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## Carrier Register

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**Cancer Genetics**

**Patient Information**



## What is the Carrier Register?

The Carrier Register is a record of NHS Cancer Genetic Unit patients at The Royal Marsden who carry a harmful gene alteration, also called a pathogenic variant or mutation. This harmful gene alteration is associated with an increased risk of cancer.

## How is information on the Carrier Register stored?

The Carrier Register is held on a database (called Trakgene), which is used in the Cancer Genetics Unit. The database can produce a list of all our patients who carry harmful alterations in cancer predisposition genes. This list is called our Carrier Register. Information stored within Trakgene is kept confidentially and is separate from the main hospital electronic medical records - only the Cancer Genetics Unit can access it.

## What is the purpose of the Carrier Register?

The Carrier Register allows the Cancer Genetics Unit to identify all carriers seen in our department. It was established to help us work with you to manage your long term genetic follow up.

## What does being on the Carrier Register mean for my follow up?

The doctor or genetic counsellor who arranged your genetic testing has discussed your results with you and arranged any referrals required at the time of your genetic result. They have also set a review date according to your age, gender, previous medical history and the specific genetic diagnosis. At this date we will review your notes to check your cancer risk management plan is up to date. We may contact you to offer an appointment, screening, referrals to other services or recruitment to genetic studies.

We hope the periodic contact from our team will help remind you to review your cancer risk management options as you get older. It remains your responsibility to request follow up appointments and/or referrals by contacting the Cancer Genetics team.

## **What if I need advice about my genetic diagnosis?**

If you are on the Carrier Register, you can call the department to request a follow up appointment in our carrier clinic. You can also ask to speak to the on-call genetic counsellor if you have a simple query that can be dealt with on the telephone. You can also contact the department via the My Marsden patient portal. If you wish to sign up for the portal, please go to [www.royalmarsden.nhs.uk/mymarsden](http://www.royalmarsden.nhs.uk/mymarsden)

You do not have to wait for a letter from the Cancer Genetics Unit to request an appointment.

## **What are the other benefits to being on the Carrier Register?**

We will contact you if there are any research studies which may be of relevance to you or your family and can let you know if we are running a patient information day.

## **How can I remove my name from the register?**

If you do not want your name on the Carrier Register, we can mark your file accordingly. Please contact the department on the telephone number below to request this. Patients who have asked to be removed from the Register will also be discharged from the Cancer Genetics Unit and will need to seek a re-referral if they wish to be seen again in the future.

## Where can I get more information?

Patient Information leaflets for the Cancer Genetics Unit are held in The Royal Marsden patient library. Please go to [www.patientinfolibrary.royalmarsden.nhs.uk](http://www.patientinfolibrary.royalmarsden.nhs.uk)

Enter the word *Genetics* in the search field to find the Cancer Genetics Unit leaflets.

## Contact details

Telephone: 020 8661 3375

Email: [cancergenetics@rmh.nhs.uk](mailto:cancergenetics@rmh.nhs.uk)

Website: [www.rmh.nhs.uk](http://www.rmh.nhs.uk)

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

## The Royal Marsden Macmillan Hotline:

020 8915 6899 (available 24 hours a day, 7 days a week)

## References

This leaflet 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 leaflet are available on request from:

The Royal Marsden Help Centre

Telephone: Chelsea 020 7811 8438 / 020 7808 2083

Sutton 020 8661 3759 / 3951

Email: [patientcentre@rmh.nhs.uk](mailto:patientcentre@rmh.nhs.uk)

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