Royal Marsden Cancer Genetics Unit

Genetics Unit resources pack (MCG GRP1)

Please read all the information in this pack. You may also find it useful to return to this information.
You should use the information in conjunction with the Breast Unit BRCA testing learning resources pack (MCG LRP1) and the Gynae Unit BRCA testing learning resources pack (MCG LRP2).
You should also view the e-learning modules MCG ELM1, MCG ELM2, MCG ELM3a, MCG ELM3b and MCG ELM4.

The pack includes the following:

- MCG GU SOP1 – Genetic Unit standard operating procedure for returning results
- MCG IS1 – BRCA1 and BRCA2 gene testing - Information sheet for patients with cancer
- MCG IS2 – Receiving a normal BRCA1 and BRCA2 test result - Information sheet for patients with cancer
- MCG IS3 – Receiving a BRCA1 and BRCA2 test result that identifies a mutation - Information sheet for patients with cancer
- MCG IS4 - Receiving a BRCA1 and BRCA2 test result that identifies a variant requiring evaluation (VRE) - Information sheet for patients with cancer
- MCG GRL1 – Template genetics results letter for BRCA testing through mainstreaming pathway – No mutation identified
- MCG GRL2 – Template genetics results letter for BRCA testing through mainstreaming pathway – Mutation identified
- MCG GRL3 – Template genetics results letter for BRCA testing through mainstreaming pathway – Variant requiring evaluation identified

Genetic Unit standard operating procedure for returning results

NO MUTATION	MUTATION	VARIANT REQUIRING EVALUATION (VRE)
1. Test report, letter (MCG GRL1) + information sheet (MCG IS2) sent to patient[1,2]. 2. Test report + letter (MCG GRL1) sent to Cancer Team[1]. 3. Genetics appt only sent if requested.	1. Test report, letter (MCG GRL2), information sheet (MCG IS3) + *FHQ sent to patient[1,2]. 2. Test report + letter (MCG GRL2) sent to Cancer Team[1]. 3. Genetics appt sent to patient.	1. Test report, letter (MCG GRL3), information sheet (MCG IS4) + *FHQ sent to patient[1,2]. 2. Test report + letter (MCG GRL3) sent to Cancer Team[1]. 3. Genetics appt sent to patient.

Notes:
[1]See genetics result letters 1-3 (MCG GRL1-3)
[2]See information sheets 1-3 (MCG IS1-4)
*FHQ = Family history questionnaire

BRCA1 and BRCA2 gene testing

Information sheet for patients with cancer

In most people cancer occurs by chance. In a minority of people with ovarian cancer (about 15%) or breast cancer (about 3%), cancer occurs because they have a mutation in the BRCA1 or BRCA2 gene. BRCA1 and BRCA2 mutations result in increased risks of breast and ovarian cancer. They occur more frequently in women who have both breast and ovarian cancer, those with particular types of cancer, and if there is a strong family history of breast and/or ovarian cancer. It is important to identify if a cancer is due to a BRCA1 or BRCA2 mutation because it provides you and your doctors with information that can help treat your cancer and to reduce your risk of future cancer. It can also provide information for relatives about their risks of cancer.

Why am I being offered this test?
You are being offered a test to look for mutations in BRCA1 and BRCA2 because of your cancer diagnosis.

What are the benefits to me?
Knowing whether or not you carry a mutation in BRCA1 or BRCA2 gives the cancer team more information about your cancer. This can help decisions about the treatments they recommend for you, for example which chemotherapy drugs or surgery would be most suitable. It will also give better information about your risk of developing cancer in the future.

Does having the test have implications for my family?
In most people the test will be normal and we will not find a gene mutation. This would be reassuring for relatives as it would indicate that your cancer was unlikely to be due to hereditary factors that would put them at very high risk of cancer. If your test shows you have a gene mutation, it is possible that some relatives also have the mutation. Relatives would be able to discuss this with a specialist geneticist and have a test if they chose to.

What will happen if NO mutation in BRCA1 or BRCA2 is found?
This is the most likely outcome, as most women with cancer do not have a mutation in BRCA1 or BRCA2. This would be reassuring in suggesting you are unlikely to be at high risk of developing another, new cancer in the future. The cancer team will be able to use this information in their management decisions. Very occasionally mutations in other genes can be involved in causing breast or ovarian cancer. Also new discoveries are

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being made all the time. If a new gene test becomes available in the future the genetics team may be able to do the test using the sample you have already provided and would send the result to you and the cancer team. If your doctors think other genetic factors might be involved in your cancer they can ask the genetics clinic to send you an appointment to evaluate this, if you have not already had an appointment with genetics.

