MACMILLAN
CANCER SUPPORT

UNDERSTANDING CANCER RESEARCH TRIALS (CLINICAL TRIALS)

About this booklet

This booklet gives information about cancer research trials or clinical trials. Doctors need clinical trials to find new and better ways to treat cancer. Trials can also look at other areas, such as ways of improving your well-being, or better ways of diagnosing or preventing cancer.

There is a list of questions you may want to ask before you decide whether to take part in a trial on pages 20 and 21. We also explain how to find out if there is a trial suitable for you (see pages 44 to 45). Turn to pages 48 to 56 for some useful addresses and helpful websites.

We cannot advise you about the best treatment for you. This information can only come from your doctor, who knows your full medical history.

In this booklet, we have included quotes from people who have taken part in clinical trials, which you might find helpful. Some are from **healthtalkonline.org** Others are from people who have chosen to share their story with us.

If you would like to discuss this information, call the Macmillan Support Line free on **0808 808 00 00**, 7 days a week, 8am to 8pm, or visit **macmillan.org.uk**. If you are hard of hearing you can use textphone **0808 808 0121**, or Text Relay. For non-English speakers, interpreters are available. Alternatively, visit **macmillan.org.uk**

If you find this booklet helpful, you could pass it on to your family and friends. They may also want information to help them support you.

Your data and the cancer registry

When you are diagnosed with cancer in the UK, some information about you is collected in a national database. This is called the cancer registry. It helps the NHS and other organisations plan and improve health and care services. Your hospital will give information about you, your cancer diagnosis and treatment to the registry automatically, unless you ask them not to. As with all medical records, there are strict rules to make sure the information is kept safely and securely. It will only be used for your direct care or for health and social care planning and research.

Talk to your doctor or nurse if you have any questions about the registry. If you do not want your information included in the registry, you can contact the cancer registry in your country to opt out. You can find more information at **macmillan.org.uk/cancerregistry**

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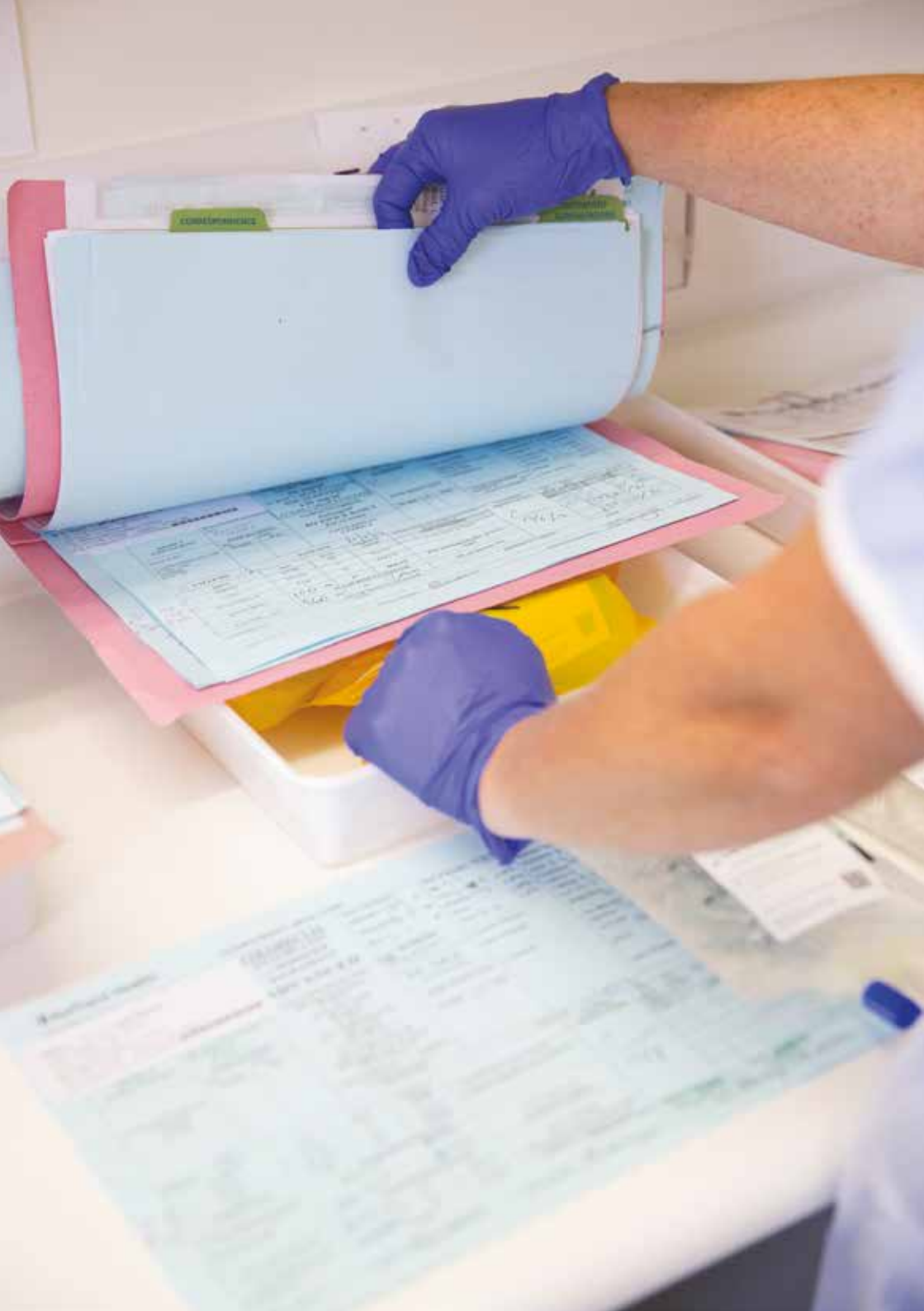


WHAT ARE CLINICAL TRIALS?

Clinical trials

Clinical trials are medical research trials involving people. They can include people with different illnesses and conditions. Sometimes, trials include healthy people who volunteer. Trials are done in all areas of medicine.

This information is for people with cancer. Cancer clinical trials only involve people with cancer and not volunteers.

Thinking about a clinical trial

Your cancer doctor or nurse may ask you to think about a clinical trial when you are first diagnosed. Or they may ask you after you have already had some treatment. They will talk to you about suitable clinical trials for your situation and give you information about them.

You may want to find out for yourself if there are any suitable trials for you. It is important to ask your cancer doctor or nurse for advice. There are different ways to find out about clinical trials (see pages 44 to 45).

Not all hospitals can take part or have the expertise to take part in certain trials. This means you may have to travel to a different hospital. To take part in any trial, your cancer doctor or GP needs to refer you to the doctor running the trial in that hospital.

Why are clinical trials important?

Doctors need clinical trials to know which new or combined treatments are safe and work better than treatments we already have. Years before a trial involves people, research starts in the laboratory. For example, the research team might start testing the effects of a drug on cancer cells in the laboratory.

Past trial results have improved cancer treatments and have helped people live longer. But cancer trials do not just involve drugs and treatments. They can look at other areas, such as diagnosing or managing side effects or symptoms.

Who is involved in a clinical trial?

Every trial is led by a main researcher, who is often a medical doctor. There is a research team that includes:

- doctors
- nurses
- research co-ordinators
- other health care professionals.

They prepare the plan for the trial, which is called the protocol. The protocol explains:

- the reasons for the trial
- what will happen during it
- who can join.

Clinical trials are often done at hospitals with cancer treatment centres. This is because they have staff with expertise and the right facilities.

Cancer treatment trials

These involve trials looking at new drugs or treatments for cancer. When we talk about treatments in this information, we are including:

- any cancer treatment, such as radiotherapy or surgery
- any cancer drugs, including chemotherapy, hormonal therapies, targeted therapies and immunotherapy drugs.

We have more information on radiotherapy and chemotherapy in our booklets and on our website (see page 48 to 52). We also have further information about treatment on our website.

Cancer treatment trials may be done to:

- test a new treatment, to find out if it is better than the current treatment used
- look at ways of combining treatments to see if this works better
- test new drugs to find out if they are safe or have side effects
- improve the way treatments are given, to reduce side effects
- find which treatments have fewer side effects and the least effect on your day-to-day life
- compare how different drugs help control symptoms.

A trial may aim to find out if a treatment:

- helps people live for longer (improves survival)
- reduces treatment side effects
- helps control the symptoms of cancer
- helps improve your well-being or quality of life.

