



Centre Number:

Participant Identification Number

**ADULT CONSENT FORM**

Title of Project: **Rare diseases of the bone, joint and vessels Study (RUDY)**

Name of Researchers: Dr M K Javaid and Professor R Luqmani  
 RUDY Study, Botnar Research Centre, Old Road, Oxford, OX3 7LD

*If you agree, please initial each box*

1. I confirm that I have read and understand the information sheet for this study. (Version 6; date 16/11/2015). I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.	
3. I agree to my GP being informed of my participation in the study.	
4. I agree to provide information about my events and their consequences using my secure personal profile on the RUDY website and for this information to be made available to the RUDY research team.	
5. I agree that my NHS records can be made available to researchers	
6. I agree that my social care records can be made available to researchers.	
7. I agree that my donated samples can be used in genetic research aimed at understanding the genetic basis for rare diseases and that any results that are clinically important as judged by the RUDY Data Oversight Governance Committee will be sent to the clinical team caring for me.	
8. I agree that any tissue removed in the course of medical care related to my condition may be used by the researchers. I consider this tissue a gift and I understand I will not gain any direct personal or commercial benefit from this.	
9. I agree that the data that is collected about me during the study may be looked at by the University of Oxford and Oxford University Hospitals NHS Trust, funding agencies, research governance monitors (where it is relevant to me taking part in this research) and also by both national and international academic researchers approved by the RUDY Data Access Committee that contribute to the aims and objectives of RUDY. I permit these individuals access to my research records.	
10. I agree that the data that is collected about me during the study may be looked at by both national and international industry researchers approved by the RUDY Data Access Committee that contribute to the aims and objectives of RUDY. I permit these individuals access to my research records.	
11. I agree that my anonymised samples/data can be deposited in research tissue banks where they can be used by other researchers, in both public and private sectors in the UK and internationally	
13. I agree for my data to be linked with the data from other research studies I have consented to using my NHS number, date of birth, surname and forename.	
14. I agree for my data to be linked to my relations whom I have indicated on my family history map using forename, surname and date of birth.	

15. I agree to be sent reminders about completing questionnaires and providing follow up information by letter, telephone, text message, or e-mail (please delete).	
16. I agree to be contacted about studies that I may be eligible for by letter, telephone, text message, or e-mail (please delete). I understand that agreeing to be contacted does not oblige me to participate in any further studies	
17. I would like to be sent updates on the progress of the study via the website, email, letter (please delete), whenever available, monthly, quarterly, annually (please delete).	

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

*For completion by person taking consent:*

\_\_\_\_\_  
Name of Person  
Taking consent.

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature