0151 706 3976.

What tests are done on the piece of tumour for prognostication?*

There are two main stages to the test carried out by our specialist laboratory staff.*

Stage 1 will confirm the diagnosis of the melanoma or whether it is a different type of eye tumour. If it is a melanoma we can usually tell by the shape of the cells.

Stage 2: more detailed tests on the tumour cells are carried out on the melanoma cells to estimate the risk of developing cancer in the liver. This test is to see whether there have been any changes in the chromosomes.

How will I be told the test results?

You can choose to have your results in one of the following ways:

- Our specialist nurses will phone you and tell you that the results are ready and arrange a suitable time to discuss them with you over the phone.

- You can attend the Liverpool Ocular Oncology Centre (LOOC) and an appointment can be arranged to see the consultant and specialist nurse in person

- We send a detailed report to your family doctor (GP) or referring ophthalmologist. You could then make an appointment to discuss them with your GP/ophthalmologist.

- We do not routinely send a detailed report to patients but if you would like to see this you can apply to access to your medical records

Who else will be informed about the test result?

We will write to your family doctor (GP), referring Ophthalmologist, and if needed an Oncologist (specialist cancer doctor).

What happens after I have been given my results?*

High Risk

If you are at **high risk** of cancer spread outside of the eye you will be referred to an Oncologist (specialist cancer doctor). You can have regular scans of your liver and blood tests (liver screening). This is usually every six months. This will be arranged by the Oncologist you are referred to

Medium Risk

If you are at **medium risk** your consultant and specialist nurse at LOOC will discuss your on-going management with you which may include regular liver scans. These can be arranged by our specialist nurse to be completed at LOOC. If you do not wish to travel to LOOC we can write to your GP and ask them to arrange them locally.

Low Risk

If you are at **low risk** of cancer spread then there is usually no need for you to be referred to an oncologist or to have regular liver scans. However, there are no clear guidelines. Some patients prefer to have regular scans and some don’t. You will be able to discuss this with your specialist nurse who will write to your GP and ask them to arrange for the scans to be completed locally.

Do I have to have the test?

The biopsy is entirely optional, you can choose whether you have the test done or not.

Whether you choose to have the test or **not,** the treatment of your eye will not be affected.

If I don’t have the test can I be given any information about my risk of developing metastases?

Your consultant will look at the clinical features (e.g. size and position) of your tumour that he/she can see and give you an estimate of your risk. This is not as accurate an estimate as taking the prognostic test.

What happens if I have the test but do not want to know the results?

You might like to have the test done, but do not want to know the results. If this is the case then this will be clearly indicated on your hospital case notes. The results will be securely kept in a safe in the laboratory for 30 years in line with the Royal College of Pathologists current guidelines. The information is **not** released to any of the medical team including your consultant, nurses, your GP or any other health professional.

You can change your mind whenever you wish. You can be given these results at any time after the results become available.

Please let us know whether you would like to be advised of the test results.

Can I change my mind about not having the test on the tumour cells?

We can perform the test on the cells up to six months after the biopsy has been taken.

Part 1: Frequently asked questions

Q. What are the chances of not getting a detailed result from the biopsy?

A. There is 5-10 % chance of not getting a result.

Q. Will the biopsy change the treatment of my eye?

A. The biopsy will not change the treatment of your eye but may influence whether you are offered liver screening.

Q. When will the biopsy be performed?

A. This will vary on the size of the tumour and the treatment you have.

Q. Can I have the biopsy done at a later stage?

A. This depends of the type of treatment you have.
For patients having an Enucleation (eye removed) or Local resection (surgical removal of tumour) it is best to do the tests straight away.

For patients having Proton Beam radiotherapy the biopsy can be performed up to one year after treatment but this will depend on the size of the tumour.

For patients having Plaque radiotherapy the biopsy can be done around six weeks after treatment as a result cannot be guaranteed after that time. It will also depend on the size of the tumour and how it has responded to the plaque treatment.