Other trials

Trials can also look at the following areas:

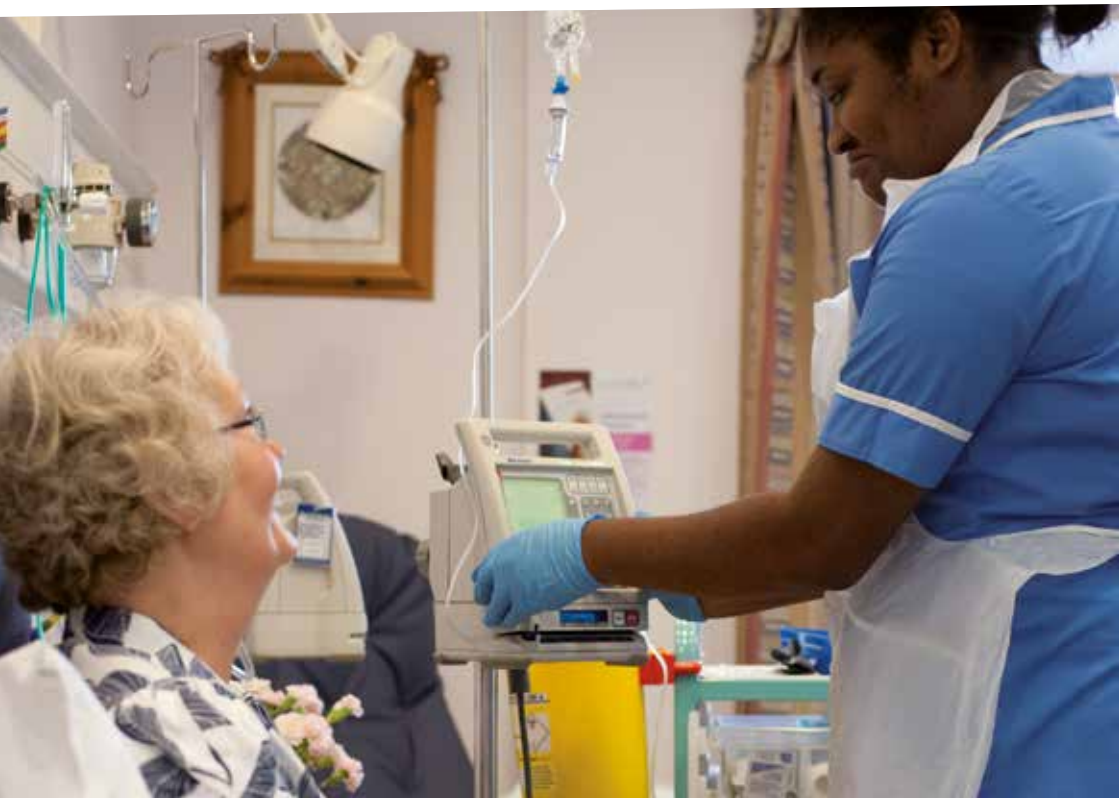
- **Prevention** – finding out if a drug or treatment lowers the risk of certain cancers in people with a higher risk. This could be linked to their family history.
- **Screening** – looking at ways of testing healthy people in the general population to see if this helps find certain cancers at an early stage.
- **Diagnosis** – using new tests or scans or to see if they improve the diagnosis of cancer.
- **Quality of life** – finding ways of improving well-being.

Quality of life trials usually include questionnaires. These usually ask about how you are feeling and how side effects are affecting your day-to-day life. They may also include people closest to you. This could be, for example, to find out if they need time off work to care for you while you have treatment. These trials are often done together with treatment trials.

Who can take part in a clinical trial?

All trials have guidelines about who can take part. These are sometimes called eligibility or inclusion criteria. For example, a trial may only include people with a certain type or stage of cancer. The stage of a cancer is its size and whether it has spread.

Trials also have guidelines about who cannot take part. These are called exclusion criteria. This is to make sure it would be safe for you to take part and that results are as accurate as possible.



Some possible reasons why you may not be able to take part in a trial are:

- you have another health condition
- you take certain medicines
- you have had certain treatments in the past.

Your cancer doctor or nurse can tell you if a certain trial is suitable for you.

Your general health

With some trials, your cancer doctor may look at your general health to decide whether it is suitable for you. They need to make sure treatments will not make you feel worse than you would without treatment.

Your cancer doctor or nurse may look at how you are able to carry out certain day-to-day activities. This includes things like getting dressed, looking after personal hygiene and feeding yourself.

They use different scales to grade how active you are. Cancer doctors call this performance status. Some trials may say people need you to have a particular performance status to take part.

A person's performance status can range between:

- being active in a similar way to before your illness
- needing some help to look after yourself
- needing help with all your care needs.

Benefits and possible risks of trials

Clinical trials are designed to benefit you as much as possible. Whatever treatment you have, there are procedures in place to make sure any risks of trials are as low as possible.

Benefits of taking part in a trial

Taking part in a trial means you may benefit from a new treatment that might not be available except in the trial. The new treatment may work better than the standard treatment. By standard treatment, we mean the most effective treatment available now.

Trial results tell doctors which treatments will benefit future patients the most.

When you take part in a trial, researchers carefully monitor you. They may want you to have regular tests during or after treatment, such as blood tests and CT scans. Your research team may also ask you extra questions about how you are feeling. All this means they can see any changes in your health and deal with them as soon as possible. Some people find this reassuring. You still have follow-up appointments with your cancer doctor after the trial.

Possible risks or disadvantages of taking part in a trial

With any trial, there is a small risk that the treatment could harm you. Or you could get unpleasant or unexpected side effects. During the trial, researchers try to reduce these risks as much as possible. They monitor you closely, so they can see any issues before they become a problem. Trials are set up to try to be as safe as possible (see pages 36 to 39).

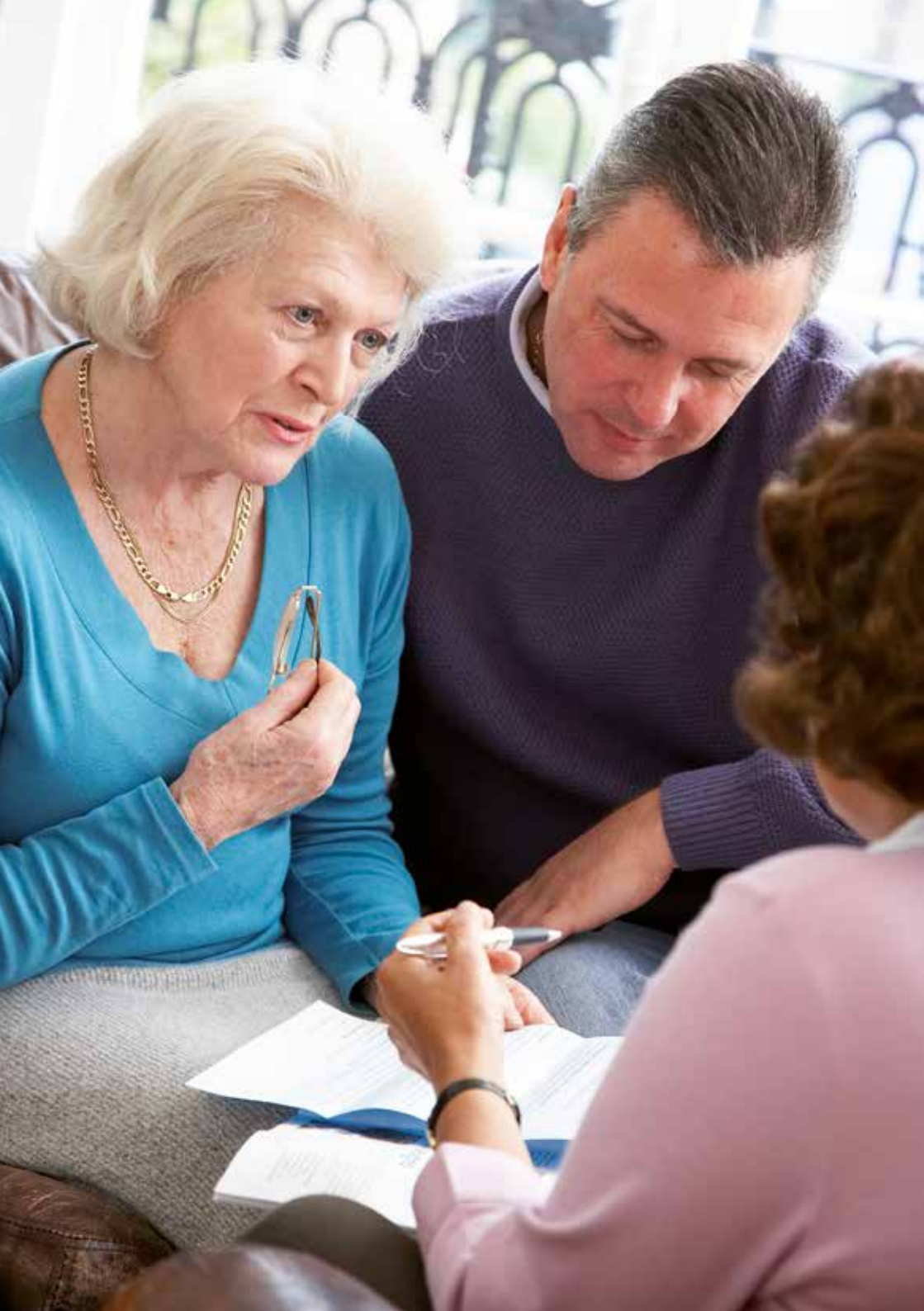
Taking part in a trial may involve some practical changes. For example, you may need to go to the hospital or see your GP more often. Sometimes you need to travel to a different hospital. We have a list of suggested questions you can ask about practical issues (see page 21).

