The ROYAL MARSDEN

NHS Foundation Trust

Welcome to the West Wing Clinical Research Centre (WWCRC)





Contents

Introduction	1
The WWCRC team	1
General information	3
Appointments	3
Consent and screening	3
Cycle 1 onwards	4
One stop	4
Two stop	5
Oral trial drugs	5
Trial drug preparation	6
Drug diaries	6
Fasting restrictions	6
Other drugs	7
Trial samples	7
Trial blood samples	7
Trial biopsy	8
Supportive treatments	8
Before leaving WWCRC	9
Expenses	9
Mobile phones	9
Wi-Fi	9
Daily newspapers	9
Infection control	10
Refreshments	10
Spiritual needs	10
Contact details	11

Introduction

The West Wing Clinical Research Centre (WWCRC) is a modern and comfortable environment for patients undergoing treatment on clinical trials. WWCRC is located on the first floor of the West Wing of the hospital. WWCRC has 24 reclining treatment chairs and four recovery trolleys – next to each of these is a chair for one relative or friend. WWCRC is open Monday to Friday, from 8am to 6pm, with appointments starting from 8.30am. The entrance doors to WWCRC are always closed but are sensor monitored for easy entrance and exit (to exit the ward, press the green button). WWCRC is closed at weekends and bank holidays. This guide provides you with the information you need during your time on any one of our trials. If you have any queries, please ask a member of our team.

The WWCRC team

WWCRC is staffed by a team of nurses, pharmacists, health care assistants, laboratory technicians, research facilitators and ward clerks, who are dedicated to supporting all our patients and their families during the period in which they are participating in a clinical trial. Coming into hospital and taking part in a trial can be an anxious time for patients and their families. WWCRC nurses are responsible for delivering your treatment, taking blood samples, ECGs and recording all the trial information. The research nurses (who can also be your key worker) deal with your trial queries, expenses, and are a point of contact for reporting side effects and concerns. The WWCRC team want to ensure that the time you are under our care is comfortable and that appointments run as smoothly as possible.

Some of our staff can be identified by their uniform:



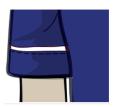
Matron

Navy blue uniform with red piping



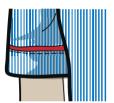
Sister

Navy blue uniform with white polka dots and white piping



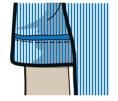
Practice Educator

Navy blue uniform with white piping



Senior Staff Nurse

Blue and white striped uniform with red piping



Staff Nurse

Blue and white striped uniform with navy piping



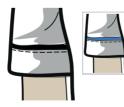
Lead Research Nurse

Navy blue uniform with light blue piping



Research Nurse

Blue uniform with navy piping



Health Care Assistant

White blouse or shirt with black or blue piping



Ward Clerk

Navy blue uniform with light blue piping

The catering team can be identified by a purple shirt. The pharmacy team does not have a uniform so they will be dressed in smart clothing. All of the staff on West Wing wear name badges for easy identification.

General information

Appointments

You will be referred to WWCRC once you have been offered the opportunity of taking part in a trial. Once you have been referred, either your research nurse will contact you or you will receive an appointment in the post to attend for consent and screening appointments. If you cannot make your appointment date or time, you must contact your research nurse or WWCRC directly. Your appointments are booked to ensure the trial is being carried out in accordance with the trial protocol.

Your research nurse and WWCRC team will communicate with you at all times to ensure that the appointments you are given are both within the specified time frame and are suitable for you. If you have a holiday planned, please ensure you inform your research nurse so that appointment times can be scheduled around this. There may be occasions when this is not possible, so please always contact your research nurse before booking holidays. Please be aware that your time with the doctor and treatment time may differ from the time on your card due to delays in the making of your treatment and delays in blood results.

Consent and screening

Consent

The doctor and research nurse will be able to discuss trial related questions you may have and explain trial related procedures and treatment schedules with you prior to signing the consent form. It may be helpful to make a list of questions to take into the consultation with you. We will give you a copy to take home with you. It also outlines the purpose of the trial, the risks and side effects of the treatment and who to get in touch with if you are

having any problems. You can withdraw or change your consent at any time and this will not affect the way you are treated by the hospital.

Screening

Once you have signed consent to take part in the trial, you will start the screening process, which is specific to each trial and will be explained to you. A list of criteria or checklist must be completed before you can enter onto a trial. This aims to ensure your safety and fitness to enter into a trial. The screening will involve various tests such as blood tests, examination by a doctor, chest x-ray, ECG (tracing of your heart), CT or MRI scans to re-evaluate the cancer. Some trials may require a biopsy.

