The ROYAL MARSDEN
NHS Foundation Trust

Clinical trials

Your questions answered

Patient Information

NHS

Foreword

This is one of a series of booklets written to provide information for patients and their relatives. It's impossible to include everything you may need to know. However, you need to feel you have been given enough information before you can make a decision about treatment. Throughout the booklet we suggest questions you may wish to ask your doctor about treatment. Your doctor or nurse will be able to answer specific questions.

This booklet has been prepared with input from Royal Marsden doctors, specialist nurses, other healthcare workers who are experts in their field and patients and carers.

Throughout the booklet, definitions of words written in **bold** can be found in the glossary at the back.

We hope you find it helpful and would welcome your comments so that the next edition can be improved further.

Contents

Introduction

When you first attend the hospital, or at some time while you are receiving treatment, you may be asked to take part in a **clinical trial**.

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. You may like to discuss any questions or concerns you have with your doctor or research nurse. They do not want you to feel that you are under any pressure to take part in a clinical trial. You may find it helpful to talk through the trial with someone who is not directly involved in your clinical care. For example, from a cancer information and support centre (see page 24 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.

We hope you find the booklet helpful and, after reading it, will think carefully about entering 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.
- The question may be "is the treatment being given the best way?" 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.

Genetics

- To help learn more about the role genes play in cancer.

Preventing cancer

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

Researchers use different methods to answer different questions; for example **randomised trials** (see page 13) or questionnaires and interviews.

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 now, 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:

- The consultant clinician
- Specialist registrars
- Research nurses

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

During a trial, you are likely to have the most contact with your research nurse. Their role is to co-ordinate your care while you are on the trial. This includes organising investigations and taking blood samples. The research nurse 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, some research nurses also give drug treatments.

How is a clinical trial planned?

Ideas for a clinical trial come from researchers, usually doctors, nurses and other specialists. 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 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
- How the results will be assessed.

When planning a clinical trial, researchers must follow certain rules. First, 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. The protocol is then passed on to a **Research Ethics Committee.**

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?

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.

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

If a trial is thought to be inappropriate or unethical, approval won't be given and the research will not be allowed to go ahead. The REC can ask for changes to the trial. Once a trial has been approved, the researcher must then ask permission before any changes are introduced. The REC is there to look after the safety and well being 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 Committee 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 include:

- You may receive a new treatment before it becomes widely available.
- You will be closely monitored. Patients on clinical trials often receive more information.
- Helping future patients with cancer.

The disadvantages of taking part in a clinical trial include:

- You may have more appointments at the hospital than if you weren't in a clinical trial.
- New treatments may have side effects or risks that doctors were not expecting.
- Participants in randomised trials (see page 13) will not be able to choose which treatment they receive.

Trials need to be a team effort to make sure they are successful. If you decide to take part, **you** are an essential member of this team. You must be given all the information you want, 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
- An explanation as to how the research effects you; for example how long the trial will last, or any extra tests or hospital visits
- The meaning of the words and phrases 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 want to do so.

There may be other questions you want to ask and you can find suggested questions on page 15.

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

What does 'giving consent' mean?

Consent is your freely given agreement to what is proposed, based on a full understanding of what is 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 **verbal**, that is saying 'yes' when asked if you agree to a blood test, for example. You may have been asked for your **written consent** 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 to keep and refer to later, as necessary.
- It is important that you understand the information you have been given – ask questions if you don't understand or if you want more information.
- To help you think about what you want to ask your doctor, you may find the questions on page 15 helpful.
- To 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.
- To check with you that you understand what has been said.

Later in the booklet we suggest some questions you might like to ask the researcher (see page 15). 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 appropriate treatment and care.

The consent form

The researcher will record on a special form that s/he has 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 doesn't affect your legal rights; it's a record that you agreed to what had 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?

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. Remember, if you decide not to take part in the trial, you will still be given the best appropriate treatment and care.

