



STUDY NAME: ENDURE

CI: Professor Andrew Hattersley

Understanding beta cell disorders through the study of rare genotypes

Version: 2 1 May 2024

Participant ID:

Adult Participants (16+ y)

CORE STUDY CONSENT STATEMENTS <i>(applicable to all participants)</i>	Please circle answer	Please initial
I have been given the ENDURE Core Study information leaflet [Version, dated/...../.....].	YES / NO	
I have had the opportunity to ask questions, and these have been answered fully.	YES / NO	
I agree to: <ul style="list-style-type: none"> • have an appointment(s) as detailed in the ENDURE study information leaflet. • provide information about my health for use in this study. • allow the research team to contact my clinicians/GP about my clinical care now and in the future. • my de-personalised samples and data being shared to support future research in and outside the UK, including with commercial partners. • my samples and data being stored for the duration of the study. 	YES / NO YES / NO YES / NO YES / NO YES / NO	
I agree to: <ul style="list-style-type: none"> • provide blood samples for analysis, including genetic studies using DNA, as detailed in the ENDURE study information leaflet. 	YES / NO	
I understand that: <ul style="list-style-type: none"> • my participation is voluntary and that I may withdraw at any time without my clinical care being affected. • samples and data I provide are gifted to the ENDURE study team and I will not benefit financially should there be a future discovery or invention. • individuals from the study team, regulatory authorities or the UK NHS Trust will have access to relevant sections of my medical notes and data collected during the study for research, monitoring and audit purposes. • my research data and samples will be stored securely using an ID format to protect my identity. • my clinical samples will be sent for testing at the Exeter Clinical Laboratories, together with three forms of identifiable information (name, DOB, NHS/CHI/hospital number) in accordance with the NHS requirements for clinical sample analysis. • results produced by studying my samples and/or data may be included in publications with no connection to my name or other personal identifiers. Results may also be placed in electronic archives only accessible to researchers on application, to ensure the results are only used to advance scientific and medical understanding. 	YES / NO YES / NO YES / NO YES / NO YES / NO YES / NO	
I agree to take part in ENDURE Core Study.	YES / NO	

Continued overleaf



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IMAGING SUB-STUDY CONSENT STATEMENTS <i>(This is an additional sub-study which is only relevant if you have been invited to it.)</i>	Please circle answer	Please initial
I have been invited to take part in the Imaging Sub-Study.	YES / NO	
I have been given the ENDURE Imaging Sub-Study Flowchart [Version, dated/...../.....].	YES / NO	
I have had the opportunity to ask questions, and these have been answered fully.	YES / NO	
I agree to: <ul style="list-style-type: none"> • have an appointment(s) as detailed in the Imaging Sub-Study Flowchart that comes with the ENDURE core study information leaflet. • have an MRI scan (as detailed in Imaging Sub-Study Flowchart) at the Mireille Gillings Neuroimaging Centre (University of Exeter). • relevant sections of my medical notes and data collected during the study being accessed by responsible individuals from the University of Exeter, or the appointed service providers and NHS Trusts, or regulatory authorities, where it is relevant to my taking part in the research. I give permission for these individuals to access my records. • my data being stored for the duration of the study. 	YES / NO YES / NO YES / NO YES / NO	
I understand that: <ul style="list-style-type: none"> • data collected during my participation in the Imaging Sub-Study will be stored electronically on secure systems, and in secure paper formats, by the Mireille Gillings Neuroimaging Centre (University of Exeter). 	YES / NO	
I agree to take part in the ENDURE Imaging Sub-Study.	YES / NO	
OPTIONAL CONSENT STATEMENTS <i>(applicable to all participants)</i>		
I agree to gift my samples and data from the study, for storage and future research, to the Genetic Beta Cell Research Bank, managed by The Royal Devon University Healthcare NHS Foundation Trust's Exeter Genomics Laboratory.	YES / NO	
I agree that information held by the Exeter Genomics Laboratory and in my medical records may be used to follow up on my future health status.	YES / NO	
I agree to be contacted by the research team about taking part in future studies.	YES / NO	
PARTICIPANT NAME (PRINT)	TELEPHONE CONSENT DATE:	
SIGNED	VISIT CONSENT DATE:	
RESEARCHER / CLINICIAN I confirm that I have obtained informed consent from the above person.		
NAME (PRINT)	TELEPHONE CONSENT DATE:	
SIGNED	VISIT CONSENT DATE:	

When completed: 1 for participant; 1 for researcher site file; 1 for MGNC (if applicable).