

### **What is the purpose of the study?**

This health study aims to find out the causes of lymphoma. Lymphoma is a disorder which starts in the lymph glands or organs such as the liver, spleen, bowel and bone marrow. We know little about why some people develop lymphoma.

### **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?**

**As a person who does not have lymphoma**, we would like to compare information you give with information supplied by persons with lymphoma. Adults who have recently been diagnosed with lymphoma living in Yorkshire, Lancashire, Cumbria or South Lakeland have already been approached to take part. Your GP has given permission for us to approach you. We would like to invite you to take part in this study.

### **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 and a small blood sample.
- access, examine and record information from your medical records.

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 mouthwash and blood samples from me?**

If you agree, you will be asked to donate a mouthwash sample. A trained person will also take a small blood sample at a time convenient to you. These samples will allow DNA to be stored anonymously and used for future research into the biological basis of serious medical conditions.

### **Will I be given any results?**

Neither you nor your doctor will be told the results from these samples. 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.

### **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 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.

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@lrf.leeds.ac.uk](mailto:enquiries@lrf.leeds.ac.uk)**



## **A Health 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.***