

INFORMATION TO THE TRIGR PARTICIPANTS

The international TRIGR (Trial to Reduce Insulin-Dependent Diabetes Mellitus in the Genetically at Risk) study was conducted in 2002–2017 in 12 European countries, Australia, Canada and USA. With the consent of the parents, the participants (2159) were followed up from birth until the youngest participant reached 10 years of age in 2017. The follow-up blood samples were collected from the participants for the determination of diabetes-associated autoantibodies and other type 1 diabetes related target biomarkers. Now the TRIGR investigators have obtained the RNAseq and ATACseq data from the analysis of peripheral blood mononuclear cells from 98 European TRIGR participants. This data should be submitted to the European Genome-phenome Archive (EGA) to make it possible for the investigators to publish these results.

EGA is a service for permanent archiving and sharing of all types of individual genetic and phenotypic data resulting from biomedical research projects. Strict protocols govern how information is managed, stored and distributed by the EGA. The EGA implements a controlled access policy whereby the access decisions resides with the Data Access Committee (DAC). For this TRIGR data, the DAC is created by the University of Helsinki and is composed of Professor Mikael Knip, the Principal Investigator of the TRIGR study and Docent Taina Härkönen, a TRIGR investigator involved in the collection and analysis of the data. The data does not include any sensitive or identifying personal data, and the study participant can not be identified from the data. More information about the EGA can be found on <https://ega-archive.org/about/introduction>.

Processing of your personal information is necessary for scientific research carried out in the public interest. Data processing during the analysis phase of the TRIGR study is based on the GDPR, 2016/679, point (j) of Article 9(2). The data controller of the TRIGR study is University of Helsinki, address: P.O.Box 3 (Fabianinkatu 33), 00014 University of Helsinki, Finland. Phone: +358 2941 911. E-mail tietosuoja@helsinki.fi

With regard to GDPR, the European Genome-phenome Archive is a data processor of the personal data and EGA has a set of security policies that are followed to minimize the risk of unauthorized data access or data loss. Their GDPR notice can be found on <https://ega-archive.org/gdpr-notice> and they can be contacted by helpdesk@ega-archive.org.

This declaration is published to inform the European TRIGR participants and their guardians of this data transfer to the EGA.

The study participant has the right to object to the processing of his or her personal data, that is, request the controller not to submit the data described above to the EGA. This request has to be submitted by July 15, 2021 to tietosuoja@helsinki.fi and mikael.knip@helsinki.fi.