EURONUMBER ID

1. DEMOGRAPHICS AND EDUCATION
Person answering questions is:

Patient/control ○ Proxy of patient/control ○

Sex: Male ○ Female ○

Date of Birth: ___ ___/___ ___/___ ___ ___ ___
M M D D Y Y Y Y

Date of Survey: ___ ___/___ ___/___ ___ ___ ___
M M D D Y Y Y Y

Highest degree attained:
○ 1=>Grade school, (grades 1-8)
○ 2=>High school diploma
○ 3=>Technical or trade school diploma
○ 4=>University degree
○ 5=>Graduate school (PhD)
○ 6=>None

2. BIOMETRICS

Current weight (kg) (self reported, whole numbers): ______

Current height (cm) (self reported, whole numbers): ______

Waist circumference (cm) (measured at the level of the navel, whole numbers): ______

Apart from when you were young, have you ever been more than 5 kilo's heavier or lighter than your current weight?

Yes ◯ No ◯

What did you *approximately* weigh at the following ages?

a. 20 years: ____________kg
b. 30 years: ____________kg
c. 40 years: ____________kg
d. 50 years: ____________kg
e. 60 years: ____________kg
f. 70 years: ____________kg

BMI (automatically calculated): ______

3. ANCESTRY

What is your country of origin: ____________

What is your province/region/county of origin: ____________

What is country of origin of biological father: ____________

What is country of origin of biological mother: ____________

What is country of origin of grandfather (paternal) : ____________

What is country of origin of grandmother (paternal) : ____________

What is country of origin of grandfather (maternal) : ____________

What is country of origin of grandfather (maternal) : ____________

4. RESIDENTIAL HISTORY

What is your current address: *will be filled in not stored and converted to geocode*

GEOCODE (provided by database): ____________

Did you always live here:

Yes ◯ No ◯

If no, from ______ (age) to ______ (age)

	Home address until current	Address (*will be filled in not stored and converted to geocode)*	From (age)	To (age)
A	First			
B	Second			
C	Third			
D	Fourth			
E	Fifth			
F	Sixth			
G	Seventh			

5. SMOKING

Cigarettes /Tobacco
Have you ever smoked?:

Yes ◯ No ◯

Year started: ______

Stopped smoking? Yes ◯ No ◯

If yes, the year you stopped: ______

How many cigarettes do/did you smoke on average per day: ______

Has there ever been a period when you smoked more than you do now:

Period of smoking more: Yes ◯ No ◯

Period 1
How many cigarettes do/did you smoke on average per day at that time?: ______

When was this: ______ year - ______ year

Period 2
How many cigarettes do/did you smoke on average per day at that time?: ______

When was this: ______ year - ______ year

Has there ever been a period when you smoked less or not at all (during the time that you were smoking cigarettes)?

Period of less smoking: Yes ◯ No ◯

Period 1
How many cigarettes do/did you smoke on average per day at that time?: ______

When was this: ______ year - ______ year

Period 2
How many cigarettes do/did you smoke on average per day at that time?: ______

When was this: ______ year - ______ year

Do/did you (also) smoke products other than cigarettes/ tobacco?
Smoking other product: Yes ◯ No ◯

Cigars.
Smoking cigars:

Yes ◯ No ◯

If yes, how many per day: ______

Year started: ______

If stopped, year stopped: ______

Pipe
Smoking pipes:
Yes ◯ No ◯

If yes, how many per day: ______

Year started: ______

If stopped, year stopped: ______

6. ALCOHOL

Do you sometimes drink alcohol or have you ever done so?:
Yes ◯ No ◯

Year started: ______
Stopped: Yes ◯ No ◯

If yes, year: ______

Has there been a period when you did not drink alcohol?

