

# Sarphati

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**amsterdam** research for  
healthy living

## Sarphati Amsterdam collaboration policy

This document describes the institute Sarphati Amsterdam, the Sarphati Cohort and the possibilities for collaboration with Sarphati Amsterdam. Researchers who want to use existing data from the Sarphati Cohort or collect new data using 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/>.

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## 1. Sarphati Amsterdam and the infrastructure

### a. Partners and research infrastructure

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 non-communicable diseases.

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 a healthy lifestyle and optimum living conditions for raising children. The institute acts as a bridge between government, academia, private partners and citizens in Amsterdam. At the same time, it also connects research, policy and practice within the institute.

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.

### b. The focus of research within Sarphati Amsterdam

Our mission is to contribute to innovative interdisciplinary research beneficial to effective and sustainable prevention of non-communicable diseases. More information about Sarphati Amsterdam research can be found on our website: [www.sarphati.amsterdam](http://www.sarphati.amsterdam).

## 2. Sarphati Cohort and the data collection

### a. 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 10,000 newborns are eligible for inclusion. Growth, health and development and their determinants are systematically monitored during 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.

Data collection employs standardized digital client files, questionnaires and medical examinations. 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, and is constantly evolving.

### b. Data sources: core set, core set-plus and sub-cohort

There are three types of data collection within the Sarphati Cohort.

#### Core set and core set-plus data

Parents provide both indirect data and direct data. Indirect data is gathered by the JGZ for standard care with all children. Within the Sarphati Cohort, this data is known as the coreset and is collected via questionnaires before the consultation/during the JGZ consultation itself (core set -

questionnaire) and via the registration of data in the digital patient file during the consultation (core set -consultation). More details about core set-consultation variables can be found in Appendix 1.

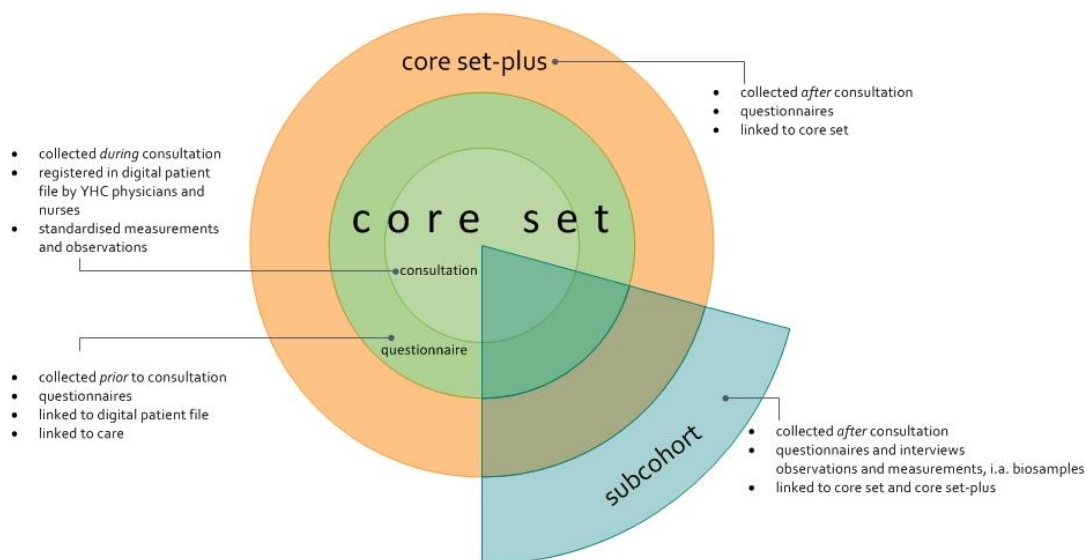
Direct data is data collected explicitly for the Sarphati Cohort. This data is called the core set-plus and concerns structured questionnaires that are sent throughout the youth of the children and are not connected to the JGZ consultations. Parents of all children receive the questionnaire at age-specific time points, but they are free to choose whether or not to complete the questionnaire. More details about core set-plus variables can be found in Appendix 2.

### Sub-cohort data

Researchers can also add additional measurements in subgroups of the Sarphati Cohort. Examples of such measurements are 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. The additional collected data within the Sarphati Cohort can be linked to existing Sarphati Cohort data. Sub-cohort projects can start prenatally, and the children will join the Sarphati Cohort after their birth.