Q. What are the risks of having the biopsy?

A. There is a 10 % chance that the biopsy will cause defects to your vision.

A. There is 5-10% risk of complications that will affect vision and require further surgery.

Q. Will my biopsy result be used for research?

A. Yes, with your permission we can do the biopsy and use the results to further our research. This will be discussed with you before the biopsy.

Q. I have read that gene expression profiling is done in the United States to see whether the tumour cells will spread. Is your test any better or worse?

A. Gene expression profiling is not done in the UK. However, our results are comparable and there is no evidence that there is any benefit or disadvantage for either test.

Supplementary information: Part One

When would the prognostic biopsy be taken?

Proton beam radiotherapy

- Usually last day of therapy.
- Up to one year after therapy.

Plaque Radiotherapy

- At the same time as the plaque is inserted or removed when you are still in hospital.
- Around six weeks after plaque removal.
- Up to six months after plaque removal.

Enucleation or surgical removal

- On the day of your operation the removed eye or a piece of the tumour will be taken to the laboratory.

What can prognostication tell me?

- High risk: anything up to 51%-100% chance of developing liver metastasis in ten years.
- Medium risk: anything up to 27%-50% chance of developing liver metastasis in ten years.
- Low risk: anything from 0% up to 26% chance of developing liver metastasis in ten years.

Is there risk involved in having the biopsy?

Risks and side effects of biopsy
(Based on a review of 1000 patients)

- 50% risk of mild bleeding into the eye. This is usually seen as ‘floaters’ and usually clears by itself. Approximately 10% of patients have more severe bleeding and require further operations to clear this.
- 5% risk of retinal detachment. This can interfere with vision and will require further surgery.
- 0.01% risk of infection. This is usually controlled but may endanger the health of the eye but very rare.
- 0.02% risk of tumour cells spreading to the surface of the eye. This can usually be controlled with other measures.

Can the biopsy testing fail?

- Yes there is a 5-10% chance of not getting enough cells for testing in small tumours (2mm or less)

What tests are done on the piece of tumour for prognostication?

There are two stages to the test

Stage One

Confirms the diagnosis based on the clinical and ‘histological’ features of the tumour. All of these provide additional information required for accurate prognostication.

- Is this melanoma coming from the eye?
- If yes, which type of cells-spindle or epithelioid?
- Has the tumour grown outside the wall of the eye? (enucleation only).

Stage Two

This is a detailed test of the melanoma cells based on:

- The rate at which the cells multiply.
- To see if there are any changes in the chromosomes, particularly on chromosome 3.

These changes are called:

- **Monosomy 3** If one of the pairs of chromosome 3 is missing and is associated with a higher risk of cancer spread.
- **Disomy 3** If both pairs of chromosomes are present it is associated with a lower risk of cancer spread.

We use all the information to find out your risk of developing metastasis over the next ten years.

Your results will be entered into a computer programme and a graph will be generated to estimate your individual risk.

What happens after I have been given my results?

- **High Risk**

If you are at high risk of cancer spread outside of the eye you will be referred to an oncologist. You can have regular scans of your liver and blood tests (liver screening). This is usually every six months.

Further information will be available once you have seen an oncologist. Oncologists are well informed about the treatment trials or options for patients whose cancer has spread.

- **Medium Risk**

If you are at medium risk your consultant and specialist nurse at LOOC will discuss your results with you. They may offer you regular liver scans. This can be done here at LOOC. Alternatively you may want to have your scans closer to home. These options will be discussed with you.

- **Low Risk**

If you are at low risk of cancer spread there is usually no need for you to be referred to an oncologist or to have regular liver scans. However there are no clear guidelines. Some patients prefer to have regular scans and some don't.

Part Two

The decision to have the prognostic biopsy

We know that your decision may be difficult to make. We have written this leaflet to help you to think about your decision. The decisions that people make about the prognostic test are based on what is important to them personally. Some patients have told us that thinking about the following are important when making this decision, they may be helpful for you as well.

- Some people do not want to think about things that worry them; others want to know as much as they can.
- Some people like their lives to be as organised as they can, others are content to just let things happen.
- Some people want to involve family and friends in their decisions, others don’t.