Yes ◯ No ◯

If yes, for how many years: ______

How many glasses of alcohol do you or did you drink on average per week?: ______

How many of these are glasses of red wine: ______

7. HORMONES (only women)

Menstruation/pregnancy

At what age did you have your first period: ______

How regular were your periods when you were about 25 years of age (do not include periods of using the pill, hormone-containing coils, pregnancies and breast-feeding):

◯ 1=>every 24 days or less

◯ 2=>every 25 or 26 days

◯ 3=>every 27, 28 or 29 days

◯ 4=>every 30 or 31 days

◯ 5=>every 32 or more

◯ 5=>irregular

◯ 6=>I no longer know

Has there ever been a time when your cycle was irregular?:

Yes ◯ No ◯ Cannot remember ◯

If yes, when: ____________year - ____________year

Has there ever been a period when you stopped menstruating for more than a year (with the exception of pregnancies)?

Yes ◯ No ◯ Cannot remember ◯

Have your periods stopped for good?:

Yes ◯ No ◯

If yes, at what age: ____________(age)

How often have you been pregnant?: ______

How many live births have you had?: ______

Breastfed your children:

Yes ◯ No ◯

How many children have you breastfed: ______

Per child, for how many months have you breastfed them:
Child 1: ____________

Child 2: ____________

Child 3: ____________

Child 4: ____________

Are you currently using hormonal contraceptives or have you ever done so?

Yes ○ No ○

If yes, what form:

○ 1=>Pill
○ 2=>Subcutaneous implant
○ 3=>Injection
○ 4=>Other ________________________

In case of pill:

Have you stopped taking the pill:

Yes ○ No ○

If yes, at what age: ____________(age)

How old were you when you started taking the pill: ____________ (age)

How long have you been using the pill?

○ 1=>never
○ 2=>less than 1 year
○ 3=>1-4 years
○ 4=>5-9 years
○ 5=>10-14 years
○ 6=>15-19 years
○ 7=>20 years or more

What are the name(s) of the pill:

Are you using or have you ever used hormone replacement therapy?:

Yes ◯ No ◯

If yes, how old when started: _____________**(age)**

For how many years: _____________**(number of years)**

What form?

◯ 1=>Pill

◯ 2=>Estrogen plaster

◯ 3=>Subcutaneous implant

◯ 4=>Injection

◯ 5=>Cream

Name(s) of these hormones:

Have you stopped ?:

Yes No

◯ ◯

If yes, at what age: ____________(age)

8. OPERATIONS

Have you had a hysterectomy?: Yes No

◯ ◯

If yes, at what age: ______________(age)

Were your ovaries removed? :

◯ 1=>No

◯ 2=>Yes, one site

◯ 3=>Yes, both

◯ 4=>I don't know

If yes, at what age? ____________(age)

8. MEDICAL HISTORY

Have you ever been diagnosed with diabetes?:

Yes No

◯ ◯

In which year was this diagnosis made? _________________(year)

Do you have raised cholesterol?

Yes No

◯ ◯

In which year was this first established: _______________________(year)

Are you NOW using medications for raised cholesterol?:

Yes ◯ No ◯

If yes, what is the name and which year did you start?:

_______________________ (name), ____________(Year)

_______________________ (name), ____________(Year)

_______________________ (name), ____________(Year)

Have you ever used any other medication for raised cholesterol:

Yes ◯ No ◯

If yes, what was the name of the drug and which year did you start? :

_______________________ (name), ____________(Year started) - _____________(Year stopped)

_______________________ (name), ____________(Year started) - _____________(Year stopped)

_______________________ (name), ____________(Year started) - _____________(Year stopped)

Have you ever had high blood pressure? (except during pregnancy):

Yes ◯ No ◯

If yes, in which year was this first found: _____________ **(year)**

Are you CURRENTLY using medications for high blood pressure?:

Yes ◯ No ◯

If yes, what is the name and which year did you start?

______________________ (name), ___________(Year started) - ____________(Year stopped)

______________________ (name), ___________(Year started) - ____________(Year stopped)

______________________ (name), ___________(Year started) - ____________(Year stopped)

Have you ever ever other medications for high blood pressure?

Yes ◯ No ◯

If yes, what is the name and which year did you start?

