

Sarphati

amsterdam research for
healthy living

Sarphati Amsterdam collaboration policy

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This document describes the institute Sarphati Amsterdam, the Sarphati Cohort and the possibilities for collaboration with Sarphati Amsterdam. Researchers who want to collaborate with Sarphati Amsterdam and/or use data from the Sarphati Cohort can find guidelines and procedures here.

This document is subject to change, so please make sure that you download the most up-to-date version from <https://sarphati.amsterdam/samenwerking/>

What is Sarphati Amsterdam?

Sarphati Amsterdam is an institute for scientific research. The City of Amsterdam (Public Health Service – GGD) and the Amsterdam knowledge institutions (UvA, Amsterdam UMC, VU, HvA) are jointly conducting innovative interdisciplinary research beneficial to the effective and sustainable prevention of *diseases of the constructed environment* (also known as non-communicable diseases). The City of Amsterdam intends this research to promote a healthy lifestyle and optimum living conditions for growing children.

At the heart of Sarphati Amsterdam is the Sarphati Cohort, a dynamic cohort study in which data collection is linked to the infrastructure of Youth Health Care (*Jeugdgezondheidszorg*; JGZ) in Amsterdam. The Sarphati Cohort makes it possible to use data exchanged between the parents of Amsterdam children and JGZ professionals during consultations, for scientific research. Innovative research designs can be built into the Sarphati Cohort to study the effects of interventions. This will form the basis for improving existing interventions or for developing new interventions.

Mission

Innovative interdisciplinary research beneficial to effective and sustainable prevention of *diseases of the constructed environment*.

Vision

Sarphati Amsterdam facilitates a unique and advanced research infrastructure and brings together excellent scientific expertise from various disciplines. In doing so, Sarphati Amsterdam contributes to the ambitious policy objectives set by the City of Amsterdam to promote healthy behaviour and improve the quality of life of growing children.

Strategy

The institute focuses on the new epidemic of *diseases of the constructed environment*. It first prioritises the more prevailing *diseases of the constructed environment*, overweight and obesity among children.

The institute acts as a bridge between government, academia, industry and citizens in Amsterdam. At the same time it also connects research, policy and practice within the institute.

Values

Innovate: Sarphati Amsterdam aims to be a world player in groundbreaking research that contributes to the promotion of healthier youth in urban settings.

Collaborate: Local to global partnerships in the areas of science, healthcare, policy, industry and citizens.

Connect: Research actively involving and benefiting citizens, connecting various policy areas and scientific disciplines.

Data collection in the Sarphati Cohort

Data collection set-up

The Sarphati Cohort is a dynamic cohort study set up in conjunction with routine JGZ consultations. The unique structure of the JGZ enables the inclusion of up to 97% (~150,000) of all Amsterdam children. Each year, approximately 11,000 newborns are eligible for inclusion. Growth, health and development and their determinants are systematically monitored during 12 JGZ consultations in the first 4 years of the children's lives. After this, the children are monitored throughout their school careers, until the age of 18 years. Monitoring moments are at 4, 9, 12 and 14 years.

Data collection employs standardised digital client files, questionnaires and medical examination. Not all data that is collected at the JGZ consultations will be available in the Sarphati Cohort. Available data will concern pregnancy, growth, nutrition, motor skills, sleep, nursing and the mental health status of the parent. More details can be found in Appendix 1.

Indirect and direct data collection

Parents provide both direct and indirect data. Indirect data is gathered by the JGZ for the purpose of standard care. Within the Sarphati Cohort this data is known as the core set and is collected via questionnaires prior to the consultation/during the JGZ consultation itself (core set questionnaire) and via the registration of data in the digital patient file (core set consultation).

Direct data is data collected explicitly for the Sarphati Cohort. This data is called the core set-plus and concerns structured questionnaires that are sent throughout the youth of the children, and are not connected to the JGZ consultations.