What will happen if a BRCA1 or BRCA2 mutation is found?
Your cancer team will use the information in their management decisions. The genetics team will send you an appointment to discuss the results and address any questions you have. They will also discuss what the test result means for your future risk of cancer, your options for future screening and measures to reduce these risks. They will evaluate your family history and can provide information for the appropriate family members should they wish to consider testing to see if they have inherited the mutation. Any relatives can be referred to a Genetics Unit, either at the Royal Marsden or more locally to them, to discuss this further.

What will happen if the test result is unclear?
Very occasionally (<1%) we find a gene change, known as a 'variant', that needs further assessment before we can decide if it is linked to why you have had cancer. If this occurs, the genetics team will send you an appointment to explain the result and to discuss with you what further information and/or tests would be helpful to find out if the variant is linked to your cancer.

Do I have to have the test?
No, having this test is optional. Your decision will not affect the standard of care you receive from the hospital or doctor, which will be based on the available information.

What if I am not sure if I want to have the test?
We would recommend for you to have further discussions with a specialist member of the genetics team.

What will happen next if I say yes?
If you decide to have the test, you will be asked to sign a consent form. A blood sample will be taken for the test.

How will I receive the results of the test?
The genetics team will send you and your cancer team the results of the test by post. The results may take up to 8 weeks, but will usually be within 4-6 weeks.

Will my information be confidential?
All data collected about you will be held under the provisions of the 1998 Data Protection Act and stored in secure files. The only people who will know your identity are the hospital staff and a few trained staff reporting the results who are bound by a professional duty to protect your privacy.

If you have any questions please contact the Royal Marsden Cancer Genetics Unit on 0208 661 3375 or cancergenetics@rmh.nhs.uk

Receiving a normal BRCA1 and BRCA2 test result

Information sheet for patients with cancer

You had a BRCA1 and BRCA2 gene test because you have had cancer.
The test result is normal.
No BRCA1 or BRCA2 mutation (gene change) was identified in your blood sample.

What does this result mean for me?
This means we have not found a BRCA1 or BRCA2 mutation which would put you at high risk of developing another cancer. The cancer team will discuss if this normal result has any implications for your cancer management.

A normal result is common. In most women with breast and/or ovarian cancer no mutation in BRCA1 or BRCA2 is found. If you have a strong family history of breast and/or ovarian cancer, or a strong family history of other cancers, or if you developed cancer at an unusually young age, it may be helpful to look into things further. The genetics or cancer team will discuss this with you, if appropriate.

Very occasionally mutations in other genes can be involved in causing breast or ovarian cancer. Also new discoveries are being made all the time. If a new gene test becomes available the genetics team may be able to do the test using the sample you have already provided and they will send the result to you and your cancer team.

What does this result mean for my relatives?
This result is good news for your relatives, as it means they are unlikely to be at high increased risk of developing breast and/or ovarian cancer themselves. You may wish to share this result with them.

All women are eligible to have mammograms from 47 years in the National Breast Screening Programme. Depending on the family history, some women may be eligible for mammograms from 40 years, even if there has been a normal BRCA1 or BRCA2 gene test in the family. There is currently no known effective form of ovarian screening. If a woman has multiple relatives with ovarian cancer removal of the ovaries is sometimes considered.

If any of your relatives wish to discuss their own risks of cancer further they should speak with their GP who can refer them for further discussions at a Family History or Genetics clinic.

If you have any further questions, please contact the Royal Marsden Cancer Genetics Unit on 0208 661 3375 or cancergenetics@rmh.nhs.uk

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Receiving a BRCA1 and BRCA2 test result that identifies a mutation

Information sheet for patients with cancer

You had a BRCA1 and BRCA2 gene test because you have had cancer.

The test result has shown that you have a mutation (gene change) in either the BRCA1 or BRCA2 gene. The exact details of the mutation are given in the test report.

BRCA1 or BRCA2 mutations result in increased risks of breast and ovarian cancer, and occasionally other cancers. Therefore this result provides an explanation for why you developed cancer.

Your cancer team will discuss with you if this result has implications for your cancer treatment and/or follow-up.

This result has implications for your future health and potentially for your relatives. An appointment has been made for you in the Genetics clinic to discuss these issues further. At the appointment you will be able discuss your future risks of cancer and your options for cancer screening and measures to reduce the risk of cancer. The potential implications for relatives will also be discussed. The processes by which your relatives can have discussions themselves to decide if they wish to have testing will be explained.

