

**Survey of Current Status for Ethics Board Permissions, Data Inspectorate Permissions and Consent for using DNA, Genome Scans, and Phenotypic Data in GENOMEUTWIN**

The purpose of this survey is to collect information regarding which parts of your data are available to be used in GENOMEUTWIN, and to outline what steps will need to be taken in order for your data to be used in this project. At many of the participating centers DNA has been collected in different studies such that different consents and ethics rulings apply to different parts of your data. If this is the case then please fill out this survey for each project as needed.

When filling in the survey add extra spaces between questions as needed to make room for your response.

All requested information should be mailed to: <mailto:Jennifer.harris@fhi.no>.

For non-electronic versions please mail to:

Jennifer Harris

The Norwegian Institute of Public Health

Division of Epidemiology, Department of Genetic and Environmental Studies (EPAM)

Post Box 4404 Nydalen

N-0403 Oslo

Norway

- 1a) Institute responsible for the twin data\_\_\_\_\_
- 1b) Name of the project for which you are completing this survey\_\_\_\_\_ (Note, you may need to complete this several times if different ethics and consent regulations apply for different projects).
- 1c) In order for the data in this project to be included in the GENOMEUTWIN study would you need to obtain consent from national partners who took parting the original projects from which the data originates? \_\_\_\_\_
- 1d) Person completing this form\_\_\_\_\_Date\_\_\_\_\_

**Questions 2a-4c pertain to the permissions granted from your ETHICS board.**

- 2) Do the permissions currently granted from your **local Ethics Board** allow for the **DNA** you have already collected to be included in the GENOMEUTWIN study?  
Yes \_\_\_\_\_ No \_\_\_\_\_ Don't know \_\_\_\_\_

- 2a) If 'Yes', please provide the information upon which this is based, including copies in English and the original language of relevant permissions' Copies of relevant permissions should be mailed to: <mailto:Jennifer.harris@fhi.no> or mail hard-copy versions only to the address listed above.
- 2b) Please provide the sample sizes (total number of individuals, include number of pairs) to which 2a applies.
- 2c) If 'No' what steps must be taken in order to obtain the necessary permission to use DNA on a sub-sample of your twins for GENOMEUTWIN? (e.g. new application to medical ethics board).
- 2d) How long do you foresee this process taking?
- 3) Do the permissions currently granted from your **local Ethics Board** allow for information from already completed **genome scans** to be shared with other researchers?
- 3a) If 'Yes' please send copies in English and in original language of relevant permissions to: <mailto:Jennifer.harris@fhi.no>, or mail hard-copy versions only to the address listed above.
- 3b) Please provide the sample sizes (total number of individuals, include number of pairs) to which 3a applies.
- 3c) If 'No' what steps must be taken in order to obtain the necessary permission?
- 3d) How long do you foresee this process taking?
- 4) Do the permissions currently granted from your **local Ethics Board** allow for the **phenotypic data** you have already collected to be included in the GENOMEUTWIN study?  
 Yes \_\_\_\_\_ No \_\_\_\_\_ Don't know \_\_\_\_\_
- 4a) If 'Yes', please provide the information upon which this is based, including copies in English and the original language of relevant permissions to which this applies. Copies of relevant permissions should be mailed to: <mailto:Jennifer.harris@fhi.no>, or mail hard-copy versions only to the address listed above.
- 4b) Please provide the sample sizes (total number of individuals, include number of pairs) to which 4a applies.
- 4b) If 'No' what steps must be taken in order to obtain the necessary permission? (e.g. new application to medical ethics board).
- 4c) How long will it take for you to receive the necessary permission?

