The ROYAL MARSDEN
NHS Foundation Trust

Clinical trials

Your questions answered

Patient Information

NHS

Contents

Introduction

When you first attend The Royal Marsden, or at some time while you are receiving treatment, you may be asked to take part in a clinical trial or a research programme. For the purpose of this booklet, we will focus on patients involved in clinical trials (please see page 2 for further details).

Clinical trials are medical research studies involving people. The purpose of clinical trials includes looking for better treatments or better ways to prevent, screen or diagnose a disease such as cancer.

If you are asked to take part in a clinical trial, you need to be given enough information to help you make up your mind as to whether or not to participate. Taking part in a clinical trial is completely voluntary. Clinical trials follow strict scientific and ethical rules to protect patients. Please discuss any questions or concerns you have with your doctor or research nurse. We do not want you to feel that you are under any pressure to take part in a clinical trial and you may find it helpful to talk through the trial with someone who is not directly involved in your clinical care. For example, with someone from a cancer information and support centre (see page 22 for details of how to find a local centre).

The aim of this booklet is to explain:

- What clinical trials are
- Why they are needed
- How you can help
- How taking part in a trial may benefit you or future patients.

After reading this booklet, please think carefully about whether you would like to enter a clinical trial if you are invited to do so.

What is a clinical trial?

A clinical trial is a carefully designed investigation of the effects of a test or treatment, for example:

Tests

- Screening – to find ways for detecting cancer at an earlier stage.
- Diagnosing cancer – looking at new tests or scans that can help detect cancer in a better way.

Treatments

- Treatment with new drugs or combinations of drugs, or new ways of giving drug treatments, surgery or radiotherapy.
- A new treatment may be compared with an older and more accepted treatment to find out which works better.
- Looking at ways to improve the delivery of treatment, for example, comparing how frequently drugs are given once a week or once a month.
- Monitoring the progress of treatment.

Supportive care

- Controlling symptoms, such as pain, nausea or shortness of breath. For example, a trial may look at new drugs or complementary therapies.
- The researcher may want to discover how best to provide support by finding out how treatment affects your everyday life and activities. Quality of Life questionnaires are sometimes used.

Preventing cancer

- These trials are conducted with people who have not had cancer. For example, they may look at drugs, vitamins and foods to reduce risk.

Genetics

- Research in genetics helps us understand more about the role genes play in cancer development and progression. It also:

– Identifies genes that predispose people to developing cancer and use this information to target screening and prevention measures

– Identifies genetic pathways in order to selectively target treatments

– Helps us explore the psychological and social impact of receiving genetic risk information.

Tissue research

Medical research depends on the use of samples of human biological material. This material often provides the best way of studying human biology and human disease including cancer. Material for research may be from healthy people or from patients. Researchers may ask volunteers to donate material (for example, blood samples) specifically for research, or may use material left over after diagnostic testing or surgery. Samples stored for one purpose may later prove useful for research that was not obvious at the time the samples were taken.

Why are clinical trials important?

Clinical trials are necessary to extend knowledge and improve current treatment and care, now and for future patients. Our examples are taken from cancer care but the same principles apply to all clinical trials. Doctors use the results of earlier clinical trials when they advise you, so you and other patients benefit from past trials. However, your doctor's main priority will be to offer you the best treatment for your situation.

Who is in the research team?

The research team includes a number of different people and you will probably meet the following:

- Consultant clinician
- Specialist registrars
- Research nurses.

The team may also include research fellows (scientists), data administrators and clinical trial co-ordinators, although you may not meet any of these team members.

During a clinical trial, you will be given the name of a designated person within your research team that you are likely to have the most contact with. Most often this will be the research nurse but it differs depending on where your treatment is being given. Their role is to co-ordinate your care while you are on the trial. This includes organising investigations and taking blood samples. They will provide you with information about the trial and answer any questions you may have. They are there to support both you and your family. Depending on the type of trial you take part in, they may also give drug treatments.

How is a clinical trial planned?

Ideas for a clinical trial come from researchers, usually doctors, nurses and other specialists, as well as drug companies. They will produce a full, detailed plan for the trial, which is called a protocol.