We thought that it may be helpful for you, to provide examples of how different people have thought about this decision previously. (These are not real patients, but the stories are based on what several patients have told us).

George

George is 78 years old, is widowed and has health problems which sometimes interfere with his daily activities. George feels that he has had a good life; he enjoyed his work until he retired and his retirement years until his wife died two years before his diagnosis. Since then life has felt more difficult. However, he is fairly active and he enjoys spending time with his grandchildren.

George doesn’t like to think too much about making decisions and trusts his “gut” feelings. This suits him and the sort of person he is. After the diagnosis he was feeling sad and worried about the future. When he was asked about the biopsy he thought about several things. On one hand, it would be great to know that he is at low risk. On the other hand, he didn’t want to find out he was at high risk.

On balance, George thought that knowing whether the cancer would spread or not would not make much difference to how he was living his life. He decided not to have the test.

“There’s no point me knowing it won’t change anything I just want to get on with my life”

Joanna

Joanna is 47 years old. She is divorced with two children aged 15 and 12. She works full-time as a senior maths teacher. At the time of the diagnosis she was thinking about applying for promotion.

Joanna felt very shocked and distraught when she was diagnosed. Having to decide about the test had made her feel very worried about her health in the future.

Joanna likes to think very hard about the pros and cons of any decision and to gather as much information to help her make decisions. Thinking about the biopsy, she does feel scared about what would happen should she be at high risk of the cancer spreading.

She was thinking about all the things she could do with her children as they got older, but now she is questioning her future. She thinks that she needs to know the result whatever it is, so that she can adjust to it. She feels she is better off knowing what the future might hold for her so that she can plan how she wants to live her life. She decided to have the test

“**I need all the information there is that way I can cope with whatever is coming.**

“It will help me plan my future”

Patricia

Patricia is 62 years old and is married. When the biopsy was first mentioned her first thought was “I don’t want to know”. She was feeling really shocked and overwhelmed by the diagnosis. She couldn’t “think straight” and didn’t want to think about the future.

Patricia says that she was finding it really hard to make the decision. Normally, when she has to make decisions she seeks the opinions of close friends and family, and trusts their judgments. Her husband and son were very keen for her to have the test. There was a part of her that wanted to face up to things and so she decided to have the test.

“**Whatever the result, my family and friends would always be there for me”**

Ian

Ian is a 59 year old engineer who manages a team of 50 people. He is married with 3 grown up children and is expecting his first grandchild. His wife suffers from a chronic pain condition. Ian doesn’t like to show his emotions and has coped with difficult life events by taking a very practical approach to problems. He is very protective of his wife because she has become depressed since her illness. His greatest concern is upsetting his wife and family and causing them to worry.

Ian likes things in his life to be ‘clear cut’. His main fear is that he might be medium risk, because then he would not know whether the cancer would spread or not.

He is very keen to get back to work and to his “normal” life as quickly as possible. Having the biopsy means that he will have to wait six weeks for the result, which he feels will be disruptive. He decides not to have the test.

“I can’t see the point of knowing, it will cause too much upset for my family.” “I would worry about the side effects such as more damage to my vision”

Is there someone I can talk to about the decision to have the test?

Some people find it helpful to talk it through with someone not personally connected to them. Our Health Psychologist, Laura Hope-Stone is here to help you think about what decision is right for you, and to give you the opportunity to talk about what having or not having the test means to you.

If you would like to talk to Laura please contact her on the numbers or email below

Tel: 0151 706 3127 Answerphone
Text phone number: 18001 0151 706 3127

Tel: 0151 706 3819 Millie Mountain (secretary)
Text phone number: 18001 0151 706 3819

Laura.Hope-Stone@liverpoolft.nhs.uk
(please **do not** put anything that identifies you in the subject heading)

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Tel: 0151 706 3976
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Gillian.Hebbar@liverpoolft.nhs.uk

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Tel: 0151 706 3819
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Notes and questions

Please use the space below to write down any questions you may have

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Further Information

Laure Hope Stone
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St Pauls' Eye Unit and Clinical Health Psychology Service
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