

D.2.3. Enrichment of existing cohorts by online data collection

Project title: Healthy minds from 0-100 years: Optimising the

use of European brain imaging cohorts

Due date of deliverable: 30th June, 2018

Submission date of deliverable: 26th June, 2018

Leader for this deliverable: VU University Medical Center Amsterdam





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	Document History								
Release	Date	Reason for Change	Status (Draft/In- review/Submitted	Distribution					
1.0.	15.05.2018	First draft to the participating sites	Sent for commenting	Email					
2.0	04.06.2018	Second draft sent to the Oslo consortium meeting participants	Sent for commenting	OneDrive, slack					
3.0.	26.06.2019	Final version	Final revision	OneDrive, slack					

Dissemination level					
PU	Public	Х			
PP	Restricted to other programme participants (including the Commission Services)				
RE	Restricted to a group specified by the consortium (including the Commission				
	Services)				
CO	Confidential, only for members of the consortium (including the Commission				
	Services)				



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Executive Summary

The aim of D2.3. is to perform data-collection for the enrichment of Lifebrain cohorts to gain – as to the extent possible – a complete set of target variables across all sites. The collaborative enrichment of existing cohorts will facilitate direct comparison and data-exchange between sites, and successful demonstration and data analysis as described in WP4 Demonstration.

Implementation included 3 major steps:

- 1) We have identified and operationalized a set of variables to be included in the enrichment, consisting of both self-report questionnaires and behavioural tasks
- 2) The participating sites have translated the instructions, questionnaires and tests, and applied for local ethics and data-sharing approvals (see table 1)
- 3) The data-enrichment is in various stages of being conducted at the different study sites (ongoing at UiO, UCAM, MPIB, UB; see table 1).

Data harmonisation (including the enrichment data) and secure data transfer from local sites to the Lifebrain central database will further follow the set-up protocol for Lifebrain data harmonisation as described in D2.1 and Lifebrain data transfer as described in D3.1.

At several sites (RegionH, MPIB), data-enrichment is run parallel with the enrichment of biological data, e.g. dried blood spots (T2.4) and buccal swabs (T2.5).

Most data collection for D2.3 is expected to be finished by the end of 2018 (excluding VUmc, MPIB).



List of acronyms / abbreviations

BASE Berlin Aging Study (MPIB)

BASE II Berlin Aging Study II (MPIB)

EB Executive Board

CALM Centre for Attention, Learning and Memory, University of Cambridge

Cam-CAN Cambridge Centre for Ageing and Neuroscience, University of Cambridge

HUBU Hjernens Udvikling hos Børn og Unge/Brain Development of Children and

Adolescents (RegionH)

HUK Hukommelse Prosjekt/Memory Project (UiO)

M Month

MPIB Max Planck Institute for Human Development Berlin

NCP Neurocognitive Plasticity (UiO)

NESDA The Netherlands Study of Depression and Anxiety (VUmc)

OS Operating System

PD Parkinson's Disease (study at UB)

PI Principal Investigator

RegionH Region Hovedstaden

SB Safety Board

SES Socio-economic Status

SFTP Secure File Transfer Protocol

TSD Services for Sensitive Data

UB University of Barcelona

UCAM University of Cambridge

UiO University of Oslo

UOXF University of Oxford

VUmc VU University Medical Center Amsterdam

WAHA Walnuts intervention (UB)



1. Introduction

1.1. Description of deliverable

D2.3: Enrichment of existing cohorts by online data collection

Task 2.3: Enrichment of existing cohorts by online data collection.

Lead: VUmc

• Participants: UiO, UmU, UOXF, MPIB, UB, RegionH, UCAM

Planning: M6-M18

Lifebrain aims to develop and apply a tool for online collection of data to enrich available database, allowing Lifebrain databases to attain data which not all sites have available and data on new variables, and by doing so optimize the utilization of the existing data (actual tool development see Task 3.6 and D3.4 Month 12).

The aim is to gain – as to the extent possible – a complete set of target variables across all sites, and be able to directly compare and exchange data. Online data collection will be opened up for all participants, who will be invited to participate through an e-mail or an invitation letter which contain personal URLs and pin codes. Participants will be instructed to enter the URL in their web browser and enter the pin code to access the online assessment tool. We will maintain options for pen-and paper data collection for those who prefer or do not have internet access. The items will be identical across cohorts, but tailored to each so that redundant information is not gathered. Specifically, data collection will consist of a general cognitive measure, a working memory measure, information on mental health (e.g. depression, sleep, anxiety), life style and (life course) socio-economic status. Overall, we will choose instruments that have been shown to be feasible in online, self-report collections and that have been validated preferably in various European studies and languages. Data instruments will be brief in order to limit overall data collection time.

1.2. Objectives

Carry out data-collection for enrichment of Lifebrain cohorts to gain an as complete as possible set of target variables across all sites, and to be able to directly compare and exchange data, in order to achieve successful demonstration and data analysis as described in WP4 Demonstration.



1.3. Collaboration among partners

During and after the Lifebrain kick-off meeting in Brussels (16-18th January 2017), the first discussions took place in the Lifebrain consortium, concerning the content and methods of enrichment. Discussions continued between the Lifebrain enrichment participating sites (UiO, MPIB, UB, RegionH, UOXF, UCAM) via skype conversations, email and slack. Close collaboration was kept with other task-groups in WP2, WP3 and WP4, specifically those involved in T2.1 Data harmonisation, T3.4 Online enrichment, WP4 Demonstration as well as WP7 Ethics with respect to the ethical, data sharing and data protection issues.

Variables for enrichment were chosen if these were only partially covered in existing Lifebrain data, or if deemed of particular interest to Lifebrain based on expertise and state-of-the-art knowledge within the various Lifebrain partner-sites. When necessary, external experts were consulted. A final set of questionnaires/questions was set-up and approved by all enrichment partner-sites. Subsequently, individual sites proceeded with translations and local ethical approvals.

2. Enrichment data collection

2.1. Enrichment variables

Based on the harmonisation overview of available data in the various cohorts (D2.1), we identified which important variables for answering specific Lifebrain research questions (e.g. (childhood-) socio-economic status) were absent in the enrichment cohorts. Furthermore, we included variables that were important for addressing specific Lifebrain research questions that were mentioned in the grant application, but were yet not covered (e.g. masculinity/femininity). Also, we included variables (e.g. urbanisation) that just recently have been associated with mental/ cognitive/ brain health in some of the Lifebrain cohorts. The choice of which specific questionnaires/questions to use was based on several factors, with a preference to include:

- Questionnaires/questions already used in some or most of the Lifebrain cohorts
- Questionnaires/questions that have been (internationally) validated, if possible also validated in required languages (i.e. English, Danish, Norwegian, Spanish, German, Dutch)
- Questionnaires/questions considered to be "Golden standard" according to experts in the field
- Questionnaires/questions that measure stable traits (instead of state measures) to allow for inferences across different time points of data collection (e.g. personality).



We provide below a short overview of included variables:

Cognition:

- Working memory: Backwards digit span task
- General intelligence: Cattell fluid intelligence task

Self-report questionnaires:

- Socio-economic status
 - Various questions concerning current and childhood socio-economic status (e.g. (parental) occupation & education)
- Lifestyle
 - o Sleep: Pittsburgh sleep quality inventory (PSQI, Buyse et al, 1989)
 - Physical activity: International Physical Activity Questionnaire (IPAQ, Booth et al, 2000), validated in most EU-languages
 - o Smoking, alcohol, drug-use, weight & height
- Mental health
 - o Depression: LIDAS lifetime depression diagnosis assessment (Bot et al, 2016)
 - Mental health: self-report of lifetime psychiatric diagnoses
 - Family mental health history: self-report of lifetime psychiatric diagnoses in 1st-degree family members
- Personality
 - Eysenck Personality Questionnaire Revised Short Scale (EPQ-RSS, Eysenck et al, 1985). The initial choice for the NEO-FFI (McCrae & Costa, 2010) was altered to EPQ-RSS due to high costs and publisher's distribution requirements towards the use of the NEO-FFI (e.g. only allowed to collect the NEO-FFI through using the publishers website).
- Gender
 - Masculinity and femininity questionnaire (Kachel et al, 2016)

For the full questionnaire, see Annex 1.



2.2. Ethics approvals and protection of personal data

Ethics approvals for the Lifebrain online enrichment were covered locally by the local ethical review boards. All enrichment sites received approval from their local ethical boards (see Table 1 for timeline). All local ethical board applications included permission to share data with the Lifebrain consortium (see also WP7 Ethics).

2.3. Means of data collection

The enrichment is performed locally at the different study sites participating in the enrichment (UB, UiO, RegionH, UCAM, MPIB, VUmc), employing the secure online data-collection on browser-based platforms available at the local sites and/or using paper self-report forms (e.g. in elderly populations) and/or face-to-face interviews. In Table 3, we provide an overview of the characteristics of the local means of data collection and (online) platforms (see also D3.4, Month 12).

