

## **Blood Matters**

A guide to the blood tests used in managing rheumatoid arthritis and adult juvenile idiopathic arthritis





#### **ABOUT US**

The National Rheumatoid Arthritis Society (NRAS) is the only patientled charity in the UK focusing specifically on **rheumatoid arthritis (RA)** and **juvenile idiopathic arthritis (JIA)**, including adult JIA. We provide information and support services for those affected by RA and JIA, their families, friends, carers and health professionals

#### **CONNECT WITH NRAS**

Our freephone helpline can be contacted by phone on **0800 298 7650** or by email at **helpline@ nras.org.uk**. Our trained helpline staff, supported by an advisory board of medical and healthcare professionals, are there to answer your questions on all aspects of living with RA and JIA.

#### HERE FOR YOU VOLUNTEERS

If you'd like to talk to someone else with rheumatoid arthritis, the helpline staff can match you with one of our trained telephone support Volunteers, who will then call you back to discuss whatever aspect of living with RA concerns you most. Find out more about the NRAS Here For You Volunteers www.nras.org.uk/resource/ here-for-you

#### NRAS AND JIA WEBSITES

Our websites offer a wealth of information about RA and JIA and their treatment, the latest research and developments, as well as lifestyle and supported selfmanagement resources.

www.nras.org.uk www.jia.org.uk

#### **OUR BOOKLETS**

NRAS produces a wide range of information booklets about RA and JIA. These can be downloaded or ordered through the website or by email at **enquiries@nras.org. uk**. If you don't have access to the internet, just call us on **01628 823524**.

#### **JOIN US**

To find out how to support the work of the charity by becoming a Member of NRAS, visit www.nras. org.uk/join or call our Membership team on 01628 823524.

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## Contents

ABOUT THIS BOOKLET	. 4
The importance of blood tests	4
Who is this booklet for?	5
The impact of COVID-19	5
How to use this booklet	6
REFERENCE RANGES EXPLAINED	. 7
SHARED CARE AGREEMENTS	. 9
UK TREATMENT GUIDELINES	.10
BLOOD TEST DIRECTORY	. 11
ABOUT THE DIRECTORY	13
DIAGNOSIS Rheumatoid factor (RF) ACPA (Anti-CCP antibodies) Other diagnostic blood tests	.14 .16
DIAGNOSIS AND MONITORING CRP Plasma viscosity (PV) ESR.	. 18 . 19
MONITORING MEDICATIONS Liver function tests. Alkaline Phosphatase (ALP) Kidney function tests	. 21 .23
FULL BLOOD COUNT. Haemoglobin (Hb). Platelets. WBC. Neutrophils. Lymphocytes.	.27 28 29 30
GENERAL HEALTH MONITORING Cholesterol (lipid) tests. Vitamin D Immunogloblulins	.32 33
TEMPLATE FOR MONITORING	36
USEFUL LINKS	42

## **About this booklet**

Blood tests are an important part of both the diagnosis and monitoring of rheumatoid arthritis (RA), and juvenile idiopathic arthritis (JIA), but the different tests, abbreviations and numbers can be confusing, and it might not always be clear to you what the purpose of each test is, why it's important and what the results mean.

We have created this resource because we strongly believe that having a good understanding of your blood tests is important to help you to manage your condition and improve outcomes. This is not to say that it is your responsibility to monitor your blood results: that should always be the responsibility of your healthcare team. But having a good understanding of your blood tests should improve the 'shared decision-making' about treatments.

### The importance of blood tests

You will have regular blood tests to monitor your condition and/ or the effects of your medication. Blood samples are taken at your GP surgery, local hospital or at your rheumatology clinic, depending on where you live and whether you have a shared care agreement in place (see page 9). Your rheumatology team or GP will arrange for the tests to be done and will let you know where you need to go. Your blood samples are sent to a laboratory for testing.

Your test results can fluctuate for many reasons not just because of your arthritis - an infection such as a cold, for example but if you monitor your results over time, you can start to see what your normal range is, which may be different to the average. You might also become aware of the causes for some fluctuations: for example, a liver function test might be higher than expected due to recent alcohol consumption while blood tests showing levels of inflammation in your blood may be lower because of a recent steroid injection or raised due to a recent flare.

Your insight into possible causes for these ups and downs can be invaluable, as can having a general understanding of what looks 'normal' for you. A healthcare professional may only consider a few of your most recent blood test results during an appointment, whereas you can add real value to the consultation by being more aware of your blood tests over a longer period of time.

### JIA transitioning of care

This booklet is aimed at those living with RA and adults living with JIA, including young patients with JIA who are transitioning from the care of paediatric rheumatology to care within an adult setting.

For more information, see our article on transition **www.jia.org. uk/resource/transition** and our **JIA publications www.jia.org.uk/ publications**.

#### The Disease Activity Score (DAS28)

One of the reasons blood tests are important is because some of them (see CRP and ESR on pages 18-20) are used, along with an assessment of your joints and your own assessment of how you are, to calculate a measure of disease activity known as DAS28. A summary of what your DAS level means is given below and more detailed information can be found on our website **www.nras.** org.uk/resource/the-das28score

### The impact of COVID-19

Some processes, such as shared care arrangements (see page 9), frequency of blood tests and face-toface appointments, may have been affected by the impact of the COVID-19 pandemic on the NHS. Any such impact is subject to regular changes and the effects of the pandemic on healthcare services can differ greatly by region. For up-to-date information on COVID-19 and the impact on services, please visit the NRAS website

DAS score	Suggests
Less than 2.6	RA is in remission
2.6 to 3.2	A low level of disease activity
More than 3.2	Active disease that may require change in treatment. You may be eligible for advance therapy treatment on a biologic, biosimilar or JAK inhibitor
More than 5.1	Severe disease activity



#### How to use this booklet

This booklet is intended to help you understand your blood test results. If you wish, you can also use it to track your test results over time by recording them in the table at the back (see page 36). How you do this will depend to a great extent on where you live and on your rheumatology team and GP.

