CANCER RESEARCH UK & UCL CANCER TRIALS CENTRE
UCL CANCER INSTITUTE

University College London
90 Tottenham Court Road
London W1T 4TJ
website: http://www.ctc.ucl.ac.uk/

Director: Professor JA Ledermann

Study title: A randomized trial for adults with newly diagnosed acute lymphoblastic leukaemia
IRAS no: 23389

UKALL14 Transparency Statement
Information about how your data are processed

Details about you, your treatment, any side effects you have, how your cancer responds to treatment, and how you are during and following study treatment will be recorded in your medical notes. The study information collected will be used to help improve our knowledge of treating ALL. This is in the public interest as it may lead to improvements in future treatments.

University College London (UCL) is the sponsor for this study based in the United Kingdom. UCL will be using information from you and your medical records in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. UCL will keep identifiable information about you for at least 5 years after the study has finished, as required by law for clinical trials.

Your rights to access, change or move your information are limited, as UCL need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, UCL will keep the information about you that we have already obtained. To safeguard your rights, UCL will use the minimum personally-identifiable information possible.

You can find out more about how UCL use your information at http://www.ctc.ucl.ac.uk/Privacy.aspx. This includes details of how to contact UCL's data protection officer and how to make complaints to the Information Commissioner's Office (ICO).

Your hospital will collect information from you and your medical records for this research study in accordance with our instructions.

Your hospital will use your name, NHS number and contact details to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study.

Individuals from UCL and regulatory organisations may look at your medical and research records to check the accuracy of the research study. Your hospital will pass your NHS number, initials and date of birth to UCL along with the information collected from you and your medical records. The only people in UCL who will have access to information that identifies you will be people who audit the data collection process. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details.

Your date of birth and initials may be marked on samples that are sent to the central laboratories for the trial. This helps to ensure that the samples are not mixed up with samples for another patient by mistake. The laboratories will store your information securely and will not share it with anyone else.

Your hospital will keep identifiable information about you from this study for at least 5 years after the study has finished.

UCL will collect information about you for research from your hospital site. This information will include your NHS number, initials, date of birth and health information, which is regarded as a special category of information. UCL will use this information to conduct our research.

When you join the study, you will be assigned a unique study number. This study number will be used instead of your name and will be linked to all of your study data. This is called pseudonymised data, and you cannot be personally identified from this.

When you agree to take part in a research study, the information about your health and care may be provided to researchers running other research studies in UCL and other organisations. These organisations may be universities, NHS organisations or companies involved in health and care research in this country or abroad. Your information will only be used by organisations and researchers to conduct research in accordance with the UK Policy Framework for Health and Social Care Research**.**

Your information could be used for research in any aspect of health or care, and could be combined with information about you from other sources held by researchers, the NHS or government.

Where this information could identify you, the information will be held securely with strict arrangements about who can access the information. The information will only be used for the purpose of health and care research, or to contact you about future opportunities to participate in research. It will not be used to make decisions about future services available to you, such as insurance.

Where there is a risk that you can be identified, your data will only be used in research that has been independently reviewed by an ethics committee.