

Sarphati

amsterdam research for
healthy living

Sarphati Amsterdam collaboration policy

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This document describes the institute Sarphati Amsterdam 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 the procedures in this document.

This document is subject to change, so please make sure that you download the most up-to-date version on www.sarphati.amsterdam.

General

Sarphati Amsterdam is an institute for scientific research in Amsterdam. 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 non-communicable diseases. The City of Amsterdam intends this research to promote a healthy lifestyle and optimum living conditions, and to prevent non-communicable diseases, such as diabetes, cardiovascular disease, mental health illness and obesity among young people in Amsterdam.

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 (YHC) in Amsterdam. The Sarphati Cohort makes it possible to use some of the data exchanged between the parents of Amsterdam children and YHC physicians and nurses for consultations at for scientific research. Innovative research designs will be built into the Sarphati Cohort to study the effects of interventions. They will form the basis for improving existing interventions or developing entirely new ones.

Mission

Innovative interdisciplinary research beneficial to effective and sustainable prevention of non-communicable diseases.

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 municipality of Amsterdam to promote healthy behavior and improve quality of life of growing up children.

Strategy

The institute focuses on the new epidemic of non-communicable diseases. It first prioritises the more prevailing non-communicable diseases, mental health illness 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 promotion of a healthier youth in urban settings.

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

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

Sarphati Cohort

Data collection

The Sarphati Cohort is a dynamic cohort study set-up in conjunction with routine Youth Health Care (YHC) consultations. The unique structure of YHC enables inclusion of up to 97% of all Amsterdam (~150,000) children from birth until the age of 18. Each year ~10,000 new-borns are eligible for inclusion. Growth, health and development (and their determinants) are systematically monitored during 12 YHC consultations in the first 4 years of their lives. After this, the children are monitored throughout their school careers, until the age of 18 years (4, 9, 12 and 14 years). Data collection includes digital client files (standardised), questionnaires and medical examination. Not all data that is collected at the YHC consultations will be available in the Sarphati Cohort. Data that will be available are around pregnancy, growth, nutrition, motoric skills, sleep, nursing and basic demographics.

Parents provide both direct and indirect data. Indirect data is gathered by YHC for the purpose of standard care. It is collected via questionnaires prior to the consultation/ during the YHC consultation itself (core set questionnaire) and via registration of data in the digital patient file (core set consultation). Direct data are data that are collected explicitly for the Sarphati Cohort. This concerns additional questionnaires and other extra research material, like observations, information from interviews and biosamples (core set –plus and subcohort)

Data collection can be categorised in three groups (see Figure 1):

1. Core set: Standard measurements that are conducted during the YHC consultations, with all children. These measurements are part of the standard YHC consultation. Also, 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. The measurements are conducted because they are necessary for research within the Sarphati Cohort, they are not necessary for YHC.
3. Subcohort: Additional measurements in subgroups of the cohort. It is possible to create your own subcohort. This can be collecting, analyzing or storing of biological material (e.g. blood, saliva, excrement), or it can be the collection of observational data related to nutrition, movement, sleeping and nursing. These data can be collected either face-to-face or through digital questionnaires. Subcohort projects can start prenatally, and after birth the children will join the Sarphati Cohort.

N.B. New subcohort studies will require informed consent from all participants and have to be approved by an METC. The METC has either to approve the study or declare that the research does not fall within the scope of the WMO.

The data that is collected during the core set and the core set-plus is listed in Appendix 1. If you want to have up-to-date information about the data that is or will be collected in the subcohorts, you can contact the research coordinator Yvonne van Dalen (yvdalen@ggd.amsterdam.nl).