After your arthritis has been diagnosed and treatment started, your rheumatology team may set up a shared care arrangement with your GP so that ongoing monitoring blood tests can be done through your local practice. In some areas blood tests are done by a monitoring clinic attached to the Rheumatology department. Find out what your local arrangements are when you discuss your treatment plan with your Rheumatology team.

Some patients can see their results through Patient Access. If you do not use Patient Access discuss with your GP or monitoring clinic how to find out your results, and how they can be entered into your Blood Matters booklet.

Your healthcare team may be able to help you enter your results into your **Blood Matters** booklet. Be sure to take it with you when you have any appointment connected with your RA or adult JIA or have it by your side if you have a phone consultation.

## **Reference ranges** explained

When you are given the results of any blood test, a natural question to ask is 'What does that number mean?' and 'how does that compare to a 'normal' range?' Unfortunately, you may find that the answer is not as simple and straightforward as you might hope.

### What are reference ranges?

Reference ranges define the 'normal' range of values for a blood test. Most people (95%) would expect their result ordinarily to fall between the upper and lower levels of the range. The reference range is indicated on each blood result which is returned to the GP or health care professional who took your blood.

#### Do they matter?

Reference ranges are a useful tool for you and your healthcare team, to give you an idea of whether your result is high, low, or around what would be expected for that particular test. However, not every healthy person (5%) will have results that fall within the 'normal' range. So, whilst reference ranges can be a good guide, they do not hold all the answers.

#### Why is it sometimes so hard to get a clear idea of what the reference range is for my blood test?

Firstly, the reference range can vary slightly between laboratories, though not usually enough to make a big difference.

Secondly, for some blood tests, other factors, such as age, gender and environmental and lifestyle factors (for example whether you drink or smoke) can alter what would be considered 'normal' for your personal circumstances.

### So, should we not bother with reference ranges?

For some tests, reference ranges will be a fairly good indicator for what would be considered 'normal' for large numbers of people. However, for tests you have regularly, you will find over time that what's considered normal for you is much more important. Monitoring these blood tests, tracking your results over time, and noting where you can the reasons for any especially high or low test results will give a much fuller picture of what's going on for you as an individual.

It is particularly important in drug monitoring to check that liver test



results have not risen significantly or that blood counts have not dropped. These tests can work as 'early warning' systems and may highlight a potential issue with a medication before you even notice any difference yourself.

#### Why might a blood test be higher or lower than my 'normal' range?

There are lots of reasons why a blood test might be higher or lower than usual. Some tests might be affected by a change in lifestyle, for example increased levels of alcohol consumption or certain restrictive diets. They can be affected by infections, even relatively common infections such as the common cold. They could also be affected by medications you are taking. For example, if you have a steroid injection, you should expect inflammation levels to drop.

RA and adult JIA are fluctuating conditions, which can also affect blood test results. An uncontrolled flare-up could cause inflammatory levels to increase to a much higher level than normal.

Whatever the cause, any 'abnormal' results should be discussed with your GP or rheumatology team, and you should be monitored more closely until they become normal again.

Get to know your blood tests. Look at how they vary over time and think about changes to medication and lifestyle that could be affecting them including any medications for other conditions or complementary or natural remedies you may be taking.

## Shared Care Agreements

A Shared Care Agreement is an agreement between you, your GP practice, and your hospital consultant. It allows the care and treatment for a specific health condition, such as RA, to be shared between the hospital and your GP practice.

These agreements are mainly used for prescribing and monitoring standard **disease modifying anti-rheumatic drugs** (DMARDs) such as methotrexate, sulfasalazine, leflunomide and hydroxychloroquine. An individual shared care agreement will be in place for each specific medication.

### How does shared care work?

The way that shared care works may be slightly different from place to place. Most areas will have shared care guidelines in place for various medicines. Your rheumatology team will discuss your treatment with you and prescribe the appropriate treatment after discussion and once a treatment plan has been agreed with you. They will arrange for monitoring, such as blood tests, to be carried out to ensure that the new treatment regime is working for you and that your body is tolerating it. Once your hospital team are satisfied that

you do not need to be monitored as closely, they will write to your GP practice and invite them to take part in shared care.

Your GP practice will then take over the prescribing and routine monitoring of your medicine. You will also stay under the care of your rheumatology team but are likely to be seen less often by them if your disease remains well controlled. Your GP practice will be able to contact the rheumatology team if they need advice or if your condition changes. You should still have access to your rheumatology nurse advice line and your rheumatology multi-disciplinary team.

It is important that you attend all appointments, whether they are with your consultant, GP, or other members of the team, such as specialist nurses or pharmacists. Attending your blood test appointments is vitally important to ensure there are no delays in your ongoing prescriptions.

### What if I start to feel worse?

If you develop new side-effects to your medicine, or your condition changes or gets worse, you should report this to your GP or rheumatology team so they can review your treatment and see if it needs to be altered or if one of your medications needs to be changed to a different one.

### Planning a pregnancy?

It is essential to let your rheumatology team know if you are planning a pregnancy as medication may need to be stopped or adjusted. Some rheumatology medications can be harmful to the baby. You should not become pregnant until you have had an opportunity to discuss timing of the pregnancy and adjustments to your treatment with your rheumatology team.

