Demystifying the Diagnostic Process – WMUK Webinar Q&As

Supporting people with a rare blood cancer.

Find answers to some of the key questions those living with WM and LPL have about the tests, results and understanding their diagnostic journey.

📞 Need Support?

If you have any more questions, you can always call the Support Line on 0300 373 8500 or email support@wmuk.org.uk.

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🔬 Diagnostic Tests & Scans

1. Why do PET scan sometimes stop before the legs, especially if someone has painful peripheral neuropathy in their legs?

PET-CT scans focus on the parts of the body where WM/LPL is most likely to affect the lymph nodes, such as the chest, abdomen and pelvis.

The lower legs and feet don't tend to be included because lymph node involvement in these areas is uncommon. Although peripheral neuropathy often affects the lower legs and feet, PET-CT scans are not designed to assess nerve damage or neuropathy symptoms.

Your doctor can decide whether other scans or tests are needed based on your symptoms and overall clinical picture.

2. When are bone marrows required, apart from the time a person is diagnosed?

Bone marrow biopsies are not only needed at diagnosis. They may sometimes be repeated if there is a concern that WM or LPL is progressing, or if doctors would like to assess how well treatment is working.

However, this is not always the case. If scans show that enlarged lymph nodes have reduced or completely disappeared after treatment, this may be sufficient information to assess response, and a further bone marrow biopsy may not be required.

Occasionally, especially where lymph nodes are not the main area affected, a bone marrow biopsy may be used to help monitor how active the condition is or whether anything has changed over time.

3. Does someone need a trephine biopsy post–chemotherapy if they already had genetic testing at diagnosis?

Yes, sometimes a biopsy is still needed. Genetic testing is always helpful at diagnosis, but a trephine biopsy shows what is actually happening in the bone marrow after treatment. For example, whether there are still any abnormal cells present, how active it is, and how the marrow is recovering.

It will also be dependent on what your team are trying to assess at this stage.

4. How are genetic mutations tested for in WM or LPL? I've already had blood tests, a bone marrow biopsy and a CT scan, but I'm not sure if genetic testing has been done or whether it should be?

Genetic testing in WM or LPL is usually performed using the bone marrow sample.

When a bone marrow biopsy is taken, it is sent to the laboratory where different types of tests are carried out. First, the cells are examined under a microscope to look at their appearance and to assess whether there are abnormal cells present.

After this, additional tests are performed on the same bone marrow sample to look for genetic changes (mutations) in the cells. These tests can help support your diagnosis and give more details about the condition.

It is very possible that genetic testing has already been done as part of your bone marrow assessment, but the results may not always be discussed in detail.

In WM and LPL, one of the most commonly tested genetic changes is the MYD88 mutation, which is found in the majority of cases and can help confirm the diagnosis.

5. I had a lymph node biopsy rather than bone marrow to confirm the diagnosis. How did they manage that?

Yes, that can happen. If someone has a large or "bulky" lymph node, doctors may take a biopsy from that node rather than starting with a bone marrow biopsy.

The lymph node sample is closely examined in the laboratory. This includes looking at the cells under the microscope and doing further tests, such as immunohistochemistry and genetic testing, to work out exactly what type of lymphoma is present.

This is important because there are many different types of lymphoma, and at the time of diagnosis the main aim is to identify which one it is. WM or LPL is not always suspected when lymph nodes are enlarged.

If the lymph node biopsy already provides enough information to confirm a WM or LPL diagnosis, a bone marrow biopsy may not be needed.

📊 Understanding Blood Results

6. What is considered a high paraprotein result?

A paraprotein level above 20 may be considered high, but the number on it's own is not always the main concern. Doctors will also look at whether the paraprotein level is stable over time.

Some people may have a higher paraprotein level that remains unchanged for many months or even years, and this can be reassuring. Greater concern usually arises when the paraprotein level is increasing over time, especially if this is accompanied by worsening symptoms or other changes in blood results.

7. What does a low lymphocyte result mean?

Lymphocytes are a type of white blood cell that help to protect the body against infections. A low lymphocyte count can mean that the immune system may not be working as effectively as it should be.

In WM or LPL, lymphocyte levels can sometimes be affected because the bone marrow is being overcrowded by abnormal cells, which interferes with normal blood cell production and affects immune function.

However, it's important to know that blood test results do not always tell the full story. Some people with WM or LPL may have lymphocyte counts that appear normal, even though the condition is affecting how well their immune system works.

This means that even when the white blood cell count appears normal, a person may still have a higher risk of infection, as WM or LPL can affect how the immune system works overall.

