

Diagnosing Arrhythmias



Working together to improve the diagnosis, treatment
and quality of life for all those affected by arrhythmias

Glossary

Ambulatory Monitoring A longer-term wearable heart monitor which allows a doctor to track and analyse your heart rhythm during normal activity over a period of 24 hours to two weeks

Arrhythmia An irregular or abnormal heart rhythm that may be excessively fast or slow

Atria The two upper chambers of the heart

AV node Part of the electrical pathway located between the atria and the ventricles

Cardiac Physiologist A healthcare professional skilled in interpreting and providing information on your heart rhythm

Catheter ablation The use of catheters to deliver energy into the heart to destroy abnormal tissues that may lead to arrhythmias

Ectopic beat Extra beats arising from the atria or ventricles

Electrode A small, sticky pad with a connector on top which picks up the electrical signal on the skin surface

Important information

This booklet is intended for use by people who would like to have more information about ECGs, manual pulse checks, 12 lead ECGs, extended continuous ambulatory monitoring, holter monitor, electrophysiology studies, procedures, inherited cardiac conditions and genetic screening. You can use this information booklet to help decide with your healthcare professional which method of diagnosis is right for you.

Contents

How does the heart work normally?

Your pulse and ECGs

Manual pulse checks

12 Lead ECGS

Extended continuous ambulatory monitoring

Holter monitor

Electrophysiology (EP) Studies

What does the procedure involve?

Inherited cardiac conditions

Genetic screening



Electrophysiology A cardiologist who specialises in the electrical aspects of the heart, meaning the heart's rhythm

Electrocardiogram (ECG) A simple non-invasive test that records the heart's rhythm and rate

Heart rate The number of times your heart beats per minute

Holter Monitor Records the electrical activity of the heart from electrodes placed on the skin over a longer period of time

Hypertrophic Cardiomyopathy (HOCM) An inherited disease of the heart, where the muscle wall of the heart becomes thickened and life threatening arrhythmias can occur

Inherited Cardiac Conditions (ICCs) Conditions that can be passed down in families via your genes

Insertable Cardiac Monitor (ICM) A small, thin device inserted under the skin to record your heart rhythm activity

Long QT Syndrome (LQTS) An inherited condition where there are problems with the electrical activity of the heart

Manual pulse check A way to check your pulse rate and rhythm by feeling the pulse in your wrist

Supraventricular Tachycardia (SVT) An abnormal heart rhythm originating in the heart's atrium

Syncope Unexplained loss of consciousness

Ventricles The two lower chambers of the heart. The right ventricle pumps blood to the lungs and the left ventricle pumps blood around the body

The heart during normal rhythm (sinus rhythm)

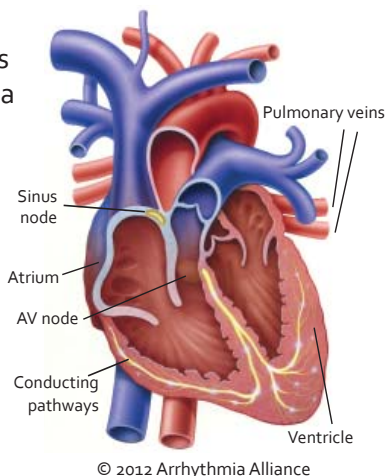
The heart is a muscular pump that delivers blood containing oxygen to the body. It is divided into two upper chambers (atria) which collect blood returning via the veins, and the two lower chambers (ventricles) which pump blood out through the aorta (main artery) and the lungs.

Normally, the heart beats in a regular, organised way, at a rate of 60-100 beats per minute. This is because it is driven by the sinus node, a clump of specialised cells situated in the right atrium which emit electrical impulses.

These electrical impulses spread through the atria and then into the ventricles via a connecting relay station (the AV node). The sinus node controls the timing of the heart according to the needs of the body. An example of this, is during exercise when the heart speeds up.

When the heart is beating normally, it is referred to as 'sinus rhythm'. In most cases, an extra beat (ectopic beat) can trigger a short circuit, and a fast heartbeat. It can travel down an extra pathway and up the normal conduction system. If this continues, palpitations can result. The heart can suddenly 'bump' then start to race, causing a fast pulse.