______________________ (name), ___________(Year started) - ____________(Year stopped)

______________________ (name), ___________(Year started) - ____________(Year stopped)

______________________ (name), ___________(Year started) - ____________(Year stopped)

Have you ever had heart problems:

Yes ◯ No ◯

If yes, did you visit a GP/doctor or hospital with these heart problems?:

Yes ◯ No ◯

Have you ever had angina pectoris:

Yes ◯ No ◯

Have you ever had a heart attack:

Yes ◯ No ◯

If yes, when? ______________ (year)

Were you ever told you have narrowing of one or both carorid arteries?

Yes No

○ ○

Did you ever have a "TIA"

Yes No

○ ○

Did you ever have a stroke:

Yes No

○ ○

Which year did you have the (first) stroke? ____________ (Year)

Have you ever undergone one of the following procedures:

Heart bypass:

Yes No

○ ○

If yes, which year? ________________(Year)

Bypass operation in the legs:

Yes No

○ ○

If yes, which year: _______________ (Year)

Balloon catheter dilatation (angioplasty) in the legs:

Yes No

○ ○

If yes, which year: ________________(Year)

Balloon catheter dilatation (angioplasty) in the heart:

Yes No

○ ○

If yes, which year: ________________ (Year)

Have you ever had cancer? :

Yes No

○ ○

If yes, what type? ______________________________________ (type)

If yes, which year? ________________(Year)

What kind of treatment did you receive (more that one answer possible):

○ 1=> Radiation therapy

○ 2=> Surgery

○ 3=> Chemotherapy

○ 4=> Other, namely: ____________

Did you have all vaccinations as a child according to the vaccination programme of your country:

Yes ◯ No ◯ I don't know ◯

9. OCCUPATIONS

Have you done military service

Yes ◯ No ◯

If so, in which of the armed forces did you serve?

____

Were you ever deployed? Yes ◯ No ◯

If so, to where?

Have you been in paid or unpaid employment ? Yes ◯ No ◯

	Occupation	Employer/company	City/Village	Can you indicate a few activities related to that occupation?	Hours per week	From (year)	To (year)
A							
B							
C							
D							
E							
F							
G							

10. PHYSICAL ACTIVITYs

Did you ever play sport when you were young (before your 18th birthday)?

Yes ◯ No ◯

Do you/Did you play sport as an adult? Yes ◯ No ◯

What is/was your sport (when you were young) and when were you active

	Sport	Hours per week	START (year)	STOP (year)
A				
B				
C				
D				
E				
F				
G				

In addition to the sports you may have mentioned, do/did you have any hobbies?

Yes ◯ No ◯

(If No, proceed with next question)

	Hobby	Hours per week	START (year)	STOP (year)
A				
B				
C				
D				
E				
F				
G				

Have you ever engaged in sport that required great physical effort, for instance running a marathon?

Yes ◯ No ◯

(If No, proceed with next question)

	STRENUOUS PHYSICAL EXERTION	When? (years)
1		
2		
3		
4		

11. TRAUMA / INJURY
Trauma/ Letsel

Have you ever had any injury requiring medical care?

Yes ◯ No ◯

If yes, please fill in the table below:

	Injury type 1=>Head injury with concussion 2=>Fracture 3=>Contusion 4=>Sprain 5=>Strain 6=>Other, namely:	At what age did injury occur?	Circumstances? 1=>Work 2=>Sport 3=>Leisure (other than sport) 4=>Traffic 5=> Other, namely:	Did injury cause disability 1=>Yes 2=>No	Injury was: 1=>Temporary 2=>Permanent	Where was Injury? 1=>Head 2=>Arms 3=>Chest 4=>Abdomen 5=>Legs 6=>Spine	Severity of injury? 1=>Mild 2=>Moderate 3=>Severe
A							
B							
C							
D							
E							
F							
G							

12. USE OF DRUGS/SUBSTANCES
Gebruik van medicijnen/ middelen

DRUGS IN SPORT

Have you ever used any of the following drugs, and if so, please indicate the age when you started and stopped:

Oral

Name of the drug:	Used: Yes or No	Age started:	Age stopped:
Creatine			
Anabolic Androgenic Steroids			
Clenbuterol, tibolone, zeranol, zilpaterol			
Amphetamines			
Adrenaline			
Heroin, fentanyl hydromorphone/ Hydromorfine, methadone, morphine, oxycodone, oxymorphone/ oxymorfine, pentazocine, pethidine			

Intramuscular performance enhancing agents?