**Questions 5-7c pertain to the permissions granted from your Data Inspection Board.**

- 5) Do the permissions currently granted from your **Data Inspection Board** allow for the **DNA** you have already collected to be included in the GENOMEUTWIN study?  
 Yes \_\_\_\_\_ No \_\_\_\_\_ Don't know \_\_\_\_\_
- 5a) If 'Yes', please provide the information upon which this is based, including copies in English and the original language of relevant permissions' Copies of relevant permissions should be mailed to: <mailto:Jennifer.harris@fhi.no> or mail hard-copy versions only to the address listed above.
- 5b) Please provide the sample sizes (total number of individuals, include number of pairs) to which 5a applies.
- 5c) If 'No' what steps must be taken in order to obtain the necessary permission to use DNA on a sub-sample of your twins for GENOMEUTWIN? (e.g. new application to medical ethics board).
- 5d) How long do you foresee this process taking?
- 6) Do the permissions currently granted from your **Data Inspection Board** allow for information from already completed **genome scans** to be shared with other researchers?
- 6a) If 'Yes' please send copies in English and in original language of relevant permissions to: <mailto:Jennifer.harris@fhi.no>, or mail hard-copy versions only to the address listed above.
- 6b) Please provide the sample sizes (total number of individuals, include number of pairs) to which 6a applies.
- 6c) If 'No' what steps must be taken in order to obtain the necessary permission?
- 6d) How long do you foresee this process taking?
- 7) Do the permissions currently granted from your **Data Inspection Board** allow for the **phenotypic data** you have already collected to be included in the GENOMEUTWIN study?  
 Yes \_\_\_\_\_ No \_\_\_\_\_ Don't know \_\_\_\_\_
- 7a) If 'Yes', please provide the information upon which this is based, including copies in English and the original language of relevant permissions to which this applies. Copies should be mailed to: <mailto:Jennifer.harris@fhi.no>, or mail hard-copy versions only to the address listed above.
- 7b) Please provide the sample sizes (total number of individuals, include number of pairs) to which 7a applies.
- 7c) If 'No' what steps must be taken in order to obtain the necessary permission? (e.g. new application to medical ethics board).
- 7d) How long will it take for you to receive the necessary permission?

Questions 8-10c pertain to CONSENT obtained from your twin cohorts.

8) Do the **consent** forms completed by your all or part of your twin cohorts allow for the **DNA** you have already collected to be used as part of GENOMEUTWIN?

Yes\_\_\_\_\_ No\_\_\_\_\_ Don't know\_\_\_\_\_

8a) If 'Yes', please e-mail a copy in English and the original language of the relevant consent form(s) to <mailto:Jennifer.harris@fhi.no>, or mail hard-copy versions only to the address listed above.

8b) Please provide the sample sizes (total number of individuals, include number of pairs) to which 8a applies.

8b) If 'No', what steps are involved in gaining this consent?

8c) How long do you foresee this process taking?

9) Do the **consent** forms completed by your all or part of your twin cohorts allow for the **genome scan data** you have already collected to be used as part of GENOMEUTWIN?

Yes\_\_\_\_\_ No\_\_\_\_\_ Don't know\_\_\_\_\_

9a) If 'Yes', please e-mail a copy in English and the original language of the relevant consent form(s) to <mailto:Jennifer.harris@fhi.no>, or mail hard-copy versions only to the address listed above.

9b) Please provide the sample sizes (total number of individuals, include number of pairs) to which 9a applies.

9c) If 'No', what steps are involved in gaining this consent.

9d) How long do you foresee this process taking?

10) Do the **consent** forms completed by your twin cohorts allow for the **phenotypic data** you have collected to be used as part of the GENOMEUTWIN

Yes\_\_\_\_\_ No\_\_\_\_\_ Don't Know\_\_\_\_\_

10a) If 'Yes', please e-mail a copy in English and the original language of the relevant consent form(s) to [Jennifer.harris@fhi.no](mailto:Jennifer.harris@fhi.no), or mail hard-copy versions only to the address listed above.

10b) Please provide the sample sizes (total number of individuals, include number of pairs) to which 10a applies.

10b) If 'No', what steps are involved in gaining this consent.

10c) How long do you foresee this process of obtaining consent to take.

11) If your center can currently contribute data to GENOMEUTWIN (consents and permissions meet the necessary requirements) what is the sample size for which you have both DNA and phenotypic information:

<b>Number of pairs with consent and ethics regulation completed for data sharing by phenotype</b>		
Phenotype	MZ pairs (n)	DZ pairs (n)
Migraine		
Coronary Disease		
Stroke		
Stature		
BMI		