A protocol gives the reasons for doing the research and is carefully designed to safeguard the health of the participants. It should include the following information:

- The background to the trial and why it should be done
- Details as to how the study will be carried out, including the numbers of patients needed and which patients can be included
- Details of the procedure or treatments to be given

- What tests the patients will have and when
- Details about how, when and what information will be collected
- Details of how the results will be analysed.

When planning a clinical trial, researchers must follow certain rules. Firstly, each trial protocol is put forward for 'independent scientific review' by people who are suitably qualified to assess it. For example, they will want to check that it is likely to produce accurate results which help to answer a research question. These results must be reliable so they can be used in the future.

Secondly, the research must be ethical. In order to check this, the protocol is reviewed by a Research Ethics Committee (REC).

Thirdly, as far as possible, any foreseeable risks must be no greater then the risks of the present treatment or illness.

What is the Research Ethics Committee (REC)?

Clinical trials are carefully regulated by research ethics committees. To meet legal requirements, every researcher planning a clinical trial must have access to a Research Ethics Committee (REC) from which it must seek advice about all research protocols.

The REC is there to provide an effective safeguard for patients and to judge the wisdom and relevance of each project. No clinical trial can be undertaken without the approval of the REC.

The REC is made up of doctors, scientists, nurses and non-medical people, such as lawyers and members of the public.

If a trial is thought to be inappropriate or unethical, approval will not be given and the research will not be allowed to go ahead. The REC can ask for changes to the trial in order for it to be approved. Once a trial has been approved, the researcher must then ask permission before any changes are introduced during the conduct of the trial. The REC is there to look after the safety and wellbeing of patients within a study. The research team will report unexpected side-effects of the treatment or medication to the REC.

At the end of the trial the REC will require a summary of results, including any problems such as difficulty recruiting patients to the study. The REC may also ask to review any articles based on the results of the trial before they are published.

The REC requires the researcher in charge of the trial or their representative, to explain the project to you and to obtain your consent before including you in the study.

How do I decide whether or not to take part in a clinical trial?

You need to feel you have been given enough information to help you decide whether or not to take part in a clinical trial.

The main benefits of taking part in a clinical trial may include:

- Receiving a new treatment before it becomes widely available
- Being closely monitored
- Receiving more information on treatment and side effects
- Helping future patients with cancer.

The disadvantages of taking part in a clinical trial may include:

- Having more appointments at the hospital than if you were not on a clinical trial.
- Having side effects or risks that doctors were not expecting.
- Participants in randomised trials (see page 12) will not be able to choose which treatment they receive.
- A delay in receiving medication. The preparation and dispensing of clinical trial prescriptions is a more complicated and time consuming process than preparing and dispensing any regular medicine, so there may on occasions be a slight delay when treatment is to be delivered to the outpatient or ward areas.

Trials need to be a team effort to make sure they are successful. If you decide to take part, you will become an essential member of the team. You must be given all the information you ask for, you

must understand what will happen, and you must freely agree to take part.

Your doctor or researcher should discuss the following points with you:

- What type of trial it is, why it is being done and how it was planned
- How the research affects you; for example how long the trial will last, or any extra tests or hospital visits that will be required
- The meaning of the words and terms that are used
- The benefits, risks and all other treatment options available to you
- The safeguards which exist to protect you
- Who you should contact if you have any concerns or problems
- How to find out the results of the research, if you wish to do so.

There may be other questions you want to ask and you can find a section on frequently asked questions on page 14.

You may find it helpful to discuss the details of a trial with a research nurse. If you wish to know more or do not understand what has been said, please ask.

What does 'giving consent' mean?

Consent is your freely given agreement to what treatment is proposed, based on a full understanding of what is going to happen.

Your consent is needed for every procedure or act of care performed by doctors, nurses or other staff. Often this may be implied; for example you roll up your sleeve so that someone can take your blood pressure. Consent may also be verbal, such as, saying 'yes' when asked if you agree to a blood test. You may have been asked for your written consent by signing a consent form before an investigation, treatment or an operation.