UCAM has programmed the behavioural tasks to be used in the online enrichment (i.e. Working memory task: Digit span; General intelligence: Cattell task; additional tasks not prioritized for Lifebrain enrichment are available (e.g. reaction time, Stroop etc.)) and arranged a publisher's license to use the Cattell task (publisher Hogrefe) for the Lifebrain enrichment. Some of the sites will collect the behavioural tasks through the UCAM server (e.g. UCAM, RegionH, MPIB - Digit span only, UiO - Cattell task only), others will use their own version of these tasks programmed on their own data collection platforms (e.g. VUmc, MPIB - Cattel task).

2.4. Data storage, security and back-up

Local: Local data storage, security and back-up protocols may differ per site (see Table 4). All sites comply with national and international data protection rules and provide secure storage on local servers (encrypted and/or firewalled), with automatic and regular back-up procedures. All stored data is pseudo-anonymised, with personal information taken out or stored separately from other data.

See also D3.1 and the following link of the UiO for the system description: https://www.uio.no/english/services/it/research/sensitive-data/about/description-of-the-system.html. In addition to standard (encrypted) tape backup, snapshots of files and folders for the last three days are also created. This allows both long-term secure data storage, in addition to fast recovery of files by the users stored in snapshots, without administrator intervention.



2.5. Data transfer

See also D3.1. Development of a data storage and management system.

Data transfer of enrichment data from the local sites to the general Lifebrain database will follow the same procedures as other Lifebrain data sharing. Data transfer is handled by a special purpose file staging service and the TSD project administrator controls access rights for all members of the Lifebrain TSD-project.

By default, Lifebrain consortium TSD project members can transfer data to site import folders and within project-specific folders they may have access to. Only the Lifebrain consortium data administrator, data manager and other selected and approved members of the export-group can transfer data out of the system. Copy/paste is disabled from the system, but users are still able to paste text into the system.

2.6. Timeline

Seeing that all participating sites include already existing longitudinal cohorts, the timelines of the enrichment of various cohorts differ slightly depending on new data-collection waves. Table 1 gives an overview of the timeline for enrichment.

UB had new data-collection waves planned in January 2017, and was therefore the first to start. This data-collection is finished, only for the DBS subsample cognition measures and a few enrichment questionnaires will be added before end of 2018. UCAM, UiO and MPIB have finished translation and ethical approvals, and are in the middle of data collection after careful preparation, designing, coding and testing the questionnaires for usage on (online) platforms. RegionH has ethical approval and prepared, designed, and tested the questionnaires on their online platform, but are awaiting approval from their data protection agency for using UCAM online cognitive tests. VUmc has a new data-collection wave planned at a later time point (starting end of 2018).

2.7. Participants

In total, we hope to invite a total of around 4.700 Lifebrain cohort participants for additional self-report questionnaire and behavioural data enrichment in 2017-2018 (UB, RegionH, UCAM, MPIB, UiO; see Table 2 for detailed overview of participants). Depending on enrichment of VUmc this number could increase (by ~2.950).

For UOXF and VUmc, the vast majority of enrichment variables was already included in their samples at a previous time point and will also be included in the new waves of data collection (e.g. digit span, personality, mental health). UOXF will therefore not participate in



the enrichment. For VUmc, some enrichment questions will be added, such as current and childhood socio-economic status. However, the enrichment wave of VUmc will take place at a later time point and data will therefore not be available in time to be included in any Lifebrain analyses planned to start in 2018 (see WP4 Demonstration).



Table 1. Timelines of ethical approval and data collection

1.	UB		RegionH	UCAM		MPIB	UiO		VUmc
	WAHA	PD	HUBU	Cam-CAN	CALM	BASE II	HUK	NCP	NESDA
Timeline ethics:		·	·			·	·	·	
Application for ethical approval	2016	2013	11.Nov.17 (Online enrichment) / dec-17 (DBS) Update data protection; Mar-18	jan-18	feb-18	march-18	in place	in place	middle of 2018
(Anticipated) ethical approval	2016	2013	21.Nov.17 (Online enrichment) / end Dec-17 (DBS) Data protection approval ~ May-June, 2018	jan-18	apr-18	apr-18	in place	in place	end 2018
Timeline data col	lection:			1	•	1	•	_	
Start of data collection	1 st wave: jan-17 2 nd wave: oct-18	feb-17	aug-18	jun-18	jun-18	may-18	jun-18	sept-18	~end 2018
(Anticipated) end of data collection	1 st wave: sep-17 2 nd wave: end 2018	jul-17	oct-18	sep-18	sep-18	sep-19	dec-18	dec -18	early 2021



Table 2. Participants for enrichment

2.	UB		RegionH	UCAM		MPIB	UiO		VUmc
	WAHA	PD	HUBU	Cam-CAN	CALM	BASE II	HUK	NCP	NESDA
Participants for	enrichment						<u> </u>		
Imaging									
Collected	0	0	0	0	0	0	0	0	0
Total anticipated	0	0	0	0	~200	0	0	0	~150
Questionnaires									
Collected	39 (1 st wave, jan-17)	8 (incomplete)	0	0	0	0	0	0	0
Total anticipated	~ 80 (2 nd wave, oct-18)	8	94	~2000	~600	1250	~400	236	~2950
Behavioural tas	ks								
Collected	39 (1 st wave, jan-17)	0	0	0	0	0	0	0	0
Total anticipated	~ 80 (2 nd wave, oct-18)	0	94	~2000	~600	1250	~400	236	2950 invited
Other (e.g. DBS	, blood, buccal	swabs)							
Collected	0	0	0	0	0	0	0	0	0
Total anticipated	DBS: ~ 80 (2 nd wave)	0	DBS & buccal swabs: 94	0	0	Blood: 1250 (older participants only)	DBS: [,] Buccal swa		Blood: ~2950



Table 3. Data collection methods

3.	UB		RegionH	UCAM MPIB		MPIB	UiO		VUmc
	WAHA	PD	HUBU	Cam-CAN	CALM	BASE II	HUK	NCP	NESDA
Means of data-co	llection:								
Paper/pencil self-report	Yes	Yes	No	Yes	Yes	Yes	Upon participant request	upon participant request	Yes
Face2face interview	Yes	No	No	No	No	Yes	No	No	Yes
Face2face behavioural assessment	Yes	No	No	No	No	Yes	No	No	Yes
Online questionnaire	No	No	Yes	Yes	Yes	Possibly, if subjects have internet	Yes	Yes	Yes
Online behavioural assessment	No	No	Yes	Yes	Yes	Yes	Yes, partly	Yes, partly	Yes
- Digit span: Working memory	No	n/a	Yes	Yes	Yes	Yes	No	No	Yes: use own version of digit span task
- Cattell task: General intelligence	No	n/a	Yes	Yes	Yes	No (similar task already included in BASE II)	Yes	Yes	No
Online Platform used	No	n/a	Redcap (Research Electronic Data Capture)	JATOS	JATOS	Not yet decided	nettskjema.uio.no	nettskjema.uio.no	NETQ healthcare



Table 4. Data storage and safety

4.	UB		RegionH	UCAM		MPIB	UiO		VUmc
	WAHA	PD	HUBU	Cam-CAN	CALM	BASE II	ник	NCP	NESDA
Data storage:									
Data storage (local)	clustered storage for neuroimaging data	clustered storage for neuroimaging data	Data protection approved RegionH servers and local servers	local, Nexenta, not encrypted (but firewall protected), desktop PCs don't have publically routable IP addresses	local, Nexenta, not encrypted (but firewall protected), desktop PCs don't have publically routable IP addresses	local servers, central network storage (protocol SMB)	Central UiO server for sensitive data (TSD)	Central UiO server for sensitive data (TSD)	Local encrypted servers (questionnaire/inter view data), store4ever IBM spectrum scale (imaging/genetics)
Back-up system in place / frequency	yes, 3 copies of raw data (neuroimaging data)	yes, 3 copies of raw data (neuroimaging data)	yes, minimally 1x per day	yes, every 4 hours, offsite in Cambridge	yes, every 4 hours, offsite in Cambridge	yes, minimally 1x per day	yes, daily	yes, daily	yes, minimally 1x per day
Encryption method used (communication / data backup / data transfer)	No	no	yes, exact method depending on server and client	HTTPS (encrypted) for server communication during internet tests, rsh (encrypted) or owncloud (encrypted) or ftp (unencrypted) for transferring data	HTTPS (encrypted) for server communication during internet tests, rsh (encrypted) or owncloud (encrypted) or ftp (unencrypted) for transferring data	yes, SSL, cryptshare for data transfer	yes, exact method depending on server and client	yes, exact method depending on server and client	yes. Method: AES 256 for data transfer
Data (pseudo-) anonymized	yes, pseudo- anonymized	yes, pseudo- anonymized	yes, pseudo- anonymized	yes, pseudo- anonymized	yes, pseudo- anonymized	yes, pseudo- anonymized	yes, pseudo- anonymized	yes, pseudo- anonymized	yes, pseudo- anonymized



			yes (access		yes (access	yes (access	yes, access	yes, access	
			only after	yes (access	only after	only after	only by LCBC	only by LCBC	
			approved	only after	approved	approved	data	data	
			research	approved	research	research	managers,	managers,	yes (access only after
	yes, for two	yes, for two	proposal; via	research	proposal/	proposal /	then two-	then two-	approved research
	copies. One	copies. One	RegionH and	proposal/ Cam-	CALM	BASE-II	step	step	proposal, and only
Authentication	copy with no	copy with no	DRCMR data	CAN data	management	steering	authenticatio	authenticatio	via NESDA data
for access	authentication	authentication	management)	management)	committee)	committee)	n for login	n for login	management)

Annex



Annex 1 - Lifebrain Enrichment Questionnaire

Lifebrain data enrichment questionnaire- FINAL SET

- < Cohort-specific introduction for questionnaire >
- < Cohort-specific identification questions >
 - Color coding: Red text = comments / additional info, not to be included in the actual questionnaire
 - PLEASE mind the comments, as some questions need to be tailored depending on age of your cohort

Demographic & family

State, missing in: UiO, HUBU, UCAM.