Name of the drug:	Used: Yes or No	Age started:	Age stopped:
Erythropoietin (EPO), dEPO, CERA or hematide			
Chorionic Gonadotrophin (CG)			
Luteinizing Hormone (LH)			
Growth Hormone (GH)			
Insulin-like Growth Factor-1 (IGF-1)			
Mechano Growth Factors (MGFs)			
Platelet-Derived Growth Factor (PDGF)			
Fibroblast Growth Factors (FGFs)			
Vascular-Endothelial Growth Factor (VEGF)			
Hepatocyte Growth Factor (HGF)			

ANTIDEPRESSANTS AND ANTIPSYCHOTICS

Have you ever been prescribed any of the following drugs and if so, please indicate the age when you started and stopped

Anti-Anxiety/ Anti Depressants

Name of the drug:	Used: Yes or No	Age started:	Age stopped:
Diazepam (Valium)			
Duloxetine (Cymbalata)			
Venlafaxine (Efexor)			
Escitalopram (Lexapro)			
Sertraline (Lustral)			
Fluoxetine (Prozac)			
Citalopram (Cipramil)			
Sodium Valproate (Epilim)			
Lamotrigine (Lamictal)			
Lofepramine (Gamanil)			
Mirtazepine (Zispin)			
Trazodone			
Paroxetine (Seroxat)			
Lithium (Priadel)			
Dothiepin (Prothiaden)			
Trimipramine (Surmontil)			
Buproprion			
OTHER			

Anti Psychotics

Name of the drug:	**Used: Yes or No**	**Age started:**	**Age stopped:**
Trifluoperazine (Stelazine)			
Arpiprazole (Abilify)			
Chlorpromazine (Largactil)			
Clozapine (Clozaril)			
Flupenthizol (Depixol)			
Sulpiride (Dolmatil)			
Ziprasidone (Geodon)			
Haloperidol (Haldol, Serenase)			
Fluphenazine			
Risperidone			
Quetiapine (Seroquel)			
Olanzepine (Zyprexa)			
Thioridazine (Melleril)			
OTHER			

<u>Have you been to a GP or hospital doctor for anything else, not mentioned above?</u>

Reason	Hospital admission	Year
	○Yes ○No	
	○Yes ○No	
	○Yes ○No	
	○Yes ○No	
	○Yes ○No	
	○Yes ○No	

Below are questions about your family history
The diseases we are interested in are across the top and the family members are along the side.(*Please note, the questions only relate to your direct family and not to relations through marriage (in-laws).)*

- If a relative has (had) ALS, Parkinson's disease or dementia, you can indicate this by colouring the "YES" circle black beside the relevant family member.

- If a **female** relative has had a heart attack or a stroke before her **65th** birthday, you can indicate this by colouring the "YES" circle black beside the relevant family member.

- If a **male** relative has had a heart attack or a stroke before his 5**5th** birthday, you can indicate this by colouring the "YES" circle black beside the relevant family member.

- If a relative has not had the disease, you can indicate this by colouring the "NO" circle black beside the relevant family member.

- If you are not sure whether a relative has (had) the disease, you can indicate this by colouring the "?" circle black beside the relevant family member.

If you do not have a particular relative (they are listed in case you DO have them), leave the circles empty.

The following questions are about your father, your mother, grandfather and grandmother on father's (F) side and grandfather and grandmother on mother's side (M).

13. FAMILY HISTORY

Parents

What is your father's date of birth? ______

If applicable, age at death? ______ (age in years)

What was the cause of death? ______

What is your mother's date of birth? _____

If applicable, age at death? _____(age in years)

What was the cause of death? _____

Siblings

How many brothers do/did you have? _____

What are the dates of birth of your brothers?

If you only know the year, fill in: 01-01-year of birth.

If applicable, please also fill in age at death and cause of death.