Consent to research is often called informed consent. Before you can

give your consent, researchers are required to:

- Explain the trial to you and provide you with information in writing – a patient information sheet. This should include information about what the treatment is likely to involve and the benefits and risks. Your doctor should also discuss with you, any available alternative treatments. There should be an opportunity to discuss this information. You should be given a copy of the information sheet to keep and refer to later, as necessary.
- Ensure that you understand the information you have been given – please ask questions if you do not understand something or if you would like more information.
- Help you think about what you want to ask your doctor. You may find the frequently asked questions in this booklet helpful (see page 14).
- Give you time to think about joining a study, to talk with your family or friends, your GP or another independent doctor, and to ask questions of the researcher.
- Check with you that you understand what has been said.

The decision to take part in a trial, or not, is yours. You may say no, or ask for more time to think about it. If you decide to enter a trial, you must give your consent freely and feel that all your concerns and questions have been satisfied. Whatever you decide, you will be given the best and most appropriate treatment and care.

The consent form

The researcher will record on a special form, known as a consent form, that they have explained the study to you. You will be asked to sign this form to show that you have given your consent. A witness may also need to sign the form to confirm this.

You should read the form carefully before signing it and you will be given a copy for reference. Signing a consent form does not affect your legal rights; it is a record that you agreed to what has been explained to you. A copy of your signed consent form will be kept in your clinical notes and may be scanned to your hospital electronic patient record.

Your family doctor will be told of your participation, if appropriate.

Occasionally, you may be asked to give verbal consent to take part in a research project. In this case, your agreement will be recorded in your medical notes by the researcher and confirmed by a witness.

How long will I have to make up my mind about treatment?

This may depend on the particular trial. Ask your doctor how long you can take to make up your mind. It is important to remember that once you have made a decision about treatment, you can change your mind at any time, even after you have signed a consent form.

What if I change my mind?

After you start receiving treatment or care according to the research protocol, you may decide you no longer wish to continue in the trial. You can withdraw your consent to take part in a trial at any time and you do not have to give a reason. The researcher will discuss your future treatment and care with you.

What if I say ‘no’?

If you decide that you do not wish to take part in the trial, please tell the researcher. Your wish will be respected and the decision not to take part will not affect your care in any way. You will be given the best and most appropriate treatment whatever you decide to do.

What types of clinical trials are there?

This section tells you about some types of trials that may be used to introduce a new treatment into everyday practice. Not all the information will be relevant to you, so please ask your doctor or researcher, what type of trial you are being asked to take part in.

Some of the procedures may appear to be complicated. However, it is only by doing trials in a particular way that we can produce results that are reliable, valuable to future patients, and at the same time protect you.

Extensive laboratory tests will have been carried out before any new anti-cancer treatment drug is introduced into a clinical trial. These will have proved that the drug can kill cancer cells and help to find out the possible side effects.

The next step is to learn what is the most effective dose that can be given safely to patients. This is called a Phase I study.

Phase I studies

Phase I clinical trials are the first stage of testing in humans. Normally, a small group of 20-100 healthy volunteers will be recruited (except in the circumstances described below). This phase is designed to assess the safety, tolerability, and metabolism of a drug. These trials are often conducted in a Drug Development Unit, where the person can be observed by staff until the drug has passed through the person's body. Phase I clinical trials normally involve increasing the dose. This is to find the best and safest dose and to learn when it is becoming too harmful for the person because of the side-effects. Phase I clinical trials most often include healthy volunteers. However, there are some trials in cancer units or hospitals when patients volunteer. These patients have tried existing standard treatments and these are not as effective anymore. Patients receive 24-hour medical attention when participating in a Phase I clinical trial and are monitored closely.

A Phase I study is designed to find out:

- What is the most effective dose of the drug and how much can be given safely. For example, the maximum acceptable dose and how often the drug can be given.
- Whether enough of the drug is circulating in the blood to kill cancer cells.
- How the body copes with the drug.
- The possible side effects of the drug.