The heart and normal conduction



Your pulse and ECGs

Why are your pulse and ECGs so important?

Your heart is an organ that pumps blood around your body regularly at a rate of about 70 times every minute. In order to do this, special cells in the heart create electrical impulses that make the muscles of the heart contract, which then pushes the blood around the body.

The electrical signal is coordinated in a certain way, and runs at a certain speed to maximise its effectiveness. So, when you are walking or climbing stairs, your heart will beat faster than when you are resting.

The ECG is a recording of the electrical signal from the heart and gives a lot of information about how well it is performing. It can tell us if the heart is beating regularly and in rhythm, and also if the heart is beating at an appropriate rate (fast enough, or too fast for example), and for trained specialists such as cardiologists, electrophysiologists, nurses or cardiac physiologists, it can provide lots more information about how well the heart is performing and indicate any possible problems.

How can your heart rhythm be measured?

There are many ways that your heart rhythm can be measured. They range from knowing your pulse (www.knowyourpulse.org), using a smartphone app or monitor, a 12 lead ECG, a patch or Holter monitor, or for more long-term monitoring of your heart rhythm, an implantable loop recorder (ILR).



Manual Pulse Checks – www.knowyourpulse.org

Measuring your own heart rhythm is easy once you know how. You have probably seen it done in films or on television where a nurse or doctor take the wrist of a patient and look at their watch at the same time. What they are feeling is the pulse of an artery in the wrist as it carries the blood. It expands a little with every beat of the heart as the blood flows through that part. Below is a step-by-step guide of how to take a pulse.

What you are feeling for, firstly, is the pulse rhythm regular? - Does it have a tick tock rhythm, or are the beats unevenly spaced? Secondly, how fast or slow is the heart beating: below 60 beats per minute is slow and above 100 beats per minute is fast. It is often normal for the speed to vary, for example if you have just exercised, you would expect the heart to beat faster and if you are resting or are extremely fit, you can expect it to be slower.

Importantly is your pulse in a regular rhythm (and not jumping around like a fish, flip/flopping, or feeling palpitations).

Know Your Pulse in four steps

1 To assess your resting pulse rate in your wrist, sit down for 5 minutes beforehand. Remember that any stimulants taken before the reading will affect the rate (such as caffeine or nicotine). You will need a watch or clock with a second hand.



2 Take off your watch and hold your left or right hand out with your palm facing up and your elbow slightly bent.

3 With your other hand, place your index and middle fingers on your wrist, at the base of your thumb. Your fingers should sit between the bone on the edge of your wrist and the stringy tendon attached to your thumb (as shown in the image). You may need to move your fingers around a little to find the pulse. Keep firm pressure on your wrist with your fingers in order to feel your pulse.



4 Count for 30 seconds, and multiply by 2 to get your heart rate in beats per minute. If your heart rhythm is irregular, you should count for 1 minute and do not multiply.

How to check your pulse

1. To assess your resting pulse rate in your wrist, sit down for 5 minutes beforehand. Remember that any stimulants taken before the reading will affect the rate (such as caffeine or nicotine). You will need a watch or clock with a second hand.
2. Take off your watch and hold your left or right hand out with your palm facing up and your elbow slightly bent.
3. With your other hand, place your index and middle fingers on your wrist, at the base of your thumb. Your fingers should sit between the bone on the edge of your wrist and the stringy tendon attached to your thumb. You may need to move your fingers around a little to find the pulse. Keep firm pressure on your wrist with your fingers in order to feel your pulse.
4. Count the beats for 30 seconds, and multiply by 2 to get your heart rate in beats per minute. If your heart rhythm is irregular, you should count for 1 minute and do not multiply.

We recommend you practice doing this when you feel healthy and fine. If you feel unwell, you may want to take your pulse to reassure yourself. Look out for the following things:

- Is it regular? Does it have a 'tick-tock' regular beat?
- Does it seem particularly slow or fast considering the situation? Remember, below 60 beats per minute is slow and above 100 is sometimes considered fast.
- Is it jumping around? Is it fast, then slow, is it irregular?