Core set, Core set-plus and Subcohort

Data collection can be categorised into three groups, as shown in Figure 1.

Sarphati Cohort

schematic overview of the data collection

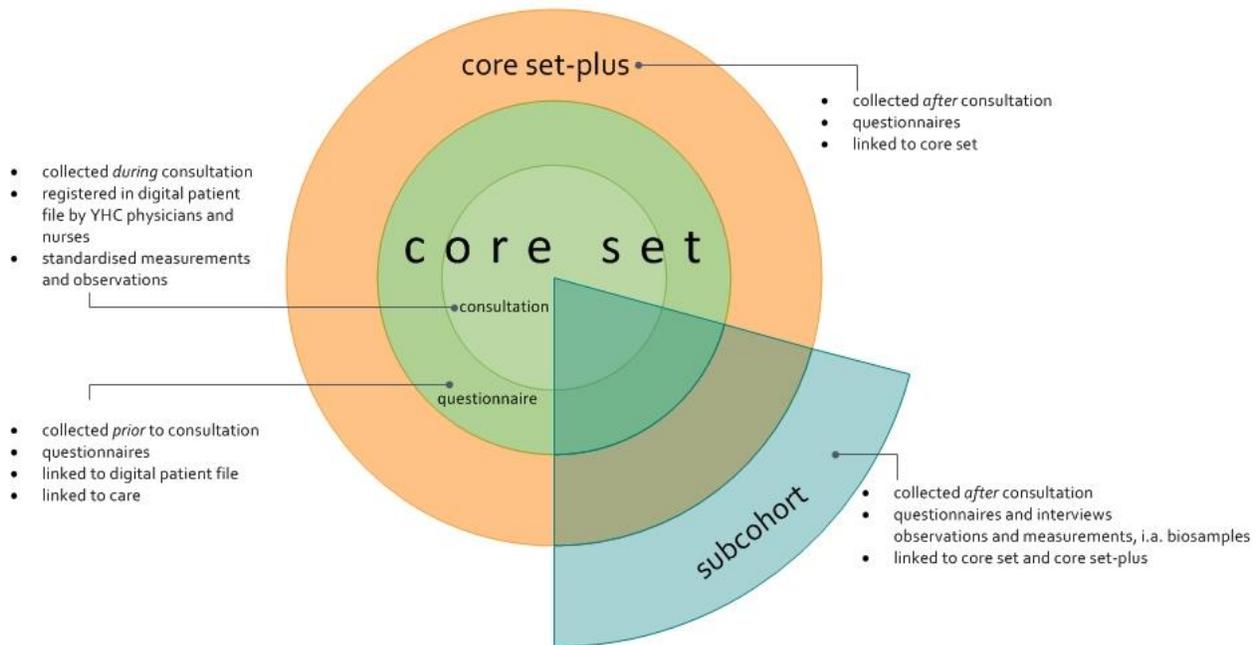


Figure 1. Data collection Sarphati Cohort

1. Core set: Standard measurements that are conducted during the JGZ consultations with all children. These measurements are part of the standard JGZ consultation. It includes short questionnaires that are completed before the consultation for care purposes.
2. Core set-plus: Standard measurements that are conducted after the consultations with all children. These measurements are collected via short questionnaires. Parents of all children receive the questionnaire, but they are free to choose whether or not to complete the questionnaire. The measurements are conducted because they are necessary for research within the Sarphati Cohort; they are not necessary for the JGZ.
3. Subcohort: Additional measurements in subgroups of the cohort, started by a partner of Sarphati Amsterdam. This can include the collection, analysis or storage of biological material, conducting interviews, or the collection of observational data related to nutrition, motor skills, sleeping and nursing. This data can be collected either face-to-face or through digital questionnaires. Subcohort projects can start prenatally, and the children will join the Sarphati Cohort after their birth.