- 1. Which of the following best describes your current situation? (YOU CAN SELECT MORE THAN ONE)
 - a) In paid employment, full time (at least 30 hours/week)
 - b) In paid employment, part-time (less than 30 hours/week)
 - c) Employed in organization with 10 or less employees
 - d) Employed in organization with more than 10 employees
 - e) Self-employed
 - f) Employer with less than 10 employees
 - g) Employer with more than 10 employees
 - h) Retired, at age
 - i) Looking after home and/or family
 - j) Unable to work because of sickness or disability
 - k) Unemployed, short term (< 12 months)
 - I) Unemployed, long term (> 12 months)
 - m) Never had a job
 - n) Doing unpaid or voluntary work
 - o) Student
 - p) Other,

< wording should match educational system in your country, and be translatable to low education level (1/2), intermediate education level (3/4), high education level (5) >

see ISCED https://en.wikipedia.org/wiki/International_Standard_Classification_of_Education



option 1: ISCED 2011 level 0 and 1 (non/primary educ), low SES

option 2: ISCED 2011 level 2 and 3 (secondary educ), low SES

option 3: ISCED 2011 level 4 and 5 (post-secondary/first stage tertiary educ): middle SES

option 4: ISCED 2011 level 6, 7, and 8 (tertiary education, Bachelor, Master): high SES

- 2. Which of the following best fits your present job, or (if no longer working) your last held job?
 - Unskilled job that usually doesn't need any schooling
 - Job that usually needs a secondary school degree or short specific training, but not a college / vocational degree
 - o Job that usually needs a college / vocational degree, but not university
 - o Job that usually needs a university degree / bachelor or master degree
 - Not applicable
- 3. What is the specific job title, level of function and responsibility for other personal (if any) of your current or last held profession? If applicable, please describe the nature and size of the organization you work for.

For example: Lead nurse, in charge of 35 nurses in a group of hospital wards in a hospital (1000 employees); Retail assistant in a clothes shop (7 employees), no responsibility for other staff; Self-employed builder, responsible for 5 staff working for me.

.....

< For relevant cohort population (e.g. young people), include questions on:

- a) highest level of education,
- b) current income >

State, missing in: UiO, HUBU, PD.

< match to age-group. Marital for elderly, relationship for young cohorts.

married/divorced, widow options can be left out for young cohorts >

- 4. a. Which of the following best describes your current marital/relationship status:
 - a) not in a stable relationship
 - b) in a stable relationship, not married (see question b)
 - c) married (see question b)
 - d) divorced
 - e) widow/widower
 - b. What is the duration of your current relationship:
 - ... years and ... months



Stable 'trait', missing in: PD, WAHA, UCAM

<use education categories tailored to cohort country >

- 5. What is/was the highest level of education completed by your parents?
 - a. Father:
 - Not applicable
 - o I don't know
 - No education
 - o Primary school
 - Special educational school
 - Secondary school
 - Vocational training
 - o University degree
 - b. Mother:
 - Not applicable
 - o I don't know
 - No education
 - o Primary school
 - Special educational school
 - Secondary school
 - Vocational training
 - o University degree
 - c. Other important care-taker: ...* (*describe relationship to you, e.g. stepfather, guardian)
 - Not applicable
 - o I don't know
 - No education
 - o Primary school
 - o Special educational school
 - Secondary school
 - Vocational training
 - University degree



- 6. During your childhood, what was your parents' longest held profession?
 - a. Father: ...
 - Not applicable
 - I don't know
 - No job
 - Unskilled job that usually doesn't need any schooling
 - Job that usually needs a secondary school degree or short specific training, but not a college / vocational degree
 - Job that usually needs a college / vocational degree, but not university
 - Job that usually needs a university degree / bachelor or master degree
 - b. Mother:
 - Not applicable
 - I don't know
 - o No job
 - Unskilled job that usually doesn't need any schooling
 - Job that usually needs a secondary school degree or short specific training, but not a college / vocational degree
 - Job that usually needs a college / vocational degree, but not university
 - O Job that usually needs a university degree / bachelor or master degree
 - c. Other important care-taker: ...* (*describe relationship to you, e.g. stepfather, guardian)
 - Not applicable
 - o I don't know
 - No job
 - Unskilled job that usually doesn't need any schooling
 - Job that usually needs a secondary school degree or short specific training, but not a college / vocational degree
 - Job that usually needs a college / vocational degree, but not university
 - o Job that usually needs a university degree / bachelor or master degree
- 7. What is/was your parents' highest attained profession, throughout their life?
 - a. Father: ...
 - Not applicable
 - o I don't know
 - o No job
 - Unskilled job that usually doesn't need any schooling
 - Job that usually needs a secondary school degree or short specific training, but not a college / vocational degree
 - o Job that usually needs a college / vocational degree, but not university
 - Job that usually needs a university degree / bachelor or master degree
 - b. Mother:
 - Not applicable
 - I don't know
 - o No job
 - Unskilled job that usually doesn't need any schooling



- Job that usually needs a secondary school degree or short specific training, but not a college / vocational degree
- Job that usually needs a college / vocational degree, but not university
- o Job that usually needs a university degree / bachelor or master degree
- c. Other important care-taker: ...* (*describe relationship to you, e.g. stepfather, guardian)
 - Not applicable
 - o I don't know
 - o No job
 - Unskilled job that usually doesn't need any schooling
 - Job that usually needs a secondary school degree or short specific training, but not a college / vocational degree
 - o Job that usually needs a college / vocational degree, but not university
 - o Job that usually needs a university degree / bachelor or master degree

Trait: New for all

- 8. <u>During your childhood</u>, how would you rate your family's economic standing compared to other families?
 - o Poor / difficult
 - o Below average
 - Average
 - o Above average
 - o Well-off
- 9. How would you rate your <u>current</u> economic standing compared to others?
 - o Poor / difficult
 - Below average
 - o Average
 - Above average
 - Well-off



Birth

Stable 'trait', missing for: UiO, UCAM, HUBU.

< Imperial units of pounds can be added for UK >

- 1. What was your birth weight in grams? (you may be able to find this info on a birth certificate, engraved on a birth gift or by asking your parents)
 - o grams
- o This is an estimation
- o This is from record
- I don't know.

Stable 'trait', missing for most

- 2. Where you born via caesarian section?
 - o yes
 - o no
 - o I don't know
- 3. Where you born too early / prematurely?
 - o yes, born at weeks (normal pregnancy duration is 40 weeks)
 - o yes, but I don't know how early
 - o no
 - o I don't know



Masculinity & femininity

Trait: New for all.

[translation available in German] Kachel et al, 2016, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4932111/

Introduction for gender questions: Each individual is unique and has different personality traits. For example, everybody falls somewhere on a masculine/feminine scale. What is considered masculine or feminine often slightly differs for each culture and/or place in time. The degree of masculinity and femininity varies in males and females and is not directly linked to biological sex. Some males have traits that are considered more feminine, and some females have traits that are considered more masculine.

The following statements refer to the way you perceive yourself as feminine or masculine. Please describe yourself by selecting the answers that match best to yourself. There are no right or wrong answers: We are interested in your own experience.

1	
_	

- a) I consider myself as...

 Totally masculine □ 1. □2. □3. □4. (intermediate) □5. □6. □7. Totally feminine □ I prefer not to answer.
- b) Ideally, I would like to be...

 Totally masculine □ 1. □2. □3. □4. (intermediate) □5. □6. □7. Totally feminine
 □ I prefer not to answer.
- c) Traditionally, my interests would be considered as...

 Totally masculine □ 1. □2. □3. □4. (intermediate) □5. □6. □7. Totally feminine
 □ I prefer not to answer.
- d) Traditionally, my attitudes and beliefs would be considered as...

