

INFORMATION SHEET
THE UK GENETICS OF TESTICULAR CANCER STUDY
(CoREC number 06/MRE06/41)

Information sheet for testicular cancer patients

We are members of a research team working on the causes of testicular cancer and we would like to invite you to take part in the study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of this study?

The causes of testicular cancer are unknown. Studies have shown that testicular cancer has a genetic component although it is rare for testicular cancer to affect more than one member of a family. This study aims to recruit 3000 men to examine the causes of testicular cancer and to identify genes that may be important in the development of this disease.

Why have I been chosen?

You have been invited to participate in this study as you have had testicular cancer.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to change your mind and withdraw at any time and without giving reason. This will not affect the standard of treatment or care you receive.

What will happen to me if I take part?

If you agree to participate, there are several parts to the study.

- You will be asked to sign a consent form.
- You will be sent a questionnaire to complete with questions about yourself and members of your family (their names, ages and whether any of them have had cancer or an undescended testis). Please check first that they are happy for you to give us their details.
- You will be asked for a small sample of blood (4 teaspoons) from which the genetic material (DNA) will be stored and used for research aimed at understanding the genetic influences of testicular cancer. All samples will be stored indefinitely and will be used for *research* purposes only. No diagnostic genetic testing will be performed. It should be noted that this is research only and for that reason will *not* have any insurance implications. It is unnecessary to disclose to your health insurers that samples have been taken for this study as there will be no individual diagnostic information from this study.
- We will request the donation of a tissue sample from your original operation that is surplus to clinical requirements. These samples would be for research purposes only and will be stored indefinitely; no diagnostic genetic testing will be performed without your consent. It should be noted that this is research *only* and for that reason will *not* have any insurance implications.
- You may be asked to approach your parents to see if they would help with this study by providing a small blood sample for which genetic material (DNA) would be stored and used for research aimed at understanding the genetic influences of testicular cancer. No member of your family will be contacted directly by us except through permission from you.
- We will request to view your medical records

What are the possible disadvantages of taking part?

There may be a small amount of discomfort from taking the necessary blood sample and there is a small chance that you may experience bruising around the area where the blood sample has been taken.

What are the possible benefits of taking part?

This study is likely to take many years. We cannot promise that the study will help you directly, however the information we get might help future patients with testicular cancer. If we can discover more about the causes of testicular cancer we may be able to develop new treatments to combat or even prevent the disease.

Will I be contacted again?

We may wish to re-contact you to discuss your form in more detail, for further information or if a point on the form requires clarification. We may wish to contact you again with regard to research into the genetics of testicular cancer, particularly if you tell us you have another family member that also has the disease. We would not necessarily require another blood sample from you as any tests could be performed on the samples you have provided for this study. However we may ask for additional information about your family. If this was the case we would also send another information sheet and consent form for the relevant research. The results of the research will be available for the study as a whole and not for any specific individual.

Will my taking part in the study be kept confidential?

We will contact your GP with your permission, to let them know that you are taking part in the study. If you consent to take part in the research an authorised member of staff may inspect your medical records for the purposes of analysing the results. Any information you give us will be considered and kept strictly confidential and no member of your family will be contacted by us, except through yourself. Information is stored on a database adhering to guidelines set out in the Data Protection Act.

What if there is a problem?

If you have any concerns about the study either before or after you have taken part please contact Mrs Dudakia. Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. If you have any complaints about the study or procedure please contact the chief investigators, Dr Huddart or Dr Rapley whose contact details are given below and we will endeavour to address them. If you are unsatisfied by our response or have a complaint regarding your treating hospital the standard NHS complaint procedures remain available to you.

Who is organising and funding the research?

The research is being organised by the Testicular Cancer Genetics Team within the section of Cancer Genetics. The research is funded by Cancer Research UK.

What will happen to the results of the study?

We cannot provide any individual feedback from the study. The overall results of the study will be available and research will be presented as research publications – nobody will be identified in these publications.

Who has reviewed the study?

The study has been reviewed by the Royal Marsden Hospital Committee for Clinical Research, Cancer Research UK programs committee and has received ethical approval from the South West MREC (Research and Ethics committee) (06/MRE06/41 and approval date).

Contact Details

If you have any questions regarding this study please contact Mrs Darshna Dudakia on 0208 722 4053 or one of the other members of the study team whose names and contact details are listed at the end of this information sheet.

Thank you reading this information sheet and considering taking part in this study

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