8. How can you measure immunity?

There isn't a single test that can fully measure how strong someone's immune system is.

Doctors may use blood tests such as immunoglobulin levels, and sometimes CD4 counts, to get an idea of someone's immune function. If immunoglobulin levels are low, this may mean a higher risk of infection.

However, these tests only provide part of the picture. At the moment, there is no reliable way to accurately measure an individual's immunity or infection risk overall.

9. What should your white blood cell count be?

A normal white blood cell count is usually around 4 – 10 or 4 – 11 $x10^9$/L, although this can vary slightly depending on the laboratory.

A mildly raised count can be seen with infections or inflammation and is not always a concern. However, higher levels may need further investigation, especially if they are significantly above the normal range.

A low white blood cell count can also occur, sometimes due to treatment or other factors, and needs to be interpreted alongside the rest of the blood results and clinical picture.

10. Please could you let me know the code for the level of paraprotein after a blood test and also the code for blood count?

Hospitals tend to display them slightly differently on their systems.

Paraprotein may be listed as "M protein", "Monoclonal protein" or sometimes under immunoglobulin (IgM) results. Blood counts are often shown as "FBC" (Full Blood Count), which includes haemoglobin, platelets and white blood cell count.

If you have access to an online portal for your blood results, it might be best to talk through how it is set up with your doctor or nurse.

11. What is the difference between lambda and kappa light chain? I have lambda. My IgM has been steady at around 15 (diagnosed Jan 2025). I've had a bone marrow biopsy which confirmed MYD88 mutation. My haematologist says my current diagnosis is IgM MGUS. Is that due to my levels being low and minimal symptoms at the moment?

Lambda and kappa light chains are both parts of antibody "building blocks" which are made by plasma cells. Usually people will have a balance of both in their blood. In blood conditions, one type can become more dominant (in your case, lambda), which helps doctors understand and monitor the condition over time.

IgM MGUS is often used when there is an abnormal protein and a MYD88 mutation, but the condition is currently at a low level with minimal symptoms. In your case, your doctor may be using this term

because your IgM is stable and you're feeling generally well, while continuing to monitor things closely over time.

📈 Monitoring & Disease Progression

12. Can it take many months to be diagnosed with WM/LPL?

Yes, it can sometimes take many months to diagnose WM or LPL.

One reason for this is that WM and LPL are rare types of blood cancer, and it's symptoms can be similar to those caused by more common conditions. This means it may not always be the first condition doctors suspect.

People who have clear symptoms may sometimes be diagnosed more quickly because doctors are actively investigating the cause of those symptoms. However, for people with few or no symptoms, WM may only become apparent through blood tests and investigations over time.

Diagnosing WM or LPL also requires several different tests to build a complete picture. Although blood results may strongly suggest WM or LPL at an early stage, a bone marrow biopsy is usually needed to confirm the diagnosis. Genetic and laboratory tests carried out on these samples can also take time to process.

13. I have never had B symptoms, but regardless of the treatment I receive, my paraprotein level only ever falls to around 4 before rising again. By the time it reaches the high 20s, I usually need treatment again. I also have bulky disease – could this be the reason I don't achieve a full remission?

Potentially, yes. In some people with WM or LPL, treatment can be very effective at lowering the paraprotein, but the level then gradually rises again over time.

For some, the disease may return more quickly between treatments, while in others it may progress slowly. This can vary from person to person and reflects how active the disease is.

There are also newer treatments available, such as BTK inhibitors (Zanubrutinib), which can be taken continuously to help control the disease over time.

Decisions about when to start treatment are often based not just on blood results, but also on symptoms and how the condition is affecting quality of life. If there are no symptoms, doctors may sometimes prefer to closely monitor rather than treat immediately.

Lymph node involvement or mutations may also influence how quickly it returns, but this can vary between individuals.

14. My anti–MAG antibodies did not change with chemotherapy, but my paraprotein levels did reduce. I have peripheral neuropathy (PN). How

is PN monitored if the anti–MAG antibody levels remain high and don't seem to change?

This can be really difficult to monitor, especially if anti–MAG antibody levels remain high and do not change with treatment.

Doctors tend to focus on the overall picture rather than the antibody level alone. A key question is whether the neuropathy improves when the paraprotein level falls. In some people it does, but in others it may remain unchanged even if treatment is working.

If symptoms do not improve, it may mean the neuropathy is not only affected by the paraprotein, or that some nerve damage is unfortunately not reversible.

Monitoring usually involves an assessment of symptoms and using nerve conduction studies, which can show how the nerves are functioning over time, rather than solely focusing on antibody results.

