



## **Appendix A – Migraine Phenotype**

Version: 2.0

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## ***Introduction***

This document describes the Phenotype Migraine and what migraine variables are stored in the GenomEUtwin databases.

The description of the phenotype (section 2) has the Migraine Group (contact person: Aarno Palotie) written. The Variable Standard Group (contact person: Ann Björklund) in the Database Core has written the information about the variables in the GenomEUtwin database and merged the to parts together to one document

NOTICE! This document does not describe how the data is stored in the database, only what data the database store.

## ***Updates***

### **Since version 1.3**

A new concept of describing the phenotypes.

### **Since version 1.2**

An introduction has been added.

### **Since version 1.1**

New/changed values in the variable MIGR\_DIAGNOSIS

A new variable MIGR\_QUESTIONNAIRE is added.

Chapter 2.1 (Clarification about some variables) and 2.2 (Missing data) is added.

## ***Description of the migraine phenotype***

Migraine is a complex neurovascular disorder and can be divided in migraine with aura and migraine without aura. These subtypes are clinically distinguishable but it is as yet unclear whether different genes are involved. The concept of describing the phenotype comprises 4 levels of information on migraine. Level 1 being the lowest and Level 4 being the highest.

### Data format

Variable Name	Description	Type	Length	Values
MIGR_HAS_MIGRAINE	Has migraine or not. (Level 1)	NUMBER	2	1. Yes 2. No 3. Possible migraine 97. Irrelevant/non-participant/non-response 98. Don't know (The diagnosis is unclear) 99. Unknown/missing
MIGR_DIAGNOSIS	Type of migraine. (Level 2)	NUMBER	2	1. Migraine with aura. 2. Migraine without aura 3. Unspecified migraine 4. Both migraine with and migraine without aura 5. Never had migraine 6. Other headache (tension headache, cluster headache) 97. Irrelevant/non-participant/non-response 98. Do not know/the diagnosis is unclear 99. Unknown/missing
MIGR_DISAB_WORK	Quantitive measures of disability. During moderate and severe headaches. <b>Going to work/school.</b> (Level 3)	NUMBER	2	1. Yes, usually/always 2. Yes, sometimes 3. No, never 97. Irrelevant/non-participant/non-response (missing) 98. Don't know 99. Unknown/missing
MIGR_DISAB_DARKNESS	Quantitive measures of disability. During moderate and severe headaches. <b>Lying or sitting in darkness.</b> (Level 3)	NUMBER	2	1. Yes, usually/always 2. Yes, sometimes 3. No, never 97. Irrelevant/non-participant/non-response (missing) 98. Don't know 99. Unknown/missing

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MIGR_DISAB_ACTIVIT Y	Quantitive measures of disability. During moderate and servere headaches. <b>Engaging in normal physical activity like walking/walking stairs.</b> (Level 3)	NUMBER	2	1. Yes, usually/always 2. Yes, sometimes 3. No, never 97. Irrelevant/non-participant/non-response (missing) 98. Don't know 99. Unknown/missing
MIGR_DISAB_NAUSEA	Quantitive measures of disability. During moderate and servere headaches. <b>Nausea.</b> (Level 3)	NUMBER	2	1. Yes, usually/always 2. Yes, sometimes 3. No, never 97. Irrelevant/non-participant/non-response (missing) 98. Don't know 99. Unknown/missing
MIGR_DISAB_VOMITI NG	Quantitive measures of disability. During moderate and servere headaches. <b>Vomiting.</b> (Level 3)	NUMBER	2	1. Yes, usually/always 2. Yes, sometimes 3. No, never 97. Irrelevant/non-participant/non-response (missing) 98. Don't know 99. Unknown/missing
MIGR_DISAB_SOUND	Quantitive measures of disability. During moderate and servere headaches. <b>Hypersensitive to sound.</b> (Level 3)	NUMBER	2	1. Yes, usually/always 2. Yes, sometimes 3. No, never 97. Irrelevant/non-participant/non-response (missing) 98. Don't know 99. Unknown/missing
MIGR_ENDOPHENO	Endophenotypes of migraine (e.g. measurements in blood) (Level 4)	NUMBER	?	????

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MIGR_DATE_DIAG	Date of diagnosis. NB! Should be a date even for unaffected patients.	DATE	8	YYYYMMDD – Year, month, day YYYYMM15 - day unknown YYYY0701 - day and month unknown NULL/blank - Irrelevant/non-participant/no response, Irrelevant/structural, Do not know, Unknown
MIGR_DATE_ACCURACY	Accuracy code for date of migraine diagnosis	NUMBER	1	1. Date is complete 2. Day is missing, coded 15 3. Day and month are missing, coded 0701 6. Irrelevant
MIGR_FREQUENCY	Frequency of migraine	NUMBER	2	1. Less than once a year 2. One to twelve times a year 3. More than once a month 97. Irrelevant/non-participant/non-response (missing) 98. Don't know 99. Unknown/missing
MIGR_DIAG_ACCURACY	Diagnostic accuracy	NUMBER	2	1. Face to face interview with neurologist 2. Telephone interview 3. Questionnaire assesment 99. Unknown

## **Clarification of some variables**

There should be a date in the variable MIGR\_DATE\_DIAG even if the patient is unaffected. This would be the last date for which it is known that the patient did not (yet) have migraine. It will leave open the possibility of doing an age-at-onset analysis later.

## **Missing data**

Several codes are used to code missing data. The different types of missing data are described below:

Irrelevant, non-participant, non-response Used when data is irrelevant for a person either due to not included in study base or due to non response to questionnaire/interview as a whole.

Irrelevant, structural Used when data is irrelevant in the context.

Do not know Used when the respondent explicitly states it.

Unknown Used when no answer is given to specific item, or when no data is available.