NHS
The Clatterbridge Cancer Centre
NHS Foundation Trust

Getting involved in research

General information

A guide for patients and carers

Contents

This information is for patients with cancer who are going to receive anti-cancer treatment. These treatments may include radiotherapy, chemotherapy or other drug therapies such as hormone treatments or biological therapies, or immunotherapies.

This leaflet will explain that The Clatterbridge Cancer Centre is a research active organisation and that you may be asked to consider taking part in a clinical trial as one of your treatment options. Research is important if we are to develop new and more effective treatments for cancer for the future and to understand how normal cells may turn into cancer cells.

Research at The Clatterbridge Cancer Centre NHS Foundation Trust

The Clatterbridge Cancer Centre hospital specialises in cancer treatments such as radiotherapy and chemotherapy. It is just one of many hospitals that make up the Clinical Research Network North West Coast. You may be

treated at one or more of these hospitals if you are diagnosed with cancer. The clinical teams in the hospitals across the network work very closely together to ensure you receive the best possible care that the NHS can provide.

The Clatterbridge Cancer Centre is a hospital with an active research department that constantly strives to encourage patients to take part in research programmes so that medical advances can be made. This means that your doctor may discuss research programmes or clinical trials with you as one of your treatment options or The Clatterbridge Cancer Centre Biobank for cancer research. Listening to the information does not commit you to take part. You will never be entered into a research programme without giving your written consent. You would always be given plenty of information about the research to enable you to consider whether to take part and a contact number for the research team so that you can discuss it further if you wish.

Why are cancer clinical trials important?

- Many of today's treatments are only available as a result of research carried out in previous trials
- Clinical trials are research studies into the prevention, detection and treatment of cancer

- More patients entering clinical trials will lead to faster results and quicker improvements in cancer treatments for future patients
- Methods to identify cancer at an early stage can be developed
- Clinical trials aim to improve the quality of life for patients living with cancer, including reducing symptoms, or side effects of treatments

  In clinical trials new ways of treating cancer are often compared with the best currently available treatment options

- The Biobank aims to collect blood and other biological material from patients or from healthy volunteers. The samples would then be used in ethically reviewed research into the mechanisms of cancer, to discover ways of detecting cancer and to work out why some patients respond better than others to treatment.

Are trials safe?

- New drug treatments are extensively tested in laboratories and on healthy people before being given to patients. While there are no guarantees of benefit to patients, the potential benefits should outweigh the risks when the trial is designed. Ethics committees look at this when the trial protocol is reviewed before the research can commence
- Ideas for clinical trials arise from questions about the effectiveness of current treatments. Some trials testing new drugs at an early stage in their development may also be the first stages of testing drugs in the human population
- Clinical trials programmes are carefully and scientifically designed to minimise the risks to patients whilst maximising any potential benefits
- Patients can only participate in studies that are suitable for their type of cancer and stage of disease. They are monitored very closely throughout their treatment
- Large numbers of patients take part in hundreds of clinical trials every year across the UK. Many of these trials are available in hospitals across the country. Much of this work is coordinated by the Cancer Research Network staff based at those hospitals
- There are no guarantees that new treatments will be better than the standard or usual treatment but there should be a reasonable expectation of some benefit to patients

- We do not always know whether a new treatment is better than the current one. Drugs that are in a very early stage of development may not be of direct benefit to the person receiving them. However, the information gained from these trials is useful in deciding if the drug should go on to the market for use. Where there is no direct benefit expected to patients, this information should be given clearly at the outset
- There are stringent processes in place that ensure the research or trial is as safe as possible. Every study is reviewed by an NHS Research Ethics Committee that can reject or request changes to the proposal if they do not feel the work is in the best interest of the patients. The role of the ethics committee is to protect the rights, dignity and wellbeing of patients
- There are strict rules by which researchers have to conduct their work

How will I get to know about clinical trials that might be suitable for my situation?

- You may be approached by your doctor or specialist nurse to participate in a clinical trial
- As part of the National Institute for Health Research 'OK to Ask' Campaign you are at liberty to ask your doctor or consultant about clinical research for you or someone you care for (http://www.crn.nihr.ac.uk/north-west-coast)
- Some clinical trials are advertised on hospital websites

- You may read about new treatments in newspapers or magazines
- You may see the trials advertised on the internet. Such reports may not be suitable or relevant to you or your type of cancer. You should discuss any information you find with your consultant or specialist nurse who will be able to help you decide if the information is useful and relevant to you

Who can help me decide if the clinical trial is for me?

You must decide for yourself whether you wish to participate. You can only do that once you have had a chance to read and discuss all the information with your doctor.

- Your doctor may ask you to have a discussion with a Research Practitioner to help you understand all the facts
- The Research Practitioner will be a qualified health professional who will support you through the treatment and advise you of the research throughout
- You may also be approached by specialist nurses or other allied health professionals, such as radiographers, physiotherapists, dietitians etc. All of the health professionals that you meet during your treatment will help identify if a trial is suitable for you

- You may wish to discuss the information about the research with your family, friends or GP to help you decide but the decision is ultimately yours
- If you decide to take part, you will be asked to sign a consent form and your doctor / research practitioner will then ensure you meet all of the requirements for the study before you start your treatment

What if I don't want to take part?

Taking part in research is voluntary. It is your right to say no if you feel the research is not in your best interest.

Similarly, if you do take part and you decide not to continue, you may withdraw at any time and without having to give a reason.

Whatever you decide, your future care will not be affected and your doctor will discuss treatment alternatives with you.

Further useful sources of information

Clinical Research Network North West Coast (based at The Royal Liverpool and Broadgreen University Hospitals NHS Trust)
www.crn.nihr.ac.uk/north-west-coast

National Institute for Health Research
www.nihr.ac.uk

National Institute for Health Research Cancer Research Network
www.ncrn.org.uk

Macmillan Cancer Support
www.macmillan.org.uk

UK Clinical Research Collaboration (UKCRC)
www.ukcrc.org.uk

Notes

How we produce our information

All of our leaflets are produced by staff at The Clatterbridge Cancer Centre and this information is not sponsored or influenced in any way. Every effort is made to ensure that the information included in this leaflet is accurate and complete and we hope that it will add to any professional advice you have had. All our leaflets are evidence based where appropriate and they are regularly reviewed and updated. If you are concerned about your health in any way, you should consult your healthcare team.

We rely on a number of sources to gather evidence for our information. All of our information is in line with accepted national or international guidelines where possible. Where no guidelines exist, we rely on other reliable sources such as systematic reviews, published clinical trials data or a consensus review of experts. We also use medical textbooks, journals and government publications.

References for this leaflet can be obtained by telephoning 0151 556 5570.

If you need this leaflet in large print, Braille, audio or different language, please call 0151 556 5570.

If you have a comment, concern, compliment or complaint, please call 0151 556 5203.

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Issue date: 01/02/17
Issue no: 4.0
Reference: LPIZINVR
Review date: 01/02/20