The data that is collected for the core set and the core set-plus is listed in Appendix 1. If you would like up-to-date information about the data that is or will be collected in the subcohorts, you can send an e-mail to Sarphati Amsterdam (info@sarphati.amsterdam).

Also, in some cases it may be possible to add measurements to the core set-plus. To find out more, you can contact the Sarphati Amsterdam programme manager, Joanne Ujcic (jujcic@ggd.amsterdam.nl).

How can I start a research project in collaboration with Sarphati Amsterdam?

Criteria

Scientific collaboration is possible only after approval of the proposal by the Sarphati Programme Board. If you want to collaborate with Sarphati Amsterdam, your research should meet at least one of the following criteria:

1. Research that makes use of data from the Sarphati Cohort
2. Research that yields useful knowledge, methodology or instruments which directly add value to the data collection of the Sarphati Cohort
3. Research that contributes to the evaluation of the Amsterdamse Aanpak Gezond Gewicht (AAGG)

Research programme

We advise you to read the Sarphati Amsterdam research programme before submitting your application. The programme describes the scope and the focus of Sarphati Amsterdam and your proposal should be in line with this document.

Procedure

In order to secure approval for collaboration with Sarphati Amsterdam, you will need to follow the procedure described below. The procedure applies to both a data request (e.g. use of core set/core set-plus data and creation of a subcohort) and a request for collaboration with Sarphati Amsterdam.

1. A research proposal should be submitted using the Research Proposal Form.
2. If you would like to make use of the Sarphati Cohort, you should also submit a Data Request Form.

3. The research coordinator determines whether the research proposal and data request meet the criteria described above, and discusses the logistical feasibility with the programme manager of the Sarphati cohort where applicable.
4. The Executive Board will judge whether the research proposal is compatible with the mission of Sarphati Amsterdam.
5. The final decision will be made by the Sarphati Amsterdam Programme Board. The Programme Board has substantial knowledge of and expertise in the research area of Sarphati Amsterdam and will judge whether the project meets the criteria detailed below and detect any possible overlap with other cohort studies.

All forms can be found on the website at <https://sarphati.amsterdam/>. Completed forms should be sent to Sarphati Amsterdam research coordinator at info@sarphati.amsterdam.

Assessment

Sarphati Amsterdam will assess research proposals based on the following criteria:

- compatibility with the mission of Sarphati Amsterdam;
- the quality of the research proposal as judged by peer reviewers;
- burden for the participants;
- possible overlap with other (cohort) studies;
- the use of the specific data relevant for the research question;
- the logistical feasibility such as expected inclusion rates, sufficient capacity within the data-infrastructure.

If the Programme Board approves the proposal, a collaboration agreement between Sarphati Amsterdam and the principal investigator of the research project will be drafted and signed by both parties. See the 'Collaboration Agreement' section for more information.

Important things to consider before your application

Be precise when determining your requested data

Make sure your data request includes all data necessary to answer your research question. Conversely, all of the data you request should be necessary for answering your research question. This means that you should use all requested data for the proposed research project. You can only submit one data request and one amendment per research project.

Avoid conflicts of interest

Your project has to fit within the municipal policy and the policy of the Amsterdam knowledge institutions. Please be particularly aware of this condition if your project is partly or fully funded by industry. For more details check the Sarphati Amsterdam Code of Conduct, which can be found at <https://sarphati.amsterdam/>.

Scientific assessment by a recognised body

We will only collaborate with projects that have been scientifically assessed by a recognised body, such as NWO, ZonMw or a scientific committee at your university.

Ethical assessment by a recognised body

All projects need to be assessed by an METC or a recognised ethical committee. This body must either approve the project or declare that the research does not fall within the scope of the WMO.

Intellectual property

GGD Amsterdam is responsible for the set-up of the Sarphati Cohort. Data on Sarphati Cohort participants is and remains the property of GGD Amsterdam. We can share this data with the partners of Sarphati Amsterdam, but it always remains the property of GGD Amsterdam.