 Totally masculine □ 1. □2. □3. □4. (intermediate) □5. □6. □7. Totally feminine
 □ I prefer not to answer.
- e) Traditionally, my behaviour would be considered as...

 Totally masculine □ 1. □2. □3. □4. (intermediate) □5. □6. □7. Totally feminine
 □ I prefer not to answer.
- f) Traditionally, my outer appearance would be considered as...

 Totally masculine □ 1. □2. □3. □4. (intermediate) □5. □6. □7. Totally feminine
 □ I prefer not to answer.



Personality

Missing for: PD, WAHA, Cam-CAN

Eysenck Personality Questionnaire - Revised Short (EPQ-RS)

- < Reference: Eysenck, Eysenck & Barrett, 1985; full original version: http://collections.crest.ac.uk/335/1/fulltext.pdf >
- < NEW ADDITION February 2018. Due to logistic and financial limitations of using the NEO-FFI, we decided to include the Eysenck personality questionnaire Revised short version instead. >

NB - answering options: The EPQ-RS originally has 2 answering categories for each question (Yes / No). In Lifebrain we have included the option to use a 4-point answering scale (Yes, a lot; Yes, a little; No, not that much; No, not at all). Region H has previously used the 4-point scale in their cohort, which gives more variance in the data with retention of the original psychometrics of the questionnaire and can easily be recoded to the original binary scales.

NB - subscale options: If time is limited, we suggest not to include all 48 questions, but the Neuroticism and Extraversion subscales only for a total set of 24 questions (i.e. the following: Neuroticism=questions 1, 5, 9, 13, 17, 21, 25, 30, 34, 38, 42, 46; Extraversion=questions 3, 7, 11, 15, 19, 23, 27, 32, 36, 41, 44, 48), as these have been most consistently associated with mental and somatic health, and to exclude the Psychoticism (questions 2, 6, 10, 14, 18, 22, 26, 28, 31, 35, 39, 43) and Social desirability (questions 4, 8, 12, 16, 20, 24, 29, 33, 37, 40, 45, 47) subscales.

Introduction (original version)

Please answer each question by clicking the 'Yes' or the 'No' button following the question. There are no right or wrong answers, and no trick questions. Work quickly and do not think too long about the exact meaning of the questions.

Answering options (original version)

- Yes
- o No

Introduction (Lifebrain version)

Please answer each question by rating how well each item fits to you and clicking one of the answer buttons following the question. There are no right or wrong answers, and no trick questions. Work quickly and do not think too long about the exact meaning of the questions.

Answering options (Lifebrain version)

- o Yes, a lot
- Yes, a little
- No, not that much
- o No, not at all



Questions

- 1. Does your mood often go up and down?
- 2. Do you take much notice of what people think?
- 3. Are you a talkative person?
- 4. If you say you will do something, do you always keep your promise no matter how inconvenient it might be?
- 5. Do you ever feel 'just miserable' for no reason?
- 6. Would being in debt worry you?
- 7. Are you rather lively?
- 8. Were you ever greedy by helping yourself to more than your share of anything?
- 9. Are you an irritable person?
- 10. Would you take drugs which may have strange or dangerous effects?
- 11. Do you enjoy meeting new people?
- 12. Have you ever blamed someone for doing something you knew was really your fault?
- 13. Are your feelings easily hurt?
- 14. Do you prefer to go your own way rather than act by the rules?
- 15. Can you usually let yourself go and enjoy yourself at a lively party?
- 16. Are *all* your habits good and desirable ones?
- 17. Do you often feel 'fed-up'?
- 18. Do good manners and cleanliness matter much to you?
- 19. Do you usually take the initiative in making new friends?
- 20. Have you ever taken anything (even a pin or button) that belonged to someone else?
- 21. Would you call yourself a nervous person?
- 22. Do you think marriage is old-fashioned and should be done away with?
- 23. Can you easily get some life into a rather dull party?
- 24. Have you ever broken or lost something belonging to someone else?
- 25. Are you a worrier?
- 26. Do you enjoy co-operating with others?
- 27. Do you tend to keep in the background on social occasions?
- 28. Does it worry you if you know there are mistakes in your work?



- 29. Have you ever said anything bad or nasty about anyone?
- 30. Would you call yourself tense or 'highly-strung'?
- 31. Do you think people spend too much time safeguarding their future with savings and insurances?
- 32. Do you like mixing with people?
- 33. As a child were you ever cheeky to your parents?
- 34. Do you worry too long after an embarrassing experience?
- 35. Do you try not to be rude to people?
- 36. Do you like plenty of bustle and excitement around you?
- 37. Have you ever cheated at a game?
- 38. Do you suffer from 'nerves'?
- 39. Would you like other people to be afraid of you?
- 40. Have you ever taken advantage of someone?
- 41. Are you mostly quiet when you are with other people?
- 42. Do you often feel lonely?
- 43. Is it better to follow society's rules than go your own way?
- 44. Do other people think of you as being very lively?
- 45. Do you always practice what you preach?
- 46. Are you often troubled about feelings of guilt?
- 47. Do you sometimes put off until tomorrow what you ought to do today?
- 48. Can you get a party going?



Mood

Trait and state: Missing for: UiO, HUBU, PD, WAHA and CALM

LIDAS

- CAREFULLY CHECK ALL SKIPS ARE CORRECT IN YOUR FINAL QUESTIONNAIRE!
- IF DONE ON PAPER: PLEASE PAY A LOT OF ATTENTION TO LAY-OUT, to make the skips clear and easy to follow!

Lifetime Screener questions:

The next questions are about periods of sadness and depression in your life.

1. weeks o	Have you or longer?	ever had a	a time in your life when you felt sad, empty or depressed for	two
		1 Yes		
) No	▶ go to question 3	
2.		•	on, think about a period of two weeks in your life when these . During this period of two weeks, how often did you feel this	way?
		1 Alm	ost every day, most of the day bgo to question 5	
) Less	often	
3. most th	•	obbies, wo	a time in your life lasting two weeks or more when you lost interestork, or activities that usually give you pleasure?	st in
		ر No	go to question 35	
4.		•	on, think about the period of two weeks in your life when your his period of two weeks, how often did you feel this way?	loss of
	□:	1 Alm	ost every day, most of the day ► go to question 7	
) Less	often ▶ go to question 35	
5. activitie	lasting tw es that usu	o weeks o	nat you felt sad, empty or depressed, did you ever have a period r more when you lost interest in most things like hobbies, work, ou pleasure?	or
		O No ► go	to question 7	
6. interest	t were wor	st. During	on, think about the period of two weeks in your life when your this period of two weeks, how often did you feel this way? every day, most of the day	loss of



Current Screener questions:

7	-	month, have you had a period when you felt sad, empty or depressed for t	wo
weeks	or longer?	V	
	□1		
0	□0 :: at a a this		
8.	_	s period of two weeks, how often did you feel this way?	
	□1 -0	0	
	□0	Less often	
9.	•	month, have you had a period lasting two weeks or more when you lost most things like hobbies, work, or activities that usually give you pleasure? Yes	
10.		s period of two weeks, how often did you feel this way?	
	_ 1		
	□0		
11. activitio	lasting two	s period that you felt sad, empty or depressed, did you have a period weeks or more when you lost interest in most things like hobbies, work, ally give you pleasure? Yes	or
	□C	No ► go to question 13	
12. your lo way?		xt question, think about the period of two weeks in in the past month very was worst. During this period of two weeks, how often did	vhen this
y.		Almost every day, most of the day Less often	
comple > Pos	rte question itive screen	Positive screener past MDD (question 2, 4 or 6 are answered with option 1: 13 to 29 (for period <u>in your life)</u> . er current MDD (question 8, 10 or 12 are answered with option 1): also comple (for period <u>in the past month)</u> .	ete:
Follow	-up questio	nnaire lifetime/current	
other p	roblems at	periods in which they feel sad, empty or depressed or lose interest, often have the same time. During the period in your life of at least two weeks when you ressed or lost interest in things:	
13.	did you □1 Yes □0 No	lack energy or feel tired more than usual?	
14.	did you □1 Yes	have less appetite than usual almost every day?	