### What if I change my GP practice?

If you move to a different GP practice, a new shared care agreement will need to be arranged between the new practice and your specialist team – this will depend on how the system works in your local area, so it is worth asking about this as far in advance as possible.

#### **UK treatment guidelines**

Treatment guidelines in the four nations of the UK can vary. To find out how blood tests contribute to the treatment pathway in relation to these guidelines, visit our website:

#### www.nras.org.uk/resource/guidelines-on-the-managementof-ra

The guidelines themselves can be found on the following web pages:

For England and Wales NICE guidelines, visit

#### www.nice.org.uk/guidance

For Northern Ireland Full details of the NICE guidelines adopted in Northern Ireland are on the NI Department of Health website at

#### www.health-ni.gov.uk

For Scotland The SMC website is at www.scottishmedicines.org.uk

## **Blood test Directory**



## **Directory Contents**

ABOUT THE DIRECTORY
DIAGNOSIS
Rheumatoid factor (RF) 14
ACPA (Anti-CCP antibodies) 16
Other diagnostic blood tests17
DIAGNOSIS AND MONITORING
CRP
Plasma viscosity (PV) 19
ESR 19
MONITORING MEDICATIONS
Liver function tests21
Alkaline Phosphatase (ALP)23
Kidney function tests24
FULL BLOOD COUNT
Haemoglobin (Hb) 27
Platelets
WBC
Neutrophils30
Lymphocytes31
GENERAL HEALTH MONITORING
Cholesterol (lipid) tests32
Vitamin D
Immunogloblulins35



# About the blood test directory

We list here the blood tests that you will have at one time or another. There are some that you will only have during the process of diagnosis, while others are only used to monitor your reactions to medication or to assess your general health.

The tests that are used for ongoing monitoring, are those that it is useful to track over time. We include a handy table later in this booklet for recording your blood test results (see page 36). Whilst some blood tests will be reviewed regularly, others may be assessed as part of an 'annual review'. Your annual review is an opportunity to assess how you are managing your condition and to identify any further support you may need.

If you use this booklet to track your blood test results, please be sure to take it along with you to your appointments.

## Diagnosis

The blood tests in this section are part of the diagnostic process for RA or JIA. However, they cannot be diagnosed by blood tests alone. Instead, they are used along with of a number of other tests, including assessment of joints, that together make a diagnosis.

#### Rheumatoid Factor | RF

#### What does it measure?

Despite its name, rheumatoid factor (RF) is not a definitive test for RA. Unfortunately, there is no such single diagnostic test. However, it is one of a number of tests commonly used in the diagnosis of RA.

RF is an auto-antibody (a type of protein made by the body's immune system that attacks some body tissues) that is found more commonly in the blood of patients with RA. It is also found in other conditions such as Sjögren's syndrome and other connective tissue diseases. It can be present in some chronic conditions and is increasingly present in healthy individuals as we age.

#### When is this test used?

Primarily used at diagnosis, but RF is occasionally used in monitoring RA.

### How often is the test typically taken?

The test is usually taken when a diagnosis of rheumatoid arthritis is being considered. If it is positive, it does not need to be repeated. If it is negative, it may be repeated during the course of the disease.

### Is it used as part of an annual review?

Though this blood test is unlikely to be re-done for the review, it may be relevant to discussions as part of your annual review. Along with ACPA test results, whether the patient is positive or negative to CCP/MCV should be noted in the review, as the antibody is linked to a higher risk of joint damage.

### How is it used in RA and adult JIA?

The higher the levels of RF in the blood, the more likely it is to be associated with inflammatory arthritis. RF can be present in those who do not have the condition (particularly the elderly) but is much more common in those with RA than in the general population.

It is also possible to be negative for RF and still have RA, a condition known as 'seronegative rheumatoid arthritis' (around 20% of patients with RA are negative for RF).

Under some circumstances, healthy individuals with RF may go on, even after a number of years, to develop rheumatoid arthritis. There is no way of predicting whether an individual who has RF in their blood will or will not ao on to develop RA. Furthermore, there is no guaranteed way of preventing this from happening but improving lifestyle choices can drastically reduce the risk. The most important risk factor identified so far is smoking. Not smoking can reduce the risk of developing RA.

#### Seropositive:

Means you have rheumatoid factor and/or ACPA in your blood.

#### Seronegative:

Means you do not have rheumatoid factor and/or ACPA in your blood.

#### Anti-CCP antibodies | ACPA

#### What does it stand for?

#### Anti-cyclic citrullinated peptide

auto-antibodies. This term covers the two currently used ACPA tests:

### CCP (cyclic citrullinated antibody) test:

This is the most commonly used of the ACPA tests.

### MCV (Mutated citrullinated vimentin) test:

This is a newer, but comparable test now used in some areas.

These are both tests for anticyclic citrullinated antibodies.

#### What does it measure?

The levels of auto-antibodies that are highly specific to RA. If the ACPA test is positive, it is a strong indication that the patient has RA or is likely to develop it.

#### When is this test used?

The test is used for diagnosis. A positive CCP/MCV strongly suggests the presence of RA, or the risk for developing it in the future. It is usually tested together with RF. However, approximately half of patients with RA are negative for CCP/MCV.

### How often is the test typically taken?

If it is positive, it does not need to be repeated. If it is negative, it may be repeated during the course of the disease.

### Is it used as part of an annual review?

Though this blood test is unlikely to be re-done for the review, it may be relevant to discussions as part of your annual review. Along with RF test results, whether the patient is positive or negative to CCP/MCV should be noted in the review, as the antibody is linked to a higher risk of joint damage.