For more information on the rules regarding intellectual property, please contact the research coordinator (info@sarphati.amsterdam).

Privacy: compliance with the latest GDPR guidelines

All projects need to comply with the latest GDPR guidelines. Collaborating researchers at universities and Sarphati Amsterdam get access to anonymised data only.

Budget

All participating partners of Sarphati Amsterdam – the City of Amsterdam, UMC, Vu, UvA and HvA – can request to use the data collected by Sarphati Amsterdam. Sarphati Amsterdam organises the infrastructure that allows the collection and sharing of the data. Costs relating to the staff and necessary resources for a research project must be covered by the applicant.

Accessibility and processing of Sarphati Cohort data

Data for scientific research will be available via a data portal. This portal enables you to access the requested data and statistical software according to your needs. The data is stripped of any information that is traceable to personal data. The data will always remain within the portal, and we will provide all the tools you may need to conduct your analyses within the portal. It is also possible to link existing data with Sarphati Cohort data on request. The possibilities for exporting files will be limited. The Sarphati Cohort data management team will be available to provide you with support if necessary. You are not permitted to share the Sarphati Cohort data with any external parties unless this has been expressly agreed with Sarphati Amsterdam.

Collaboration agreement

A collaboration agreement will be drawn up once Sarphati Amsterdam has decided to enter into a collaboration with a research project. This agreement will be signed by the Executive Board of Sarphati Amsterdam and the principal investigator of the research project. Important subjects that will be part of the agreement are listed below.

Intellectual property

We will make project-specific agreements with respect to intellectual property.

Treatment of Sarphati Cohort participants

Sarphati Amsterdam will act as a gatekeeper for participants in the Sarphati Cohort. We will work closely together with the researchers to determine how they will communicate with the participants. Important project-specific details relating to this communication will be defined in the collaboration agreement.

Scientific and ethical assessment

Every project must be assessed for scientific and ethical soundness by a recognised body. Proof that these assessments have taken place must be included as an appendix to the collaboration agreement.

Financial contribution

As part of the agreement, the project must contribute to Sarphati Amsterdam either financially or in kind. The contribution requested is negotiated with Sarphati Amsterdam on a case-by-case basis and details are specified in the collaboration agreement.

Monitoring

Sarphati Amsterdam must be updated regularly on the progress of the research project. The details of the updates, such as the frequency, will be specified in the collaboration agreement.

Publications

Sarphati Amsterdam must be informed about any publications relating the project. In the event of any such publications, we would like to receive a copy of the publication and a short summary in Dutch, which we can share on the Sarphati Amsterdam website.

The Sarphati Cohort should be properly acknowledged in all publications and the presentation of the data should be in line with the conditions given.

Details relating to publications will be included in the collaboration agreement.

Appendix 1 – Data collection

Core set

	4-8 days	2 wks	1 mos	2 mos	3 mos	4 mos	6 mos	11 mos	14 mos	18 mos	2 yr	3 yr	3,9 yr
Growth													
Perception parent growth		1 ¹	2	3	4	5	6	7	8	9	10	11	12
Birth weight	0												
Dysmature	0												
Body height		11	2	3	4	5	6	7	8	9	10	11	12
Body weight		11	2	3	4	5	6	7	8	9	10	11	12
Head circumference		11	2	3	4	5	6	7					
Nutrition													
Satisfaction parent nutrition		1	2	3	4	5	6	7	8	9	10	11	12
Breast vs. formula fed	0	1	2	3	4	5	6	7	8	9			
Vitamin K administration birth	0												
Vitamin K use		1	2	3	4								
Vitamin D use		1	2	3	4	5	6	7	8	9	10	11	12
Introduction solid food (timing)						5	6	7					
Introduction solid food (type)						5	6	7					
Motor skills													
Perception parent motor skills						5	6	7	8	9	10	11	12
Development motor skills (Van Wiechen)			2	3	4	5	6	7	8	9	10	11	12
Sleep													
Satisfaction parent sleep						5	6		9	10	11	12	
Sleep pattern: difficulty falling asleep						5	6		9	10	11	12	
Sleep quality: waking rested										10	11	12	
Demographics													
Type and timing consultation		1	2	3	4	5	6	7	8	9	10	11	12
Code number	0												
Sex	0												
Date of birth	0												
Country of birth	0												
Date of death	0												
Date of side intake/ outflow	0												
Country of birth mother	0												
Country of birth father	0												