There are two issues to consider in this type of study. Firstly, patients treated at the lowest dose may not benefit significantly from the new drug. Secondly, patients treated later at, or near, the maximum dose may have more side effects. Doctors try to adjust the dose as quickly and safely as possible while avoiding any unnecessary side effects.

If it is thought that the new drug may be active against particular cancers, patients with those cancers will be selected for the trial. However, finding out which cancers respond best to the drug is the main aim of the Phase II study.

Phase II studies

Phase II clinical trials will be carried out on patients with different cancers so that the doctors can find out how active a particular drug is. Only about 20-30 patients with each type of cancer are needed to take part in this early work for each tumour type. They will be watched very carefully for the effects and side effects of treatment using regular checks-ups, blood tests, x-rays or scans. If the drug does not work, no more clinical trials will be carried out. However, if a significant number of responses are seen, a Phase III study will be designed.

Phase III studies

A Phase III study will try to compare a new treatment with the best treatment currently available and the patients are monitored to assess:

- The effect the treatment has on the cancer
- How long the effects last
- The side effects of the treatment
- Any possible long term problems which could develop.

If the differences between the new treatment and the existing treatment are small, hundreds of patients may need to take part before one treatment is identified as being better than the other. Several hospitals may be recruiting patients, and not just in the UK. Patients in Europe or America may also be recruited.

Phase III trials are usually randomised and may include a double blind procedure (see page 13).

How are clinical trials organised?

There are many ways of organising clinical trials but not all of these are used in cancer care. The most common terms are included here. If you hear other phrases which you do not understand, please ask your researcher to explain them.

A randomised trial

In a randomised trial, patients may receive either the best available treatment or a new type of treatment. To make sure that one treatment is not favoured over the other, the treatment each patient receives is decided by a process called randomisation. This means that the treatment is not chosen by the patient or their doctor but by a computer. There is usually an equal chance of receiving any one treatment. A computer will randomly allocate you to one of two possible methods of treatment. Your research team will discuss this with you further if you are to take part in this type of clinical trial.

A blind trial

In a blind trial, the patient does not know whether they are receiving the new treatment or the standard treatment. This is to avoid

influencing how the patient reports back to the researcher. The treatment that all the people in the trial are given will look the same whether it is the new treatment, standard treatment or a placebo (see below).

A double-blind trial

A double-blind trial means that neither the patient nor the hospital staff will know which treatment is being given. A special code is used and this is broken at the end of the trial to analyse the results. The advantage of the code is it prevents the staff from favouring a treatment when assessing the benefits or side effects.

The code is always available and can be broken to identify the treatment if it is thought to be necessary or in the patient's best interests.

A placebo controlled trial

A placebo is an inactive substance, such as sugar. It is made into a tablet or injection identical in size, shape and colour to a specific treatment. The patient will not know whether they are receiving the treatment or placebo (such as sugar). A placebo controlled trial may also be part of a double-blind clinical trial.

A proportion of patients will feel better even though their illness is not directly affected by the treatment they are given. This is known as the 'placebo effect'. It is thought that this happens because we believe a new tablet or injection must be making us better.

Placebo controlled trials will be clearly identified to you before your participation.

Frequently asked questions

Not all of these questions will be relevant to every trial but your designated contact person should be able to provide more specific answers and information if you require this. If you think of other questions you can make a note of them on page 22.

Many of the clinical trials taking place in cancer care involve new drugs, so we use the example of new drugs throughout the booklet.

What is known about the new treatment or procedure?

What is known about the trial treatment offered to you will vary, depending on the stage of development. When drugs have been recently developed there may not be very much information available but please ask if you would like further information. If several other trials have been carried out already, a more detailed explanation should be possible.

How is the treatment given?

The researcher will be able to tell you how treatment is to be given. This is decided when a protocol is drawn up. If any changes need to be made later, they will be made clear to you.

What are the possible side effects if I take part in a trial?

What your doctor, or research team will be able to tell you about side effects depends on how much the drug has been used. Some clinical trials are conducted specifically to find out about possible side effects. You should be told, as far as possible, what to expect. It is important that you report any symptoms or hospital admissions elsewhere, to your research team, nurse or doctor, as this may be due to your treatment.