Making a decision

It is important to know there is no right or wrong decision. Any decision you make will be the right one for you at the time. If you decide not to take part in a trial, your cancer doctors and nurses will respect your decision. You do not have to give a reason and it will not influence your future care. Your cancer doctor will give you the standard treatment and care for the type and stage of cancer you have.

'It was purely up to me... they explained why they were doing it and said it was totally up to me.'

Hazel



TAKING PART IN A CLINICAL TRIAL

Information and giving your consent

A doctor or nurse from your cancer team can explain the possible benefits or risks of joining a trial (see pages 12 to 13). They should tell you any other treatments that may be right for your situation.

Before you join a trial, the research team will ask for your permission. They cannot enter you into the trial or do any necessary tests until you give them permission (consent) in writing.

To help you decide, researchers should tell you:

- what the trial is trying to find out
- what the trial will involve
- what you will have to do.

'The doctor asked "Are you prepared to become part of a drug trial?" We discussed the options as a family and decided to go with it – there was nothing to lose.'

Peter

There are guidelines for researchers about the information people need to help them decide about taking part in a trial. But how much information people want to know may be different from person to person.

It is important that you have as much information as you need to make an informed decision. You can have a relative or friend with you when you talk to the research team to help you decide. They can help you remember what the researchers said and talk it over with you later.

You should feel able to ask any questions that will help you. It is also important to think about any practical issues that could affect your decisions. For example, this could include:

- having extra hospital appointments
- needing different tests
- having time off work.

We have a list of general and practical questions that you may want to ask (see page 21).

A nurse or doctor from the research team will give you an information leaflet about the trial. You can take this away and read it in your own time. It can help to talk it over with your family or friends and to think about any practical issues involved.

We have more information about making a decision that may help you (see page 13).

If you decide you want to take part in the trial, the doctor or nurse from the research team will write it in your notes. They will ask you to sign a consent form saying you agree to take part. Your cancer doctor will also sign it and give you a copy to keep. During the trial, the research team are responsible for your care. They will talk to you about any day-to-day decisions needed for your treatment and care.

Confidentiality

If you agree to take part in a trial, your GP will be informed. They are responsible for your day-to-day health at home, so it can help them to know.

Your medical records about the trial are confidential. But your records can be looked at by:

- people from the drug company involved in the trial
- the staff who are co-ordinating the trial.

This is to check they are collecting all the necessary information accurately.

No one who looks at your notes can give information to anyone outside the healthcare and research team looking after you. All your information is confidential to the trial research team and your healthcare team.

In the same way, when the results are published, you will not be named.

If you want to leave a trial

Even if you agree to take part in a trial, you can leave at any time. You do not need to give a reason. Before you make the decision, it is a good idea to talk it over with your:

- cancer doctor
- specialist nurse
- research nurse.

This will help them know if there is anything they can do to help you or if there is anything you do not understand.

If you have been having a new treatment as part of a trial, you may not be able to continue with it. But your doctor will give you the standard treatment for the type of cancer you have. By standard treatment, we mean the most effective treatment available now.

'If they see that it's having serious effects and negative effects, they'll pull you out of it. So you always have the option of stepping back from it.'

Tom

Questions to ask

Here are some questions you might like to ask before you decide whether to take part in a trial. Your cancer doctor or nurse will probably answer most of these when they tell you about the trial. Most of them will also be covered in the written information your doctor gives you about the trial.

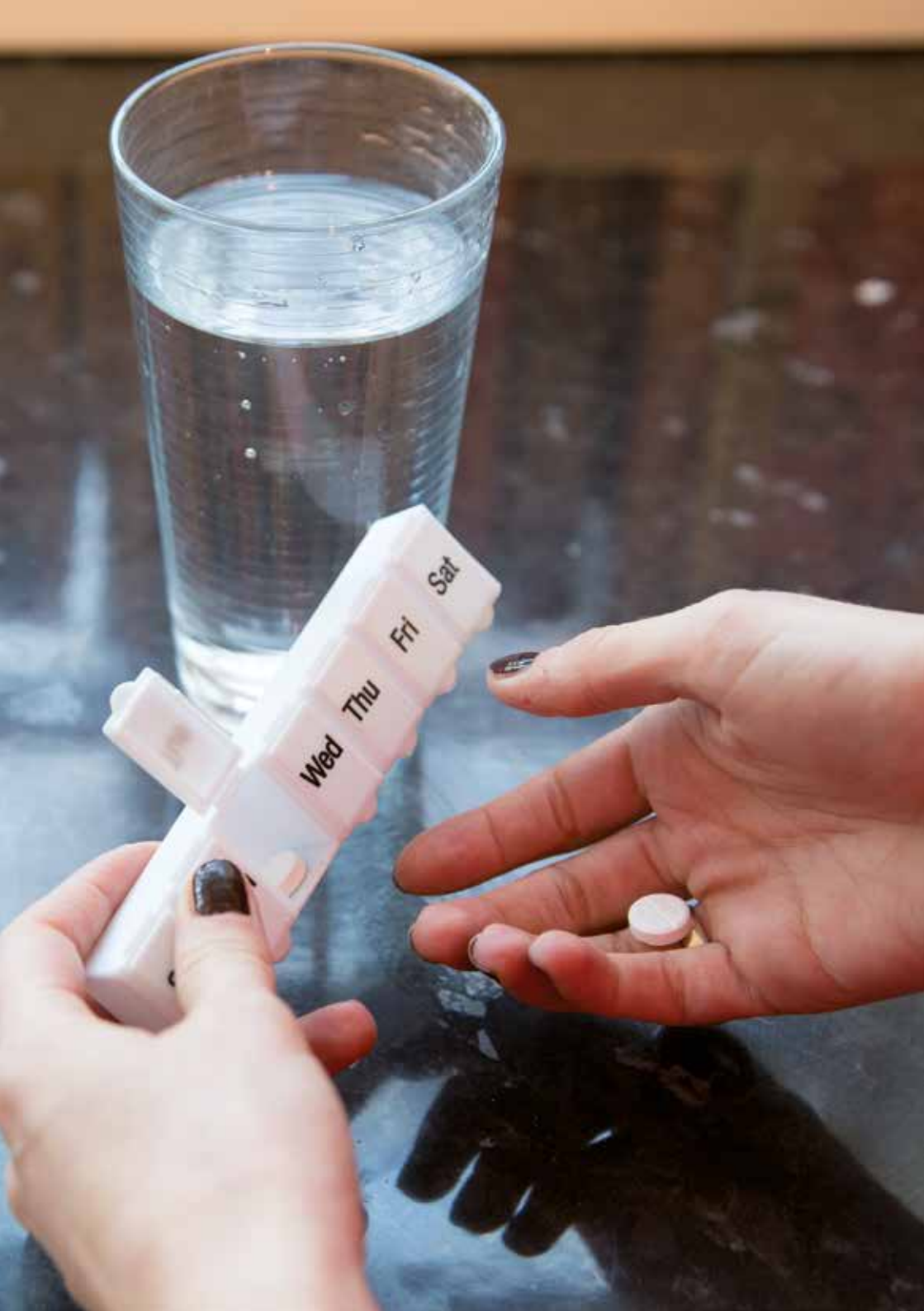
General questions

- What is the aim of the trial and how will it help people?
- What are the treatment choices in the trial?
- What are the possible benefits of the trial for me?
- What are the possible risks?
- How long is the trial expected to last?
- If I do not take part in the trial, what treatment will I get?

