

What is the purpose of the study?

We know little about why some people develop lymphoma and why patients respond differently to treatments for lymphoma. We aim to find the causes of lymphoma and how to improve the use of our medical treatments for lymphoma in the future.

Who is doing the study?

The study is being organised by the Epidemiology and Genetics Unit at the University of Leeds and is funded by the Leukaemia Research Fund, which is a registered charity (Charity Number 216032).

Why have I been chosen?

Adults aged between 16 and 69 years and living in Yorkshire, Lancashire, Cumbria or South Lakeland have been chosen in one of two ways. All adults who have been recently diagnosed with lymphoma are being invited to take part. With their GP's consent, a sample of adults who do not have lymphoma are being asked to help on a voluntary basis.

What does the study involve?

If you decide to take part, a researcher will ask you to read and sign a consent form. With your permission, we would like to:

- interview you about your health and lifestyle.

- ask you to give a mouthwash sample.
- carry out research on a blood sample and a tissue sample which were taken when you were diagnosed.
- access, examine and record information from your medical records.
- possibly invite your family members to help in a further study.

On the consent form, you can give your permission to whichever parts of the study you would like to assist with. If there is any part of the study you would not like to be involved in, your wishes will be respected.

What does the interview involve?

A researcher will ask you some general questions about your health and your family's health, addresses where you have lived, and jobs you have held. The interview generally takes about 1 hour. A researcher can visit you at a place and time that is convenient with you.

Why do you need a mouthwash sample from me?

If you agree, you will be asked to donate a mouthwash sample. This will be stored anonymously and used for future research into the biological basis and treatment of lymphomas.

Why do you need my blood and tissue samples?

We would like to use samples of blood and tissue you may have had taken when you were first diagnosed with lymphoma. These samples will allow DNA to be stored and used for future research into the biological basis and treatment of lymphomas.

Will I be given any results?

Neither you nor your doctor will be told the results from these samples nor will the results guide treatment decisions. These samples will not be used for "genetic tests", so if asked by insurance companies if you have had any genetic tests, you can answer no.

Why do you need to access my medical records?

It would be useful for us to know more details about any illnesses you may have had, and any medicines and treatments you may have been prescribed.

Why do you want my family to help in the study?

Using the information you supply when you are interviewed, we will identify a number of families who we would like to be involved in further research. If we would like your family to be involved, we will contact you to ask if

we can approach your family members.

How do you ensure confidentiality?

All data provided will be kept under conditions of strict security, as required by the Data Protection Act. Information is processed by a restricted number of staff working on the study, all of whom have been trained in confidentiality procedures. No personal information is ever released to unauthorised individuals, groups or companies. No individual is ever identified in any published material.

How do I know the study is ethical?

This research is carried out with the approval of your local research ethics committee. The members of this committee include doctors, health professionals and lay people.

Why should I help?

Between January 1998 and December 2004, we aim to invite 1400 adults with lymphoma and 1400 adults without lymphoma to take part in the study. By collecting a broad range of information from you and other adults, this important study could improve the understanding of the causes and treatment of lymphoma. We would really appreciate your help in our study.

What should I do now?

Please indicate whether or not you would like to participate in the study on the attached reply form and return the form in the enclosed stamped addressed envelope. If you agree to participate, a researcher will contact you shortly.

You are under no obligation to participate in the study. If you decide to take part, you are free to withdraw at anytime without giving a reason. Whatever your decision, it will not affect the standard of care you receive.

THANK YOU FOR SPARING THE TIME TO
READ THIS LEAFLET.



For further information, please contact:

Mrs Jan Parker
Epidemiology & Genetics Unit
Margaret Smith Building
University of Leeds
Leeds LS2 9JT
Freephone: 0000 000 0000
Email: enquiries@lf.leeds.ac.uk



Lymphoma Study

INFORMATION

University of Leeds

You are being invited to take part in a research 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. If after reading this leaflet you would like more information, you can find contact details on the back page.