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

Sarphati Cohort

schematic overview of the data collection

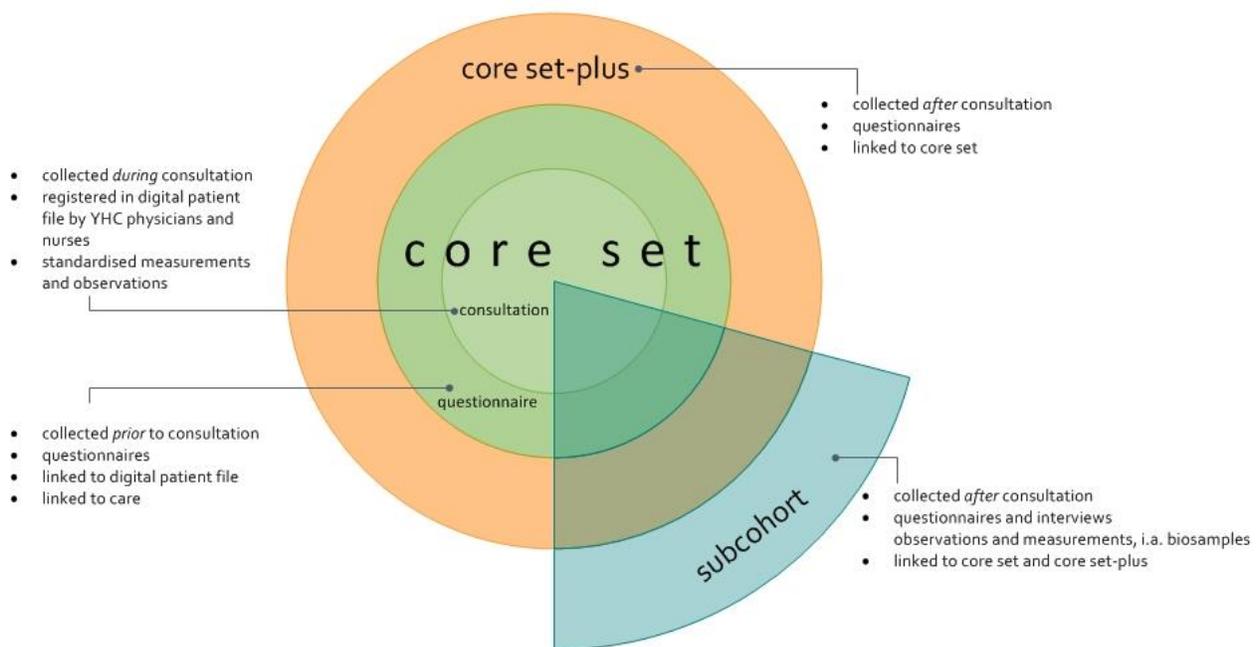


Figure 1. Data collection Sarphati Cohort

Collaboration

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 (Core set, Core set-plus and/or subcohorts)
2. Research that yield useful knowledge, methodology or instruments which directly fit the mission of Sarphati Amsterdam (e.g. research with children in school- or healthcare setting)
 - Research with existing cohorts (e.g. ABCD and HELIUS).
 - Research that fits within the Amsterdam healthy weight program ('Amsterdamse Aanpak Gezond Gewicht')

Procedure

In order to secure approval of collaboration with Sarphati Amsterdam, below procedure has to be followed. The procedure applies to both a data request (e.g. use of core set (-plus) data and creation of a subcohort) as a request for collaboration with Sarphati Amsterdam. A schematic overview of the procedure can be found in Appendix 2.

1. A research idea should be submitted using the Research Idea Form. In case you want to make use of the Sarphati Cohort, you should also submit a Data Request Form.
2. The research coordinator determines whether the Research Idea and Data Request meet the above mentioned criteria and discusses the logistical feasibility with the programme manager of the Sarphati cohort if applicable.
3. In case the research coordinator gives a green light, a Full Research Proposal Form should be submitted. In this form we ask for more extensive information about the project.
4. The board of directors 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 substantive knowledge and expertise on the research area of Sarphati Amsterdam and will judge the quality of the research proposal and possible overlap with other cohort studies.

N.B. All forms can be found on the website

<https://sarphati.amsterdam/>. The completed forms should be sent to the research coordinator of Sarphati Amsterdam (yvdalen@ggd.amsterdam.nl).

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;
- possible overlap with other (cohort) studies;
- the use of the specific data relevant for the research question;
- the logistical feasibility.

In case 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 below).

Accessibility and processing of Sarphati Cohort data

Data for scientific research will be available via a Citrix data portal. In this portal you can access the requested data and statistical software according to your needs. The data is stripped from information of any data that is traceable to personal data. The data will always remain within the portal. Within the portal we will provide you with all the tools you may need to do your analyses. On request, it will also be possible to link existing data with Sarphati Cohort data. The possibilities for the export of files will be limited. The Sarphati Cohort data management team will be available to support you. You are not able to share the Sarphati Cohort data with any external parties unless agreed with Sarphati Amsterdam.

GGD Amsterdam is responsible for the set-up of the Sarphati Cohort. Data on Sarphati Cohort participants are and remain the property of GGD Amsterdam. Collaborating researchers at universities and Sarphati Amsterdam get access to anonymised data only. Data are stored on a dedicated “Sarphati” server that is accessible for system administrators and data managers of GGD Amsterdam only.

Please make sure your data request includes all necessary data that are needed to answer your research question. You can only submit 1 data request and 1 amendment per research project. All requested data should be required to answer your research question, and all data that is requested should be used for the submitted research project.

Collaboration agreement

Contribution

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

Monitoring

In case collaboration with Sarphati Amsterdam is approved by the program board, the project status should be shared with Sarphati Amsterdam via a Progression Form. Details on the frequency will be included in the collaboration agreement. You can find the Progression Form on our website www.sarphati.amsterdam. Please send the completed form to the research coordinator (yvdalen@ggd.amsterdam.nl).