Can I get pregnant/father a child while I am on a clinical trial?

If you are receiving a clinical trial drug treatment you will have to agree to use a barrier form of contraception for the duration of the

treatment and for a specified length of time once the treatment stops. Your research team will advise you on this further.

Can I take all my other medicines while I am on a clinical trial?

You will need to give the research team a list of all the medicines you are taking. These include prescribed, over-the-counter and complementary medicnes, as well as supplements. They will advise you if any need to be changed before you start any trial drug treatment.

What other treatments are available if I decide not to take part in this trial?

When you are invited to take part in research looking at treatment you will always be told what other treatments are available, along with the benefits and risks of these other treatments. Your research team will discuss this with you.

Will I need to attend hospital more often?

During a clinical trial, all participants are carefully monitored; therefore it is possible that you may find yourself attending more frequently. However, overall, many studies have shown that patients on clinical trials feel well supported because they are visiting the hospital more often for scans, and blood tests. Other patients find too many visits tiring, but the team will take this into account when planning your care.

You should be told how often you will need to visit the hospital and how long the visits may be. Extra visits may cost you time and money. Ask your research nurse if there is money available from research funds to cover your travel expenses.

If the clinical trial is not at a hospital near you, ask if you can attend your local hospital for any of the trial treatment. For example, you may be able to have a blood test locally.

How is the trial treatment different?

Your doctor will be able to explain to you what other treatments are available and the exact differences between those and the clinical trial being offered to you. Sometimes differences may be only slight but sometimes they may be quite big. Occasionally, there may not be an alternative treatment, for example if a drug or therapy is very new or if you have exhausted all known treatment options.

Will the treatment benefit me?

Each person can respond differently to treatment. It often takes time to find a therapy which suits you best and controls your cancer. This is also true with clinical trial treatments.

Your doctor may be able to tell you in general terms how many people appear to have benefitted from new drugs. The doctor will not offer you a treatment unless there is considered to be a benefit. If you do not respond to treatment, your doctor will withdraw you from the trial and discuss your future care with you.

Will I have any extra investigations or tests?

Your doctor may be able to find out how effective a new treatment is by using the same blood tests or scans that you would normally have. However, if the treatment is new, different side effects may occur and more tests may be needed. You will be told what these tests are and what they involve if they are required.

Will I be asked to take part in more than one trial?

A member of your research team may ask you to take part in another study which is running alongside a treatment trial. For example a new way of managing side effects of a treatment.

It is also quite common to study how treatments affect you, your everyday life and daily activities. These ‘quality of life’ studies may be part of a trial or form part of a separate project. Researchers may ask you to fill in a questionnaire or take part in an interview. Your participation in these studies is also completely voluntary. However, you should consider whether you are prepared to complete such

questionnaires regularly, as time and extra effort is involved.

If you have been in a clinical trial previously, you might like to ask the researcher how the current trial differs from the previous one.

Will my family doctor be informed?

Your hospital doctor or researcher are likely to contact your family doctor (GP) to tell them that you are taking part in a clinical trial. If specific details of your study do need to be passed on, the research team will discuss this with you. We encourage you to talk to your GP about taking part in a clinical trial if you feel this would be helpful.

What if I am worried about an unusual reaction?

If you are worried about an unusual reaction, or one which you have not been made aware of, please phone the research team straight away. Ask to speak to your research nurse or a doctor on call for that team, who will discuss what action should be taken. Likewise, if a symptom you have been told to expect does not occur, you may also be concerned. Again, please phone the research team.

What if new information becomes available?

Your doctor or researcher should inform you if any new information becomes available during the trial about the treatment/drug that is being studied. Your doctor will discuss with you whether you want to continue in the study. If you decide to withdraw, your doctor will make arrangements for your care to continue. If you decide to continue in the study, you may be asked to sign an updated consent form.

What happens when the research study stops?

Once the research study has stopped, your treatment plan will be discussed with you. However before you begin the trial, you may wish to discuss what treatment options may be available to you once the trial finishes.

What if something goes wrong?