Practical questions

You can ask some practical questions to make sure you understand how the trial may affect your day-to-day life:

- How much time will it take to have the treatment?
- Will I need extra tests or appointments?
- Do I have to take time off work?
- Will I need extra help from family and friends?
- Will my transport costs to and from the hospital be paid?
- Do I have to collect the drug from the hospital?
- Will it involve filling in a questionnaire or keeping a diary?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HOW ARE TRIALS CARRIED OUT?

Different phases of clinical trials

Researchers carry out treatment trials in a series of phases (steps). They test possible new cancer drugs or treatments in a laboratory first.

To make sure drugs are safe, researchers test them on animals before they give them to people in trials. Using animals in research is highly regulated. **Gov.uk** and **Cancer Research UK** have more information about this (see **Other Useful Organisations** section on pages 53 to 57).

If the drugs are effective in laboratory tests, researchers test them in **phase 1** trials with people affected by cancer.

If these are successful, researchers test the drugs in **phase 2** trials and then **phase 3** trials. **Phase 4** trials test drugs that are already licensed for use.

Phase 1 trials

Phase 1 trials are the first tests involving people for a new drug or type of treatment. Before this, it has only been tested in the laboratory.

These trials usually involve individual drugs rather than a combination of drugs. For example, it could be a trial of a new targeted drug, immunotherapy drug or chemotherapy drug.

Phase 1 trials usually happen in cancer clinical research units at specialist hospitals. Sometimes this means you have to travel further to a hospital to have the trial.

A phase 1 trial aims to find out:

- how much of a drug can be given safely
- what side effects it causes
- whether it has any effect on the cancer.

These trials involve very few people. People taking part have usually already had treatments, but they are no longer working for them. Other standard cancer treatments are unlikely to be helpful for them.

To take part, you need to meet the inclusion criteria to make sure you are reasonably well (see page 10). This is because these trials are used to find out about side effects.

Before you can enter a trial, doctors or nurses may ask questions to see how well you manage day-to-day activities. Doctors call this performance status (see page 11). It makes sure people who are already feeling unwell do not have a treatment that may not work for them and may make them feel worse.

How phase 1 trials work

The research team give the first people in the trial a small dose of the drug that is expected to be safe. Depending on the side effects, the next group get a higher dose. The dose keeps increasing with each group.

Researchers look carefully at the different side effects and whether they are mild, moderate or severe. This helps them work out the best dose to give.

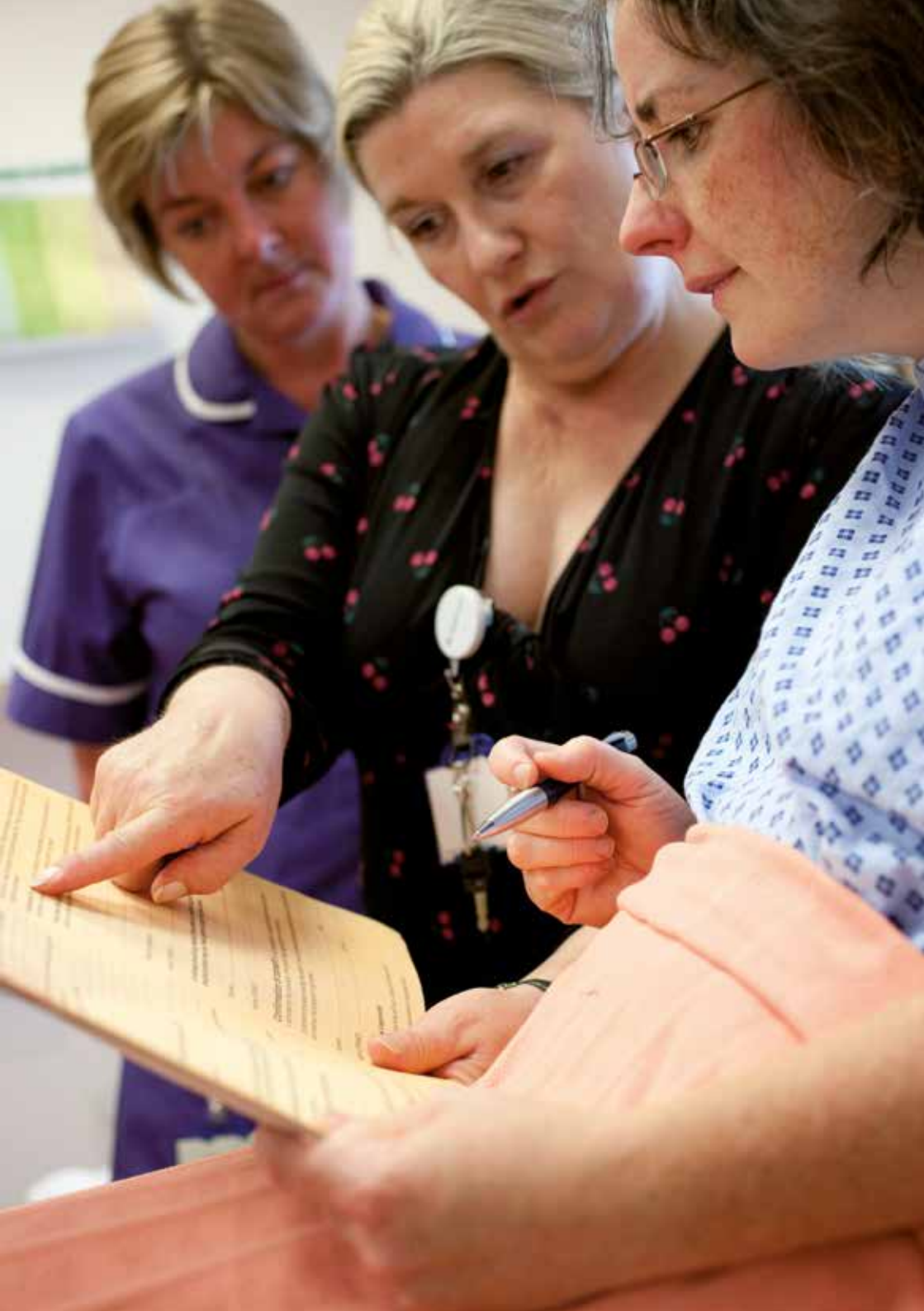
In a phase 1 trial, researchers do not know whether people will benefit from the new treatment. Finding out the best dose to give and its side effects is an important stage before testing how effective the drug is.

The drug or treatment goes on to a phase 2 trial if:

- it is safe
- there are signs that it may have an effect on the cancer.

'They don't know what the results or side effects will be. It's got to be started somewhere – they might be able to adjust it so the drug is used in a different way.'

Kaya



Phase 2 trials

A phase 2 trial aims to find out:

- what types of cancer the drug might be best used to treat
- more about the side effects of the drug and how to manage them.

Phase 2 trials involve more people, who are monitored closely to see how well the drug or treatment is working against the cancer. Even though it has been through a phase 1 trial, researchers still look at the side effects. They test in bigger groups to find any side effects they have not seen before.

The drug or treatment goes on to a phase 3 trial if:

- it has an effect on the cancer
- it is safe.

Phase 3 trials

A phase 3 trial involves bigger groups of people. It compares trial treatments that are giving good results with the current best standard treatments. It may also give more information about any side effects the new treatment may cause.

A phase 3 trial looks at whether a new treatment:

- is as good as the standard treatment
- causes fewer side effects.

Phase 3 trials usually involve a randomisation process (see page 34). A computer chooses the groups, to avoid bias.

The trial compares the standard treatment with the new treatment. It may also involve a placebo (see page 35). A placebo looks the same as the drug or treatment being tested, but it does not act on the cancer.

Once phase 3 trials have shown a drug to be safe and effective, manufacturers of the drug can apply for a drug license. Licensed drugs are available for use. Most licences are given by the European Medicines Agency (EMA). Or the Medicines and Healthcare products Regulatory Agency (MHRA) can give a licence for a drug to be used in the UK only.

Drugs that are licensed may go through phase 4 trials for further research.

Phase 4 trials

These are done after a drug has proved to work well and is licensed. They aim to find out:

- how well the drug works when it is used more widely
- the long-term risks and benefits of the drug
- more about possible rare side effects and the safety of the drug.

Multi-arm trials

In a multi-arm trial, researchers look at different treatments at the same time. They compare these with a group of people having a control treatment. People in the control group get a treatment that is already in use or a placebo (see page 35).

Researchers compare the results from this control group with other groups getting different or newer treatments.

Some types of multi-arm trials may stop one of the treatment arms, if early results show a treatment is:

- not working as well as the others
- working more successfully than others
- causing more side effects.

'I took part in a clinical trial of a new chemotherapy treatment. Under the trial protocol, I ended up having the original chemo treatment. My progress would be measured against the new variety.'

Ron

Trial design

With phase 2 or phase 3 trials, you may hear your research team use different words. These describe the different ways that trials are set up to give the best results.

They include:

- controlled trials
- randomised trials
- placebo and blind trials.

Controlled trials

In most trials, one group of patients will have the trial treatment and one group will have the standard treatment. Groups are randomly selected (see page 34).

Sometimes, the standard treatment is to 'watch and wait'. This is when you do not need to have any treatment, unless the cancer starts to develop or cause symptoms.

The people with cancer who are having the trial treatment are called the **trial group**. The people having the standard treatment are called the **control group**. The researchers will compare the results of the trial group against the control group.

Researchers compare the results of both groups to find out if:

- there is any benefit from the new treatment
- the side effects are better, worse or different.

If the trial group shows any improvement, the researchers also measure:

- how much of the improvement is due to the new treatment
- how much would have happened by chance.

Randomised trials

Some phase 2 and phase 3 trials are randomised, controlled trials. This means that a computer programme randomly (by chance) chooses the groups for each treatment.

The computer matches the different groups to make sure they are as similar as possible. For example, this means they will have a mix of people with similar ages, gender or state of health.

Everyone taking part will get a code number and will be put into to the different treatment groups randomly. They may get:

- the new treatment
- the standard treatment, and sometimes an inactive treatment (a placebo) with it (see page 35).

When people are put into treatment groups by a computer, it avoids any bias. If doctors or researchers decide who should get which treatment, they could be influenced by what they already know. Without realising it, they may put people more likely to respond to a new treatment into that particular group. This would affect the results of the trial and make a treatment look better than it is.

There is an infographic that explains randomisation on the next page.

Randomisation

Patient information is entered into a computer.

The computer randomly assigns patients to two or more groups. This helps to prevent bias.

Control group receives standard treatment.

Trial group receives new treatment.

Placebo and blind trials

A placebo is an inactive treatment that looks the same as the drug or treatment that is being tested. But it does not act on the cancer.

It may be used when a new drug is added to a standard treatment. One group will get the standard treatment plus the new drug. The other group will get the standard treatment plus a placebo. If you are in this group, it does not mean you will not receive any treatment. The placebo is given along with the standard treatment.

You will not know if you are getting the trial treatment or a placebo. This is called a blind trial. Researchers compare the responses to the placebo and the treatment being tested to find out if it has any benefit.

In many trials, doctors do not know whether you are getting the placebo or the treatment being tested. These are called double-blind trials.

In an emergency, your doctor can find out this information from the trial co-ordinators or the pharmacy department at the hospital.

Blind trials or double-blind trials aim to reduce any bias. For example, knowing you are having a new treatment might make you feel more positive or negative. This could influence what you report to the researchers. Also, your doctor may judge your response differently if they know you are having a treatment that they feel positive about.

Making sure a clinical trial is safe

Understandably, anyone who joins a clinical trial wants to know it is safe for them. There are different ways that people are protected before and during a trial.

Ethics committees

All research in the UK involving people must be approved by an ethics committee who review the trial plan (protocol).

An ethics committee is a group that protects the rights, interests and well-being of the people taking part in the trial. They put this at the centre of their decision-making. The ethics committee is independent of the trial sponsors, funders and investigators.

They look at each research suggestion (proposal). Then they give an opinion about the trial and whether the research is ethical.

An ethics committee makes sure that:

- the trial is well planned
- the likely benefits are greater than the possible risks
- people are recruited to the trial correctly
- information about the trial is clear and accurate.

An ethics committee includes a mix of health professionals and non-medical people. This can include patients, lawyers and members of the public. Having non-medical people is important, as they can look at the trial from a different point of view.

Patient involvement

Patients and members of the public are becoming more involved with trial research teams. They bring the patient's point of view of the illness and treatment. This helps researchers understand why people might want to take part in a trial and what might put them off.

Patients and members of the public can also suggest new areas for research. And they can help write information about clinical trials for the public.

Data monitoring committees (DMCs)

Before a trial starts, a DMC is usually set up. The DMC:

- oversee how the trial is designed
- monitor people's safety
- monitor the effectiveness of the treatment during the trial.

If the DMC are concerned that a new drug or treatment is causing harm, they can work with the research ethics committee to stop a trial. For example, they could stop a trial if people are having severe side effects. This is unlikely to happen in phase 3 or 4 trials, because researchers test new drugs or treatments well during phases 1 and 2.

The DMC will also stop trials early if the results from the new treatment are looking much better than standard treatment. This means doctors can start using the new treatment instead of the standard treatment. People sometimes move from the control group to the new treatment group, so everyone in the trial can benefit from it.

Medicines and Healthcare products Regulatory Agency (MHRA)

The MHRA is a government body that makes sure trials meet standards of good practice to protect the people taking part. The MHRA must give approval for all trials before they can start. It continues to monitor trials for as long as they last.

It can also make changes to the trial plan (protocol) and interrupt or end the trial in some circumstances. Researchers must report all serious side effects from a trial treatment to the MHRA. Then this is reviewed.

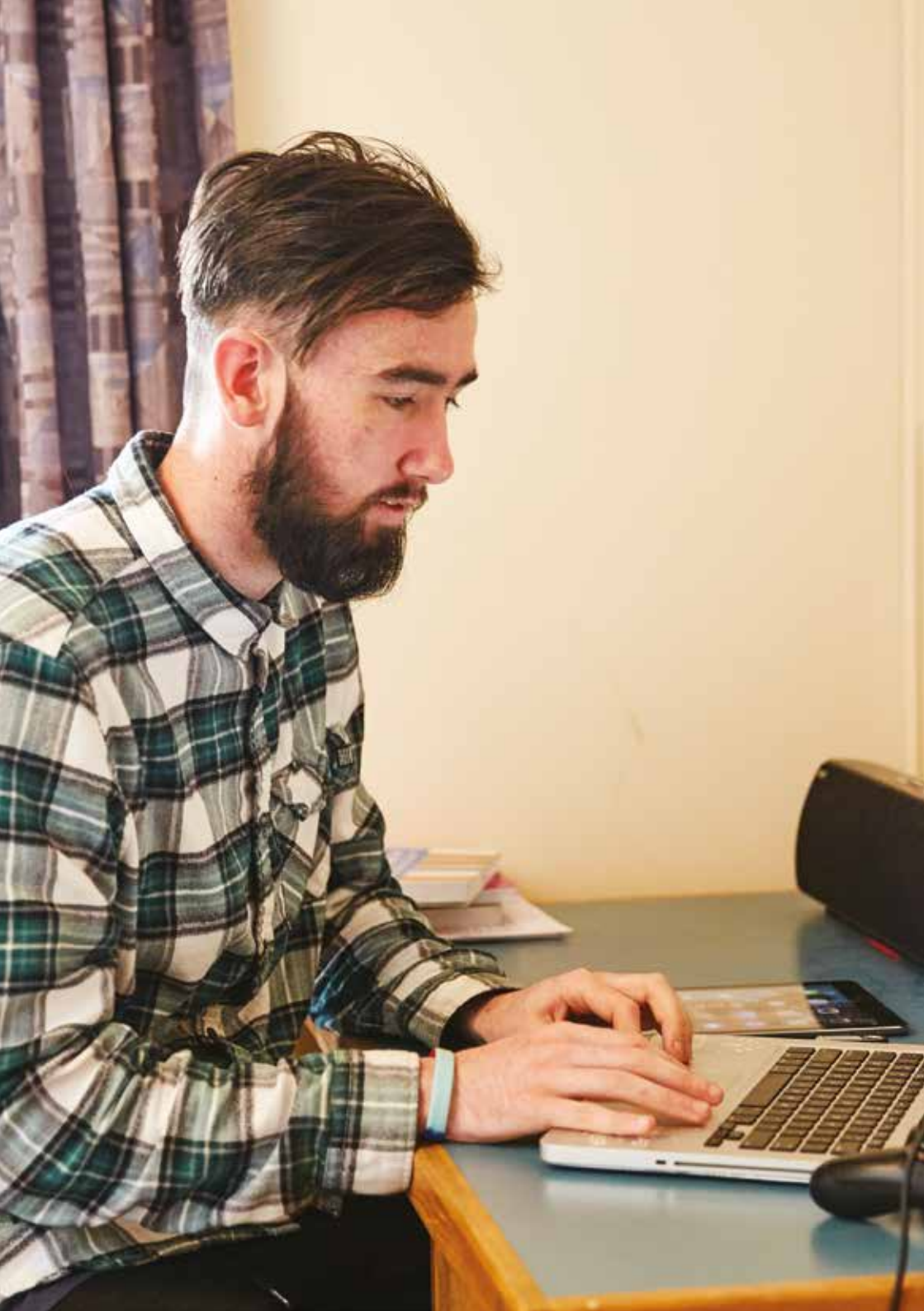
Insurance

All trials must have insurance. There are different arrangements for this, depending on who is running the trial. Research ethics committees will not approve trials where there is no insurance or compensation, if it is needed. All trials have a legal sponsor to make sure there are arrangements (such as insurance) to protect people taking part.

Drug companies who are funding trials are insured. If a drug harms someone taking part in the trial, compensation can be paid. Some drugs may cause unpleasant side effects, but it is rare for a drug to seriously harm anyone in a trial.

Trials that are funded by other organisations (not by drug companies) will pay compensation for any serious injury caused. This follows guidelines set by the **Association of the British Pharmaceutical Industry** (ABPI).

Individual NHS trusts are responsible for insuring themselves against any possible harm that local trials cause.



WHERE CAN I FIND OUT MORE?

Finding out about trial results

Trial results

It may take many years to get the results of a trial. This is because hundreds and sometimes thousands of people need to take part in a trial to show the difference between treatments.

Some trials look at how much longer people live after treatment (survival). For these trials, researchers need to monitor people for 5 years, 10 years or even longer. They continue to collect this information during this time.

The information is collected from the hospital, GPs' records or national records. They remove names, so individual people are never identified in the study results.

Understanding trial results

Researchers need to collect information to help them decide which treatment is safest and most effective. Researchers call this the outcome or end-point of the trial.

In a phase 2 trial, the first outcome that researchers look for is how effective the treatment has been in treating the cancer.

When most cancers stop growing, shrink or disappear, doctors call this a response. Doctors use different words to describe your response to treatment:

- A **complete response** means all signs of the cancer that can be seen through tests have disappeared for at least 4 weeks.
- A **partial response** means the cancer has shrunk by at least 30% for at least 4 weeks. There are no signs that it has grown anywhere else in the body.
- **Stable disease** means the cancer has shrunk by less than 30%. There are no signs that it has grown anywhere else in the body.

A complete response is a good result, but it does not always mean a cure. It takes several years with no signs of the cancer returning (recurrence) before doctors consider it cured. It also depends on the type of cancer.

Finding out results

Researchers publish the results of most clinical trials in medical journals. But they may not publish the final report until years after giving the treatment. Sometimes results are reported in newspapers or discussed on TV or radio. This is usually after the results have been presented at a medical conference or published in medical journals.

Generally, the best way to find out results is to ask your specialist. But nowadays, more patients are being contacted directly when results of trials are available.

Finding out about on-going trials

Your specialist doctor or nurse can tell you about trials that may be suitable for you and give you advice. You can also talk to one of our cancer support specialists on **0808 808 00 00** for information about on-going trials in the UK. You can search for trials in the UK on websites such as:

- Cancer Research UK (see page 53)
- UK Clinical Trials Gateway **www.ukctg.nihr.ac.uk.**

Trials abroad

It is sometimes possible to take part in a trial in a country outside the UK. This might mean you need to pay for the treatment as well as travel costs, which can be expensive. Try to get as much information as possible about the trial from trustworthy sources and websites.

Trials that happen abroad may not be regulated in the same strict way as trials in the UK.

It is a good idea to be cautious of trials that are run by small clinics rather than research hospitals. Be careful to avoid trials that offer 'miracle cures'. These are unlikely to help you and they are often expensive.

You can search for trials abroad on websites such as the US website National Cancer Institute (see page 55). This website also lists UK trials.

Future research

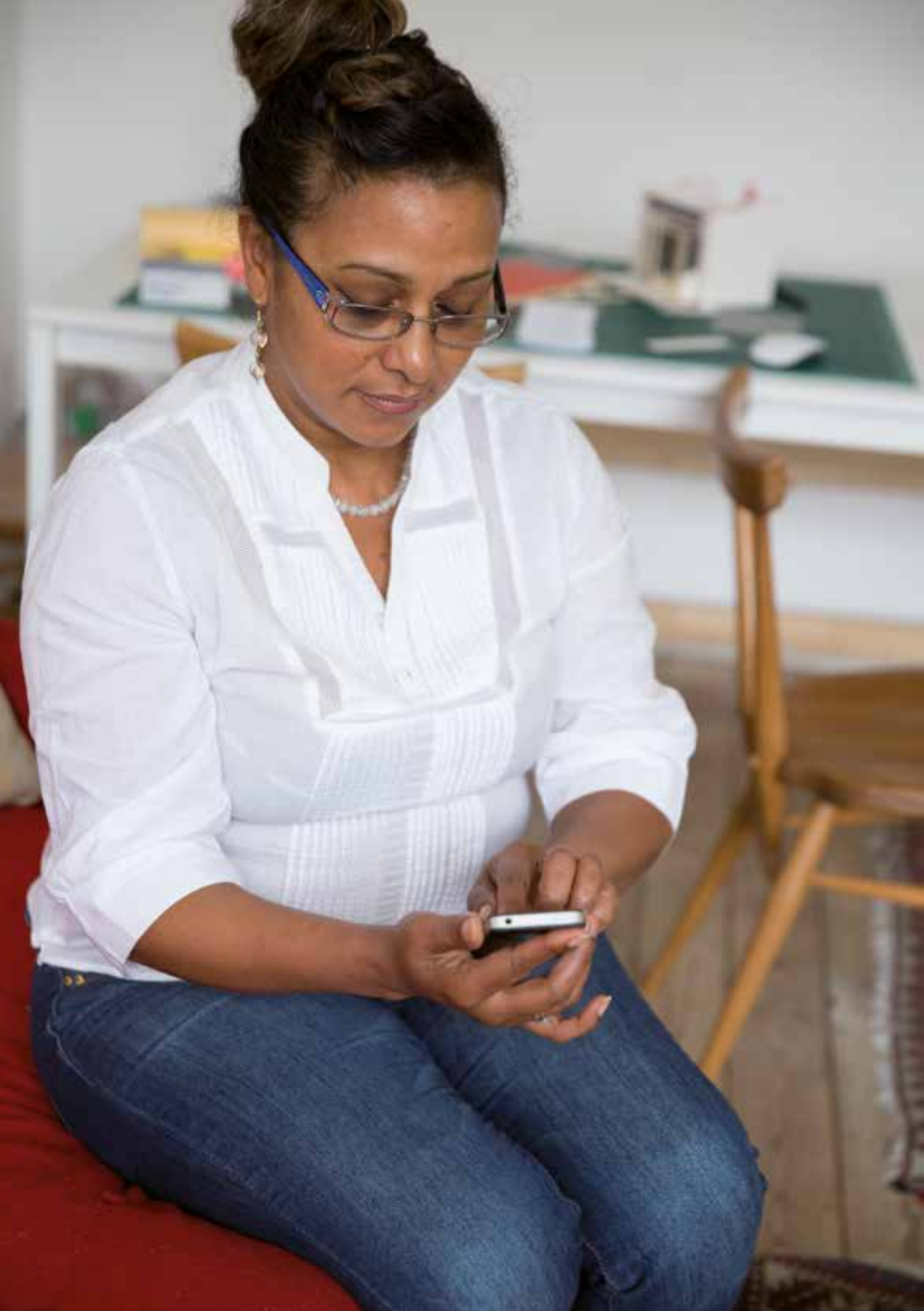
Researchers set up new trials all the time. Some of the organisations that set up trials include:

- the government-funded Medical Research Council (MRC)
- the National Cancer Research Institute (NCRI)
- charities, such as Cancer Research UK
- international organisations
- drug companies.

You can find the contact information for some of these organisations in the **Other Useful Organisations** section of this booklet (pages 53 to 57).

