



Description of the LifeGene Resource

Version 2.4

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1. LifeGene overview of resource

LifeGene is a national collaborative project designed to build up a resource for research in all medical disciplines, enabling new and groundbreaking research on the relationships among heredity, environment and lifestyle and its impact on disease. The LifeGene project will include studying 200 000 Swedes mainly aged 0-50 with the aim of creating new tools to prevent, diagnose and treat our most common diseases.

LifeGene will follow the participant over long time with follow-up surveys and repeated baseline test at Test Center. By combining a biological perspective with e-epidemiology, LifeGene will open up new possibilities for a greater understanding of the interplay between heredity, lifestyle and the environment as regards to our most common diseases, possibilities strengthened by the longitudinal aspects of the study.

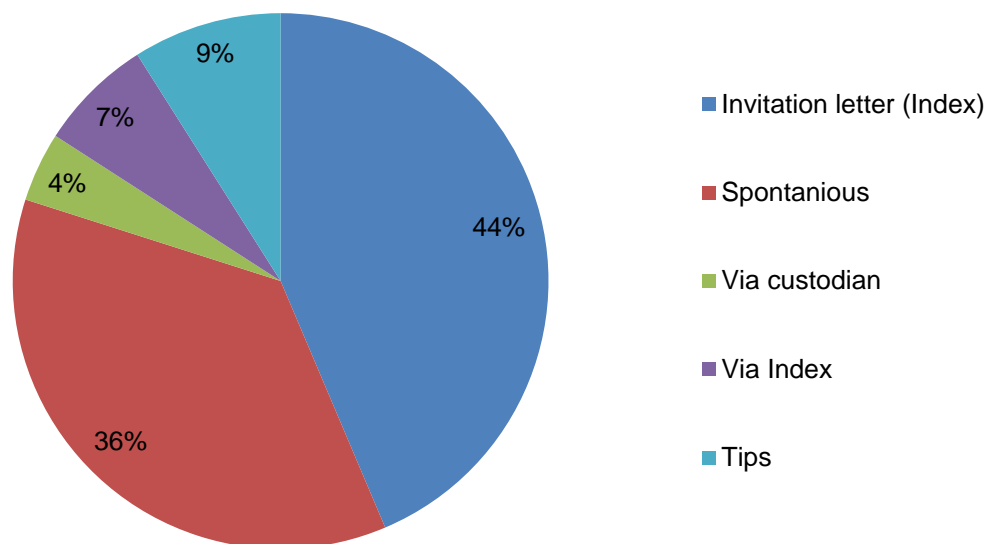
2. Recruitment process

Invited persons are 18-50 years of age and randomly selected by the supplier of addresses; SPAR or Skatteverket. SPAR or Skatteverket supplies LifeGene with name and addresses. The invitation letters sent to the index persons contains information about the study and how to activate the account on the LifeGene web page. Upon activation the index persons register civic registration number, email address and telephone numbers. From the participants personal web page there is also an opportunity to invite other members of the household to the study, this includes children.

Under aged children has to be invited by a legal custodian, Via custodian in figure 1. Upon invitation of a child, the custodians are instantly verified against central registers.

Other persons interested in participating in the study have the possibility to register via the LifeGene website, Spontaneous in figure 1. These persons must be at least 18 years of age to be able to register. This group of participants is also asked to invite household members to join LifeGene. All participants of legal age can also, using functionality on the web page, recommend other people outside their household to participate in the study, Tips in the figure 1.

Figure 1. Methods of recruitment



3. In Person Testing (IPT) or Base line test

At dedicated LifeGene Test Centers, the study participants are subjected to a number of physical measurements (3.1) and biological samples are collected for biobanking (3.2) and clinical chemistry (3.3).

3.1 Physical measurements

An overview of the physical measurements performed at the Test Center are shown in table 1.