Brother	Date of birth (dd-mm-yyyy)	Age at death (in years)	Cause of Death
1			
2			

3			
4			
5			
6			
7			
8			

How many sisters do/did you have? _____

What are the dates of birth of your sisters?
If you only know the year, fill in: 01-01-year of birth.

If applicable, please also fill in age at death and cause of death.

Sister	Date of birth	Age at death (in years)	Cause of Death
1			
2			
3			

4			
5			
6			
7			
8			

Twins

Do you have a twin brother or – sister? Yes ◯ No ◯

If yes, what type of twin are you?

◯ 1=> Identical

◯ 2=> Non-identical

◯ 3=> Unknown

If unknown:
When you were children, did you and your twin brother or –sister look identical or was there only the usual family resemblance?

◯ 1=> Identical

◯ 2=> Normal family resemblance

When you were children, did your parents/brothers/sisters/ teachers have trouble telling you apart?

Yes	No
◯	◯

What is the gender of your twin?

◯ 1=> Male

◯ 2=>Female

Which disorder(s) has/have been found in your twin brother or –sister?
(more than one answer possible)

- ◯ 1=> ALS
- ◯ 2=> Polyneuropathy
- ◯ 3=> PLS
- ◯ 4=> PSMA
- ◯ 5=> Parkinson disease
- ◯ 6=> Dementia
- ◯ 7=> Other, namely ____
- ◯ 8=> None of the above

Has you twin brother or –sister died? Yes ◯ No ◯

(If applicable) When did he/she die? (dd mm yy)

What the cause of death? ____

Uncles and Aunts

How many brothers does/did your father have? ____
In which years were your father's brothers born?
If applicable: age at death?

Brother of father	Year of birth	Age at death (in years)
1		
2		
3		
4		
5		
6		
7		
8		

How many sisters does/did your father have? _____

When were your father's sisters born?

(If applicable): age at death?

Sister of father	Year of birth	Age at death (in years)
1		
2		
3		
4		
5		
6		
7		
8		

How many brothers does/did your mother have? _____

When were your mother's brothers born?

(If applicable): age at death?

Brother of mother	Year of birth	Age at death (in years)
1		
2		
3		
4		
5		
6		
7		
8		

How many sisters does/did your mother have? _____

When were your mother's sisters born?

(If applicable): age at death?

Sister of mother	Year of birth	Age at death (in years)
1		
2		
3		
4		
5		
6		
7		
8		

Parents and grandparents

	ALS	PLS	PSMA	Poly neuro pathy	Parkinson's disease	Dementia	Stroke, brain infarction, brain haemorrhage	Depres-Sion	Alcoholism	Suicide	Heart attack
Father	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?
Mother	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?
Grand-father (F)	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?
Grand-mother (F)	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?
Grand-father (M)	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?
Grand-mother (M)	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?

Brothers

	ALS	PLS	PSMA	Poly neuro pathy	Parkinson's disease	Dementia	Stroke, brain infarction, brain haemorrhage	Depres-Sion	Alcoholism	Suicide	Heart attack
Brother 1	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?
Brother 2	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?
Brother 3	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?
Brother 4	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?
Brother 5	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?
Brother 6	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?

Sisters

	ALS	PLS	PSMA	Poly neuro pathy	Parkinson's disease	Dementia	Stroke, brain infarction, brain haemorrhage	Depres-Sion	Alcoholism	Suicide	Heart attack
Sister 1	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?
Sister 2	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?
Sister 3	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?
Sister 4	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?
Sister 5	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?
Sister 6	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?	○No ○Yes ○?

How many of these family members suffer or suffered from the following conditions:

	TOTAL NUMBER of family members you have/had:	ALS	PLS	PSMA	Poly neuro pathy	Parkinson's disease	Dementia	Stroke, brain infarction, brain haemorrhage	Depres-Sion	Alcoholism	Suicide	Heart attack
Father's brothers (uncles)												
Father's sisters (aunts)												
Male cousins from father's side												
Female cousins from father's side												
Mother's brothers (uncles)												
Mother's sisters (aunts)												
Male cousins from mother's side												
Female cousins from mother's side												