	□0 No						
15.	did you lose weight without trying to, as much as a kilo a week for several weeks? □1 Yes						
	□0 No ► go to question 17						
16.	About how much weight did you lose in these weeks during the period in your life? kg						
_	nis period <u>in your life</u> of at least two weeks when you felt sad, empty or depressed or lost in things:						
17. more?	did you have a much larger appetite than usual almost every day for two weeks or						
	□2 Yes □1 Yes, only because of pregnancy or a growth spurt □0 No						
18.	did your eating increase so much that you gained weight, as much as a kilo a week for several weeks? □1 Yes						
	□0 No ► go to question 20						
19.	About how much weight did you gain in these weeks? kg						
_	nis period <u>in your life</u> of at least two weeks when you felt sad, empty or depressed or lost in things:						
20.	did you have trouble sleeping almost every night, either trouble falling asleep, waking in the middle of the night, or waking up too early? □1 Yes						
	□0 No ► go to question 22						
21. weeks?	did you wake up at least two hours before you wanted to, every day for at least two						
	□1 Yes □0 No						
22.	were you sleeping too much almost every day? □1 Yes □0 No						

During this period <u>in your life</u> of at least two weeks when you felt sad, empty or depressed or lost interest in things:



23. that o		you talk or move more slowly than is normal for you almost every day, in a way ple have noticed?
	□2 □1 □0	Yes, I talked or moved more slowly and other people did notice Yes, I talked or moved more slowly but other people did not notice No
24.		you have to be moving all the time, that is, you couldn't sit still and paced up and
		n't keep your hands still when sitting, in a way that other people noticed?
	□2	Yes, I had to be moving all the time and other people did notice
	□1 □0	Yes, I had to be moving all the time but other people did not notice No
25. than u	_	this period <u>in your life</u> of two weeks, did you have a lot more trouble concentrating
	□1	Yes
	□0	No
26.	_	this period, were you able to make up your mind about things you ordinarily had iding about?
110 110		Yes
	□0	No
27.		sometimes feel down on themselves, no good, or worthless. During this of two weeks <u>in your life</u> , did you feel guilty or ess? Yes No
28. own, s	someone	this period of two weeks <u>in your life</u> , did you think a lot about death – either your else's, or death in general? Yes
	□0	No
		uestion, please think about the periods of at least two weeks <u>in your life</u> when you sad, empty or depressed or lost interest in things.
29. job, ta		y period lasting two weeks or longer seriously interfere with your ability to do your of your house or family, or take care of yourself? Yes
	□0	No
INFO (ON SKIPS	: < If positive screener for current MDD (question 8, 10 or 12 are answered with option

| Page | **31**

1): continue with question 13*>

< If no positive screener for current MDD: go to question 30 >



You indicated that you also felt sad, empty or depressed or lost interest in thing during a period of at least two weeks <u>during the past month</u>. Now we will repeat the previous questions, but now about the period <u>during the past month</u>.

People who have periods in which they feel sad, empty or depressed or lose interest, often have other problems at the same time. During the period in the past month of at least two weeks when you felt sad, empty or depressed or lost interest in things:

13*.	did you lack energy or feel tired more than usual? □1 Yes □0 No
14*.	did you have less appetite than usual almost every day? □1 Yes □0 No
15*.	did you lose weight without trying to, as much as a kilo a week for several $\;\;$ weeks? $_{\Box 1}$ Yes
	□0 No ► go to question 17*
16*.	About how much weight did you lose in these weeks during the past month? kg
_	this period <u>in the past month</u> of at least two weeks when you felt sad, empty or depressed or erest in things:
17*. more?	did you have a much larger appetite than usual almost every day for two weeks or
	□2 Yes □1 Yes, only because of pregnancy or a growth spurt □0 No
18*. several	did your eating increase so much that you gained weight, as much as a kilo a week $$ for weeks? $$ $\!\!$ $\!\!$ $\!\!$ $\!\!$ $\!\!$ $\!\!$ $\!\!$
	□0 No ► go to question 20*
19*.	About how much weight did you gain in these weeks during the past month? kg
	this period <u>in the past month</u> of at least two weeks when you felt sad, empty or depressed or erest in things:
20*.	did you have trouble sleeping almost every night, either trouble falling asleep, waking in the middle of the night, or waking up too early? $\Box 1$ Yes
	□0 No ► go to question 22*



21*. weeks?		you wake up at least two hours before you wanted to, every day for at least two
	□1	Yes
	□0	No
22*.		e you sleeping too much almost every day?
	□1	Yes
	□0	No
_	this peri erest in	iod <u>in the past month</u> of at least two weeks when you felt sad, empty or depressed or things:
23*. that otl		you talk or move more slowly than is normal for you almost every day, in a way ble have noticed?
	□2	Yes, I talked or moved more slowly and other people did notice
	□1 □0	Yes, I talked or moved more slowly but other people did not notice No
24*. down o	-	ou have to be moving all the time, that is, you couldn't sit still and paced up and n't keep your hands still when sitting, in a way that other people noticed?
	□2	Yes, I had to be moving all the time and other people did notice
	□1	Yes, I had to be moving all the time but other people did not notice
	□0	No
25*.		this period <u>in the past month</u> of two weeks, did you have a lot more trouble trating than usual?
	□1	Yes
	□0	No
26*. no trou	•	this period, were you able to make up your mind about things you ordinarily had ding about?
	□1	Yes
	□0	No
27*.	•	sometimes feel down on themselves, no good, or worthless. During this of two weeks in the past month, did you feel guilty or worthless?
	□ 1	Yes
	□0	No
28*.	_	this period of two weeks <u>in the past month</u> , did you think a lot about death — either eone else's, or death in general?
your ov	vii, soiiii □1	Yes
	□0	No
	_0	•••

For the next question, please think about the periods of at least two weeks <u>in the past month</u> when you when you felt sad, empty or depressed or lost interest in things.



29*. job, tak		y period lasting two weeks or lor of your house or family, or take o Yes No	_	•		your
INFO FO	OR SKIP:	S: <following onc<="" only="" questions="" td=""><td>e, for po</td><td>sitive sc</td><td>reener lifetime MDD: ></td><td></td></following>	e, for po	sitive sc	reener lifetime MDD: >	
_	-	e, you may have had one or mor ost interest in things.	e period	ls when	you when you felt sad, empty o	•
30.	About how long did the longest of periods like this last? You may give an estimate weeks					
31.	How many periods like this did you have in your life? $\Box 1 \qquad 1 \\ \Box 2 \qquad 2 \text{ or more}$					
32.	Did you have a period like this in the last 12 months? □1 Yes □0 No					
33.	About how old were you the first time you had a period like this? (whether or not you received any help for it) years					
34.	Did you ever tell a professional about these problems (for example a medical doctor, psychologist, social worker, nurse, or other helping professional)? □1 Yes □0 No					
MDD. T and the	hese ca 2 35-37 (d 36 car	in be used to select 'pure' contro are to additionally screen for life In be excluded if family history qu	ls, i.e. po time ML	articipar DD >	positive/negative screener lifetin nts without lifetime psychopatho cluded (this also asks about lifet	logy,
□a □b	l doctor Ever di Depres Bipolar	disorder (manic depression)	swer.	or: □h □i	Post-traumatic stress disorder Phobia	or
□c □d □e □f □g	Eating Anxiety Panic o	ohrenia or psychosis disorder y disorder lisorder iive compulsive disorder	□k □n	□l □m	ADD/ADHD ality disorder Alcohol addiction Drug addiction namely:	
□o	None of these disorders ▶ go to question 37					



36.	Please tick the disorders that you have ever received treatment for by a professional or				
medica	I doctor. You can tick more than one ar	iswer.			
	Ever received treatment by a profession	nal/med	dical doc	tor:	
□a	Depression		□i	Phobia	
□b	Bipolar disorder (manic depression)		□j	ADD/ADHD	
□C	Schizophrenia or psychosis		□k	Personality disorder	
□d	Eating disorder	□l	Alcoho	l addiction	
□ e	Anxiety disorder		$\square m$	Drug addiction	
□f	Panic disorder		□n	Other, namely:	
□g	Obsessive compulsive disorder	□O	None of these disorders		
□h	Post-traumatic stress disorder				
37.	Did you ever have the following treatmonth and Antidepressants b Psychotherapy (for example cognity other consultations with a psychologisty of Conline help program or e-health into the Running therapy or physical activity be Light therapy f Hospitalization in psychiatric hospity therapy (ECT) h Other, namely: i None of these treatments	ive beha t or psyc terventic	vioral th hothera	erapy, interpersonal therapy	or