Many of these organisations have patient groups that help choose areas that need further research. Cancer specialists know there are gaps in their understanding in areas such as diagnosing and treating cancer. But patients, their families and friends have views on other areas of their care that need more research. If you have any thoughts about research that might be useful, talk to your doctor or nurse.

The organisation INVOLVE has information and advice about how you can get involved with research (see page 54).



FURTHER INFORMATION

About our information

We provide expert, up-to-date information about cancer. And all our information is free for everyone.

Order what you need

You may want to order more leaflets or booklets like this one. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

We have booklets on different cancer types, treatments and side effects. We also have information about work, financial issues, diet, life after cancer and information for carers, family and friends.

Online information

All of our information is also available at **macmillan.org.uk/information-and-support** There you'll also find videos featuring real-life stories from people affected by cancer, and information from health and social care professionals.

Other formats

We also provide information in different languages and formats, including:

- audiobooks
- Braille
- British Sign Language
- easy read booklets
- eBooks
- large print
- translations.

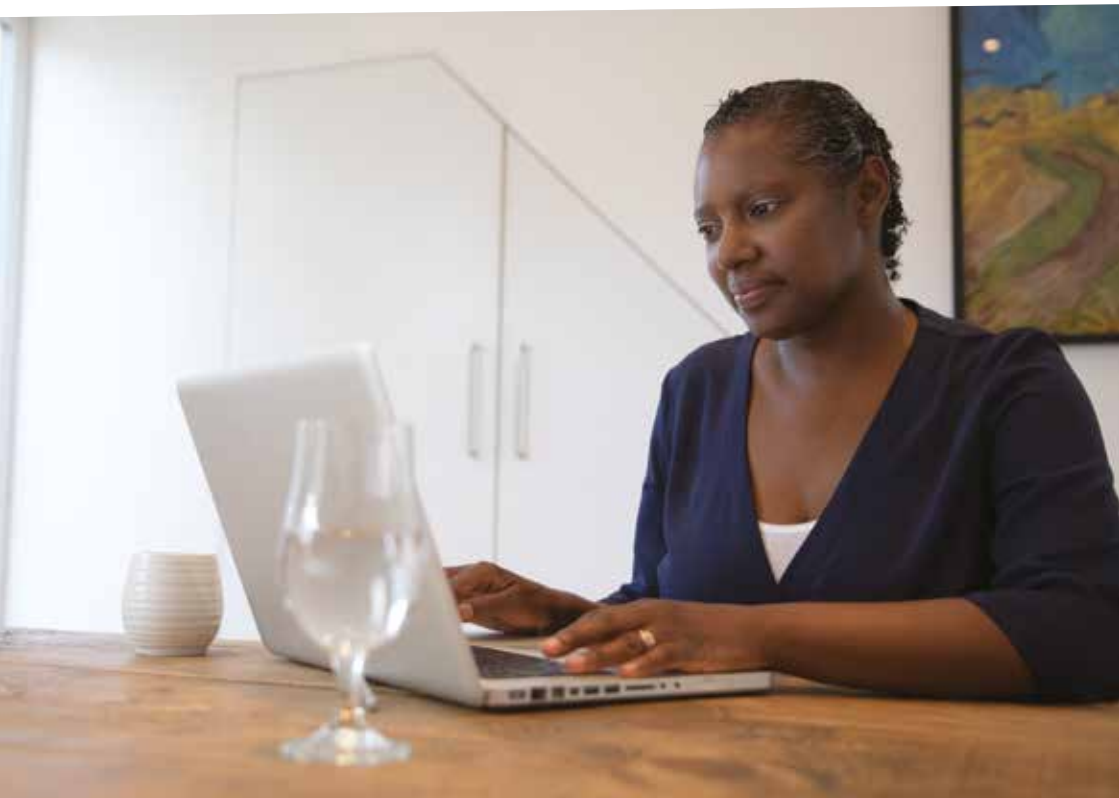
Find out more at **macmillan.org.uk/otherformats** If you'd like us to produce information in a different format for you, email us at **cancerinformationteam@macmillan.org.uk** or call us on **0808 808 00 00**.

Help us improve our information

We know that the people who use our information are the real experts. That's why we always involve them in our work. If you've been affected by cancer, you can help us improve our information.

We give you the chance to comment on a variety of information including booklets, leaflets and fact sheets.

If you'd like to hear more about becoming a reviewer, email **reviewing@macmillan.org.uk** You can get involved from home whenever you like, and we don't ask for any special skills – just an interest in our cancer information.



Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we're here to support you.

Talk to us

If you or someone you know is affected by cancer, talking about how you feel and sharing your concerns can really help.

Macmillan Support Line
Our free, confidential phone line is open Monday to Friday, 9am to 8pm. Our cancer support specialists can:

- help with any medical questions you have about cancer or your treatment
- help you access benefits and give you financial guidance
- be there to listen if you need someone to talk to
- tell you about services that can help you in your area.

Call us on **0808 808 00 00** or email us via our website, **macmillan.org.uk/talktous**

Information centres
Our information and support centres are based in hospitals, libraries and mobile centres. There, you can speak with someone face to face.

Visit one to get the information you need, or if you'd like a private chat, most centres have a room where you can speak with someone alone and in confidence.

Find your nearest centre at **macmillan.org.uk/informationcentres** or call us on **0808 808 00 00**.

Talk to others

No one knows more about the impact cancer can have on your life than those who have been through it themselves. That's why we help to bring people together in their communities and online.

Support groups

Whether you are someone living with cancer or a carer, we can help you find support in your local area, so you can speak face to face with people who understand. Find out about support groups in your area by calling us or by visiting **macmillan.org.uk/selfhelpandsupport**

Online Community

Thousands of people use our Online Community to make friends, blog about their experiences and join groups to meet other people going through the same things. You can access it any time of day or night. Share your experiences, ask questions, or just read through people's posts at **macmillan.org.uk/community**

The Macmillan healthcare team

Our nurses, doctors and other health and social care professionals give expert care and support to individuals and their families. Call us or ask your GP, consultant, district nurse or hospital ward sister if there are any Macmillan professionals near you.

'Everyone is so supportive on the Online Community, they know exactly what you're going through. It can be fun too. It's not all just chats about cancer.'

Mal

Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you've been affected in this way, we can help.

Financial guidance

Our financial team can give you guidance on mortgages, pensions, insurance, borrowing and savings.

Help accessing benefits

Our benefits advisers can offer advice and information on benefits, tax credits, grants and loans. They can help you work out what financial help you could be entitled to. They can also help you complete your forms and apply for benefits.

Macmillan Grants

Macmillan offers one-off payments to people with cancer. A grant can be for anything from heating bills or extra clothing to a much-needed break.
Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants.

We can also tell you about benefits advisers in your area. Visit **macmillan.org.uk/financialsupport** to find out more about how we can help you with your finances.

Help with work and cancer

Whether you're an employee, a carer, an employer or are self-employed, we can provide support and information to help you manage cancer at work. Visit **macmillan.org.uk/work**

My Organiser app

Our free mobile app can help you manage your treatment, from appointment times and contact details, to reminders for when to take your medication. Search 'My Organiser' on the Apple App Store or Google Play on your phone.

Other useful organisations

There are lots of other organisations that can give you information or support.

Finding a clinical trial

Association of the British Pharmaceutical Industry (ABPI)
Tel 020 7930 3477
www.abpi.org.uk
Brings life-saving and life-enhancing medicines to patients. ABPI represent companies who supply more than 80 per cent of all branded medicines used by the NHS. These companies are researching and developing the majority of the current medicines pipeline, ensuring that the UK remains at the forefront of helping patients prevent and overcome diseases.

Cancer Research UK
Tel 0808 800 40 40 (Mon–Fri, 9am–5pm)
www.cancerresearchuk.org/about-cancer/find-a-clinical-trial
The world's leading independent organisation dedicated to cancer research. Supports research into all aspects of cancer. Its website contains information on how trials are conducted, and you can search a database of trials currently recruiting cancer patients in the UK.

European Medicines Agency

Tel 020 3660 6000
www.ema.europa.eu/ema
The European Medicines Agency (EMA) is a decentralised agency of the European Union (EU). The Agency is responsible for the scientific evaluation, supervision and safety monitoring of medicines in the EU. EMA protects public and animal health in 28 EU Member States, as well as the countries of the European Economic Area, by ensuring that all medicines available on the EU market are safe, effective and of high quality.