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 may withdraw your consent to take part in a trial at any time and you don't 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, tell the researcher. Your wish will be respected and you will be offered the best available treatment and care for your illness. Your decision to say no or change your mind will not affect your care in any way. You will be given the best 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; 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's only by doing trials in a particular way that we can produce results we can rely on, which are of value 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 discover what is the most effective dose that can be given safely to patients. This is called a **Phase I study.**

Phase I studies

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.
- The possible side effects of the drug.

There are two problems 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 raise 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

Doctors use the information gathered in a Phase I study to help decide:

- The dose of treatment
- The frequency of treatment
- And possibly the particular cancers which may respond best to the treatment.

Several Phase II trials will be carried out on different cancers so that the doctors can find out how active a particular drug is. Only about 20-30 patients with each 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 test, x-rays or scans. If the drug doesn't work, no more trials will be carried out. However, if a significant number of responses are seen, the doctors will design a **Phase III study**.

Phase III studies

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

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

If the differences between the new treatment and the existing treatment are small, hundreds of patients many need to take part before one is identified as better that the other. Several hospitals many be recruiting patients and not just in the UK. Patients in Europe or America many 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 don't understand, please ask your researcher to explain them.

A randomised trial

In a randomised trial, patients may receive either the best available treatment or the new one. To make sure that one treatment isn't 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.

Equal numbers of patients of similar age, gender etc, will be put into each treatment group. As far as possible, the only difference between the groups is the treatment they receive. Several hundred patients may be needed to show a difference which is greater than that which could occur by chance.

Treatment will only be chosen in this way if there is no evidence that one is clearly better than the other.

A blind trial

In a **blind trial**, the patient doesn't know whether they are receiving the new treatment or 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**.

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 one treatment or the other 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 interest. A double-blind trial can only be used when no special precautions or procedure are needed with one or other treatment.

A placebo controlled trial

A placebo is an inactive substance, such as chalk, salt or sugar. It is made into a tablet or injection identical in size, shape and colour to a specific treatment. The patient won't know whether they are receiving the treatment or placebo. A **placebo controlled trial** may also be double-blind.

A proportion of patients will feel better even though their illness isn't directly affected by the treatment they are given – the so-called "placebo effect". It's thought that this happens because we believe a new tablet or injection must be better, even though there has been no change in our health. This effect must be separated from that of the actual treatment, which should give better results than the placebo. If the treatment doesn't work, the results will be similar to the placebo.

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

Questions to ask

Some questions you may like to ask when you are invited to take part in a clinical trial are listed on the following pages. Not all of these questions will be relevant to every trial. If you think of other question you can make a note of them on page 26.

Many of the trials taking place in cancer care involve new drugs, so this example is used 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 its stage of development (see What types of clinical trials are there? page 11). 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 the researcher, 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. You must also report to the doctors or research nurses anything unusual which could be due to treatment.

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

If you are receiving a 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.

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

You will need to give the research team a list of all the medicines (prescribed, over-the-counter and complementary, as well as supplements) you take and they will advise if any need to be changed before you start any trial drug treatment.

What other treatments are available if I don't take part in this trial?

When you are invited to take part in research looking at treatment you should always be told what other treatments are available, and the benefits and risks of these other treatments.

Will I get better treatment if I agree to enter a trial?

Often it's difficult to say whether your treatment will be better as part of a trial, especially if a treatment is very new. Many trials are done to find out which is the better treatment by comparing the best known available with a new therapy. During a trial, all participants are carefully monitored. As soon as it's known one treatment is better than another, the results will be reviewed and a decision will be made about continuing the trial. All patients will be offered the better treatment for them. However, overall, many studies have shown that patients on clinical trials often receive more attention as they are seen by the clinical team more frequently.

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 trial being offered to you. Sometimes differences may be only slight but sometimes they may be quite marked. Occasionally, there may not be an alternative treatment, if a drug or therapy is very new or if you have exhausted all known treatment options.