If your pulse is irregular and seems either particularly fast or slow, call NHS 111 and give them the information you have from taking your pulse, as well as letting them know how you feel. You can also pass this information on to your doctor to help them better understand and monitor in case you have an underlying arrhythmia (irregular heart rhythm).

ECG recorder and smartphone apps

In 2017, research found that 85% of the UK adult population now owns a smartphone. Smartphones have all kinds of interesting health associated apps including those that can record your heart rate or take an ECG.

AliveCor Kardia mobile ECG is currently the main mobile application used in the UK and recommended for use by NHS England. It allows electrode attachments to connect with a compatible mobile device (smartphone or tablet computer) and transmit, record, auto-analyse, store and view an ECG recording using a dedicated app. The ECG is captured digitally and can be viewed and emailed to your doctor for a diagnosis. The app also has built in AF detection algorithms that provides an instant interpretation to the user.

Unlike other devices, Kardia Mobile documents the symptoms and rhythms at the moment they occur – and is the only device to offer this “symptom + rhythm” correlation, which is important to a Cardiologist who is making the diagnosis. All other devices require follow-on ECG or symptom diaries/ human memory.

There are several smartphone apps that determine heart rate using the built-in camera, but these are not yet validated. These apps use the smart phone flash or light source and camera to obtain a recording of pulse waves.



It is important that your heart rhythm is determined and not just your heart rate. If you decide to use one of these apps to check your heart rhythm, we recommend you use it when you are feeling in good health for practice to ensure you are happy with how it is working. If you record a rate and/or rhythm that seems unusual, sit down, relax and take a deep breath, and then take another reading or use the manual technique described in this booklet. If the reading is still high and you feel unwell, call the NHS helpline (111) immediately and pass the information on to them with a description of how you are feeling.



12 Lead ECG

The 12 lead ECG is a very useful way for doctors and other health specialists to gain more information about how your heart rhythm is performing. The test is painless, easy and simple to carry out, it is often performed in the GP surgery or local hospital by a nurse or physiologist and only takes a few minutes. You will need to remove your outer clothes so that sticky electrodes can be attached to your skin to pick up the electrical signals from your heart, so wear something loose and easy to remove when you expect to have an ECG.

The recording is made on a special machine that has a number of wires coming from it that connect to the electrodes attached to your chest. There is a screen and a printer to print out the ECG.

The electrode is a small, sticky pad with a connector on top that is used only for you and picks up the electrical signal on the skin's surface. Good contact between the electrode and the skin is required, so the specialist may want to clean the skin lightly or remove any hair. After that, all you have to do is lie down, relax and breathe and let the specialist do their work. Within minutes it will be done and your doctor will have the information they need to help with your any diagnosis and potential treatment.

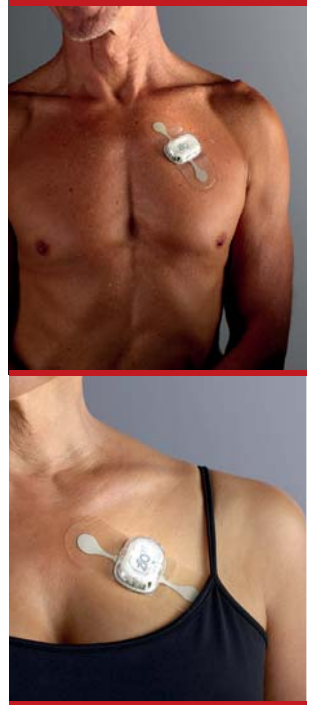
The 12 lead ECG shows whether the heart is beating fast or slow and also shows if the rhythm is regular. Because there are many electrodes on the chest and legs, this gives different views of the electrical activity of the heart and allows a specialist to understand better if there is anything unusual.



Extended continuous ambulatory monitoring

Often, arrhythmias (irregular heart rhythms) may occur occasionally or intermittently. Therefore, it may not be detected during a routine 12-lead ECG. Longer, continuous ECG may be required to capture the arrhythmia, to enable your doctor to diagnose or confirm there is no irregularity.