Publications

Sarphati Amsterdam should be informed about any publication of the project. In this case we would like to receive the publication and a short Dutch summary, which we can share on the Sarphati Amsterdam website.

In all publications, the Sarphati Cohort should be properly mentioned and the presentation of the data should be in line with the conditions given.

Details on any publication 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		1 ¹	2	3	4	5	6	7	8	9	10	11	12
Body weight		1 ¹	2	3	4	5	6	7	8	9	10	11	12
Head circumference		1 ¹	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
Codenummer	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												
Body height biological mother			2										

¹Only at SAG

	4-8	2	1	2	3	4	6	11	14	18	2	3	3,9
	days	wks	mos	yr	yr	yr							
Body height biological father			2										
Educational level mother		1											
Educational level father		1											
Spoken language at home		1											
Low- 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	Nutrition	Milk feed	Sort, amount, scheme, timing, moment start supplementary feed
		Eating behavior	Baby Eating Behaviour Questionnaire (BEBQ, Llewellyn et al., 2011 ²)
	Sleep	Sleeping time & rythm	Brief Infant Sleep Questionnaire (BISQ, Sadeh, 2004 ³)
	Health parents	Health parents	Experienced health, limitations, chronic diseases
		Mental health parent	Kessler Psychological Distress Scale (K6, Kessler et al. 2002 ⁴)
	Pregnancy	Course pregnancy	Diseases mother, weight gain mother, smoking mother
		Course delivery	Way of giving birth, complications
Day-care	Sort & frequency		
12 mos	Nutrition	Nutrition child	Milk food, vegetables, fruit, snacks, sweetened drinks
		Eating moments	Number, breakfast, rythm
		Eating behavior child	Child Eating Behaviour Questionnaire - Toddler (CEBQ-T)
	Housing & environment	Indoor environment	Cooking on gas, smoking, fungus and humidity
		Satisfaction	House, house environment, services around the house
		Noise	Nuisance, quiet side house
	Daycare	Sort & frequency	
18 mos	Sleep	Time and rythm	Brief Infant Sleep Questionnaire (BISQ, Sadeh, 2004 ³)
	Screen usage	Screen usage child	Duration & frequency, timing, rules
	Parenting	Load and joy	Opvoeding Belasting Vragenlijst – verkort (OBVL-k, Vermulst et al. 2013 ⁵)
	Health parents	Health parents	Experienced health, limitations, chronic diseases
		Mental health parents	Kessler Psychological Distress Scale (K6, Kessler et al. 2002 ⁶)
2 yrs	Nutrition	Nutrition child	Milk food, vegetables, fruit, snacks, sweetened drinks
		Eating moments	Number, breakfast, rythm
		Eating behavior child	Child Eating Behaviour Questionnaire - Toddler (CEBQ-T)
	Sleep	Sleeping time & rythm	Brief Infant Sleep Questionnaire (BISQ, Sadeh, 2004 ³)
	Movement	Movement behavior child	Means of transport, playing outside, organized movement activities
	Parenting	Load and joy	Opvoeding Belasting Vragenlijst – verkort (OBVL-k, Vermulst et al., 2013 ⁵)

² 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.

³ Sadeh A. (2004) A Brief Screening Questionnaire for Infant Sleep Problems: Validation and Findings for an Internet Sample. *Pediatrics*, 113, e570-e577.

⁴ 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.

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.

	Daycare	Sort & frequency	
3 yrs	Nutrition	Nutrition child	Milk food, vegetables, fruit, snacks, sweetened drinks
		Eating moments	Number, breakfast, rythm
		Eating behavior child	Child Eating Behaviour Questionnaire - Toddler (CEBQ-T)
	Sleep	Sleeping time & rythm	Brief Infant Sleep Questionnaire (BISQ, Sadeh, 2004 ³)
	Movement	Movement behavior child	Means of transport, playing outside, organized movement activities
	Screen usage	Screen usage child	Duration & frequency, timing, rules
	Parenting	Load and joy	Opvoeding Belasting Vragenlijst – verkort (OBVL-k, Vermulst et al., 2013 ⁵)
	Housing & 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)
	Daycare	Sort & frequency	
3,9 yrs	Sleep	Sleeping time & rythm	Brief Infant Sleep Questionnaire (BISQ, Sadeh, 2004)
		Nutrition	Nutrition child
		Eating moments	Number, breakfast, rythm
		Eating behavior child	Child Eating Behaviour Questionnaire (CEBQ, Wardle et al., 2001 ⁸ ; Sleddens et al., 2008 ⁹)
	Movement	Movement behavior	Means of transport, playing outside, organized movement activities
	Screen usage	Screen usage child	Duration & frequency, timing, rules
	Parenting	Load and joy	Opvoeding Belasting Vragenlijst – verkort (OBVL-k, Vermulst et al., 2013)
	Daycare	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.

Appendix 2 – Procedure submission research proposals