¹Only at SAG

	4-8 days	2 wks	1 mos	2 mos	3 mos	4 mos	6 mos	11 mos	14 mos	18 mos	2 yr	3 yr	3,9 yr
Body height biological mother			2										
Body height biological father			2										
Educational level mother		1											
Educational level father		1											
Spoken language at home		1											
Subliterate or illiterate parent				3									
Pregnancy and delivery													
Gestational age		0	1										
Type of birth		0											
APGAR score 1		0	1										
APGAR score 2		0	1										
Smoking during pregnancy		0	1										
Alcohol use during pregnancy		0	1										
Drug use during pregnancy		0	1										
Multiple birth			1										
Number multiple			1										
Number of pregnancies		0											
Miscarriages/abortions		0											
Number of children born alive		0											
Number of living children		0											

Core set-plus

Age child	Subject		
6 mos	Sleep	Sleeping time & rhythm	Brief Infant Sleep Questionnaire (BISQ, Sadeh, 2004 ²)
	Nutrition	Milk feed	Sort, amount, scheme, timing, moment start supplementary feed
	Eating behaviour		Baby Eating Behaviour Questionnaire (BEBQ, Llewellyn et al., 2011 ³)
	Course pregnancy		Diseases mother, weight gain mother, smoking mother, way of giving birth, complications
12 mos	Day-care	Sort & frequency	
	Sleep	Sleeping time & rhythm	Brief Infant Sleep Questionnaire (BISQ, Sadeh, 2004 ⁴)
	Nutrition	Nutrition child	Milk food, vegetables, fruit, snacks, sweetened drinks

² Sadeh A. (2004) A Brief Screening Questionnaire for Infant Sleep Problems: Validation and Findings for an Internet Sample. *Pediatrics*, 113, e570-e577.

³ Llewellyn CH, van Jaarsveld CH, Johnson L, Carnell S, Wardle J. Development and factor structure of the Baby Eating Behaviour Questionnaire in the Gemini birth cohort. *Appetite*. 2011;57(2):388-96.

⁴ Sadeh A. (2004) A Brief Screening Questionnaire for Infant Sleep Problems: Validation and Findings for an Internet Sample. *Pediatrics*, 113, e570-e577.

