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GDPR INFORMATION TO BE PROVIDED TO ALL PARTICIPANTS

We will be using information from you and/or your medical records in order to undertake this study. Research is a task that we perform in the public interest. The University of Oxford, as sponsor, is the data controller. This means that we, as University of Oxford researchers, are responsible for looking after your information and using it properly. We will use the minimum personally-identifiable information possible. If you have consented to be approached to take part in future ethically approved research studies, we will keep your contact details for more than 3 years after the study has finished. We will store the anonymised research data and any research documents with personal information, such as consent forms, securely at the University of Oxford for 20 years after the end of the 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. You can make changes to your consent preferences within your profile page in RUDY concerning what happens to your data. If you withdraw from the study, we will remove your webpage and any information you have given us. It will not be possible to remove or recall any information that has been anonymised and made available for research analyses. To safeguard your rights, we will use the minimum personally-identifiable information possible. You can find out more about how we use your information by contacting rudy@ndorms.ox.ac.uk. Further information about your rights with respect to your personal data is available at <http://www.admin.ox.ac.uk/councilsec/compliance/gdpr/individualrights/> If you have given consent to participate in this research,, RUDY study (Oxford site) can use your name, NHS number and contact details including date of birth, telephone number and email/address 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 Oxford and regulatory organisations may look at your medical and research records to check the accuracy of the research study. RUDY study (Oxford site) will pass these details to University of Oxford along with the information collected from you and/or your

medical records. The only people in University of Oxford who will have access to information that identifies you, will be people who need to contact you for various reasons as per your consent choices or 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, NHS number or contact details.

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.

Yours sincerely,

Dr MK Javaid
Chief Investigator RUDY study