Gov.uk

www.gov.uk/government/collections/clinical-trials-for-medicines
Clinical trials for medicines.

Involve

Tel 023 8059 5628
Email involve@nihr.ac.uk
www.invo.org.uk
INVOLVE is part of, and funded by, the National Institute for Health Research, to support active public involvement in NHS, public health and social care research. As a national advisory group their role is to bring together expertise, insight and experience in the field of public involvement in research, with the aim of advancing it as an essential part of the process by which research is identified, prioritised, designed, conducted and disseminated.

Medical Research Council

Tel 01793 416200
Email corporate@headoffice.mrc.ac.uk
mrc.ukri.org
The Medical Research Council funds research across the biomedical spectrum, from fundamental lab-based science to clinical trials, and in all major disease areas.

National Cancer Institute (NCI)

www.cancer.gov/clinicaltrials
Part of the National Institutes of Health (NIH), which is one of 11 agencies that compose the Department of Health and Human Services (HHS) in the United States. The 'Find a clinical trial' database has details of open cancer trials, providing details of trials in the UK and many other countries.

General cancer support organisations

Cancer Black Care

Tel 020 8961 4151
Email
info@cancerblackcare.org.uk
www.cancerblackcare.org.uk
Offers UK-wide information and support for people with cancer, as well as their friends, carers and families, with a focus on those from BME communities.

Cancer Focus Northern Ireland

Helpline 0800 783 3339
(Mon to Fri, 9am to 1pm)
Email
nurseline@cancerfocusni.org
www.cancerfocusni.org
Offers a variety of services to people affected by cancer in Northern Ireland, including a free helpline, counselling and links to local support groups.

Cancer Support Scotland

Tel 0800 652 4531
(Mon to Fri, 9am to 5pm)
Email
info@cancersupportscotland.org
www.cancersupportscotland.org
Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

Maggie's Centres
Tel 0300 123 1801
Email
enquiries@maggiescentres.org
www.maggiescentres.org
Has a network of centres in various locations throughout the UK. Provides free information about cancer and financial benefits. Also offers emotional and social support to people with cancer, their family, and friends.

Teenage Cancer Trust
Tel 0207 612 0370
(Mon to Fri, 9am to 5.30pm)
Email
hello@teenagecancertrust.org
www.teenagecancertrust.org
A UK-wide charity devoted to improving the lives of teenagers and young adults with cancer. Runs a support network for young people with cancer, their friends and families.

Tenovus
Helpline 0808 808 1010
(Daily, 8am to 8pm)
Email
info@tenovuscancercare.org.uk
www.tenovuscancercare.org.uk
Aims to help everyone in the UK get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, benefits advice and an online 'Ask the nurse' service.

Cancer registries

The cancer registry
A national database that collects information on cancer diagnoses and treatment. This information helps the NHS and other organisations plan and improve health and care services. There is one in each country in the UK:

You can search for more organisations on our website at **macmillan.org.uk/organisations** or call us on **0808 808 00 00**.

National Cancer Registration and Analysis Service

Tel 020 7654 8000
Email enquiries@phe.gov.uk
www.ncras.nhs.uk
Tel (Ireland) 021 4318 014
www.ncri.ie

Scottish Cancer Registry

Tel 0131 275 7050
Email nss.csd@nhs.net
www.isdscotland.org/health-topics/cancer/scottish-cancer-registry

Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Tel 0292 037 3500
Email general.enquiries@wales.nhs.uk
www.wcisu.wales.nhs.uk

Northern Ireland Cancer Registry

Tel 0289 097 6028
Email nicr@qub.ac.uk
www.qub.ac.uk/nicr

Counselling and emotional support

British Association for Counselling and Psychotherapy (BACP)

Tel 01455 883 300
Email bacp@bacp.co.uk
www.bacp.co.uk
Promotes awareness of counselling and signposts people to appropriate services across the UK. You can search for a qualified counsellor at **itsgoodtotalk.org.uk**

LGBT-specific support

LGBT Foundation

Tel 0345 330 3030
(Mon to Fri, 10am to 6pm)
Email helpline@lgbt.foundation
www.lgbt.foundation
Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.

Disclaimer

We make every effort to ensure that the information we provide is accurate and up to date but it should not be relied upon as a substitute for specialist professional advice tailored to your situation. So far as is permitted by law, Macmillan does not accept liability in relation to the use of any information contained in this publication, or third-party information or websites included or referred to in it. Some photos are of models.

Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by our Chief Medical Editor, Prof Tim Iveson, Consultant Medical Oncologist.

With thanks to: Dan Collins Senior Pharmacist Haematology; Jac Samuel, Senior Research Nurse, Cancer Research UK; Kelly Leonard, Lead Urology Research Nurse; Dr Rhona McMenemin, Consultant Clinical Oncologist; and the people affected by cancer who reviewed this edition.

We welcome feedback on our information. If you have any, please contact **cancerinformationteam@macmillan.org.uk**

Sources

We've listed a sample of the sources used in this publication below. If you'd like further information about the sources we use, please contact us at **cancerinformationteam@macmillan.org.uk**

Gillies et al.: Making a decision about trial participation: the feasibility of measuring deliberation during the informed consent process for clinical trials. Trials. 2014. 15:307.
Good Research Practice. July 2012. Medical Research Council (MRC).
Guidelines for Phase 1 Clinical Trials. 2012. Association of the British Pharmaceutical Industry (APBI).

Can you do something to help?

We hope this booklet has been useful to you. It's just one of our many publications that are available free to anyone affected by cancer. They're produced by our cancer information specialists who, along with our nurses, benefits advisers, campaigners and volunteers, are part of the Macmillan team. When people are facing the toughest fight of their lives, we're there to support them every step of the way.

We want to make sure no one has to go through cancer alone, so we need more people to help us. When the time is right for you, here are some ways in which you can become a part of our team.

Share your cancer experience
Support people living with cancer by telling your story, online, in the media or face to face.

Campaign for change
We need your help to make sure everyone gets the right support. Take an action, big or small, for better cancer care.

Help someone in your community
A lift to an appointment. Help with the shopping. Or just a cup of tea and a chat. Could you lend a hand?

Raise money
Whatever you like doing you can raise money to help. Take part in one of our events or create your own.

Give money
Big or small, every penny helps. To make a one-off donation see over.

Call us to find out more

0300 1000 200

macmillan.org.uk/getinvolved

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £

(Please delete as appropriate)
I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support

OR debit my:
Visa / MasterCard / CAF Charity Card / Switch / Maestro

Card number

Valid from

Expiry date

Issue no

Security number

Signature

Date / /

Don't let the taxman keep your money

Do you pay tax? If so, your gift will be worth 25% more to us – at no extra cost to you. All you have to do is tick the box below, and the tax office will give 25p for every pound you give.

☐ I am a UK tax payer and I would like Macmillan Cancer Support to treat all donations I make or have made to Macmillan Cancer Support in the last 4 years as Gift Aid donations, until I notify you otherwise.

I understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference. I understand Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.

Macmillan Cancer Support and our trading companies would like to hold your details in order to contact you about our fundraising, campaigning and services for people affected by cancer. If you would prefer us not to use your details in this way please tick this box. ☐

In order to carry out our work we may need to pass your details to agents or partners who act on our behalf.

Registered with FUNDRAISING REGULATOR

If you'd rather donate online go to macmillan.org.uk/donate

Please cut out this form and return it in an envelope (no stamp required) to: Supporter Donations, Macmillan Cancer Support, FREEPOST LON15851, 89 Albert Embankment, London SE1 7UQ

This booklet is about cancer research trials (or clinical trials). It is for anyone who is thinking about taking part in a clinical trial.

The booklet explains how doctors need clinical trials to find new and better ways to treat cancer. Trials can also look at other areas, such as ways of improving your well-being, or better ways of diagnosing or preventing cancer.

We're here to help everyone with cancer live life as fully as they can, providing physical, financial and emotional support. So whatever cancer throws your way, we're right there with you. For information, support or just someone to talk to, call 0808 808 00 00 (7 days a week, 8am to 8pm) or visit macmillan.org.uk

Would you prefer to speak to us in another language? Interpreters are available. Please tell us in English the language you would like to use. Are you deaf or hard of hearing? Call us using NGT (Text Relay) on 18001 0808 808 00 00, or use the NGT Lite app.

Need information in different languages or formats? We produce information in audio, eBooks, easy read, Braille, large print and translations. To order these, visit macmillan.org.uk/otherformats or call our support line.

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