#### Sarphati Cohort

schematic overview of the data collection



Also, in some cases, it may be possible to add measurements to the core set-plus. To find out more, you can contact Sarphati Amsterdam via [info@sarphati.amsterdam](mailto:info@sarphati.amsterdam).

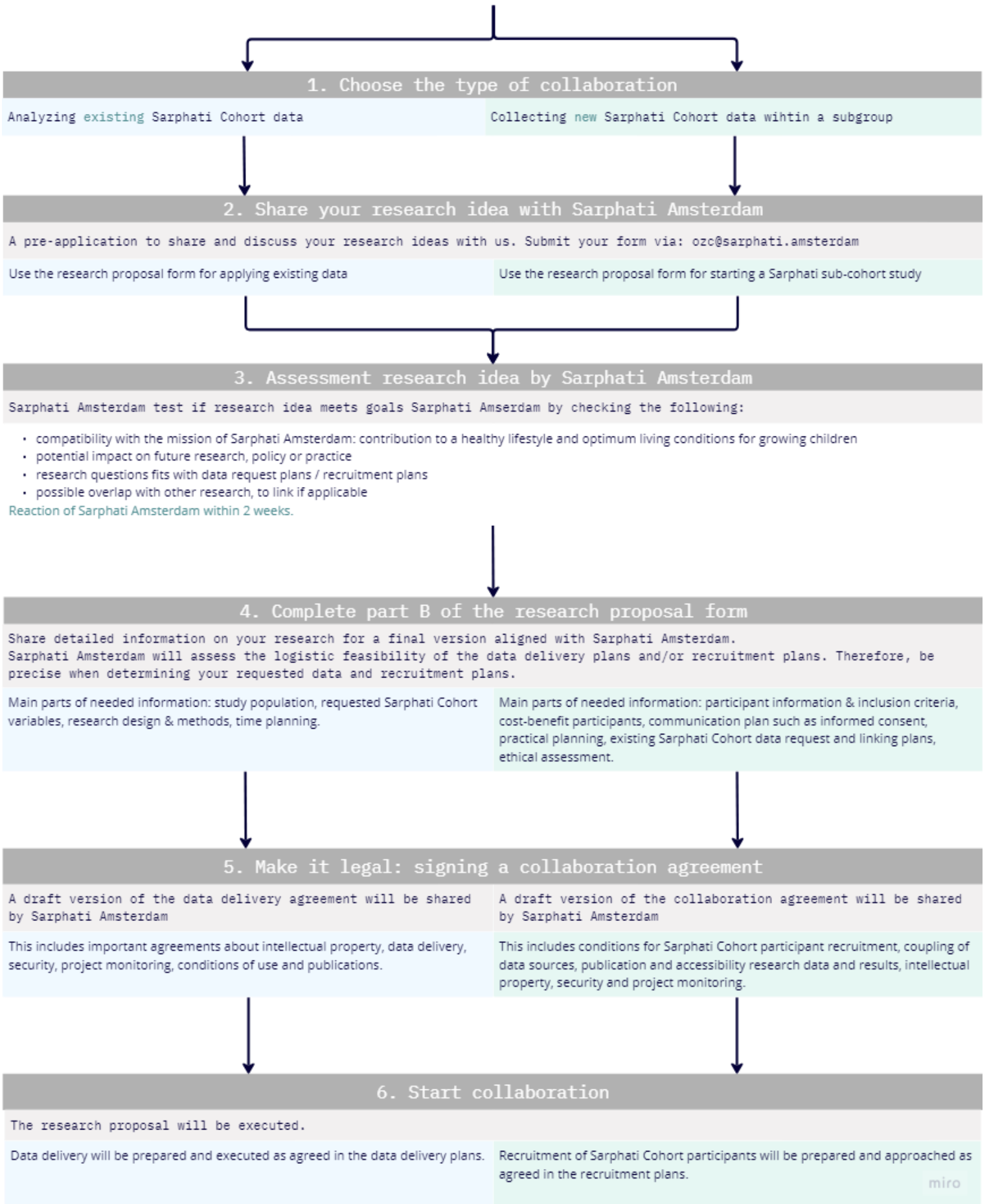
## 3. Procedures for starting a research project within Sarphati Amsterdam

### a. Procedures flow for using Sarphati Cohort

To secure approval for collaboration with Sarphati Amsterdam, you will need to follow the procedure described below. The procedure applies to both a request for existing Sarphati Cohort data from the coreset and/or core-set plus, and a request for collecting new data within the Sarphati Cohort by starting a sub-cohort.

