

Ethical framework for DECIPHER

The DECIPHER project was given Research Ethics Committee (REC) approval by Eastern MREC (04/MRE05/50) in 2004. Cambridge South REC is now responsible for the continued oversight of the study. The Research Ethics Service in the UK (<https://www.hra.nhs.uk/about-us/committees-and-services/res-and-recs/research-ethics-service>) is one of the Health Research Authority's core functions, committed to enabling and supporting ethical research in the NHS. It protects the rights, safety, dignity and wellbeing of research participants.

The DECIPHER website portal is hosted by the European Molecular Biology Laboratory, European Bioinformatics Institute ([EMBL-EBI](#)) and the study sponsor is Cambridge University Hospitals, NHS Foundation Trust.

EMBL-EBI is an Inter-Governmental Institution established by treaty with a site in the UK based on the Wellcome Genome Campus at Hinxton, Cambridgeshire, CB10 1SD. EMBL enjoys a number of privileges and immunities, including immunity from suit and legal process (<https://www.embl.org/about/embl-legal-status>). EMBL remains committed to the responsible and ethical conduct of research and this is strictly regulated in several of its internal policies. EMBL has an established and experienced ethics committee that is responsible for ensuring that relevant bioethical issues pertaining to the use of data derived from humans are appropriately considered in research conducted at EMBL (the Bioethics Internal Advisory Committee). The Committee is supported by the Bioethics Office, who provide a governance and monitoring function for these activities.

Previously (2004-2023) DECIPHER was hosted by the [Wellcome Sanger Institute](#). A substantial amendment to the REC for the transition of the DECIPHER database and website to EMBL-EBI was given a favourable opinion (Amendment 8; 19 April 2022).