



Longitudinal Evaluation of the Growth and Acquisition of Clones over Years in the blood

Consent Form

Part	ticipant Identification Number:	
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1.	I confirm that I have read and understood the Participant Information Sheet (version dated) for the LEGACY study. The study procedures and information have been explained to me and I have had the opportunity to ask questions.	
2.	I understand my participation in this study is voluntary and that I am free to withdraw at any time, without giving a reason and without my legal rights being affected.	
3.	I understand that I will be contacted to schedule a study visit once every ~6 weeks (for a total of 12 visits) to provide blood samples (including a fingerprick blood sample), a saliva sample +/- a buccal swab sample and to answer a questionnaire related to my health and lifestyle.	
4.	I understand that any information I give will be treated in confidence.	
5.	I understand that my samples and data will be stored indefinitely unless I withdraw from the study and request that my samples and data are destroyed.	
6.	I give permission for the LEGACY research team to access my medical and other health-related records, including those held and maintained by my GP, NHS Digital, Health and Social Care Information Centre, Office of National Statistics, Public Health England, and other central UK NHS bodies, for up to 15 years, starting from the time of my enrollment in the LEGACY study. I understand that this may involve the LEGACY research team sending my name, date of birth, NHS number and postcode to these bodies to receive this information.	
7.	I understand that no results from tests (including genetic tests) on my samples will be given to me or my GP. I understand that the only exception to this is if results from non-genetic tests suggest the possibility of a significant and previously unknown health condition that requires further investigation. If this situation arises, I am happy for contact to be made with me and/or my GP.	
8.	I understand that I will not benefit financially from participating in this study.	
9.	I understand that my anonymised genetic information may be held indefinitely on international databases with controlled access for researchers worldwide.	*********
10.	I understand that I may be recontacted by the LEGACY research team after I have completed the 12 study visits (e.g. to provide further blood and/ or saliva and/ or buccal swab samples and to answer more questions). I understand that I am free to refuse without giving a reason.	
11.	I understand that I will be provided with a Fitbit, or can agree to use my own Fitbit for the purposes of the LEGACY study. I agree to authorize LEGACY research staff to access and download de-identified data gathered from my Fitbit, as detailed in the Participant Information Sheet (version), for ~18 months, starting from the time of my enrollment in the LEGACY study.	





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12.	I understand that in order for research staff to access my Fitbit data I will be asked to authorize a third party, Fitabase, owned and operated by Small Steps Labs LLC, via an online form. I understand that I may be sent a link, via email, to provide my authorization.								
	Please provide your preferred email address:								
	email address:								
13.	I understand that Fitabase is a research platform that collects data from internet connected consumer activity devices. I understand that Fitabase will connect to my Fitbit account to access and download my Fitbit data for ~18 months, starting from the time of my enrollment in the LEGACY study. I understand that any information I provide to Fitbit.com should be regarded as accessible by Fitabase.								
14.	I understand that I will not be required to give my Fitbit password or other personal information to LEGACY research staff and that my Fitbit username and password will not be accessed, viewed, or stored by Fitabase, Small Steps Labs LLC or any LEGACY research staff. I understand that a de-identified study ID number will be used within the Fitabase platform.								
15.	5. I understand that by authorizing Fitabase to access and store my Fitbit data I am agreeing to the Terms of Use and Privacy Policy set by Fitabase.								
16.	16. I agree to take part in the LEGACY study.								
Please indicate whether you would be happy to be notified (via email newsletter) of any publications arising from this study. Any results will be anonymous and you will not be identifiable from any data.									
	No	☐ Yes	email address (f different from above):					
PART B: Consent for use of samples and data in future research projects :									
1. I agree that my blood samples, saliva samples, buccal swab samples, Fitbit data and the information I have given as part of the LEGACY study can be used in future ethically approved research, which may include research collaborators in the UK and overseas and the commercial sector. I understand my right to confidentiality will be protected at all times.									
Please sign below to confirm that you agree to all the statements that you have initialed.									
Par	ticipant:	Signed:		Print name:		Date:			
Res	earcher:	Signed:		Print name:		Date:			