	Eating moments	Number, breakfast, rhythm	
	Eating behaviour		Child Eating Behaviour Questionnaire - Toddler (CEBQ-T)
	Experiencing the joys and challenges of parenting	Load and joy	Opvoeding Belasting Vragenlijst – verkort (OBVL-k, Vermulst et al. 2013 ⁵)
	Home & environment	Indoor environment	Cooking on gas, smoking, fungus and humidity
		Satisfaction	House, house environment, services around the house
		Noise	Nuisance, quiet side house
	Childcare	Sort & frequency	
18 mos	Sleep	Time and rhythm	Brief Infant Sleep Questionnaire (BISQ, Sadeh, 2004 ^{Fout!} Bladwijzer niet gedefinieerd.)
	Use of Electronic Devices	Screen Time	Duration & frequency, timing, rules
	Health parents	Health parents	Experienced health, limitations, chronic diseases
		Mental health parents	Kessler Psychological Distress Scale (K6, Kessler et al. 2002 ⁶)
	Childcare	Sort & frequency	
24 mos	Sleep	Sleeping time & rhythm	Brief Infant Sleep Questionnaire (BISQ, Sadeh, 2004)
	Nutrition	Nutrition child	Milk food, vegetables, fruit, snacks, sweetened drinks
		Eating moments	Number, breakfast, rhythm
	Eating behaviour		Child Eating Behaviour Questionnaire - Toddler (CEBQ-T)
	Exercise Questionnaire	Movement behaviour child	Means of transport, playing outside, organised movement activities
	Experiencing the joys and challenges of parenting		Opvoeding Belasting Vragenlijst – verkort (OBVL-k, Vermulst et al., 2013)
	Childcare	Sort & frequency	
36 mos	Sleep	Sleeping time & rhythm	Brief Infant Sleep Questionnaire (BISQ, Sadeh, 2004)
	Nutrition	Nutrition child	Milk food, vegetables, fruit, snacks, sweetened drinks
		Eating moments	Number, breakfast, rhythm
	Eating behaviour		Child Eating Behaviour Questionnaire - Toddler (CEBQ-T)
	Exercise	Movement behaviour	Means of transport, playing outside, organised movement

⁵ A.A. Vermulst, G. Kroes, R.E. De Meyer, L. Nguyen & J.W. Veerman. 2013 OBVL-K - VOOR OUDERS VAN JEUGDIGEN VAN 0 T/M 18 JAAR

⁶ Kessler RC, Andrews G, Colpe LJ, Hiripi E, Mroczek DK, Normand SL, Walters EE, Zaslavsky AM. Short screening scales to monitor population prevalences and trends in non-specific psychological distress. Psychol Med. 2002;32(6):959-76.

Questionnaire	child	activities
Use of Electronic Devices	Screen time	Duration & frequency, timing, rules
Experiencing the joys and challenges of parenting		Opvoeding Belasting Vragenlijst – verkort (OBVL-k, Vermulst et al., 2013 ^{Fout! Bladwijzer niet gedefinieerd.})
Home & Living Environment	Indoor environment	Cooking on gas, smoking, fungus and humidity
	Satisfaction	House, house environment, services around the house
	Noise	Nuisance, quiet side house
Health parents	Health parents	Experienced health, limitations, chronic diseases
	Mental health parents	Kessler Psychological Distress Scale (K6, Kessler et al. 2002 ⁷)
Childcare	Sort & frequency	
45 mos	Sleep	Sleeping time & rhythm
		Brief Infant Sleep Questionnaire (BISQ, Sadeh, 2004)
Nutrition	Nutrition child	Milk food, vegetables, fruit, snacks, sweetened drinks
	Eating moments	Number, breakfast, rhythm
Eating behaviour		Child Eating Behaviour Questionnaire (CEBQ, Wardle et al., 2001 ⁸ ; Sleddens et al., 2008 ⁹)
Exercise Questionnaire	Movement behaviour	Means of transport, playing outside, organised movement activities
Use of Electronic Devices	Screen time	Duration & frequency, timing, rules
Experiencing the joys and challenges of parenting		Opvoeding Belasting Vragenlijst – verkort (OBVL-k, Vermulst et al., 2013)
Childcare	Sort & frequency	

⁷ Kessler RC, Andrews G, Colpe LJ, Hiripi E, Mroczek DK, Normand SL, Walters EE, Zaslavsky AM. Short screening scales to monitor population prevalences and trends in non-specific psychological distress. *Psychol Med.* 2002;32(6):959-76.

⁸ Wardle J, Guthrie CA, Sanderson S, Rapoport L. Development of the children's eating behaviour questionnaire. *J Child Psychol Psych.* 2001;42(7):963-70.

⁹ Sleddens EF, Kremers SP, Thijs C. The children's eating behaviour questionnaire: factorial validity and association with Body Mass Index in Dutch children aged 6-7. *Int J Behav Nutr Phys Act.* 2008;5:49.