A long-term, wearable heart monitor allows a doctor to track and analyse your heart rhythm during normal activity. The monitor comes in the form of a small adhesive patch that you can wear on the upper left side of your body for up to two weeks, during which time the device will record and store data from your heartbeat and rhythm. You can also highlight the points at which you experience symptoms, by pressing a button on the patch to enable your doctor to see any correlations with your heart rhythm. At the end of the prescribed period you can remove the patch, post it back in the box provided, and a detailed report will be generated and sent to your doctor to identify whether you have an arrhythmia and to determine diagnosis appropriate treatment if needed.



Who is it designed for?

For an individual whose symptoms are infrequent, the 24/48-hour monitor would not be appropriate. However, a monitor that will span up to two weeks is more likely to detect an episode. The device is unobtrusive and provides complete data with minimal disruption.

How is it fitted?

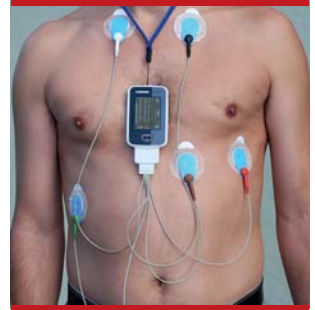
The patch is a one-time use monitor that can be applied by your GP/ nurse or at home. The skin is cleansed so the patch will stick effectively and remain in place for the prescribed period. You will be asked to record any symptoms by pressing a button on the patch and noting it in a booklet.

Will it affect my day to day activities?

This new form of monitor is designed for extended wear with as little upset to an individual's lifestyle as possible. There are no wires to manage or batteries to charge. You will be able to continue most normal activities, including showering and exercise, but not swimming. The only attention to your monitor is pressing a button to mark symptoms and promptly mailing back the patch upon completion.

Holter Monitor

The 12 lead ECG is very helpful to your doctor to help them understand what is happening with your heart in a more detailed way, but it only tells them what is going on the time it is taken. Sometimes your heart will only occasionally beat in an unusual way and the Holter recording device is designed to record the activity of your heart over a longer period.



The Holter is named after the doctor who invented longer-term recording of the ECG. The recording may be taken for one, two or sometimes three days (24, 48 or 72 hours). Similarly to the 12 lead ECG, a specialist will place electrodes on your chest. This time, though, they will be connected to a small, battery operated mobile recording device. This will normally slip into a holder on a belt around your waist or other comfortable position. The electrodes will need to stay in place for the whole time the recording is taking place, and you may also be asked to keep a diary of how you feel so that this can be compared to your heart rhythm.

You can go about your normal day when you are wearing the recorder, but swimming and showering are not recommended, as the recorder needs to be kept dry.

Once the recording has been made, a specialist will review the ECG over the whole period and see if there is anything out of the ordinary with your heart rhythm during that time.

Insertable Cardiac Monitor

Another way to record a long-term ECG that will give the doctor even more information is to use an Insertable Cardiac Monitor (ICM). An ICM is applicable for arrhythmias that happen infrequently. Perhaps you experience recurrent syncope events and the cause has not been explained because it was not possible to capture an ECG at the time of the event.

The ICM is a small, thin device that is inserted under the skin and can record an ECG for up to three years. It can be set to be manually activated when you feel unwell or to record automatically if it detects something unusual or during a syncopal event. Your doctor will advise you on how it is set and what to do in the event of an episode.

