Local Contact Details

Patient Information Sheet – General Data Protection Regulation (GDPR)

Trial Title: AML17 - Working parties on Leukaemia in adults and children trial in acute myeloid leukaemia or high risk myelodysplastic syndrome 17
EudraCT number: 2007-003798-16
Trial Sponsor: Cardiff University
Chief Investigator: Professor Nigel Russell

Local Investigator: _____

Cardiff University is the sponsor for the AML17 trial based in the United Kingdom. We will be using information from you and/or your medical records in order to undertake this trial and will act as the data controller for this trial. This means that we are responsible for looking after your information and using it properly. Cardiff University will keep identifiable information about you for a minimum of 15 years after the trial has finished.

Under data protection law, the University has to specify the legal basis that we are relying on to process your personal data. In providing your personal data for this research we will process it on the basis that doing so is necessary for our public task for scientific and historical research purposes in accordance with the necessary safeguards, and is in the public interest. The University is a public research institution established by royal charter to advance knowledge and education through its teaching and research activities. The charter can be found on the Cardiff University website.

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

Cardiff University has a Data Protection Officer who can be contacted at inforequest@cardiff.ac.uk. Further information about Data Protection, including your rights and details about how to contact the Information Commissioner's Office should you wish to complain about how your personal data has been handled, can be found at https://www.cardiff.ac.uk/public-information/policies-and-procedures/data-protection

[NHS site] will collect information from you and your medical records for this research trial in accordance with our instructions.

[NHS site] will keep your name, NHS number and contact details confidential and will not pass this information to Cardiff University. [NHS site] will use this information as needed, to contact you about the research trial, and make sure that relevant information about the trial is recorded for your care, and to oversee the quality of the trial. Certain individuals from Cardiff University and regulatory organisations may look at your medical and research records to check the accuracy of the research trial. Cardiff University will only receive information without any identifying information. The people who analyse the

information will not be able to identify you and will not be able to find out your name, NHS number or contact details.

[NHS site] will keep identifiable information about you from this trial for a minimum of 15 years after the trial has finished.

When you agree to take part in a research trial, the information about your health and care may be provided to researchers running other research studies in this organisation and in 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**.**

This information will not identify you and will not be combined with other information in a way that could identify you. The information will only be used for the purpose of health and care research, and cannot be used to contact you or to affect your care. It will not be used to make decisions about future services available to you, such as insurance.

Thank you for taking the time to read this additional information sheet in relation to your data protection rights. If you have any questions please ask your Consultant and/or Research Nurse.