15. Is there a way for patients to view their blood test results directly? Consultant letters can sometimes take several weeks, and the level of detail provided may vary. Are results usually available more quickly or consistently through the NHS App or other systems?

It can vary between hospitals, as different systems work in different ways.

In some areas, blood results are not automatically uploaded to the NHS App. Because of this, it is a good idea to ask during your appointment if you would like your results to be available via the NHS App or sent to your GP. This helps ensure the correct option is selected at the time the test is requested.

If results are not easily accessible, patients can also request a copy from their haematology team or key worker. As these are your results, they can usually be shared with no issues.

16. I have been on active monitoring for 8 years with six–monthly check–ups. I have recently noticed enlarged glands in my neck, along with neuralgia on the right side of my face. Is this something that should be assessed as a cause for concern?

If you develop new symptoms like this, especially involving changes in sensation in the face, it is important to have this checked as soon as possible.

It would be best to contact your clinical team and ask whether your next appointment can be brought forward so you can be reviewed and have blood tests done if needed.

Lymph nodes in the neck can sometimes swell in response to infections or recent vaccinations, or conditions such as colds, toothache or ear infections. In these cases, they often settle down on their own.

However, if the swelling is persistent, or if it is associated with new symptoms such as facial nerve or sensation changes, it is important to get it assessed.

17. Is there a difference between familial and non-familial WM?

Familial means there is a family history of WM or related blood conditions, whereas non-familial occurs in people without a known family history of WM.

At present, both are clinically monitored and treated in the same way, especially as the same genetic mutations can be seen in both. Having a familial condition doesn't necessarily mean the condition will behave differently or be more severe.

🦴 Bone Marrow & Bone Health

18. Can a bone marrow procedure lead to osteoporosis or low bone density, or is it more likely to be related to chemotherapy side effects?

A bone marrow isn't known to cause osteoporosis. Low bone density can sometimes be linked to steroids (such as prednisolone), treatments or a blood condition, rather than the biopsy itself.

19. How much infiltration in your bone marrow is considered dangerous?

There isn't a specific percentage of bone marrow infiltration that is considered dangerous on it's own. It is often dependent on your symptoms, current blood results and how your WM is behaving overall.

Doctors tend to look at the full clinical picture rather than a single result; this will determine when treatment is needed and how urgent it is.

If you have been given a percentage, it would be best to talk it through with your clinical team so they can explain what it means for you.

20. Can chemo result in lowered bone density and/or curvature of spine (these are my current back conditions)?

In most cases, chemotherapy itself is not a direct cause of these changes. However, there are some treatment-related factors that can occasionally have an indirect impact on bone health over time, such as steroid use, changes in overall health during treatment and reduced exercise.

Treatment & Management

21. Is it dangerous to fly if you have high IgM levels but no symptoms?

It depends on your individual situation. If you have high IgM levels but no symptoms and you are not on treatment, it is usually safe to fly. It is always best to check with your clinical team before travelling.

In most cases, people with WM or LPL do travel without problems, especially when their IgM level is stable.

Extra caution is needed if IgM levels are rising quickly or if there are symptoms of hyperviscosity (for example, headaches, dizziness or visual changes). This can mean the blood is thicker than normal and may increase the risk of complications such as blood clots.

Other factors, such as low platelets or bleeding risk, may also need to be discussed with your doctor before flying.

22. Is there anything I can do to help my immunoglobulin levels improve?

There is unfortunately nothing specific that you can do to improve immunoglobulin levels.

In WM or LPL, changes in immunoglobulins are part of the underlying condition, and they are not usually something that can be influenced by diet, lifestyle, or supplements.

In some other conditions, immunoglobulin replacement (IVIG) may be used, but this is not commonly needed in WM or LPL because the issue is often related to abnormal production of proteins rather than a simple deficiency.

23. What are plasma viscosity treatment options?

Plasma viscosity is a blood test which reflects how "thick" your blood currently is.

If your levels are higher than what they should be or causing symptoms, a procedure called plasma exchange (plasmapheresis) may be advised to quickly reduce the IgM levels and relieve symptoms. In the long term, your doctor's main focus will be to manage the underlying WM/LPL and keep your blood results stable.

24. How long does treatment last when you are starting for the first time?

The length of treatment can vary, depending on which treatment is used and how well it is working for you. Generally speaking, treatments are given in 3–4 week cycles over a period of 3–6 months. Other treatments, such as zanubrutinib (an oral BTK inhibitor), are given continuously for as long as it's effective.

Your haematology team will be able to discuss the most suitable first treatment for you, based on your current symptoms, blood results and overall health.

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