During any treatment you will be observed very closely to make sure that your health is monitored. When you enter a clinical trial, the tests and checks on your health may need to be increased, and you will be asked to report anything unusual to your research team at, and in between your appointments. Any extra tests are to help safeguard you from any possible effects associated with the new treatment. Minimising the risk of side effects is one of the aims of all clinical trials.

If you have a serious reaction to a new or standard treatment, it will be stopped. Your research team will do all they can to make sure you do not suffer any lasting consequences. However, if something does occur, your medical team will look after you and make sure you receive the appropriate follow up care.

Who is organising and funding the research?

You may want to ask who is funding the trial.

Sometimes sponsors of a study will support a hospital department by funding the research so that patients can participate in a clinical trial.

Sponsors could include:

- An institution for example, the Institute of Cancer Research or Biomedical Research Centre (BRC)
- A charity for example, Cancer Research UK or Macmillan Cancer Support
- A pharmaceutical company.

What happens to information gathered for the trial?

All the records kept about you during the trial are kept confidential. However, data may be sent to a company or organisation sponsoring a study. Your records may also be inspected by national or international bodies who oversee clinical trials, to make sure a trial is being carried out correctly.

Any information which goes outside the hospital will be coded and so it will not be possible to identify you as an individual. Also, you will not be named in any articles when the trial results are published.

Can I find out the results of the trial?

Yes, you may ask your researcher about the progress of the results. Some trials are completed in weeks or months and these results are available quite quickly. Other trials are carried out over several years and it may be a long time before the final results are known. However, you may be able to find out how the trial is progressing.

Contact details

You will be given the names and contact details of the health care professionals to contact if you have any questions or concerns while you are taking part in the trial. If your concern or worry is out-of-hours (usually before 9am or after 5pm, during the weekend or bank holidays) then please call The Royal Marsden Macmillan Hotline (020 8915 6899).

Based on their assessment patients may require telephone advice only, early outpatient review or urgent hospital attendance for assessment/ admission. It is important when calling the hospital to have your hospital number available and any information from your research team available; especially about what clinical trial you are participating in, or what team you are under.

For patients who are part of a trial based on Oak Ward (sometimes called the Drug Development Unit or DDU) please either phone Oak Ward directly or call the Royal Marsden Macmillan Hotline (020 8915 6899).

Contact numbers

Hospital switchboards

Chelsea: 020 7352 8171

Sutton: 020 8642 6011

Your hospital doctors .....

Tel no:

Your research nurse .....

Tel no:

Your researcher .....

Tel no:

Conclusion

We hope this booklet has helped you to understand what clinical trials are and why they are necessary. Although it may have answered some of your questions, it may have suggested others that you wish to ask your doctor or researcher. You may find it helpful to write these down so that you do not forget them.

Only when all of your concerns have been answered should you make your decision. Remember your participation in a clinical trial is voluntary.

Please take as much time as you need to make your decision about taking part. Your doctors and nurses are here to help you. They need to know that you have been given enough information to make your decision. The patient always comes first in all clinical trials, which are designed to improve healthcare while minimising any risk to the patient.

The Royal Marsden Macmillan Hotline: 020 8915 6899

You can ring the hotline 24 hours a day, 7 days a week.

Call us straight away if you are feeling unwell or are worried about the side effects of cancer treatments.

This service provides specialist advice and support to all Royal Marsden patients, as well as to their carers, and both hospital and community-based doctors and nurses caring for Royal Marsden patients.

Notes/Questions

You may wish to use this space to make notes or write down questions as they occur to you, to discuss with your research nurse or doctor.

Sources of information and support

Biomedical Research Centre

The Royal Marsden's Biomedical Research Centre (BRC) is the UK's only BRC solely concerned with cancer. Our main aim is to drive pioneering research into the prevention, diagnosis and treatment of cancer and to translate advances in biomedical research into patient benefits. We support clinical trials and research within The Royal Marsden and our partner the Institute of Cancer Research. Our research benefits from patient and public involvement and through the unique insight patient's can offer to the research journey, which ultimately results in the highest quality research which will help those diagnosed with cancer.