### How is it used in RA and adult JIA?

A positive CCP/MCV test makes it very likely that the patient has, or is likely to develop, RA.

C ACPA TEST RESULT



#### Other diagnostic blood tests

As we have already noted, a diagnosis of RA or JIA cannot be made with blood tests alone. The two tests already listed in this section - RF and ACPA - can be highly suggestive of a positive diagnosis, but it is possible to be negative for these tests and still have RA or JIA and, particularly in the case of RF, to be positive for reasons other than RA or JIA. Therefore, other tests may be used as part of your diagnosis, including some from the next section, on tests used for both diagnosis and monitoring.

Other tests might also be used, to rule out other possible causes

for symptoms. One of the more common examples of this is ANA, which stands for Anti-Nuclear Antibody. These antibodies are produced when your immune system malfunctions and starts to attack cells and tissue instead of foreign substances such as viruses and bacteria. ANA may be present in people with other conditions such as systemic lupus erythematosus (Lupus, or SLE), Sjögren's syndrome, and many other autoimmune and nonautoimmune conditions. This test is not taken regularly but may be repeated if symptoms change.

## Diagnosis and monitoring

The tests listed in the previous section are usually only used for diagnosis. The tests in this section are used during diagnosis but also for ongoing monitoring of your arthritis.

#### C-reactive protein | CRP

#### What does it measure?

CRP is an 'inflammatory marker', giving an indication of the level of inflammation in your body. This can be due to inflammatory conditions such as RA or could be a sign that the immune system is active for other reasons, such as infections.

#### What is the test used for?

Diagnosis and ongoing monitoring

### How often is the test typically taken?

CRP is more usually used now than ESR to calculate the DAS28 score (see page 5). CRP is a more sensitive measure of inflammation than ESR because, ordinarily, there is very little if any CRP in the blood. It is therefore done whenever the DAS28 score is calculated. It is also repeated if there is any concern that the RA is in flare. Some GPs will repeat CRP with each monitoring blood test. While that is not essential, it can be helpful to pick up an early warning for a flare. It is usually repeated monitored as the flare is treated.

The CRP test is particularly important in the early months of treating newly diagnosed RA when it is repeated monthly to make sure that the disease is coming under control.

### Is it used as part of an annual review?

Yes. Like the other inflammatory markers, it should be reviewed at the annual review to ensure that your RA or JIA is adequately controlled.

### How is it used in RA and adult JIA?

CRP is used to support diagnosis of RA and JIA and also to monitor how active it is, which can in turn help to show whether a medication is working.

Higher levels of CRP can indicate more active RA, so it is expected to be higher before starting medication and during a flareup and lower after starting treatment, particularly after a steroid injection or during a course of steroid tablets.

As mentioned above, the CRP test is also used to calculate your DAS 28. Alternatively, the ESR test may be used. Whichever it is – CRP or ESR - the same one must be used each time to get a consistent reading.

#### Plasma viscosity | PV

#### What does it measure?

Plasma viscosity measures the 'thickness of blood' and is sometimes referred to as 'blood viscosity'. PV can be affected by certain proteins in the blood that are produced as a response to inflammation, whether caused by RA, an infection or several other conditions.

### How often is the test typically taken?

Clinicians may request plasma viscosity blood test at intervals to monitor disease activity.

### Is it used as part of an annual review?

Yes. The plasma viscosity together with other inflammatory markers such as CRP or ESR should be reviewed at the annual review to make sure that the RA is being adequately controlled and inflammation levels are normal or near normal.

### How it is used in RA/adult JIA?

Clinicians may request the plasma viscosity blood test at intervals to monitor disease activity. However, the test is not specific for inflammation related to inflammatory arthritis and may be affected by a number of other conditions. A high result may be due to various causes, including infection, inflammation and other blood conditions. In the context of known RA, raised levels are likely to indicate a flare if there are no other causes present such as an infection.

#### Erythrocyte Sedimentation Rate | ESR

#### What does it measure?

ESR is an 'inflammatory marker', giving an indication of the level of inflammation in your body. This can be due to inflammatory conditions such as RA or could be a sign that the immune system is active for other reasons, such as infections.

### How often is the test typically taken?

The CRP test is more usually used now to calculate the DAS score. However, some rheumatology units may still use ESR. In that case, it will be done whenever the DAS28 score is calculated.

It is also repeated if there is any concern that the RA is in flare. Some GPs will repeat the ESR test with each monitoring blood test. While that is not essential, it can be helpful to see what level of ESR is normal for the patient and to pick up an early warning for a flare. A disadvantage of ESR is that it takes longer than CRP to return to normal once the flare or infection has settled.

### Is it used as part of an annual review?

Yes. Like the other inflammatory markers, it should be reviewed at the annual review to ensure that the RA is adequately controlled.

### How is it used in RA and adult JIA?

ESR is used to help diagnose RA and also to monitor how active it is, which can in turn help to show whether a medication is working.

Higher levels of ESR can indicate more active RA, so it is expected to be higher before starting medication and during a flareup and lower after starting treatment, particularly after a steroid injection or during a course of steroid tablets. Please note that ESR levels in the blood can increase with age. This should be taken into consideration when discussing results. ESR is also used to monitor overall disease activity by contributing to the calculation of your DAS28 or disease activity score (see page 5). Whilst either ESR or CRP can be used to determine your DAS28, the same one must be used each time to get a consistent reading.

CRP and ESR are used to calculate your disease activity score (DAS28). If you don't know your DAS, ask your rheumatology team.

(For more information on DAS, see page 5).