Table 1. Physical measurements

Physical measurement	Device	Output	Ages (years)
Height	Seca 202	cm	All
Thorax circumference 20091007-20101101	Measuring tape	cm	≥ 6
Thorax circumference 20101101-20140819	Measuring tape	cm	≥ 10
Waist circumference	Measuring tape	cm	≥ 3
Hip circumference	Measuring tape	cm	≥ 3
Weight	Tanita BC-418 MA	kg	All

Bioimpedance	Tanita BC-418 MA	%	≥ 7
BMI	Tanita BC-418 MA	kg/m ²	≥ 7
Total Body Water (TBW)	Tanita BC-418 MA	kg	≥ 7
Blood pressure	Manual measuring device	systolic/diastolic (mmHg)	≥ 5
Heart rate	Stethoscope	Beats per minute	≥ 5
Audiometry 20091007-20120501	SA 202 (audiometer) + Sennheiser HDA-200 (ear phones)	Right ear/ left ear audiogram, frequencies - 500, 1000, 2000, 3000, 4000, 6000 Hz	≥ 6
Spirometry (LifeGene pilot) 20091007-20101031	Jaeger Masterscope	VC (vital capacity), FEV (forced expiratory flow, FVC, FEC %	≥ 6
Spirometry 20101005-	MiniSpir	FEV (forced expiratory flow) FVC, FEV1	≥ 10

For a complete list, see document at www.lifegene.se

3.2 Biobank sampling

The biological samples collected at Test Centers are available as aliquots stored at KI Biobank. The tubes are handling in a cold-chain that starts within one hour after the blood is taken. The biological samples are listed in table 2. Each tube, except from EDTA for DNA-extraction, will be aliquoted in 8 small REMP-tube à 225 µL.

Table 2. Biobank samples

Sample type	End product	Ages (years)
EDTA whole blood	DNA aliquots	All
EDTA plasma with gel (PPT)	Plasma (EDTA) aliquots	≥ 7
Li-Hep plasma with gel	Plasma (Heparin) aliquots	≥ 7
Citrat 3,8% plasma 20091007-20141031	Plasma (Citrate) aliquots	> 18
Urine (w/o preservatives)	Urine aliquotes	All
Trace metal serum	Serum (trace metal) aliquots	All

3.3 Clinical chemistry analyses

For participants aged 15 years or older one sample tube of EDTA whole blood and one sample tube of Li-Hep plasma that is collected are analyzed at the Karolinska Universitetslaboratoriet from 20101101. At the LifeGene pilot, 20091007-20100331, the clinical chemistry were analyzed at Unilabs S:t Göran. A table of the clinical chemistry and hematological analyses performed is shown here (table 3). During the LifeGene pilot, the clinical chemistry and hematological analyses were only performed on participants aged 18 and older.

Table 3. Clinical chemistry analyses

Analysis name	Sample used	Result (Unit)
B-Hemoglobin	EDTA whole blood	g/L
B-Blodstatus	EDTA whole blood	
B-Diff (maskinell)	EDTA whole blood	$\times 10^9/L$
B-HbA1c	EDTA whole blood	mmol/mol
P-Kreatinine	Li-Hep with gel plug	mikromol/L
P-Cholesterol	Li-Hep with gel plug	mmol/L
P-Apolipoprotein A1	Li-Hep with gel plug	g/L
P-Apolipoprotein B	Li-Hep with gel plug	g/L
P-CRP, (high-sensitivity)	Li-Hep with gel plug	mg/L
P-ALAT 20091007-20100331	Li-Hep with gel plug	microcat/L
P-Triglycerider 20091007-20100331	Li-Hep with gel plug	mmol/L
P-Cystatin C 20091007-20100331	Li-Hep with gel plug	mg/L
Pt-GFR(CystC,beräkn) 20091007-20100331	Li-Hep with gel plug	mL/min/1.73 m*2

For a complete list, see document at www.lifegene.se

4. Questionnaire

4.1 Overview

The baseline survey is built up by instruments covering a vast range of the epidemiological research on physical, social and mental well-being by this date, and is designed for study participants in the age range from 0 to 50 at baseline. In total, the survey delivers 4.000 variables out of a bank of 1.300 questions for adults and 1.050 questions for parents and children. An adult study participant receives on average a 1 hour long web interview generating approximately 850 variables of epidemiological interest.

The questionnaire is available to the study participants through a web portal designed as a circular clock-like menu with questionnaire themes on the dial, see picture below. Eight or nine themes are shown to adults dependent on their sex; and four to nine themes are available to the parents and children. The parents answer for their children of age 0 to 14 and the children answer for themselves from age 11. This means that the survey system collects data from both parents and children in the ages from 11 to 14.