The Royal Marsden and the Institute of Cancer Research, London
Website: *www.cancerbrc.org*

Macmillan Cancer Support

89 Albert Embankment
London SE1 7UQ

Macmillan's Cancer Support (freephone): 0808 808 0000 (Monday to Friday, 9am - 8am)
Website: *www.macmillan.org.uk*

Macmillan Cancer Support provides free information and emotional support for people living with cancer and information about UK cancer support groups and organisations. There is free confidential information about cancer types, treatments and what to expect. They also have details about current UK trials.

Cancer Research UK

Angel Building
407 St John Street
London EC1V 4AD

Support Contact Line (freephone): 0300 123 1022
Monday to Friday 8am-6pm
Email: *supporter.services@cancer.org.uk*
Website: *www.cancerresearchuk.org*

Trained cancer nurses can give information and support relating to cancer and its treatments. Publications are available and their patient information website has information on specific cancers.

NIHR CRN National Coordinating Centre

7th Floor
18 King William Street
London EC4N 7BP

Telephone: 020 3328 6700
Website: *www.nihr.ac.uk*

In 2006, the Department of Health set up the National Institute for Health Research to create a world-class health system within the NHS, and the Clinical Research Network is part of this wider organisation. The network has a collection of high quality clinical studies that benefit from the infrastructure provided by the Clinical Research Network. Many of these studies are randomised controlled trials – considered by many in the medical profession to be the most robust form of clinical trials – although we also support other types of well designed research. The aim of the CRN is to increase involvement and recruitment into clinical trials and to provide clinical support by research nurses, doctors, pharmacists and other health professionals to carrying out high quality research.

INVOLVE

Alpha House
University of Southampton Science Park
Chilworth
Southampton
SO16 7NS

Telephone: 023 8059 5628

Email: involve@nihr.ac.uk

Website: www.invo.org.uk

INVOLVE is an organisation that promotes public involvement in research. Its focus is on Research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them. This includes, for example, working with research funders to prioritise research, offering advice as members of a project steering group, commenting on and developing research materials and undertaking interviews with research participants.

National Institute for Health and Clinical Excellence (NICE)
10 Spring Gardens
London SW1A 2BU

Telephone: 0300 323 0140
Website: *www.nice.org.uk*

NICE provides guidance for healthcare professionals, patients and their carers, that will help to inform their decisions about treatment and healthcare.

Revised June 2018
Planned review June 2021

This booklet is evidence based wherever the appropriate evidence is available, and represents an accumulation of expert opinion and professional interpretation.

Details of the references used in writing this booklet are available on request from: The Royal Marsden Help Centre
Freephone: 0800 783 7176
Email: patientcentre@rmh.nhs.uk

The Royal Marsden NHS Foundation Trust
Fulham Road Downs Road
London SW3 6JJ Sutton, Surrey SM2 5PT

www.royalmarsden.nhs.uk

No conflicts of interest were declared in the production of this booklet.

The information in this booklet is correct at the time of going to print.

Printed by
Print Room, The Royal Marsden NHS Foundation Trust
Downs Road, Sutton, Surrey SM2 5PT PI-0184-09

The Royal Marsden publishes a number of booklets and leaflets about cancer care. Here is a list of information available to you.

Diagnosis

- A beginner's guide to the BRCA1 and BRCA2 genes
- CT scan
- MRI scan
- Ultrasound scan
- Lynch Syndrome

Patient Information

Treatment

- Central venous access devices
- Chemotherapy
- Clinical trials
- Radiotherapy
- Radionuclide therapy
- Your operation and anaesthetic

Patient Information

Supportive care

- Eating well when you have cancer
- Lymphoedema
- Reducing the risk of healthcare associated infection
- Support at home
- Your guide to support, practical help and complementary therapies

Patient Information

Your hospital experience

- Help Centre for PALS and patient information
- How to raise a concern or make a complaint
- Making your stay with us safe
- Your health information, your confidentiality

Patient Information

Please visit **www.royalmarsden.nhs.uk/patientinformation** where several patient information booklets are available to download.

Radiotherapy and
Chemotherapy Services
F538021 & P538022