## **Monitoring medications**

Some of the medications used to treat RA and JIA can affect the functioning of the liver and kidneys. Once you start taking one of these medications, the tests will be repeated at intervals to check whether it is suitable and whether the dose needs to be modified.



#### Liver function tests (LFTs) | ALT, AST and albumin

#### What does it stand for?

ALT: Alanine aminotransferase AST: Asparate aminotransferase

#### What does it measure?

The liver function test, also known as the liver blood test, includes

a panel of tests all performed on the same blood sample. It measures the level of certain chemicals (enzymes, proteins and other substances) produced by the liver.

Both ALT and AST are enzymes found in the cells of the liver and are released into the blood if there is a damage or inflammation in these cells. ALT is found mainly in the liver and AST is found throughout the body

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but mostly in the liver and the muscles, including the heart. ALT and AST rise when the liver is inflamed, which can be triggered by several of the disease modifying anti-rheumatic drugs (DMARDs).

Albumin is the main protein produced by the liver. It can be low for a number of reasons, including infections and kidney damage.

#### When is the test used?

Prior to starting medication and to monitor for any potential side-effects.

### How often is the test typically taken?

It is normally checked at intervals in line with national guidelines for the monitoring of medications. The intervals may change depending on the patient, clinical symptoms, and previous results.

### Is it used as part of an annual review?

Yes. Levels are reviewed to make sure the patient's liver is tolerating the medication. Abnormal results may also indicate other causes for an upset liver which might need the rheumatoid medications to be reduced or stopped.

### How is it used in RA and adult JIA?

The test is generally used for monitoring the impact of medication, such as side-effects.

However, abnormal liver function tests are relatively common, and most people with these results have normal liver function. Multiple factors affect the liver function tests and if they are outside the normal range, the result will be interpreted by your health professional.

Factors that affect the results include alcohol, medications such as non-steroidal antiinflammatory drugs (ibuprofen, for example) and also some over-the-counter and herbal treatments. Fatty liver (which may be associated with increased body weight) can also be a factor, as can some other conditions.

#### **BLOOD MATTERS**



### Alkaline Phosphatase

#### What does it measure?

ALP is an enzyme found throughout the body but particularly in the liver, bones, kidneys, and digestive system. High levels of ALP can indicate liver disease or bone disorders.

#### When is the test used?

Prior to starting medication and to monitor for potential sideeffects.

### How often is the test typically taken?

At baseline when treatment is initiated and with monitoring blood tests.

### Is it used as part of an annual review?

Yes. It will be reviewed together with other monitoring blood tests.

### How is it used in RA and adult JIA?

It is used to check the ongoing health of the liver during treatment. If it rises above normal, the causes for it doing so need to be reviewed. A high ALP is commonly due to fatty liver, but other causes are also possible. Rheumatoid drugs that can affect the liver may need to be stopped or the dose reduced as a high ALP indicates problems with liver function.

#### Kidney function tests | urea, creatinine, sodium, potassium and eGFR

#### What does it stand for?

The kidney function test may vary depending on the laboratory, but it typically includes: urea, creatinine, sodium, potassium and eGFR (estimated glomerular filtration rate).

#### What it measures

The kidney function test, also known as renal profile, includes a panel of tests all performed on the same blood sample. One of the kidney's main functions is to filter waste products from the blood and send them out of the body in urine. This blood test helps to identify how quickly the body waste products are being removed by the kidneys.

Sodium and potassium are salts that are normally present in body fluids. Urea and creatinine are both waste products. Urea is a waste product that comes from the breakdown of protein that you eat. Creatinine is a waste product that is produced from the normal wear and tear of the body muscles. The eGFR estimates how well the kidneys are removing the waste products and excess fluid from the blood.

#### When is the test used?

Prior to starting medication and to monitor for potential sideeffects.

### How often is the test typically taken?

It is normally checked at intervals in line with national guidelines for the monitoring of medications. The intervals may change depending on the patient, clinical symptoms, and previous results.

### Is it used as part of an annual review?

Yes.

### How is it used in RA and adult JIA?

The test is generally used for monitoring the impact of medications. Where kidney function is impaired before treatment is started, a different medication may be chosen, or the dose may be adjusted.

Multiple factors affect the kidney function tests and if they are outside the normal range, the result will be interpreted by your health professional. Factors that affect the results include medications, age and other medical conditions, such as high blood pressure and diabetes.

**BLOOD MATTERS** 

## Full blood count | FBC

The Full Blood Count may be taken as part of the diagnosis process, for monitoring your reaction to medications or for general health monitoring.



Red blood cell (erythrocytes)

White blood cell (leucocytes)

Platelets (thrombocytes)

#### What does it measure?

The FBC is a group of tests that measure the different types of cells in your blood.

Your blood contains three main types of blood cell:

#### Red blood cells (erythrocytes)

contain haemoglobin (Hb) and carry oxygen from your lungs to the rest of the body.

#### White blood cells (leucocytes)

are part of the immune system. Different types of white blood cells have different roles and form a complex network to fight viral and bacterial infections. **Platelets (thrombocytes)** are fragments of cells that stick together to stop bleeding when blood vessels are damaged, for example when cut yourself.

Apart from telling us how many of each of the types of blood cell there are, the FBC also gives us information about the different types of cells:

#### **Red Blood Cells**

 Haemoglobin: the substance that gives red blood cells their colour and allows them to carry oxygen around the body.

- MCV (Mean cell volume): the average size of red blood cells
- MCH (Mean cell haemoglobin) and MCHC (Mean cell haemoglobin concentration): the average amount of haemoglobin in the red blood cells, described in two different ways.

