
Carrier Register

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 have a mutation in a gene that could increase their risk of cancer, or are at risk of inheriting a familial mutation and are in the process of deciding if they would like testing.

How is information on the Carrier Register stored?

The Carrier Register is part of a database (called Trakgene), used in the Cancer Genetics Unit which contains information about Cancer Genetics patients at The Royal Marsden. The database can produce a list of all our patients who have mutations – this list is our Carrier Register. Information stored within Trakgene is kept confidentially and is separate from the main electronic medical records database, 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 and was established to help us manage the long term follow up of mutation carriers.

If you carry a mutation there will be different issues arising for you at different stages of your life. From year to year your risk management plan may not change significantly, so there is no need for you to be seen every year by the genetics clinic. By establishing the Carrier Register we have a system to recall and contact patients at key points to ensure their management plan is up to date.

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

Initially the doctor or genetic counsellor who arranged your genetic testing will set a review date dependant on your personal circumstances. Once you have had all the appointments you need following on from your genetic diagnosis, the file will be marked for review on the Carrier Register at specific intervals; depending on your age, gender and genetic diagnosis.

We will review your notes at these stages and may send you a clinic appointment, refer you for cancer surveillance or write to ask you if you would like a clinic appointment.

What if I need advice about my genetic diagnosis?

If you are on the Carrier Register you can call the department at any time 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 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/

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

Website: 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

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