Will the treatment benefit me?

Every 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 trial treatments.

Your doctor may be able to tell you in general terms what percentage of people can be expected to benefit from new drugs. The doctor won't offer you a treatment unless there is a benefit. If you don't respond to treatment, your doctor will withdraw you from the trial and discuss with you, your future care.

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 affects may occur and additional and more tests may be needed. You should find out what these might involve.

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 some time and extra effort is involved.

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

Do I need to come to the hospital more often?

A member of your research team will tell you about the time commitments required of you if you decide to take part in the trial.

This will vary from trial to trial and will often involve more visits than usual to the hospital. 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.

Your doctor or researcher should be able to provide a plan for you but, as with all treatments, this may need to be adjusted as situations change. The plan should tell you what tests to expect. These may include for example, blood tests, x-rays, and interviews.

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.

Will my family doctor be informed?

Your hospital doctor or researcher may contact your family doctor (GP) to tell him/her that you are taking a part in a clinical trial. This depends on the type of trial and it may not always be necessary. If specific details of your study do need to be passed on, the doctor will ask your permission to do this. You will be asked if you mind having your hospital doctor contact your GP about your participation. You will be given the opportunity to ask your GP for advice about taking part if you would like this.

What if I am worried about an unusual reaction?

If you or your family doctor are worried about an unusual reaction, or one which you haven't been made aware of, phone the hospital 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 doesn't occur, you may also be concerned. Again, please phone the hospital.

Before leaving the ward or clinic you should have been given contact names and phone numbers of health care professionals who can answer your questions at all times. These details should also have been filled in on your patient information sheet.

What if new information becomes available?

Your doctor or researcher should inform you if any 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?

You may want to ask what treatment you will be given if you need further treatment when the trial finishes.

What if something goes wrong?

During any treatment you would be observed very closely to make sure that you're not placed in danger. When you enter a clinical trial, the tests and checks on our health may need to be increased, and you will be asked to report anything unusual to your research team between appointments (such as inpatient admissions to other hospitals). Any extra tests are to help safeguard you from any possible effects associated with the new treatment. Minimising your risk of side effects and any harm is a major goal of all trials.

If you have a serious reaction to a new or standard treatment, it will be stopped. Your doctor, or other researchers, will do all they can to make sure you don't suffer any lasting consequences. However, if something does occur, you may be eligible for some compensation.

Who is organising and funding the research?

You may want to ask who is funding the trial. The research may be funded by:

- An academic institution (for example, the Institute of Cancer Research, or a hospital department)
- A charity (for example, Cancer Research UK)
- A drug (pharmaceutical) company

Sometimes, sponsors of a study will pay a hospital department or research fund for the patients included in a study. Or, the doctor conducting the research may be paid for looking after patients in the study.

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 medical trials, to make sure a trial is being carried out correctly.

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

Can I find out the results of the trial?

Yes, 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.

Who can I contact if have any concerns or problems?

You should 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.

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 which you wish to ask your doctor or researcher. You may find it helpful to write these down so you don't forget.

Only when all your concerns have been answered should you make your decision. **Remember you are a volunteer.**

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.

Glossary

These are some of the terms you may come across.

Term	Definition
Blind trial	The patient doesn't know whether they are receiving the new treatment or standard treatment. The treatment will look the same whether it is the new treatment, standard treatment or a placebo.
Clinical trial	Research into the possible benefits and drawbacks of treating cancers.
Double-blind trial	Neither the patient nor the hospital staff know which treatment is being given.
Implied consent	For example, you roll up your sleeve so that someone can take your blood pressure.
Informed consent	Agreement to what is proposed (for example, treatment or procedure) based on a full understanding of what is to happen.
Phase I study	Aims to find the best way to give a new treatment and how much of it can be given safely.
Phase II study	Aims to find out what cancers respond best, and the best dose and frequency of treatment.
Phase III study	Usually compares a new treatment with standard treatment.
Placebo	An inactive substance, such as chalk, salt, or sugar
Placebo controlled trial	The patient doesn't know whether they are receiving the treatment or placebo. A placebo controlled trial may also be double-blind.
Protocol	Plan of treatment