#### White Blood Cells

 Differential: this tells us how many of each of the different types of white blood cell are in your blood. Only the five most common types of white blood cell are usually included in the differential: neutrophils, lymphocytes, monocytes, eosinophils and basophils.

#### When is the test used?

As part of the diagnostic process. Anaemia – low levels of red blood cells or haemoglobin – can indicate active inflammation. A baseline test is done to screen for any abnormalities in the blood. The test is an essential part of monitoring for potential sideeffects to medication.

### How often is the test typically taken?

When starting a new treatment, the FBC is usually checked to establish a baseline and then every two weeks thereafter until you have been on a stable dose for six weeks. It is then checked monthly for three months, and then every three months. Your rheumatology team or GP may recommend more or less frequent monitoring depending on your personal circumstances. If the dose of your medication is changed then you may need to have blood tests more often.

### Is it used as part of an annual review?

Yes.

### How is it used in RA and adult JIA?

#### **Red Blood Cells**

Your red blood cells can be affected by many of the medications that are used to treat RA and adult JIA. When you are taking these medications, it is not unusual to have an MCV which is slightly higher than normal, or an MCH which is slightly low. If the MCV continues to rise (or the MCH continues to fall) then your GP or rheumatology team may want to carry out more blood tests to see what is causing it. The production of red blood cells can be affected if you have low levels of iron or certain vitamins, for example folic acid or vitamin B12, or if you have been drinking more alcohol than recommended.

#### White Blood Cells

The white blood cell count can also be affected by many of the medications that are used to treat RA and adult JIA. It is not unusual to have a lower-thannormal number of certain types of white blood cell, or a lower overall white blood cell count while taking these medications.

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However, if the amount of white blood cells (and particularly lymphocytes and neutrophils) falls too low then your risk of infections is higher. If this happens then your medication may need to be stopped until your white blood cell count is back to normal. In some cases, the medication may need to be changed.

A high white cell count can be seen if you have an infection but can also be a side-effect of longterm treatment with steroids such as prednisolone.

#### **Platelets**

A low platelet count can be a side-effect of many of the medications that are used to treat RA. It is not unusual to have a lower-than-normal platelet count while taking these medications, but if it is too low then there is a risk that your blood may not clot properly if you injure yourself. If your platelet count is too low, your medication may need to be stopped until it is back to normal.

A high platelet count can be caused by active inflammation, so in some people it may be higher before starting medication or during a flare-up.

#### Haemoglobin | Hb



#### What does it measure?

Hb is a key blood test in the monitoring of your medication. Hb is a protein in your red blood cells. The red blood cells carry oxygen to the body's organs and transport carbon dioxide back to your lungs. Chronic inflammation and being on long-term medication can cause levels of red blood cells to fluctuate.

Normal ranges are slightly different for men and women.

#### When is the test used?

Prior to starting medication to ensure that the body is fit and healthy for the medication to be prescribed and to monitor for potential side-effects. People with RA are prone to have anaemia, which is indicated by a lowered Hb.

### How often is the test typically taken?

Hb is checked as part of routine blood monitoring. If it is low or abnormally high, further tests will be needed to understand why. If the haemoglobin drops, it may be due to medication that may need to be stopped temporarily or permanently.

### Is it used as part of an annual review?

Yes. It should be reviewed along with the other monitoring blood tests.

### How is it used in RA and adult JIA?

People with RA are more susceptible to anaemia, a condition that causes low red blood cell count and Hb levels. The rheumatology team will look for signs of anaemia, such as extreme tiredness and breathlessness. If levels of Hb are found to be low, further tests will be requested to find out more about the cause of anaemia.

#### **Platelets**



#### What it measures

Platelets are small blood cells which help to form clots and stop bleeding. They are made in the bone marrow, so a normal platelet count is a sign that the bone marrow is working properly.

The platelet count is measured as part of the full blood count. The test measures that the platelet count is in the normal range. High or low levels are seen in some conditions other than inflammatory arthritis and might result in a change in diagnosis.

A high platelet count is also seen during a flare of inflammatory arthritis so may be high before treatment is started and during flares.

#### When is the test used?

The test is done during the diagnostic process, partly to check that symptoms are not due to other conditions. It is also used when monitoring certain standard DMARDs (disease modifying anti-rheumatic drugs) and advanced treatments such as Biologic/Biosimilars/JAK inhibitors. (If you want to know more about the different types of medications please refer to RA Medicines Booklet [add link].

The platelet count should be normal or a little high if inflammation is active, before DMARDs or biologics are started. The platelet count is checked both to ensure that medication is not affecting the bone marrow and as a sign of active inflammation.

### How often is the test typically taken?

The platelet count is usually checked at diagnosis and then with blood monitoring. If the count is higher or lower than usual, it may be checked more frequently.

### Is it used as part of an annual review?

Yes. The platelet count is reviewed at the annual review to make sure that it is stable.

### How is it used in RA and adult JIA?

The platelet count is looked at during diagnosis, partly to check that there isn't another medical diagnosis to account for the symptoms. It usually needs to be in the normal range or slightly higher (if there is active inflammation) before standard DMARDs or advanced treatments are started.

#### White blood cell count | WBC



#### What does it measure?

As the name suggests, this test

is used to measure the number of white blood cells in the blood. White blood cells are an important part of the immune system, so a high number of these cells can indicate that the immune system is particularly active while a low number indicates that the immune system is impaired.

#### When is the test used?

The test is used at diagnosis to screen for other causes for joint pain and inflammation and to ensure that disease modifying drugs can be used safely. It is then part of routine monitoring to check that disease modifying drugs are not affecting the bone marrow.