Family Health History

Trait/state: missing for UiO, PD, WAHA, UCAM, medical health in HUBU

1. How would you rate your own health in general?

ExcellentGoodFairPoorVery poor			
Please respond on a scale of 1 to 10,	where 1 is "not		ly".
amily health questions, please design a ilities>	set-up that fits	with local online or paper o	questioning
· · · · · · · · · · · · · · · · · · ·		· ·	•
 Biological father Biological mother Sister(s), (indicate how many Brother(s), (indicate how many) y)	health information:	
ctive online forms the follow-up can be	shaped based o		rther (with
doctor with a severe or chronic illne	ss or psychiatric	disorder. And if so, did yo	
a i	o Good o Fair o Poor o Very poor Overall, how satisfied are you with your Please respond on a scale of 1 to 10, □ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □ 7 □ 8 □ 9 □ Interpretation of the second of	Overall, how satisfied are you with your life nowaday Please respond on a scale of 1 to 10, where 1 is "not □ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □ 7 □ 8 □ 9 □ 10 milly health questions, please design a set-up that fits lities> milly health questions, please design a set-up that fits lities> milly health questions, please design a set-up that fits lities> milly health questions, please design a set-up that fits lities> milly health questions, please design a set-up that fits lities> milly health questions, please design a set-up that fits lities> milly health questions, please design a set-up that fits lities> milly health questions, please design a set-up that fits lities> please indicate for which family members you have	o Good o Fair o Poor o Very poor Overall, how satisfied are you with your life nowadays? Please respond on a scale of 1 to 10, where 1 is "not at all" and 10 is "complete □ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □ 7 □ 8 □ 9 □ 10 Implies to ask you some questions, please design a set-up that fits with local online or paper of lities> Int to ask you some questions concerning your health and that of your direct fam let family we mean your parents, brothers and sisters, and any children you may Please indicate for which family members you have health information: o Biological father o Biological mother o Sister(s), (indicate how many) o Child(ren), (indicate how many) child(ren), (indicate how many) ive: Use a primary question to identify family members that will be investigated furtive online forms the follow-up can be shaped based on these answers. iver: let people fill in the column titles themselves. > a. Please indicate if you have ever been diagnosed by a healthcare professional doctor with a severe or chronic illness or psychiatric disorder. And if so, did you treatment for this by a healthcare professional or medical doctor? o Diabetes



	0	Depressive disorder	diagnosis	☐ treatment
	0	Anxiety disorder	diagnosis	☐ treatment
	0	Alcohol or drug abuse	diagnosis	☐ treatment
	0	Attention Deficit Disorder or Atte	ention Deficit-Hy	peractivity Disorder (ADD, ADHD)
		diagnosis	☐ treatment	
	0	Schizophrenia	diagnosis	☐ treatment
	0	Other, specify	diagnosis	☐ treatment
	0	None of these disorders		
1	_	Has your biological father over be	on diagnosad by	a haalthaara professional ar a madical
4.			-	a healthcare professional or a medical
				disorder. And if so, did he ever receive
		eatment for this by a healthcare properties.		
	0	Diabetes	diagnosis	☐ treatment
	0	Stroke	diagnosis	☐ treatment
	0	Heart disease / heart infarct	diagnosis	☐ treatment
	0	High blood pressure	diagnosis	☐ treatment
	0	Cancer	diagnosis	☐ treatment
	0	Dementia	diagnosis	treatment
	0	Depressive disorder	diagnosis	☐ treatment
	0	Anxiety disorder	diagnosis	☐ treatment
	0	Alcohol or drug abuse	diagnosis	☐ treatment
	0	Attention Deficit Disorder or Atte		peractivity Disorder (ADD, ADHD)
	_	Cahizanhrania	diagnosis	☐ treatment
	0	Schizophrenia	diagnosis	☐ treatment
	0	Other, specify	diagnosis	treatment
	0	None of these disorders		
	0	I don't know		
5.	a.	Has your biological mother ever b	een diagnosed b	by a healthcare professional or a medical
			_	disorder. And if so, did she ever receive
		eatment for this by a healthcare p		
	0	Diabetes	diagnosis	☐ treatment
	0	Stroke	diagnosis	☐ treatment
	0	Heart disease / heart infarct	diagnosis	☐ treatment
	0	High blood pressure	diagnosis	☐ treatment
	0	Cancer	diagnosis	☐ treatment
	0	Dementia	diagnosis	☐ treatment
	0	Depressive disorder	diagnosis	treatment
	0	Anxiety disorder	diagnosis	☐ treatment
	0	Alcohol or drug abuse	diagnosis	☐ treatment
	0	_	_	peractivity Disorder (ADD, ADHD)
	J	According Deficit Disorder of Acc	diagnosis	treatment
	0	Schizophrenia	diagnosis	☐ treatment
	0	Other, specify	diagnosis	
	0	None of these disorders	_ 5	
	0	I don't know		

< etc. For each of the family members indicated above >



Depending on the system you use or if you use paper questionnaires, you can also put the family health questionnaire in table form, e.g.:

	you	biological	biological			
		mother	father	_		
	diagnosis	diagnosis	diagnosis	diagnosis	diagnosis	diagnosis
Diabetes	☐ treatment	☐ treatment	treatment	treatment	treatment	treatment
Stroke	diagnosis	diagnosis	diagnosis	diagnosis	diagnosis	diagnosis
Stroke	treatment	☐ treatment	treatment	☐ treatment	treatment	treatment
Heart disease or	diagnosis	diagnosis	diagnosis	diagnosis	diagnosis	diagnosis
heart infarct	treatment	☐ treatment	treatment	☐ treatment	treatment	☐ treatment
High blood	diagnosis	diagnosis	diagnosis	diagnosis	diagnosis	diagnosis
pressure	treatment	☐ treatment	treatment	☐ treatment	treatment	☐ treatment
	diagnosis	diagnosis	diagnosis	diagnosis	diagnosis	diagnosis
Cancer	treatment	☐ treatment	treatment	treatment	treatment	☐ treatment
	diagnosis	diagnosis	diagnosis	diagnosis	diagnosis	diagnosis
Dementia	treatment	☐ treatment	treatment	☐ treatment	treatment	treatment
Depressive	diagnosis	diagnosis	diagnosis	diagnosis	diagnosis	diagnosis
disorder	treatment	☐ treatment	treatment	☐ treatment	treatment	treatment
	diagnosis	diagnosis	diagnosis	diagnosis	diagnosis	diagnosis
Anxiety disorder	treatment	☐ treatment	treatment	treatment	treatment	treatment
Alcohol or drug	diagnosis	diagnosis	diagnosis	diagnosis	diagnosis	diagnosis
abuse	treatment	☐ treatment	treatment	☐ treatment	treatment	treatment
400 40110	diagnosis	diagnosis	diagnosis	diagnosis	diagnosis	diagnosis
ADD or ADHD	treatment	☐ treatment	treatment	☐ treatment	treatment	treatment
	diagnosis	diagnosis	diagnosis	diagnosis	diagnosis	diagnosis
Schizophrenia	treatment	☐ treatment	treatment	☐ treatment	treatment	treatment
0.1	diagnosis	diagnosis	diagnosis	diagnosis	diagnosis	diagnosis
Other	treatment	☐ treatment	treatment	☐ treatment	treatment	treatment
0.1	diagnosis	diagnosis	diagnosis	diagnosis	diagnosis	diagnosis
Other	treatment	☐ treatment	treatment	☐ treatment	treatment	treatment
Oth	diagnosis	diagnosis	diagnosis	diagnosis	diagnosis	diagnosis
Other	treatment	☐ treatment	treatment	treatment	treatment	treatment
None of these						
disorders						
I don't know						



STATE LIFESTYLE & HEALTH

OPTIONAL to repeat: State of lifestyle variables (BMI, smoking, alcohol, sleep, PA) = available for all at earlier timepoints, potentially repeat cohort-specific questions for current info on, or use the basic versions as below

Weight & height

What is your height in cm? Please round your answer to the nearest whole number.	
cm	
What is your weight in kg? Please round your answer to the nearest whole number.	
kg	

Smoking

most sites have info on smoking status and nr of cigarettes per day, so preferable that you have that in your cohort at at least 1 timepoint

Do you smoke?

□ No, I have never smoked
☐ No, but I have smoked in the past
☐ Yes. on average cigarettes per day

<or add Fagerstrom on nicotine dependence, 6 questions >
https://cde.drugabuse.gov/sites/nida_cde/files/FagerstromTest_2014Mar24.pdf

Alcohol

most sites have info on nr. of alcoholic units per week, , so preferable that you have that in your cohort at least 1 timepoint

How often do you have a drink containing alcohol?

- o never
- o monthly or less
- o 2-4 times a month
- o 2-3 times a week
- 4 or more times a week



How many drinks containing alcohol do you have on a typical day when you are drinking?

- o 1 or 2
- o 3 or 4
- o 5 or 6
- o 7 to 9
- o 10 or more

< or use full AUDIT, 10 questions, http://auditscreen.org/page.php?Download-2>

Physical activity

most sites have info on MET/min per week (such as IPAQ), so preferable that you have that in your cohort for at least 1 timepoint

< short IPAQ below, or use full IPAQ, see https://sites.google.com/site/theipaq/questionnaire_links for versions and translations, available in Dutch, Danish, German, Norwegian, Spanish >

We are interested in finding out about the kinds of physical activities that people do as part of their everyday lives. The questions will ask you about the time you spent being physically active in the last 7 days. Please answer each question even if you do not consider yourself to be an active person. Please think about the activities you do at work, as part of your house and yard work, to get from place to place, and in your spare time for recreation, exercise or sport.

Think about all the vigorous activities that you did in the last 7 days. Vigorous physical activities refer to activities that take hard physical effort and make you breathe much harder than normal. Think only about those physical activities that you did for at least 10 minutes at a time.