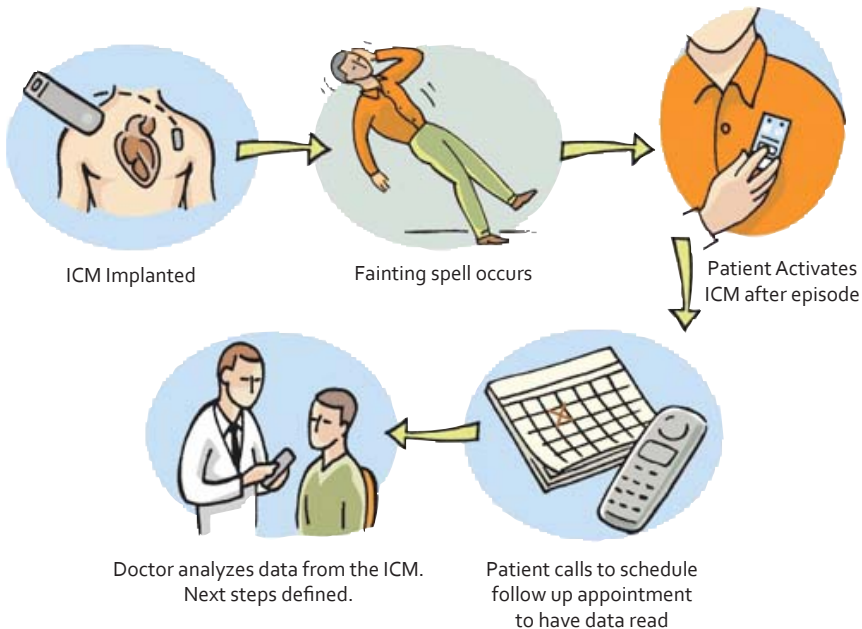


The minimally invasive insertion needs to be undertaken in a sterile environment and it will be performed by a trained clinician. It takes about 15 to 20 minutes.

You will be awake during the procedure and receive a local anaesthetic. The implant is carried out in sterile conditions and the wound will have a dressing on it. You should keep the area clean and dry until it has healed, which usually happens quickly.

Specialists can receive information from the device by placing a special reader over the area. If the device model is wireless, the specialist can also receive information directly from the device without any action needed from you.

They can then look at that information to see if there has been anything unusual with the rhythm of your heart. This is particularly useful if you have had any symptoms during this time.



Electrophysiology (EP) studies

Why do I need an electrophysiology study?

An electrophysiology study is a procedure by a heart rhythm cardiologist (electrophysiologist) in a hospital. Patients can be seen as a day case or an overnight stay. Electrophysiology studies test the electrical activity of your heart to find where an arrhythmia (abnormal heartbeat) is coming from.

These results can help you and your doctor decide whether you need medicine, an ablation, a pacemaker or an implantable cardioverter defibrillator (ICD).

Recording wires are carefully placed in the heart, through needle punctures into the veins. These recording wires are used to analyse the function of the heart's electrical system. It can enable your doctor to determine the cause or risk of abnormal heart rhythms and assist him/ her in making decisions in relation to future treatment if required.

What can happen if an abnormality in the electrical system of my heart is found?

If the abnormal heart rhythm comes from the upper chambers of the heart, this is known as supraventricular tachycardia (SVT). These types of heart rhythm disturbances are usually not life threatening, but can cause unpleasant symptoms and interfere with your quality of life.

If the abnormal heart rhythm comes from only the lower, pumping chambers of the heart (the ventricles), it can be dangerous, particularly if it is associated with fainting, and especially if a patient already has a heart condition such as a previous heart attack scar.

What does the procedure involve?

You may be asked to stop taking some of your medications before the study is performed, depending on your individual doctor's preference prior to the procedure. You will also have some routine tests such as blood sampling, a physical examination and an ECG. Your doctor/nurse will see you ahead of admissions (a pre-admission visit) to discuss the details of the procedure, and any risks and benefits that may be associated with it. You will be given the opportunity to ask questions prior to signing a consent form for the procedure.

Your electrophysiology study will be performed in a cardiac catheter laboratory. The doctor or electrophysiologist will carry out the procedure with the help of a physiologist who gives technical support, nurses who will look after you and assist the doctor, and a radiographer who will assist with the x-ray equipment.

An EP study is an invasive procedure, usually carried out under local anaesthetic, and small needle punctures are used to access the heart via the veins. You may be given some sedation, which makes you feel relaxed and sleepy.

During the study, you will be required to lay flat, and the local anaesthetic will be administered to your right groin and possibly in the side of your neck or upper chest. Some fine tubes (catheters) will then be inserted into the vein where the local anaesthetic has been applied.