The survey themes are:

- Socio demography
- Lifestyle
- Self care
- Woman's health (puberty for adolescence)
- Living habits
- Health history
- Injuries
- Asthma and allergies
- Mental health

4.2 Questionnaire modules and sections by themes

4.2.1 Adult

Theme, module and section
Socio-demography General Living Family / household Descent Education Occupation Work history Working shift Working nights Unemployment Working environment Physiological discomfort / chemical exposures Psychological discomfort / social situations Stress at work Sick-leave Sleep, private life
Lifestyle General General health Life satisfaction and happiness Overall health state Stress Pain Fatigue Diet Meals Beverages Food / groceries Dishes Potatoes, pasta, vegetables, and sauce Portion sizes Fat and salt Food supplements Physical activity Activity during occupational hours

<ul style="list-style-type: none"> Transport to occupation Leisure time activities Sport activities Sexual behavior <ul style="list-style-type: none"> General Sexually transmitted diseases Wireless devices <ul style="list-style-type: none"> Mobile telephone DECT phone Wireless computer devices
<p>Self-care</p> <ul style="list-style-type: none"> Medication OTC Complementary and alternative medicine <ul style="list-style-type: none"> Products Treatments Techniques
<p>Woman's health</p> <ul style="list-style-type: none"> Menstruation / contraceptives Pregnancy / giving birth Gynecological surgery Infertility / diseases / vaccine Menopause / osteoporosis Incontinence
<p>Living habits</p> <ul style="list-style-type: none"> Smoking <ul style="list-style-type: none"> Smoking history Smoking dependency Present smoking and quitting attempts Snus <ul style="list-style-type: none"> Snus use history Snus dependency Present snus use and quitting attempts Peers Alcohol <ul style="list-style-type: none"> Alcohol onset Present alcohol use Alcohol risk behavior Alcohol addiction Alcohol and heredity Friends

Drug use
Present or previous drug use
Drug addiction

Medical history

Dental

Oral health
Fillings and dental disease

Infections

Common infections
Sick-leave and medication

Diseases

Eating disorder

Introductory questions
Weight and body shape
Anorexia
Binging
Purging

Reflux, IBS

Sleep

Sleeping quality and sleeping time
Sleeping difficulties, snoring, apnea
Means to sleep better
Sleep disturbance

Headache

Daily or recurrent headaches
Headache symptoms
Quality of life, diagnose, medication

Hearing

Hearing self-estimation
Use of earphones
Tinnitus
Dizziness
Hearing impairment

Injuries

Last year injuries
Injury cause
Body parts inflicted
Medical attention due to injury
Injury long-term effects
Risk behavior

Asthma and allergy

General exposures

- Floors and bed
- Ventilation
- Mold and use of gas stove

Asthma

- Wheezing or whistling in the chest
- Attack of shortness of breath
- Asthma
- Hospital visit
- Medication

COPD

- Cough and phlegm
- Shortness of breath

Allergy and chronic sinusitis

- Nasal allergies and non-allergic rhinitis
- Food allergies
- Other allergies
- Medication
- Chronic sinusitis

Mental health screener and personality questions

Personality questions

Screening questions

- Depression
- Perinatal depression
- Premenstrual symptoms
- Suicidality (incl. follow-on questions)
- General anxiety disorder
- Panic disorder
- Agoraphobia
- Obsessive compulsive disorder (OCD)
- Post Traumatic Stress Disorder
- Social phobia
- Specific phobia (incl. follow-on)
- ADHD (incl. follow-on)
- Traumatic life events
- Chronic fatigue syndrome
(incl. follow-on)
- Gambling (incl. follow-on)
- Tourette's syndrome (incl. follow-on)

Mental health follow-on questions

Depression
 Perinatal depression
 Premenstrual symptom
 Panic disorder
 Agoraphobia
 Obsessive compulsive disorder
 Post traumatic stress disorder
 Social phobia

4.2.2 Child / parent

Theme, module, and section	Age				
	0-3	4-6	7-10	11-14	15-17
Socio-demography					
Household structure	x	x	x	x	x
Lifestyle					
Daycare and school	x	x	x	x	x
Cleanliness	x	x	x		
Sun	x	x	x	x	x
Diet	x	x	x	x	x
Physical activity	x	x	x	x	x
Sexual behavior					x
Wireless devices	x	x	x	x	x
Pets	x	x	x	x	x
Self-care					
Medication over the counter	x	x	x	x	x
Alternative medical products, treatments, techniques			x	x	x
Puberty and woman's health					
Puberty					
Woman's health			xA	x	x
					x
Living habits (tobacco, alcohol and drug use)					