1.	During the last 7 days, on how many days did you do vigorous physical activities like heavy lifting, digging, aerobics, or fast bicycling? days per week
	 No vigorous physical activities> Skip to question 3
2.	How much time did you usually spend doing vigorous physical activities on one of those days?
	hours per day
	minutes per day
	 Don't know/Not sure



Healthy minds from 0-100 years: Optimising the use of European brain imaging cohorts

Think about all the moderate activities that you did in the last 7 days. Moderate activities refer to activities that take moderate physical effort and make you breathe somewhat harder than normal. Think only about those physical activities that you did for at least 10 minutes at a time.

3.	During the last 7 days, on how many days did you do moderate physical activities like carrying light loads, bicycling at a regular pace, or doubles tennis? Do not include walking.
	days per week
	 No moderate physical activities> Skip to question 5
4.	How much time did you usually spend doing moderate physical activity on one of those days? hours per day
	minutes per day
	o Don't know/Not sure
to trav	about the time you spent walking in the last 7 days. This includes at work and at home, walking el from place to place, and any other walking that you have done solely for recreation, sport, se, or leisure.
5.	During the last 7 days, on how many days did you walk for at least 10 minutes at a time? days per week No walking> Skip to question 7
6.	How much time did you usually spend walking on one of those days? hours per day
	minutes per day
	o Don't know/Not sure
spent a	st question is about the time you spent sitting on weekdays during the last 7 days. Include time at work, at home, while doing course work and during leisure time. This may include time sitting at a desk, visiting friends, reading, or sitting or lying down to watch television.
7.	During the last 7 days, how much time did you spend sitting on a week day? hours per day
	minutes per day



Don't know/Not sure

SLEEP

Sleep quality = State, available at all sites, repeat cohort-specific questions or PSQI

Pittsburgh Sleep Quality Inventory

< https://www.opapc.com/uploads/documents/PSQI.pdf >

Instructions: The following questions relate to your usual sleep habits during the past month only. Your answers should indicate the most accurate reply for the majority of days and nights in the past month.

P	lease	answer	all o	uestions.

During the past month,

ıı ıg	the past month,
1.	When have you usually gone to bed at night?::
2.	How long (in minutes) has it taken you to fall asleep each night? minutes
3.	When have you usually gotten up in the morning?::
4.	How many hours of actual sleep did you get at night? (This may be different than the number of hours you spend in bed) hours of sleep per night

5.

During the past				
month, how often have you had	Not during the	Less than once a	Once or twice a	Three or more
-	_			
trouble sleeping	past month (0)	week (1)	week (2)	times a week (3)
because you				
a. Cannot get to				
sleep within 30				
minutes				
b. Wake up in the				
middle of the				
night or early				
morning				
c. Have to get up				



to use the		
bathroom		
d. Cannot breathe		
comfortably		
e. Cough or snore		
loudly		
f. Feel too cold		
g. Feel too hot		
h. Have bad		
dreams		
i. Have pain		
j. Other reason(s),		
please describe,		
including how		
often you have		
had trouble		
sleeping because		
of this reason(s):		

- 6. During the past month, how would you rate your sleep quality overall?
 - Very good
 - Fairly good
 - o Fairly bad
 - o Very bad
- 7. During the past month, how often have you taken medicine (prescribed or "over the counter") to help you sleep?
 - Not during the past month
 - Less than once a week
 - o Once or twice a week
 - Three or more times a week
- 8. During the past month, how often have you had trouble staying awake while driving, eating meals, or engaging in social activity?
 - Not during the past month
 - o Less than once a week
 - Once or twice a week
 - o Three or more times a week
- 9. During the past month, how much of a problem has it been for you to keep up enthusiasm to get things done?
 - o No problem at all
 - Only a very slight problem
 - Somewhat of a problem
 - o A very big problem



OPTIONAL ADDITIONS

Other suggestions that may be of interest for Lifebrain, but not prioritized for enrichment

URBANISATION

1.	 Which of these three categories best describes the area you live in CURRENTLY? City with more than 100,000 inhabitants Town with more than 10,000 Rural area
2.	Up until the age of 15 how many years have you spent living in towns/cities with more than 100,000 inhabitants? years.
3.	Up until the age of 15, how many years have you spent living in towns with more than 10,000 inhabitants? years.
4.	Up until the age of 15, how many years have you spent living in rural areas? years.

SAFETY AND BASIC RESOURCES

< include if these make sense in your cohort, e.g. elderly that may have been through war, poor/immigrant populations >

1.

- a) Was there ever a period in your life when you felt unsafe?
 - o no (continue to question X)
 - o yes
- b) When was this period?
 - O When I was around ... years until ... years old.
- c) Can you indicate the reason you felt unsafe?
 - o War / civil unrest
 - o Unsafe neighborhood environment
 - Unsafe home environment
 - o Other, ...



2.

- a) Was there ever a period in your life when you did not have access to basic resources (e.g. due to famine, war, poverty)?
 - o no (continue to question X)
 - yes
- b) When was this period?
 - When I was around ... years until ... years old.
- c) Can you indicate the reason you did not have access to basic resources?
 - War / civil unrest
 - o Famine
 - Poverty
 - o Unsafe neighborhood environment
 - Unsafe home environment
 - o Other, ...

WOMEN'S HEALTH

< Only in relevant cohort populations (i.e. including middle-aged / elderly women) >

State, missing for UiO, HUBU (not relevant), PD, WAHA (already started enrichment)

- 1. Have you had your menopause (that is, have your periods stopped)?
 - o Yes
 - No (go to next question)
 - Not sure had a hysterectomy (go to next question)
 - Not sure other reason (go to next question)
 - b. How old were you when your periods stopped?

	years	O	ld
--	-------	---	----

- o I do not know
- c. Have you ever been on hormone replacement therapy due to menopause?
 - o Yes
 - o No

LONELINESS

3 item loneliness scale

< Hughes et al 2008, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2394670/, based on UCLA loneliness scale, Russel et al >

- 1. How often do you feel that you lack companionship?
 - Hardly ever
 - Some of the time
 - Often



- 2. How often do you feel left out?
 - Hardly ever
 - Some of the time
 - Often
- 3. How often do you feel isolated from others?
 - Hardly ever
 - Some of the time
 - Often

SOCIAL ACTIVITIES

Based on Cam-CAN list

- 1. How often do you see any of your relatives to speak to?
 - o No relatives (continue to question 4)
 - o Never
 - o Daily
 - o 2-3 times a week
 - At least weekly
 - At least monthly
 - o Less often
- 2. How often do you speak to your relatives over the phone?
 - o Never
 - Daily
 - o 2-3 times a week
 - At least weekly
 - o At least monthly
 - o Less often
- 3. How often do you text/email your relatives?
 - Never
 - Daily
 - o 2-3 times a week
 - o At least weekly
 - At least monthly
 - Less often
- 4. How often do you see any of your friends to speak to?
 - No friends (continue to question 7)
 - o Never
 - o Daily



- o 2-3 times a week
- At least weekly
- At least monthly
- Less often
- 5. How often do you speak to your friends over the phone?
 - o Never
 - Daily
 - o 2-3 times a week
 - At least weekly
 - At least monthly
 - o Less often
- 6. How often do you text/email your friends?
 - Never
 - Daily
 - o 2-3 times a week
 - At least weekly
 - At least monthly
 - Less often
- 7. Do you attend meetings of any community, religious or social groups? (YOU MAY ANSWER MORE THAN ONE)

EACH BOX TICKED WILL BE FOLLOWED BY HOW OFTEN RATING

- o No clubs
- Political parties
- Trade unions (including student union)
- o Environmental groups
- o Tenants, residents group or neighbourhood watch
- Evening classes / Adult learning
- o Arts, music or singing group
- o Charity, volunteer or community group
- Group for the elderly
- Youth group (guides, scouts, youth club)
- Women's Institute
- Social club (rotary, working men's)
- o Sports club, gym, exercise group
- o Religious group
- Other group or organisation

How often?

- Daily
- o 2-3 times a week
- At least weekly



- At least monthlyLess than monthly
- Less than yearly
- 8. Do you have friends in these communities?
 - o No
 - Yes
- 9. How often do you see any of your neighbours to have a chat or do something with?
 - No neighbours
 - Never
 - o Daily
 - o 2-3 times a week
 - o At least weekly
 - At least monthly
 - Less often

CHRONOTYPE (morning/evening person, Munich chronotype questionnaire)

< Roenneberg et al, 2003, https://www.thewep.org/documentations/mctq.

More stable sleep-trait, also related to health outcomes >

1.	I have a regular work schedule (this includes being, for example, a housewife or
	househusband):

a)	Yes, I	work \square :	1 🗆 2 🛭	□ 3 □	4 🗆 5	□ 6 □ 7	day(s)	per	week.
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b) No

Is your answer "Yes, on 7 days" or "No", please consider if your sleep times may nonetheless differ between regular 'workdays' and 'weekend days' and fill out the following questions in this respect.