Fine wires or electrical recording catheters are then passed through the tubes and positioned within the heart. This is done with the guidance of an x-ray machine; therefore, it is important that you tell your nurse before the procedure if you think you may be pregnant. This may delay your procedure.

Once the wires are positioned into place within the heart, the doctor is able to record electrical activity from specific areas of your heart. Extra beats are delivered using an external pacemaker, which may bring on palpitations, but this is necessary to see where the abnormal heart rhythm is coming from.

It is possible to put the heart back into normal rhythm by delivering some extra beats. Electrical signals produced by your heart will be picked up by the special catheters and recorded. This is called cardiac mapping.

The procedure should enable your doctor to detect any abnormalities in the electrical system of your heart, and normally takes between 45 and 60 minutes.

After the procedure, the wires and tubes will be removed, and the nurse or doctor will apply light pressure that to these areas for a few minutes to stop any bleeding. You will then be transferred back to the ward where you will be asked to rest in bed for two to four hours. In some centres under certain conditions, your electrophysiologist may have talked to you about proceeding directly to a catheter ablation treatment immediately after the study is complete, and the number, type and location of extra pathways in your heart have been demonstrated.

The reason for proceeding directly, is the desire to avoid having to go through a further similar procedure all over again. If ablation is being completed after the study, this will have been fully explained to you in advance, and you will have been asked to consent to the procedure and to sign that you have understood the risks and benefits fully.



These heart rhythm disturbances can be treated in a variety of ways and your doctor will discuss treatment options with you, either before or after he/she has performed your electrophysiology study.



What are the benefits and risks of an electrophysiology study?

The benefit of having an electrophysiology study, is that it can enable your doctor to determine the cause or risk of any abnormal heart rhythms and assist them in making recommendations in relation to your future treatment if required.

There is no risk-free procedure in medicine, and electrophysiology is no exception, although it is very safe. The risk of any serious complications occurring during the study is less than 0.1%. Your doctor or nurse will discuss this with you in more detail before the procedure is performed but the most common risks are arrhythmias, blood clots, and small groin injuries or infections. If a catheter ablation procedure is done after the electrophysiology study, the additional risks will have been explained in full.

How long will I have to stay in hospital?

Most people recover quickly, and tend to feel well enough to go home on the same day. However, your doctor may want to initiate further treatment while you are in hospital depending on the findings of your study. This will be discussed with you after the procedure. You should be able to carry on with normal activities the next day, but avoid lifting anything heavy for two weeks afterwards.

If your doctor goes on to perform an ablation procedure, DVLA restrictions will apply to driving. If your arrhythmia causes incapacity, or is likely to cause incapacity like fainting, then there is a driving restriction until your doctor has treated this. It is recommended that you rest the groin area and not drive for two days.

Inherited Cardiac Conditions (ICCs)

What is an inherited cardiac condition (ICC)?

Inherited Cardiac Conditions (ICCs), for example Hypertrophic Cardiomyopathy (HOCM) and Long QT Syndrome (LQTS), are conditions that can be passed down in families via your genes. Genes act as instructions telling our bodies how to grow, develop and function. There are many genes known to be involved with ICCs. A change, or 'spelling mistake', in one of these genes can cause someone to be affected by, or be at risk of, an ICC.



The way these 'spelling mistakes' are inherited can vary, but there is usually a 50:50 or one in two chance that a close blood relative (child, parent, sister or brother) also has the 'spelling mistake' themselves, and therefore has the risk of developing the ICC too. Most people with ICCs do not suffer troublesome ongoing symptoms. However, a small number of people are at risk of dangerous heart problems and it is important to have regular heart checks, as many of these problems are treatable or preventable.

What is genetic testing?

A genetic test is a type of medical test that is used to try and identify the gene change, or 'spelling mistake' that can cause an ICC. For example:

A correctly 'spelt' gene: **THE CAT SAT MAT**

A gene with a 'spelling mistake': **THE CAT TSA TMA T**

Within the genes that are associated with causing ICCs, there are a large number of different gene changes that can cause the condition. It is not always possible, using current technology, to find the 'spelling mistake'. If this is the case, your sample may be kept and stored as it may be possible to do additional testing

in the future. Even if the gene change causing the condition in your family is found, your sample may still be stored for further testing if and when medical knowledge increases and new technologies become available.