You will be seen also by a nurse/health care assistant who will record your height, weight, as well as your vital signs (blood pressure, pulse, oxygen saturation rate, respiratory rate and temperature). Local bloods and trial bloods may be taken. Local bloods are processed and analysed within the hospital and the results are recorded in your medical notes. Trial bloods are processed on WWCRC but are sent to the trial company for analysis and are not recorded in your hospital notes.

If you are due to have a scan on the same day as your appointment, you may have a cannula placed in your arm. Once all screening checks are done and your results have been checked by the doctor (and there are no problems) you will then be given a date to start the trial.

Cycle 1 onwards

After your screening visit, there are two options of how your appointments can be organised; one stop or two stop. This applies for trials with infusions only and those that allow this process.

One stop

With a one stop chemotherapy appointment, you will have your blood test, pre-treatment assessments and doctor's appointment in the morning and will receive your chemotherapy treatment later that same day. This means that your wait may be up to five hours between your morning appointments and chemotherapy appointment whilst your tests are being analysed and chemotherapy is being made. It is important that you arrive on time for your morning appointment.

Two stop

With a two stop chemotherapy appointment, you will have your blood test, pre-treatment assessments and doctor's appointment on one day and will receive an appointment to return to WWCRC on a different day for your treatment. This will usually be no later than three days.

Please note that your treatment may be delayed or rescheduled if you do not make your appointment on time.

Oral trial drugs

If you are due to collect oral trial drugs on your visit, please note that once your drug has been confirmed with pharmacy, oral drugs may take over an hour to be dispensed.

- Never take your trial drug on a day you have an appointment
 with the WWCRC unless told otherwise. You may take all your
 other medication. Once you have been seen by the doctor, you
 will be told whether or not to take your drug.
- **Never** independently change the dose you have been prescribed. If you are unwell or unable to take it, please call your research nurse or The Royal Marsden Macmillan Hotline for advice. If out of hours, please call the emergency contact numbers which we will give to you. The advice may include any or some of the following: to stop taking the drug, to attend the unit or, if you live some distance away, you may be asked to go to your GP, or in an emergency to go to your local Accident and Emergency department.

Always bring all your trial drug supplies with you, including
empty bottles and give them to the nurse who is looking after
you. On each visit, the nurse assigned to you will need to
perform a drug compliance check to ensure you are taking the
drug as prescribed. Please let the nurse know whether any doses
have been missed or if any tablets or capsules have been lost.

Trial drug preparation

Some trials may require your oral or intravenous (IV) trial drugs to be allocated an electronic identification number from the sponsor of the trial. This allocation process is called IVRS (Interactive Voice Response System) and it is used to monitor what treatment you are receiving. This process needs to be completed before any of your drugs can be dispensed. Pharmacy will then select the allocated trial drug by the identification number and prepare this for your treatment.

Drug diaries

Some trials require you to complete a drug diary. The diary may ask you to record the date, time and how many tablets you have taken. If you have been given a drug diary, please ensure you complete it accurately. The nurses will show you how to do this, but please ask if you are unsure. **Always** bring in **all** completed drug diaries to every appointment – we'll provide you with a new one at each visit.

Fasting restrictions

Some trials impose fasting restrictions, either for the blood tests needed before you have the drug, for the drug itself, or sometimes both. If this is the case with your trial drug, you will be told this regularly at your appointments. At screening, this will be discussed with you during your initial appointments and it will be stated in your consent form. Please note that if you are told to fast, this means you can only drink plain water. With some trials you may also be allowed black, sugarless tea or coffee, and you will be advised if this

is the case. If you are told to be 'nil by mouth' (NBM), this means you must not eat or drink **anything**. Please check with the nurses if you are uncertain.

Other drugs

Once recruited onto the trial, please take existing medication including supplements and complementary medicines to your appointment. The doctors need to be made aware of any other medication, in case of any potential interaction with your trial drugs. Please phone and inform your doctor or research nurse of any new medication before you take it during the course of the trial. If you are on any pain medication, please bring this with you on treatment days.

Trial samples

Due to the nature of clinical trials, during your trial period you will have regular assessments and your research nurse will discuss this with you. This may include having regular trial specific blood tests, urine tests, heart tracings (ECG), biopsies, scans or may require you to stay in after your treatment to be observed for a specific time period. Please refer to your trial specific patient information sheet for specific assessments and their frequency for your particular trial.

Trial blood samples

To obtain the frequent and regular blood samples often required during your trial visit, a venous access device, such as a plastic cannula (small tube), is generally inserted into one of your veins. Once all blood samples have been obtained, the cannula will be removed. If you already have a permanent central venous access device (PICC or Port) this will be used instead. If, however, your drug is given intravenously (IV), the venous access device in which the drug is given through cannot be used to take your trial specific bloods. On these occasions you will need to have a second venous access device, going into a different vein.

Trial biopsy

Some clinical trials require tissue samples to tailor treatments to individual patients before and during their specific clinical trial. This is done using real time ultrasound guided techniques to carefully insert a biopsy needle into the soft tissues. The sterile procedure is performed by an imaging expert and dedicated nursing staff – they will also administer intravenous analgesia to relieve any pain as a result of the procedure. Patients are monitored carefully on the unit for four hours after the procedure to ensure there are no adverse effects. If you are having a deep tissue biopsy, ensure you are not driving yourself. Someone will need to be home with you for 24 hours.

All necessary precautions are taken prior to the biopsy between your doctors, research nurse or staff on the WWCRC. This will be discussed with you at your enrolment onto the trial where you will have an opportunity to clarify any questions that you may have. This procedure can be carried out in the WWCRC or at the Chelsea site.

Supportive treatments

On occasion, you may require supportive treatments such as blood transfusions, intravenous fluids or bisphosphonate infusions. The waiting times for intravenous fluids and bisphosphonate infusions are much shorter and, if known in advance, the drug can be preordered. Blood transfusions will take longer. You will initially need to have a blood sample taken for a cross match, to ensure you are given blood that is compatible with you. This can be taken the day before the blood transfusion, in which case your blood is generally available within half an hour of your arrival on the day of transfusion. If, however, you are cross matched and require the blood to be transfused on the same day, you may have to wait three to four hours for the blood to become available.

Before leaving the WWCRC

Please check the date for your next appointment with the receptionist. If an appointment has not already been booked, please book one at this point. Appointments are sometimes sent out in the post, so please inform staff if you have moved or you are staying with relatives. If you are unsure when your next appointment should be scheduled for, please check with the research nurse for your trial or at the WWCRC reception.

Expenses

Some trial companies may offer travel expenses for the duration of time you are on their study. Please discuss this with your research nurse.

Mobile phones

Mobile phone signals can interfere with some types of medical equipment. For that reason, there are clearly signposted areas where we ask patients not to use mobile phones. Please observe these instructions. When you use your mobile phone, please be considerate to others around you. The Trust does not have good mobile reception, therefore please note you may not be able to make calls whilst within the hospital. Our staff use a cordless internal phone system that does not affect medical equipment.

Wi-Fi

The Trust has patient accessible Wi-Fi. Please ask a member of staff to advise you if you need assistance. You may bring in your laptop, computer tablet or smart phone to connect to the Wi-Fi.

Daily newspapers

If you would like any newspapers these can be bought from the shop located on the ground floor (next to the main entrance, open 10am – 4pm).

Infection control

Strict infection control is essential, therefore please observe the following:

- Use alcohol hand gel on entering and leaving the unit.
- Before, or on arrival, please notify the receptionist and the nurse
 if you have had an inpatient admission to another hospital since
 your last visit or if you have any flu-like or respiratory symptoms
 or diarrhoea.

Refreshments

You and your relatives or visitors can purchase meals or light snacks and refreshments from the Cherry Tree Café, coffee bar and the shop, all located on the ground floor. Please ask a team member if you require further direction.

Spiritual needs

The Royal Marsden cares for patients and relatives with many different religious needs. A resident Anglican chaplain is always on call. Part-time Roman Catholic, Free Church, Jewish and Muslim clergy visit the hospital regularly. Representatives from any faith can always be sent for. The chaplains can also provide a variety of non-Christian reading matter and devotional aids.

There is both a multi-faith prayer room and chapel available in the hospital, located on the third floor of the West Wing. The hospital chapel is always open for a time of quiet reflection and prayer, regardless of faith. Everyone is welcome to use both the prayer room and the chapel. If you do not feel well enough to walk, arrangements can be made to take you in a wheelchair.

The sacraments of Holy Communion, Reconciliation and Anointing of the Sick are always available at your request. If you would like a chaplain or religious leader to come and see you, please ask a member of staff who will be happy to arrange this.

Contact details

If you have any questions or concerns about your trial, please get in touch with your research nurse or the west wing clinical research staff.

WWCRC: 020 8915 6669/6668

Opening times: 8am – 6pm Monday to Friday (closed on

weekends and bank holidays)

At your screening appointment we will give you a card with our **out of hours** contact details for weekends and bank holidays, along with the unique reference number (referred to as the 'CCR number') of the trial you have agreed to take part in. Alternatively, please call:

The Royal Marsden Macmillan Hotline: 020 8915 6899

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

It is important that you call your research nurse or the hotline number if you are feeling unwell or are worried about the side effects of your cancer treatment.

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.

The West Wing Clinical Research Centre appreciates your participation in our clinical trials. We value the time and contributions which will help others in the future. Also we acknowledge that on occasion your treatment may be delayed and we would like to thank you, in advance for your patience and understanding. We are grateful for any feedback we receive.

Notes and questions				

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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

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Should you require information in an alternative format, please contact The Royal Marsden Help Centre.

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