- 2. On workdays:
 - a) I wake up at o'clock
- 3. On evenings before workdays:
 - b) I go to bed at o'clock
 - c) I need minutes to fall asleep
- 4. On free days:
 - a) I would like to sleep until o'clock
 - b) I usually wake up at o'clock
- 5. On evenings before free days:
 - a) I go to bed at o'clock
 - b) I need minutes to fall asleep



After you have answered the preceding questions, you should have a feeling to which chronotype (time-of-day-type) you belong to. If for example, you like (and manage) to sleep quite a bit longer on free days than on workdays, or if you cannot get out of bed on Monday mornings, even without a Sunday-night-party, then you are more a late type. If, however, you regularly wake up and feel perky once you jump out of bed, and if you would rather go to bed early than to an evening concert then you are an early type. In the following question, you should categorise yourself.

6. I am an:

- extreme early type
- moderate early type
- slight early type
- normal type
- o slight late type
- moderate late type
- o extreme late type

COGNITIVE STIMULATING ACTIVITIES (WILSON)

Wilson 2003 https://www.ncbi.nlm.nih.gov/pubmed/12815501

< Included questions will depend on age-range of local cohort >

In order to learn how experiences early in life affect health later in life, we are asking questions about experiences at different points in your life.

Childhood - Age 6

My first questions are about when you were 6 years old, or thereabouts. I know it may be hard to remember that far back; I just want your best recollection.

- 1. When you were 6, how often did you play games like tic-tac-toe, checkers, or other board games, cards, or word games? Would you say every day or almost every day, several times a week, several times a month, several times a year, or once a year or less?
 - 1 Every day or almost every day
 - o 2 Several times a week
 - o 3 Several times a month
 - 4 Several times a year
 - o 5 Once a year or less
- 2. How often did someone in your home read to you when you were 6? Would you say every day or almost every day, several times a week, several times a month, several times a year, or once a year or less?
 - 1 Every day or almost every day



- o 2 Several times a week
- o 3 Several times a month
- 4 Several times a year
- o 5 Once a year or less
- 3. How often did someone in your home tell you stories when you were 6? Would you say every day or almost every day, several times a week, several times a month, several times a year, or once a year or less?
 - 1 Every day or almost every day
 - o 2 Several times a week
 - o 3 Several times a month
 - o 4 Several times a year
 - o 5 Once a year or less

Teens - Age 12

Now I have some questions about when you were 12 years old, or thereabouts.

- 4. When you were 12, how often did you visit a library? Would you say every day or almost every day, several times a week, several times a month, several times a year, or once a year or less?
 - o 1 Every day or almost every day
 - o 2 Several times a week
 - o 3 Several times a month
 - 4 Several times a year
 - 5 Once a year or less
- 5. When you were 12, how often did you read newspapers? Would you say every day or almost every day, several times a week, several times a month, several times a year, or once a year or less?
 - 1 Every day or almost every day
 - o 2 Several times a week
 - o 3 Several times a month
 - 4 Several times a year
 - 5 Once a year or less
- 6. When you were 12, how often did you read magazines? Would you say every day or almost every day, several times a week, several times a month, several times a year, or once a year or less?
 - 1 Every day or almost every day
 - o 2 Several times a week
 - o 3 Several times a month



- 4 Several times a year
- 5 Once a year or less
- 7. When you were 12, how often did you read books? Would you say every day or almost every day, several times a week, several times a month, several times a year, or once a year or less?
 - 1 Every day or almost every day
 - o 2 Several times a week
 - 3 Several times a month
 - 4 Several times a year
 - 5 Once a year or less
- 8. When you were 12, how often did you write letters? Would you say every day or almost every day, several times a week, several times a month, several times a year, or once a year or less?

Note: You may include writing emails (if applicable) that are of a letter length, when answering this question.

- o 1 Every day or almost every day
- o 2 Several times a week
- o 3 Several times a month
- o 4 Several times a year
- 5 Once a year or less

Teens - Age 18

Now, I have some questions about when you were 18 years old, or thereabouts.

- 10. When you were 18, how often did you visit a library? Would you say every day or almost every day, several times a week, several times a month, several times a year, or once a year or less?
 - 1 Every day or almost every day
 - o 2 Several times a week
 - o 3 Several times a month
 - 4 Several times a year
 - 5 Once a year or less
- 11. When you were 18, how often did you read newspapers? Would you say every day or almost every day, several times a week, several times a month, several times a year, or once a year or less?
 - 1 Every day or almost every day
 - 2 Several times a week
 - o 3 Several times a month



- 4 Several times a year
- o 5 Once a year or less
- 12. When you were 18, how often did you read magazines? Would you say every day or almost every day, several times a week, several times a month, several times a year, or once a year or less?
 - 1 Every day or almost every day
 - o 2 Several times a week
 - 3 Several times a month
 - 4 Several times a year
 - 5 Once a year or less
- 13. When you were 18, how often did you read books? Would you say every day or almost every day, several times a week, several times a month, several times a year, or once a year or less?
 - 1 Every day or almost every day
 - 2 Several times a week
 - o 3 Several times a month
 - o 4 Several times a year
 - 5 Once a year or less
- 14. When you were 18, how often did you write letters? Would you say every day or almost every day, several times a week, several times a month, several times a year, or once a year or less?

Note: You may include writing emails (if applicable) that are of a letter length, when answering this question.

- 1 Every day or almost every day
- o 2 Several times a week
- o 3 Several times a month
- 4 Several times a year
- 5 Once a year or less
- 15. When you were 18, how often did play games like checkers or other board games, cards, puzzles, word games, mind teasers, or any other similar games? Would you say every day or almost every day, several times a week, several times a month, several times a year, or once a year or less?
 - 1 Every day or almost every day
 - o 2 Several times a week
 - o 3 Several times a month
 - 4 Several times a year
 - o 5 Once a year or less



Adulthood - Age 40

- 16. When you were 40, how often did you read newspapers? Would you say every day or almost every day, several times a week, several times a month, several times a year, or once a year or less?
 - 1 Every day or almost every day
 - 2 Several times a week
 - o 3 Several times a month
 - 4 Several times a year
 - 5 Once a year or less
- 17. When you were 40, how often did you read magazines? Would you say every day or almost every day, several times a week, several times a month, several times a year, or once a year or less?
 - 1 Every day or almost every day
 - o 2 Several times a week
 - o 3 Several times a month
 - 4 Several times a year
 - o 5 Once a year or less
- 18. When you were 40, how often did you read books? Would you say every day or almost every day, several times a week, several times a month, several times a year, or once a year or less?
 - 1 Every day or almost every day
 - o 2 Several times a week
 - o 3 Several times a month
 - o 4 Several times a year
 - 5 Once a year or less
- 19. When you were 40, how often did you write letters? Would you say every day or almost every day, several times a week, several times a month, several times a year, or once a year or less?

Note: You may include writing emails (if applicable) that are of a letter length, when answering this question.

- 1 Every day or almost every day
- o 2 Several times a week
- o 3 Several times a month
- 4 Several times a year
- o 5 Once a year or less



- 20. When you were 40, how often did you play games like checkers or other board games, cards, puzzles, word games, mind teasers, or any other similar games? Would you say every day or almost every day, several times a week, several times a month, several times a year, or once a year or less?
 - 1 Every day or almost every day
 - 2 Several times a week
 - o 3 Several times a month
 - 4 Several times a year
 - o 5 Once a year or less

Present Time

Now I have some questions about the present time.

- 21. How often do you read newspapers? Would you say every day or almost every day, several times a week, several times a year, or once a year or less?
 - 1 Every day or almost every day
 - 2 Several times a week
 - o 3 Several times a month
 - 4 Several times a year
 - o 5 Once a year or less
- 22. How often do you read magazines? Would you say every day or almost every day, several times a week, several times a month, several times a year, or once a year or less?
 - 1 Every day or almost every day
 - o 2 Several times a week
 - o 3 Several times a month
 - 4 Several times a year
 - 5 Once a year or less
- 23. How often do you read books? Would you say every day or almost every day, several times a week, several times a month, several times a year, or once a year or less?
 - 1 Every day or almost every day
 - o 2 Several times a week
 - o 3 Several times a month
 - 4 Several times a year
 - o 5 Once a year or less
- 24. How often do you write letters? Would you say every day or almost every day, several times a week, several times a month, several times a year, or once a year or less?



Note: You may include writing emails (if applicable) that are of a letter length, when answering this question.

- o 1 Every day or almost every day
- o 2 Several times a week
- o 3 Several times a month
- o 4 Several times a year
- o 5 Once a year or less
- 25. How often do you play games like checkers or other board games, cards, puzzles, word games, mind teasers, or any other similar games? Would you say every day or almost every day, several times a week, several times a month, several times a year, or once a year or less?
 - o 1 Every day or almost every day
 - o 2 Several times a week
 - o 3 Several times a month
 - 4 Several times a year
 - o 5 Once a year or less