Smoking (passive)	x	x	x	x	x
Snus				x	x
Alcohol					x
Drug use					
Medical history					
Dental		x	x	x	x
Infections	x	x	x	x	x
Diseases	x	x	x	x	x
Health control	x	x	x	x	x
Vaccination	x	x	x	x	x
Sleep	x	x	x	x	x
Pacifier					
Nap					
Sleeping time					
Sleeping problems					
Headache				x	x
Hearing				x	x
Injuries					
	x	x	x	x	x
Asthma and allergy					
Asthma	x	x	x	x	x
Allergy	x	x	x	x	x
Eczema	x	x	x	x	x
Mental health					
Infant behavior	xB				
Infant toddler socio-emotional questions	xC				
Parenting					
Family environment	x	x	x	x	x
Screening questions	x	x	x	x	x
Strengths and difficulties		x	x	x	x
Social Aptitudes Scale					
Development					
Separation anxiety					
Social phobia					
Generalized anxiety					
Depression					
Attention / hyper-activity					
Troublesome behavior					

Diet, weight and body shape				
Tics				
Friendship				
Follow-on questions				
Development	x	x	x	x
Strengths and difficulties				
Social Aptitudes Scale				
Development				
Separation anxiety				
Social phobia				
Generalized anxiety				
Depression				
Attention / hyper-activity				
Troublesome behavior				
Diet, weight and body shape				
Tics				
Friendship				

- xA Puberty for parents at age 10
- xB From age 0 to 1
- xC From age 2 to 3

4.3 Questionnaire documentation

The baseline and the follow-up questionnaires are available in pdf at www.lifegene.se

See also document at www.lifegene.se

5. Study protocols

All adult participants have the same baseline study protocol; questionnaire and IPT. There are adults in LifeGene that not are participants themselves but solely have questionnaires about their participating children. Children have their own LifeGene webpage and questionnaire from the age of 11. The custodians have questionnaires about children aged 14 and younger.

Each baseline questionnaire has a short follow-up questionnaire launched one year after the baseline questionnaire. The first follow-up questionnaire was launched 20110223. We have now 5 identical follow-up questionnaires. IPT will be followed-up each 10th year.

Table 4. Study protocol

	Questionnaire	IPT	Comment
Adult participant	Yes	Yes	
Not participant custodian	Only about their children	No	
Child 15-17	Yes	Yes	
Child 11-14	Yes	Yes	Custodians also answer questionnaires about their children
Child 0-10	No	Yes	Custodians answer questionnaires about their children

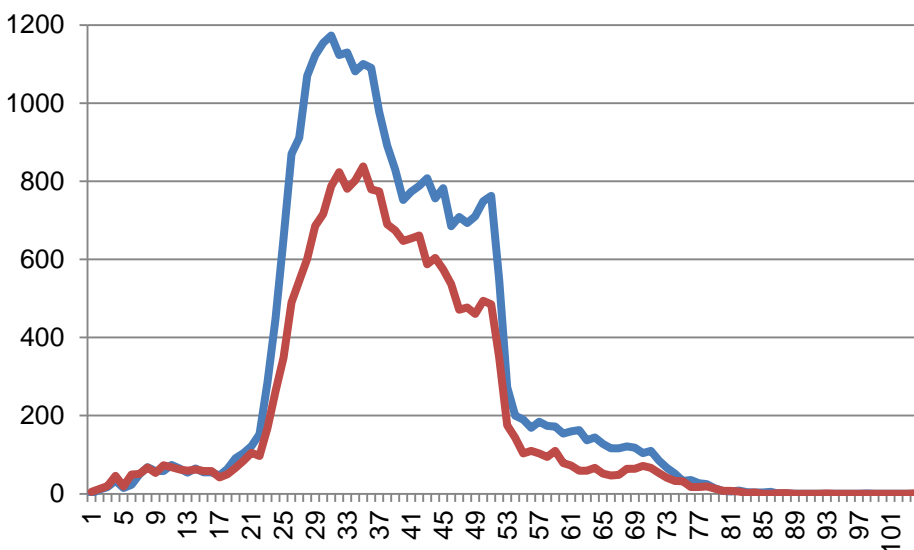
6. Participant demography and statistics

Participation numbers are based on data collected from the start of the pilot 20091007 to 20160209. In order to evaluate the pilot and improve performance and stability in the IT system all data collection was paused during the period 20100331-20101101. We also paused all data collection at Test Center during the juridical process between 20120401-20131215 and after 20161223.

