

CONSENT FORM

100,000 Genomes Project – Cancer Sequencing



Trial
Trial number
DOB

If you agree to take part, please initial each box and sign this form.

1. I have read and understood the information sheet for this study (Version ____ dated ____). I have had the opportunity to ask questions and have had these answered satisfactorily.	
2. I understand that my participation is voluntary, that I am free to withdraw at any time without giving a reason, and that withdrawing will not affect my present or future medical care and legal rights in any way.	
3. I agree to allow samples sent to the UK CLL Trials Biobank to be used for this research.	
4. I agree to allow a copy of this consent form to be sent to Genomics England	
5. I understand that any of my donated samples can be used to extract DNA for whole genome sequencing. This genetic information may be used in research aimed at understanding the genetic influences that contribute to the development of CLL and its response to treatment. Samples may also be used to study proteins and other structures.	
6. I understand that my DNA sequence and anonymised clinical data will be deposited in a secure database held by Genomics England, where they can be accessed by approved investigators from the public or private sectors, for scientific or clinical purposes. I agree to my sequencing data being stored in a secure database at the University of Oxford while the Genomics England database is being constructed.	
7. I understand that I will not gain any direct personal or commercial benefit as a result of taking part in this project, or in further research undertaken through resulting Genomics England research resource.	
8. I agree that Genomics England staff can collect and store securely information from my health care records, now and in the future. I agree to my GP being contacted and asked to share information about my medical history and to give access to medical records. I understand that Genomics England researchers will keep my information confidential. Information will only be passed on in a form that protects my identity.	
9. I understand that data collected during the study may be looked at by authorised individuals from Genomics England Ltd, and other study monitors where it is relevant to my taking part in this research. I permit them to access my medical records.	
10. I agree that if information is discovered from genetic and other testing by Genomics England related to my CLL or its treatment, this will be fed back to my clinician and may be discussed with me regarding its use in decisions about my treatment. I understand that it is not yet known how long it would take to receive such results.	
11. I understand and agree that I will NOT be informed of any results of genetic analysis of my sample where these are not relevant to the management of my CLL.	
12. I agree to be contacted in future about this study and other ethically approved research studies for which I may be suitable. I understand that agreeing to be contacted does not oblige me to participate.	
Name of participant (please print)	Signature
Date	

For completion by person taking consent: I confirm that the purpose of the research, its voluntary nature and its procedures have been explained in terms understandable to this participant.

Name (print)	Signature	Date