



**Consultant:**

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REC Reference: 16/SC/0346  
**CONSENT FORM FOR PATIENT - ADULT**  
**(Version 2, 1<sup>st</sup> October 2016)**

*Thank you for reading the information about our research project. If you would like to take part, please read and sign this form*

**Title of Project: Clinical Registry for Endocrine and Metabolic Disorders**

Name of Researcher: Professor R V Thakker

*Please initial box*

1. I have read the attached information sheet on this project dated 1<sup>st</sup> October 2016 (Version 2) and have been given a copy to keep. I have had the opportunity to consider the information, ask questions about the project and have had these answered satisfactorily.
2. I understand that my participation is voluntary, and that I am free to leave the study at any time, without having to give a reason for leaving, and without this affecting my medical care or legal rights. I understand that my consent will be assumed to continue after my death unless I indicate otherwise.
3. I give permission for someone from the research team to look at my medical records to get information on this endocrine and metabolic condition. I understand the steps that have been taken to keep my personal details confidential and that such details will be stored on secure, password-protected databases. I understand that if this data has been fully anonymized, i.e. can not be traced back to me, then it will not be possible to withdraw its use from the study.
4. I understand that data collected during the study may be looked at by authorized individuals from the University of Oxford, the *[insert name of participating hospital]*, funding agencies and study monitors, where it is relevant to my taking part in this research. I permit these individuals access to my research records.
5. I consider these data a gift, and understand that I will not benefit financially if this research leads to the development of a new treatment or medical test.

6. I understand that for some research and teaching it may sometimes be helpful to publish facial (or other) photographs as this may aid other doctors in recognising the condition. We would disguise the photograph so that you cannot be identified from it. I give permission for such use of photographs.
7. I know how to contact the research team if I need to, and how to get information about the results of the research.
8. I understand that data collected during the study will be stored in a national registry that will record only clinical details in an anonymized form, so that the prevalence and natural history, e.g. dietary and environmental factors, that may modify the disease can be determined. I agree that the information gathered about me can be stored by Professor R V Thakker at the Radcliffe Department of Medicine, University of Oxford, for possible use in future related projects that are investigating similar conditions.
9. I understand that some of these projects may be carried out by researchers other than Professor R V Thakker's Academic Endocrine Unit, Oxford, who ran the first project, including researchers working for commercial companies. This registry will be accessed by external researchers only if approved by the Data Access Committee. I understand that if the data is used for these other projects, then the data will be used in an anonymized form.
10. I understand that future research using the data I give may include research aimed at understanding the genetic influences on endocrine and metabolic conditions, but that the results of these investigations may not have any implications for me personally.
11. I understand that the research may produce findings of direct clinical significance for me, such as identification of a high risk of developing a particular problem that would benefit from earlier screening and interventions. I would\* / would not\* like to be informed of these findings. (\*delete as applicable)
12. I understand that it may be desirable for researchers to contact me should further clarification of family history or clinical information be required. I am\* / am not\* happy to be contacted either by \*telephone / \*letter / \*email to provide this information. (\*delete as applicable)
13. I want\* / do not want\* to be provided with information to participate in another research study that will collect tissue samples (i.e. blood, urine) to identify new genetic causes of endocrine and metabolic disorders. (\*delete as applicable)
14. I would\* / would not\* like my GP to be informed of my participation in this study. (\*delete as applicable)

***Additional – this section is optional and not part of the main study***

15. I would\* / would not\* like to be informed of opportunities to participate in related research. I give consent for my contact details to be retained in order to recontact me. I understand that this does not commit me to any future involvement. (\*delete as applicable)

*Please provide details of most suitable contact address and telephone numbers, and times when we may contact you on attached sheet.*

_____ Name of Patient (BLOCK capitals)	_____ Date	_____ Signature
Address		
_____		
_____		

_____ Date of birth	_____ Telephone number	_____ Times and dates for contact
_____	_____	_____

_____ Researcher	_____ Date	_____ Signature
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**Thank you for agreeing to participate in this research**

1 for patient; 1 for researcher; 1 to be kept with hospital notes