
Your health
information, your
confidentiality

Patient Information



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What information do we hold about you?

During your visit or stay at The Royal Marsden NHS Foundation Trust we will ask you for information about yourself, and will hold this alongside other information so that we can care for you safely and effectively. The information we hold typically includes:

- Personal details such as your name, address, date of birth, ethnicity and religion, NHS number, next of kin and GP details.
- Details and records about your treatment and care.

We will ensure the information we hold about you is accurate, up to date and high quality.

We will also ensure your information is stored securely and only staff involved in the management of your care will have access to your information.


How do you use my health information?

The people caring for you use your information to:

- Provide treatment
- Check the quality of your care
- Help you make good decisions about your health
- Investigate complaints
- Conduct Holistic Needs Assessments.

How else does The Royal Marsden use information about my health?

- To find out how many people have a particular illness or disease
- To look at how safe and effective a treatment is
- To check that The Royal Marsden is providing a good service
- To plan how many beds, wards and staff are needed
- To train students and staff

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- To ensure that The Royal Marsden spends public money appropriately
 - For research
 - To ensure fair access to health services
 - To help investigate any concerns or complaints you or your family may have about your healthcare.

Wherever possible we will remove information that identifies you, however, we will seek your permission first if we share your personal information with any third parties for reasons other than direct care.

When can my personal health information be shared outside The Royal Marsden?

The Royal Marsden is commissioned to provide your healthcare by either NHS England, CCG's (Clinical Commissioning Groups) across England, or sometimes private health insurers. We are required under contract to supply information routinely to these organisations and their nominated recipients. This information is always transmitted securely, and typically the only identifiable information included is your unique NHS number, date of birth and postcode. This information is used by these organisations for the purpose of validating the clinical activity that happens at this hospital, as well as monitoring quality of healthcare and public health nationally. We do not share more data than we are required to share under contract.

We may also need to share information about you with other people involved in your care, such as your GP, dentist, health visitor, community nurse or social worker.

For example, information is shared if:

- Your GP refers you to a hospital
- You need support at home
- You are moved from one hospital to another.

How your records are used to help the wider NHS

Your anonymised information may be used to help assess the needs of the general population and support the Trust in making informed decisions about the provision of future services. Information can also be used to conduct health research and to develop and monitor NHS performance. This means we may share anonymised data with organisations who have legitimate interests, such as universities, community safety units and research institutions.

Where anonymous information is used for statistical purposes, strict measures are taken to ensure individual patients cannot be identified.

Things you can do to help us


- Make sure that we have accurate and up to date personal information about you, including any changes to your address, name or contact details, including next of kin
- Tell us if any information in your record is missing or inaccurate
- Allow us to share as much information about you as we need to, to provide you with healthcare.

Disclosure of information

You have the right to restrict how we share your personal information which can identify you in your records. You also have the right to restrict with whom it is shared with. This must be noted explicitly within your records so that all health and social care professionals treating you and involved in your care are aware of your decision. We advise you discuss this with your clinical team. You can change your mind at any time about a disclosure decision.

When might you use information that identifies me without asking my permission?

Sometimes the law requires The Royal Marsden to share your personal health information without your permission, for example, to investigate a serious crime or to protect a child.



Some important health research involves thousands of patients. In these cases, contacting every patient for their permission may not be practical.

In all cases, we will only provide the information needed. Wherever possible, we will tell you. For example, we may need to:

- Report some infectious diseases
- Provide information to be used in court
- Give information to the police to help detect or prevent a crime.

The Royal Marsden will not share your personal health information with people such as a relative, carer or friend without your permission. However, there are exceptions:

- If you are a child, and your doctor does not think you can make decisions about your healthcare, someone with parental responsibility for you may be allowed to see your records and discuss your care.
- If you are an adult who cannot make decisions for yourself, or cannot tell others your decisions, the law allows someone to see your records and discuss your care, if:
 - You have given them a lasting power of attorney, or
 - A court has given them a guardianship.

In these cases, the person allowed to see your health information:

- Will only be able to see information that is necessary for them to make particular decisions for you about your healthcare.
- Will not receive information that staff feel would be harmful to your health or the health of others.

Anyone who receives information from us is also under a legal duty to keep it confidential.

Sharing information with family and friends

It is important that we know which of your family members or friends we may share information with about you. You can choose one of these as your next-of-kin. When you first attend the hospital and register, we will ask you for the name and contact details of your next-of-kin. This person does not need to be related to you but should be able to reflect your wishes at all times, even if you were unable to do so yourself.

How does The Royal Marsden keep my personal health information confidential?

You have the right to expect us to keep your health information private. You also have rights to make sure we keep your details confidential under the Data Protection Act, Human rights legislation and the common law.

- All staff at The Royal Marsden have a professional, ethical and legal duty to keep information about you confidential, secure and accurate and to abide by the NHS Confidentiality Code of Practice
- The Royal Marsden stores your personal health information securely
- Only relevant information is shared inside the NHS or with outside organisations
- The Royal Marsden will not give information about you to organisations such as benefits agencies, employers or the media without your permission.

If we find that someone has deliberately accessed records about you without permission or good reason, we will take action which may include disciplinary action.



Summary Care Records

Summary Care Records provide basic medical information about you so that you can be treated in an emergency or when your GP is closed. For more information, please visit

www.digital.nhs.uk/services/summary-care-records-scr

The NHS Care Record Guarantee

Everyone working within the NHS has a legal duty to keep information about you confidential. Similarly, anyone who receives information from us has a legal duty to keep it confidential.