You will be asked for your written consent before you give a sample, and your permission will also be gained before any results are shared for the purposes of helping other family members who are also considering genetic testing.

Different types of genetic tests

There are two different types of genetic tests: 'genetic screening' and 'pre-symptomatic' or 'familial' testing. The first affected person in the family to come forward for testing will be offered a genetic screen; if a causative spelling mistake is found, then their relatives may be offered a familial test. The process involved and implications to consider are quite different for each type of test and for each individual concerned.

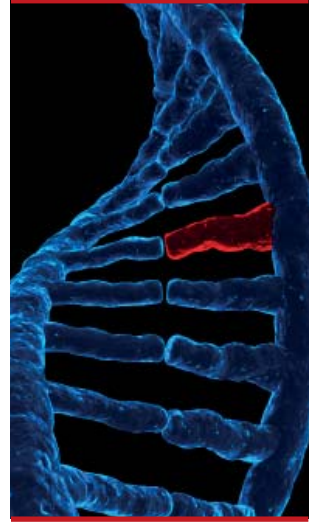
Genetic Screening

What is genetic screening?

Genetic screening can be offered to someone who has been diagnosed with an ICC by their specialist heart doctor (cardiologist) based on the results of clinical tests (like ECG and echocardiography) and examination.

The aim of genetic screening is to try and identify the genetic cause of your ICC. The results of a genetic screen may not change anything for you in terms of your diagnosis and management – these decisions are usually based on the results of clinical tests and examination.

However, if the causative spelling mistake is found, it can be a very useful and efficient tool for finding out who else in your family may be at risk of developing the same ICC as you.



There are several possible results from 'genetic screening':

- 1) A genetic 'spelling mistake' is found which is believed to be responsible for causing your ICC. This allows for pre-symptomatic genetic testing of family members to be offered.
- 2) The responsible genetic 'spelling mistake' is not found. This does not mean you do not have the ICC you were clinically diagnosed with, or that it is not an inherited condition, just that the specific responsible genetic 'spelling mistake' in you has not been identified. This may be because the testing procedure was unable to identify your particular gene alteration or because the particular gene alteration is in genes that the laboratory does not test, or have not been discovered yet. In this situation, pre-symptomatic genetic testing cannot be offered to other family members. However, usual practice is to store your sample, in case additional testing becomes possible in the future.
- 3) A genetic 'spelling mistake' is found, but it is not yet certain whether this is what is causing your ICC. In this situation, further genetic tests and clinical investigations of your family may be needed to learn more about this gene change.

Pre-symptomatic genetic testing

If an ICC-causing gene change is found in a family member who has already been diagnosed with an ICC (see genetic screening section), pre-symptomatic genetic testing can be offered to blood relatives who are not already known to have the ICC. In the first instance this would usually mean offering testing to close relatives such as parents, brothers, sisters and children, depending on their age. If a relative chooses to have pre-symptomatic testing, there are two possible outcomes:

- 1) The causative gene change is found. That person is at increased risk of developing the ICC and should have their heart checked by a cardiologist. If they have children, they too would be at risk of the familial ICC and genetic testing and/or screening would be recommended, depending on their age.
- 2) The causative gene change is not found. That person is not at increased risk of developing the ICC and does not need heart checks. If they have children, then they do not need genetic testing or heart checks either.

This approach of finding out who else in the family may have inherited the ICC is sometimes called 'cascade screening'. The aim of pre-symptomatic testing is to predict someone's future risk of developing the ICC that is known to run in the family. By identifying family members who also have the genetic 'spelling mistake', it is hoped that their risk of ill-health and dangerous heart problems can be reduced through screening, surveillance and appropriate medical and/or surgical therapy.

If you would like to find out more about genetic testing, you should ask your GP or cardiologist to refer you to a specialist inherited cardiac conditions clinic or your local clinical genetics department.

