

King's College Hospital

NHS Foundation Trust

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CONSENT FORM (Version 3, 22/01/2019)

Title of project: MND Population Register for England, Wales and Northern Ireland

Name of Principal investigators: Professor Ammar Al-Chalabi and Professor Kevin Talbot

Please initial box

1.	I confirm that I have read and understood the information sheet dated (Version 4 22.01.2019) for the above study. 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 understand that sections of my medical notes may be looked at by responsible individuals from King's College London, Oxford University, regulatory authorities, or the local care team to enter my details into the register. I give permission for these individuals to use my details to access follow-up data from GP records and the NHS Care Records Service.		
4.	By signing this document, I understand that I give consent for the storage of identifiable data on myself in the MND Population Register for England, Wales and Northern Ireland.		
5.	I understand that my de-identified, data will be shared with third parties including commercial entities, provided a legal agreement is in place.		
6.	I understand that the data I provide may be used to inform and plan future research		
7.	I understand that the results from future research may not have any direct implications for me or my family.		
8.	I am happy to consent to be included in this register.		
Additional:			
9.	I agree that I may be contacted about further ethically-approved research projects for which I may be suitable. I understand that agreeing to be contacted does not oblige me to participate in any further studies. This is optional – please initial yes or no.	Yes	No

 Name of Patient

 Date

 Signature

Name of person signing form (if patient unable to sign form): _____

 Name of health professional taking consent

 Date

 Signature

1 x form for Patient, 1 x form to be kept as part of the study documentation, 1 x form to be kept with medical notes (optional)