### How often is the test typically taken?

To establish baseline when treatment is planned and then with routine blood monitoring once treatment is commenced.

### Is it used as part of an annual review?

Yes. It should be reviewed together with other monitoring blood tests.

### How it is used in RA/adult JIA?

In a normally functioning immune system, a high white blood cell count could be due to the body fighting off an infection, inflammation or treatment with steroids.

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#### **Neutrophils**

#### What it measures

Neutrophils are white blood cells that fight infection by bacteria. They are made in the bone marrow, so a normal neutrophil count is a sign that the bone marrow is working properly.

The neutrophil count is measured as part of the full blood count. The test measures that the neutrophil count is in the normal range.

High levels are seen in infections, particularly bacterial infections, and some other conditions. Low levels may be caused by some other conditions or may be caused by some medications.

#### When is the test used?

The test is done during the diagnostic process, partly to check that symptoms are not due

to other conditions. It is also used as part of routine monitoring.

A normal neutrophil count is normally necessary before standard DMARDs or biologics are started. The neutrophil count is then monitored during treatment with certain antiarthritis medications to check that they are not affecting the bone marrow.

### How often is the test typically taken?

The neutrophil count is usually checked at diagnosis and then with blood monitoring. If the count is higher or lower than usual, it may be checked more frequently.

### Is it used as part of an annual review?

Yes. The neutrophil count is examined at the annual review to make sure that it is stable.

### How is it used in RA and adult JIA?

The neutrophil count is looked at during diagnosis, partly to check that there isn't another medical diagnosis to account for the symptoms. It usually needs to be in the normal range before standard DMARDs or advanced treatments are started. It then forms part of routine monitoring tests.

#### Lymphocytes

#### What does it measure?

Lymphocytes are white blood cells which fight infection particularly by viruses. There are many different types of lymphocyte.

Lymphocytes are made in the bone marrow so a normal lymphocyte count is a sign that the bone marrow is working properly.

The lymphocyte count is measured as part of the full blood count. The test measures that the lymphocyte count is in the normal range.

High levels are seen in viral infections and some other conditions. Low levels may be caused by other health conditions and may be caused by some medications.

#### When is the test used?

The test is done during the diagnostic process, partly to check that symptoms are not due

to other conditions.

A normal lymphocyte count is usually necessary before standard DMARDs or biologics are started. The lymphocyte count is then monitored during treatment with standard DMARDs to check that they are not affecting the bone marrow.

### How often is the test typically taken?

The lymphocyte count is usually checked at diagnosis and then with blood monitoring. If the count is higher or lower than usual, it may be checked more frequently.

### Is this used as part of an annual review?

Yes. The lymphocyte count is reviewed at the annual review to make sure that it is stable

### How is it used in RA and adult JIA?

The lymphocyte count is looked at during diagnosis, partly to check that there isn't another medical diagnosis to account for the symptoms. It usually needs to be in the normal range before standard DMARDs or biologic treatments are started. It is then checked during monitoring.

## Monitoring general health

RA and JIA may affect aspects of your general health. The tests listed in this section will help keep you as healthy as possible by alerting you and your healthcare to any potential problems.



#### Cholesterol tests | Lipid profile

#### What does it measure?

Lipid means fat, and the lipid profile is a range of blood tests that measures the levels of two kinds of fat in the body: **cholesterol**, both high-density lipoprotein (HDL) and lowdensity lipoprotein (LDL), and **triglycerides**.

HDL is sometimes referred to as 'good' cholesterol, as it carries

LDL cells and triglycerides to the liver, where they are broken down, ready to be expelled from the body. LDL is often described as 'bad' cholesterol, as high levels of LDL in the body can cause a build-up of plaque in the arteries, which can lead to complications such as heart disease and strokes.

Triglycerides are fat cells found in the blood. When you eat, your body uses food for energy, but any excess food is turned into these fat cells and stored in the body. The production of too many of these cells causes weight gain and can lead to obesity.

#### When is the test used?

Cholesterol is monitored as part of the long-term care of rheumatoid arthritis and adult JIA patients. Chronic inflammation increases the risk of heart disease and stroke. Patients should maintain a healthy lifestyle, and cholesterol is monitored as part of the annual review so that lipid lowering treatment can be started if necessary, and lifestyle can be discussed.

### How often is the test typically taken?

Routinely, once a year. More often for patients at risk of heart disease and stroke. Patients used to be required to fast before these tests. This is no longer standard practice but could still be required under certain circumstances.

### Is it used as part of an annual review?

Yes.

### How is it used in RA and adult JIA?

RA and adult JIA patients are unfortunately more prone to heart disease than the general population. These tests will therefore be performed along with other assessments to make sure your arteries are healthy and if there are causes for concern enable you to take the appropriate preventative measures such as treatment with medication and changes to your diet and your levels of exercise.

#### Vitamin D



#### What does it measure?

Vitamin D is a hormone that helps with the absorption of calcium from the intestines and is important for the maintenance of strong bones. Vitamin D is produced by the skin through direct exposure to sunlight. Vitamin D is also found in fatty fish (tuna, salmon, mackerel), eggs and fortified foods such as bread and breakfast cereals. The test measures the level of vitamin D.

#### When is the test used?

As part of bone health investigations.



Vitamin D is normally checked in patients at risk for osteoporosis (weakened bones).

### How often is the test typically taken?

It is normally checked in patients at risk for osteoporosis (weakened bones), at risk of falls or who have had fractures without significant trauma. RA patients are at increased risk of osteoporosis. Long-term steroid usage further increases the risk. The calcium profile is used in patients at increased risk of osteoporosis. Some patients who rarely go outdoors and patients whose complexion increases their risk of vitamin D deficiency should be tested and considered for vitamin D supplementation.

### Is it used as part of an annual review?

Yes. It may be discussed at the annual review. If your Vitamin D levels have not been checked, you may be recommended for this test.

### How is it used in RA and adult JIA?

Osteoporosis is commonly experienced by people with inflammatory arthritis. This is a condition that weakens bones and which puts patients at greater risk of fractures. Having low vitamin D increases the risk of osteoporosis and the blood test may help diagnose if the patient is vitamin D deficient or not.

#### Immunoglobulins | IGs

#### What does it measure?

The total amount of immunoglobulins in your blood, and the amount of each of the three main types of immunoglobulins (IgA, IgG, and IgM). Immunoglobulins are antibodies, a type of protein produced by white blood cells, and they play a key role in the immune system. The first time you are infected or exposed to a bacteria or virus, your body starts to produce antibodies that stick to the infective agent and neutralise the threat. If you are exposed to the same bacteria or virus later, your immune system recognises it right away and produces large amounts of antibodies quickly to stop the infection taking hold. Vaccinations use the same process to train your immune system to recognise bacteria and viruses before you have been exposed to them.

The different types of immunoglobulin have slightly different roles and may also be found in different parts of the body.

#### When is the test used?

It is not used to diagnose inflammatory arthritis but can help to rule out other conditions that may have similar symptoms. It might also be used if you often have infections, to make sure that your immune system is producing the right amounts of immunoglobulins.

### How often is the test typically taken?

It is not generally taken regularly, only if required before treatment with specific biologic treatments, such as rituximab.

### Is it used as part of an annual review?

No

### How is it used in RA and adult JIA?

Some medications that are used to treat inflammatory arthritis – particularly rituximab – can cause immunoglobulin levels to fall. Your immunoglobulin levels should be checked before each course of rituximab to make sure they are high enough for you to have treatment (sometimes a reduced dose of rituximab will be used in patients with low Immunoglobulin G).

## Monitoring your blood test results

Date	CRP	PV	ESR	Hb	Neutrophils	Lymphocytes	Platelets

Test name	Meaning	Purpose	Page no.
CRP	C-reactive protein	Diagnosis and monitoring   DAS28	
PV	Plasma viscosity or 'blood thickness'	Monitor disease activity	
ESR	Erythrocyte Sedimentation Rate	Monitor disease activity   DAS28	
Hb	Haemoglobin	Full blood count   diagnosis and monitoring	
Neutrophils	Part of white blood cell count	Full blood count   diagnosis and monitoring	

This table can be used to record the main blood tests used for ongoing monitoring, and includes two 'other' columns to add in any blood tests that might be particularly relevant to you.

It is also available to download from our website: www.nras.org.uk/product/blood-matters

ALT/AST	ALP	Creatinine	Other	Other	Comment
				<u> </u>	

Test name	Meaning	Purpose	Page no.
Lymphocytes	Part of white blood cell count	Full blood count   diagnosis and monitoring	
Platelets	Blood cells found in bone marrow	Full blood count   diagnosis and monitoring	
ALT/AST	Liver function	Monitoring	
ALP	Liver function and bone health	Monitoring	
Creatinine	Kidney function	Monitoring	

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Date	CRP	PV	ESR	Hb	Neutrophils	Lymphocytes	Platelets

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ALT/AST	ALP	Creatinine	Other	Other	Comment

#### NATIONAL RHEUMATOID ARTHRITIS SOCIETY

Date	CRP	PV	ESR	Hb	Neutrophils	Lymphocytes	Platelets

#### **BLOOD MATTERS**

ALT/AST	ALP	Creatinine	Other	Other	Comment

## **Useful links**

#### Lab tests online UK

#### labtestsonline.org.uk

Here, you can get information on any blood test, including what it's used for and what the results mean. This covers all blood tests, not just those used for inflammatory arthritis.

#### NHS information on blood tests

#### www.nhs.uk/conditions/blood-tests

Offers a good overview of blood tests, including what they are used for and what to expect when you go for a blood test.

#### Anxiety UK information on needle phobia www.anxietyuk.org.uk/anxiety-type/injection-phobia

An overview of what needle phobia is, with useful information on evidence-based approaches to treating fear of injections.

#### **Yellow card scheme**

#### yellowcard.mhra.gov.uk

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The Yellow Card scheme is run by the Medicines and Healthcare products Regulatory Agency (MHRA) and is the UK system for collecting and monitoring information on safety concerns, such as suspected sideeffects or adverse incidents involving medicines and medical devices.

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nras.org.uk/resource/gifts-in-wills

## **Other NRAS publications**



#### New2RA

*New2RA* is for people who are newly or relatively newly diagnosed and contains the information you need to help you make sense of and understand what RA is and what you have been told by your rheumatology team.



#### Living Better with RA

*Living Better with RA* is a self-help guide for people with established disease, including Juvenile Idiopathic Arthritis.



#### **Medicines in Rheumatoid Arthritis**

We believe it is essential that people living with RA understand why certain medicines are used, when they are used and how they work to manage the condition.



#### **Fatigue Matters**

Advice and resources to help improve the management of fatigue for people with RA.

For all other NRAS publications, visit www.nras.org.uk/publications

To obtain copies of any of our other booklets, or more copies of this one, please call **01628 823 524** or email **enquiries@nras.org.uk**. Copies can also be downloaded from our website at **www.nras.org.uk/publications** 



## **Blood Matters**

A guide to the blood tests used in managing rheumatoid arthritis and adult juvenile idiopathic arthritis

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