You should be offered a genetic counselling appointment with a specialist health professional (usually a genetic counsellor or doctor) to discuss genetic testing in greater depth. If, for any reason, you do not want to have pre-symptomatic genetic testing you can still have clinical tests such as ECG and echocardiography. Your GP should refer you to a specialist inherited cardiac conditions clinic for this.



What is genetic counselling?

Your genetic counselling appointment is a chance to learn more about the genetic basis of your ICC and to discuss what having the condition may mean for you and your family. You will be able to discuss the pros and cons of genetic testing in reference to your own personal situation, so you can work out whether having a genetic test really is the right choice for you.

Genetic counselling has an especially important role when you are considering pre-symptomatic genetic testing. Discovering you are at increased risk of an ICC when you feel well can have a significant impact on your life, and people can often react to this in different ways. It is worth thinking about your motivation for having genetic testing and finding out what genetic testing can actually tell you. For example, pre-symptomatic genetic testing will only be able to tell you whether you are at an increased risk of developing the ICC. It will not be able to tell you if you will ever develop symptoms, when you will develop them or how severe they may be.

If your pre-symptomatic genetic test shows that you do carry the 'spelling mistake', an outpatient appointment with a heart specialist (cardiologist or specialist nurse) is recommended and this can have implications for insurance, exercise, lifestyle and career choice. So, it is worth thinking about how it may affect you and your lifestyle, before and during your appointment. A genetic counselling appointment will typically last 30-45 minutes and can be used to discuss a variety of issues, as mentioned above, as well as any other questions you may have. The genetic counsellor or doctor will draw a family tree and discuss any health issues in the family. You should therefore come prepared with as much relevant personal and family information as possible (including documents where available).

How is the genetic testing done?

The genetic test itself involves you giving a blood sample or cheek swab. This will then be sent away to a specialist genetics laboratory.

If it is a genetic screening test, scientists there will look at the genes in your sample to see if they can find a gene change that might be responsible for causing your ICC. They will only look in the genes they know are involved in causing your ICC, not in any other genes, so it will not usually be possible to tell whether you are also at increased risk of other inherited conditions. The results of genetic screening can take several months (sometimes longer) to come through as this is a complex process.

If it is a pre-symptomatic genetic test, the scientists in the lab simply look to see whether you carry the same gene change as your relative(s) or not. The results for pre-symptomatic genetic tests therefore take less time to come back – usually about a month.

Results will be sent back to the genetic counsellor or doctor you saw originally and they will then let you know by whatever means you arranged e.g. another appointment, telephone, letter or email. When your genetic counsellor or doctor informs you of your results, you can have another discussion as to what the appropriate next steps are to take and ask any more questions that you may have.



Arrhythmia Alliance

www.heartrhythmalliance.org

Working together
to improve the
diagnosis, treatment
and quality of life for
all those affected by
arrhythmias

Arrhythmia Alliance
Unit 6B
Essex House
Cromwell Business Park
Chipping Norton
Oxfordshire
OX7 5SR

+44 (0)1789 867 501

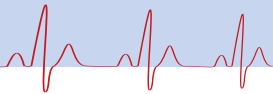
@ info@heartrhythmalliance.org

www.heartrhythmalliance.org

Registered Charity No. 1107496

©Arrhythmia Alliance

Published May 2018



endorsed by
Department
of Health

Please remember that this publication provides general guidelines only. Individuals should always discuss their condition with a healthcare professional.

Acknowledgements:

Arrhythmia Alliance would like to thank all those who helped in the development and review of this publication.

President:

Prof. A John Camm

Patrons:

Prof. Hein J J Wellens

Prof. Silvia G Priori

Mr W B Beaumont OBE

Rt. Hon Tony Blair

HM King Constantine of Greece

Trustees:

Mr Mark Bullock

Mr Nigel Farrell

Dr Adam Fitzpatrick

Prof. Richard Schilling

Founder & Trustee:

Trudie Lobban MBE

If you would like further information or would like to provide feedback please contact Arrhythmia Alliance.