Randomised trials	Patients may receive either the best available treatment or the new one. Usually, this is decided by a computer.
Research Ethics Committee (REC)	A REC is made up of professionals and members of the public. They provide a safeguard for patients by deciding whether or not a research project is ethical.
Verbal consent	For example, saying “yes” when asked if you agree to a blood test.
Written consent	A written record that you have agreed to the planned treatment.

Sources of information and support

Macmillan Cancer Support

89 Albert Embankment
London SE1 7UQ
Macmillan freephone helpline: 0808 808 0000

Website: *www.macmillan.org.uk*

Provides free information and emotional support for people living with cancer and information about UK cancer support groups and organisations. Offers free confidential information about cancer types, treatments and what to expect. They also have details about current UK trials.

Cancer Research UK

PO Box 123
London WC2 3PX
Cancer Information Service available on

Freephone: 0808 800 4040
Mon-Fri 9am-5pm

Textphone: 020 7061 8484

Email: *cancer.info@cancer.org.uk*

Website: *www.cancerresearch.org.uk*

Website: *www.cancerhelp.org.uk*

Trained cancer nurses can give information and support relating to cancer and its treatments. Publications are available and their patient information website, www.cancerhelp.org.uk has information on specific cancers. Click on 'Clinical Trials' icon on this website home page to access up to date details on current UK clinical trials.

The National Cancer Research Network (NCRN)

University of Leeds
MacMillan Wing, Fairbairn House
71-75 Clarendon Road
Leeds LS2 9PH

Website: *www.ncrn.org.uk*

The aim of the National Cancer Research Network (NCRN) was to improve the organisation and support within the NHS for clinical research in cancer. This was to ensure that research is better integrated with cancer care as outlined in the Report of the Science and Technology Committee on Cancer Research (2000).

The NCRN aims to increase involvement and recruitment into trials through the creation of cancer research networks across England, closely aligned to cancer service networks. NCRN funding is allocated to these networks to appoint research staff such as research nurses, doctors, pharmacists and other health professionals necessary for high quality research.

The NCRN is part of the National Institute for Health Research, Clinical Research Network (NIHRCRN) *www.ukcrn.org.uk*

National Institute for Health and Clinical Excellence (NICE)

MidCity Place
71 High Holborn
London WC1V 6NA

Website: *www.nice.org.uk*

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

Websites

NHS Evidence

www.library.nhs.uk

National UK health information site – covers all aspects of health illness and treatments.

Notes / Questions

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

Where can I get help?

If you have queries about your illness or treatment or experience any unexpected problems, please contact:

Your hospital doctor (consultant)

or one of his/her team

or your researcher

or your research nurse

at _____ Hospital

Telephone number

Revised July 2011
Planned review July 2013

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

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Fulham Road
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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
Lundie Brothers Ltd.
Croydon, Surrey

PI-0184-04

The Royal Marsden publishes a number of booklets and leaflets about cancer. 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

Patient Information

Treatment

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

Patient Information

Supportive Care

- After treatment
- Coping with nausea and vomiting
- Eating well when you have cancer
- Infection Prevention and Control
- Lymphoedema
- Support at home
- Your guide to support, practical help and complimentary therapies

Patient Information

Your hospital experience

- Help Centre for PALS and patient information
- How to raise a concern or make a complaint
- Your comments please
- Your health information, your confidentiality

Patient Information

Life demands excellence

ICR
The Institute of Cancer Research

POSITIVE ABOUT DISABLED PEOPLE

BSI
Radiotherapy and Chemotherapy Services
FS38021 & FS38022

The Information Standard
Certified member

CUSTOMER SERVICE EXCELLENCE
UK
The Government Standard