



UNIVERSITY OF
BIRMINGHAM

NHS REC reference: 11/WM/0220

TEAMM- Tacking early morbidity and mortality in myeloma patients

DATA TRANSPARENCY STATEMENT

University of Birmingham and The University of Warwick are both the sponsors and Data Controllers for this study based in the United Kingdom. The University of Birmingham and University of Warwick will be using information from you and your medical records in order to undertake this study. This means that we are responsible for looking after your information and using it properly. The University of Birmingham and University of Warwick will keep identifiable information about you for at least 5 years after completion of the study. Blood and Urine samples collected from you as part of the study will be held in an NHS Laboratory for up to 10 years and will not be used for any testing that is not related to this study.

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 study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

As a University and NHS organisation, we use personally-identifiable information to conduct research to improve health, care and services. As publicly-funded organisations, we have to ensure that it is in the public interest when we use personally-identifiable information from people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use your data in the ways needed to conduct and analyse the research study. You can find out more about how we use your information here:

<https://warwick.ac.uk/services/idc/dataprotection/privacynotices/researchprivacynotice>

<https://www.birmingham.ac.uk/research/activity/mds/trials/crctu/crctu-privacy-notice>

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

Your NHS Hospital will use your name, NHS number, hospital 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 University of Birmingham, The University of Warwick, and NHS organisations may look at your medical and research records to check the accuracy of the research study. **Your NHS Hospital** will pass these details to the sponsors on your behalf along with the information collected from you and your medical records. 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.

Your NHS Hospital will keep identifiable information about you from this study for at least 5 years after completion of the study. Blood and Urine samples collected from you as part of the study will be held in an NHS Laboratory for up to 10 years and will not be used for any testing that is not related to this study. 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 University of Birmingham, The University of Warwick and in other organisations. These organisations may be universities, NHS organisations, charities 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.