Table 5. Gender distribution among active participants

Female	30 000	59,1%
Male	20 799	40,9%
Grand Total	50 799	

Chart 1. Age and gender distribution among participants (blue women, red men)



7. Completion rates

Chart 2. IPT per year and Test Center until 20170101

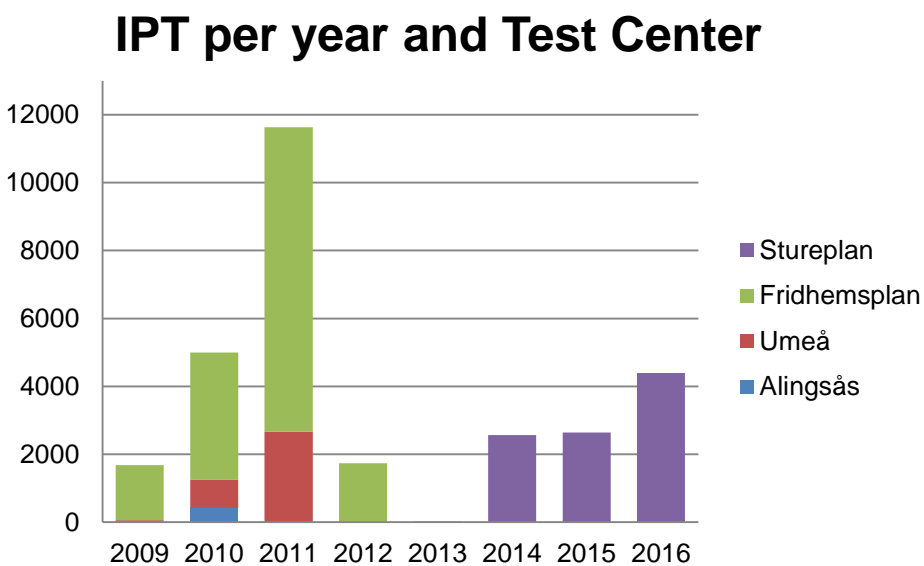


Table 6. Numbers of each activity

Total number of completed IPT	29 823
Total number of completed/started baseline questionnaires	39 765
Total number of completed/started follow-up questionnaires 1	20 960
Total number of completed/started follow-up questionnaires 2	15 639
Total number of completed/started follow-up questionnaires 3	10 524
Total number of completed/started follow-up questionnaires 4	8 034
Total number of completed/started follow-up questionnaires 5	260

Table 8, Children in LifeGene																			
Data from 2015-02-16		Only custodian answer surveys						Custodian and child answer surveys						Only the child answer surveys					
Age	0	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	Tot
Numbers	6	22	56	25	48	98	123	88	103	122	95	96	114	86	94	71	89	88	1424
Female	1	9	21	13	18	48	66	45	46	63	46	45	60	44	43	35	46	42	691
Male	5	13	35	12	30	50	57	43	57	59	49	51	54	42	51	36	43	46	733
Baseline test (IPT)	1	14	45	17	20	24	42	34	31	46	30	41	41	23	34	21	32	21	517
Baseline surveys (completed/started) answered by custodian	8	10	56	26	44	80	104	76	81	26	74	71	84	48	70				858
Baseline surveys (completed/started) answered by child												9	5	7	2	7	30	19	79
Follow-up 1 (completed/started) answered by custodian	0	0	34	14	28	34	48	29	34	40	33	35	39	23	23				414
Follow-up 1 (completed/started) answered by child												0	2	3	1	3	8	0	17
Follow-up 2 (completed/started) answered by custodian	0	0	13	8	18	27	42	23	25	35	23	29	27	18	23				311
Follow-up 2 (completed/started) answered by child												0	0	3	1	1	6	0	11
Follow-up 3 (completed/started) answered by custodian	0	0	0	1	9	10	26	12	9	18	10	16	8	8	9				136
Follow-up 3 (completed/started) answered by child												0	0	0	1	1	2	0	4