The Care Record Guarantee is our commitment that we will use records about you in ways that respect your rights and promote your health and wellbeing. Copies of the full document can be found via ***www.digital.nhs.uk***

How long health records are retained

All patient records are managed in accordance with the NHS Retention Schedule, which sets out the appropriate length of time each type of NHS record is retained.

All records are destroyed confidentially once the Trust has made the decision that the records are no longer required.

Access to your Health Record

Under data protection legislation, you have the right to request a copy of the information we hold about you. You can request a copy of your medical records free of charge. For further information, please contact our Access to Health Records Officer on 020 7352 8171 or email

AccesstoHealthRecords2@rmh.nhs.uk

Further Information

Data Protection Officer
Email: dpo@rmh.nhs.uk
Tel: 020 7352 8171

Caldicott Guardian
Email: Caldicott@rmh.nhs.uk
Tel: 020 7808 2121

To raise a concern please contact the Patient Advice and Liaison Service (PALS):

Freephone: 0800 783 7176

Or email patientcentre@rmh.nhs.uk

The Royal Marsden Macmillan Hotline: 020 8915 6899

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

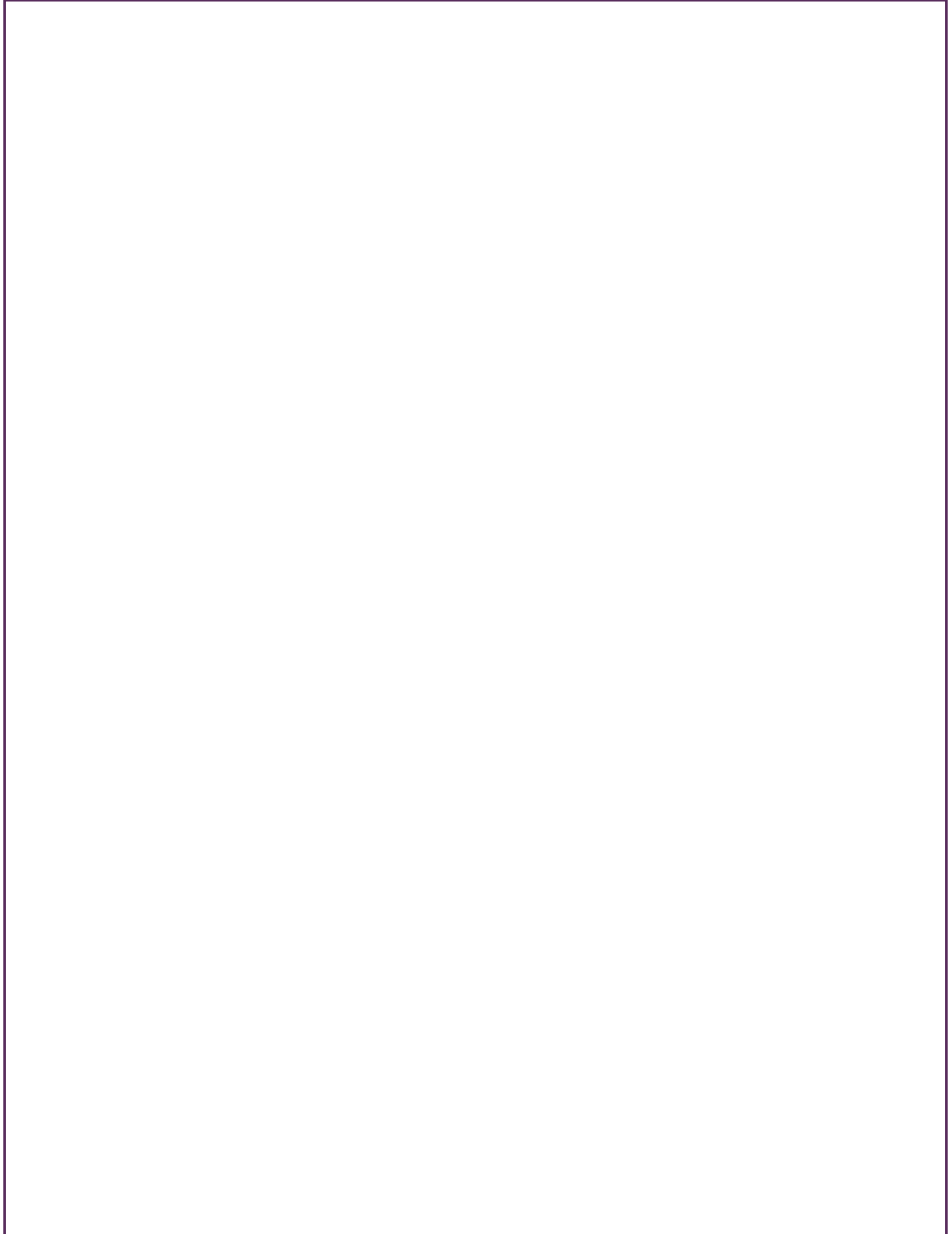
Call us straight away if you are feeling unwell or are worried about the side effects of cancer treatments.

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

Notes/Questions

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Revised January 2022
Planned review January 2025

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

Should you require information in an alternative format please contact:
The Royal Marsden Help Centre (see details below).

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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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.

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The Royal Marsden Help Centre.

PI-0981-10

The patient information service is generously supported
by The Royal Marsden Charity.

royalmarsden.org

Registered Charity No.1095197



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



Treatment

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



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



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



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



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Chemotherapy Services
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