

GUIDELINES FOR APPLICATION OF SAMPLES AND REGISTER DATA FROM THE SWEDISH ADDISON REGISTER

APPROVAL OF A PROJECT

The first step when planning to use samples or data from The Swedish Addison Register is to contact one of the coordinators¹ for The Swedish Addison Register for a discussion and thereafter complete the application form with appendices. The application is submitted to the coordinator and may be approved by the steering committee of The Swedish Addison Register with or without reservations.

WHERE ARE THE SAMPLES AND THE DATABASES?

All blood-samples are held in a biobank at Uppsala University. All original data files are in The Swedish Addison Register-computer at Uppsala University and data files are generated from this computer to you. A copy of the file transferred to you will be held at The Swedish Addison Register.

AGREEMENT FOR THE USE OF SAMPLES AND DATA

After approval of an application an agreement is established between the applying researcher and The Swedish Addison Register. The agreement specifies the use and handling of the samples and data received for the project, the forms of collaboration, authorship in publications and possible costs.

OVERLAPPING PROJECTS

Projects using the data in The Swedish Addison Register may be partly overlapping (e.g. identical basic data will be used when describing the study population. Written delimitations of the different studies are made by the steering committee of The Swedish Addison Register.

TIME LIMIT FOR THE ANALYSES

The approval for the use of samples and register data is limited in time. The time limit for each project is defined in the agreement. In those cases analyses of samples/data are not completed within this time the steering committee of The Swedish Addison Register may extend the approval after application.

PUBLICATION

In general the PI and/or the representative of The Swedish Addison Register scientifically mostly involved in the project should be co-author on publications on material from The Swedish Addison Register, under the condition that the terms of the Vancouver rules of authorship (http://www.icmje.org/ethical_1author.html) are fulfilled. The Swedish Addison Register should always be mentioned in acknowledgements. All manuscripts based on The Swedish Addison Register data and/or samples should be reviewed by an authorized representative of The Swedish Addison Register before submission for publication.

¹ Dr Sophie Bensing and professor Anna-Lena Hulting, Kliniken för Endokrinologi, Metabolism och Diabetes Karolinska Universitetssjukhuset Solna D2:04, 171 76 Stockholm