You may find it helpful to read the information booklet “A Beginner’s Guide to BRCA1 and BRCA2” which gives more detailed information. This can be downloaded from www.royalmarsden.nhs.uk/brca

If you need to discuss anything urgently prior to your appointment, or wish to alter the date of your appointment, please contact the Royal Marsden Cancer Genetics Unit on 0208 661 3375 or cancergenetics@rmh.nhs.uk

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Patient information

Receiving a BRCA1 and BRCA2 test result that identifies a variant requiring evaluation (VRE)

Information sheet for patients with cancer

You had a BRCA1 and BRCA2 gene test because you have had cancer.

The test result has shown that you have a gene change (variant) in either the BRCA1 or BRCA2 gene that requires further evaluation.

At the moment, we do not have enough information to decide if this variant is linked to why you have had cancer.

Variants in the BRCA1 and BRCA2 genes are common, and most do not cause cancer. Very occasionally, we find a variant that requires further assessment before we can decide if it leads to an increased risk of cancer. In some cases, we may need to do further blood tests to help us find out more about the impact of the variant.

We have made an appointment for you in the Genetics clinic to discuss your result further. At the appointment we will explain in more detail about the result and any further tests that may be required. We will also discuss the process and timeframe for deciding if the variant is likely to be linked to your cancer.

It is important for us to have as much information as possible when we see you. We have enclosed a family history questionnaire with your letter, and would be very grateful if you would fill this in and return it to us before we see you in clinic.

If you need to discuss anything urgently prior to your appointment, or wish to alter the date of your appointment, please contact the Royal Marsden Cancer Genetics Unit on 0208 661 3375 or cancergenetics@rmh.nhs.uk

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Template genetics results letter for BRCA testing through mainstreaming pathway

MCG GRL1 - NO MUTATION IDENTIFIED

Please insert appropriate text into the grey boxes in the template letter below.

Dear [patient],

You had a BRCA1 and BRCA2 gene test because you have had cancer.

We are writing with the results of the test. The test result is normal. No mutation was identified. We enclose the test report. We also enclose an information sheet which provides further details about this result. We have sent a copy of this letter to your cancer doctor so they know the test was normal.

If you have any questions about this result, please contact the Genetics Unit on [Genetics Unit contact details].

Yours sincerely,
[Genetics Team]

Enclosed**:** Test report, Information sheet MCG IS2
cc**:** [Cancer Team]

Template genetics results letter for BRCA testing through mainstreaming pathway

MCG GRL2 - MUTATION IDENTIFIED

Please insert appropriate text into the grey boxes in the template letter below.

Dear [patient],

You had a BRCA1 and BRCA2 gene test because you have had cancer.

We are writing with the results of this test. The test has identified a mutation (change) in [BRCA1/BRCA2 known as XXXX] in your blood sample. We enclose your test report. This result may have implications for your cancer treatment and/or follow-up. Your cancer doctor will discuss this with you. It also has implications for your future health and may have implications for your relatives.

We enclose an information sheet with some basic information. You may also like to read the information booklet, "A Beginner's Guide to BRCA1 and BRCA2" which can be downloaded from www.royalmarsden.nhs.uk/brca.

An appointment has been made for you to meet with a member of the Genetics team to discuss the issues in more detail.

The appointment is on [date/time] at [place].

If this appointment is not convenient please contact us on [Genetics Unit contact details] so we can rearrange it.

We enclose a Family History Questionnaire for you to complete and bring to your appointment so we can evaluate which relatives could benefit from gene testing. After your appointment we will provide you with a letter to give to other family members so they can arrange an appointment to discuss testing, should they wish to.

Yours sincerely,
[Genetics Team]

Enclosed: Test report, Information sheet MCG IS3, Family History Questionnaire FHQ
cc**:** [Cancer Team]

Template genetics results letter for BRCA testing through mainstreaming pathway

MCG GRL3 - VARIANT REQUIRING EVALUATION IDENTIFIED

Please insert appropriate text into the grey boxes in the template letter below.

Dear [patient],

You had a BRCA1 and BRCA2 gene test because you have had cancer.

We are writing with the results of this test. The test has identified a [BRCA1/BRCA2] gene variant (change) that requires further evaluation. We enclose the test report. We also enclose an information sheet which provides further details about this result. An appointment has been made for you to meet with a member of the Genetics team to discuss the result in more detail.

The appointment is on [date/time] at [place].

If this appointment is not convenient for you please contact us on [Genetics Unit contact details] so we can rearrange it.

We enclose a Family History Questionnaire for you to complete and bring to your appointment. This information will help us in our evaluations.

Yours sincerely,
[Genetics Team member name]

Enclosed: Test report, Information sheet MCG IS4, Family History Questionnaire FHQ
cc**:** [Cancer Team]