## 0. Read information about collaboration policy for the use of Sarphati Cohort infrastructure

Information about	Source
<ul style="list-style-type: none"><li>• Sarphati Cohort</li><li>• Procedures</li><li>• Variables</li></ul>	<ul style="list-style-type: none"><li>• <a href="https://www.sarphaticohort.nl/">https://www.sarphaticohort.nl/</a></li><li>• read this collaboration policy document</li><li>• see appendixes of this document</li></ul>



Research must be conducted by existing legislation and regulations. Sarphati Amsterdam researchers must adhere to the Netherlands Code of Conduct for Research Integrity. More information on the website [www.sarphati.amsterdam](http://www.sarphati.amsterdam).

## 4. Collaboration agreement subjects

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.

### a. 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. We will make project-specific agreements concerning intellectual property.

### b. Conflict of interest

Avoid conflict 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.

### c. Scientific and ethical assessments

All projects that reach out to Sarphati Cohort participants need to be assessed by a METC or a recognized ethical committee. This body must either approve the project or declare that the research does not fall within the scope of the WMO. Projects that only use existing Sarphati Cohort data don't need an ethical assessment.

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

Proof that these assessments have taken place must be included as an appendix to the collaboration agreement.

### d. Privacy and compliance with the latest GDPR guidelines

All projects need to comply with the latest GDPR guidelines (AVG). Collaborating researchers get access to anonymized data only.

### e. Financial contribution

Sarphati Amsterdam organizes the infrastructure that allows the collection and sharing of the data. All participating partners of Sarphati Amsterdam – the City of Amsterdam, Amsterdam UMC, VU, UvA and HvA – can request to use existing Sarphati Cohort data without a financial contribution. Costs relating to the staff and necessary resources for starting a sub-cohort and for other organizations must be covered by the applicant. The contribution requested is negotiated with Sarphati Amsterdam on a case-by-case basis and details are specified in the collaboration agreement.

### f. Accessibility and processing of Sarphati Cohort data

Sarphati Cohort data for scientific research will be available via a secured environment of the GGD Amsterdam: a ftp server. This portal enables you to access the requested data with a username and

a password that we will share with you. The data is stripped of any information that is traceable to personal data. 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 support you 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.

#### g. 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.

#### h. Publications

Sarphati Amsterdam must be informed about any publications relating to the project. Note that publication must be aligned with Sarphati Amsterdam for the cohort descriptions. The Sarphati Cohort should be properly acknowledged in all publications and the presentation of the data should be in line with the conditions given. In the event of any publications, we would like to receive a copy of the publication and a summary in Dutch, which we can share on the Sarphati Amsterdam website. Details relating to publications will be included in the collaboration agreement.

## 5. Appendix 1 – data collection coreset-consult

Variabele naam	Leeftijd kind tijdens consult												
	4-8 dg	2 wkn	1 mnd	2 mnd	3 mnd	4 mnd	6 mnd	11 mnd	14 mnd	18 mnd	2 jr	3 jr	3,9 jr
<b>Groei</b>													
perceptie ouder groei		1	2	3	4	5	6	7	8	9	10	11	12
geboortegewicht	0												
lengte		1	2	3	4	5	6	7	8	9	10	11	12
gewicht		1	2	3	4	5	6	7	8	9	10	11	12
hoofdomtrek		1	2	3	4	5	6	7					
<b>Voeding</b>													
tevredenheid ouder voeding		1	2	3	4	5	6	7	8	9	10	11	12
melkvoeding	0	1	2	3	4	5	6	7	8	9			
vitamine K toediening geboorte	0												
vitamine K gebruik		1	2	3	4								
vitamine D gebruik		1	2	3	4	5	6	7	8	9	10	11	12
moment start vaste voeding						5	6	7					
soort vaste voeding start						5	6	7					
<b>Motoriek</b>													
perceptie ouders motoriek						5	6	7	8	9	10	11	12
van Wiechen ontwikkelingsonderzoek			2	3	4	5	6	7	8	9	10	11	12
<b>Slaap</b>													
tevredenheid ouder slaap						5	6			9	10	11	12
slaapritme: makkelijk inslapen						5	6			9	10	11	12
slaapkwaliteit: uitgerust wakker											10	11	12
<b>Achtergrondvariabelen</b>													
soort en moment consult		1	2	3	4	5	6	7	8	9	10	11	12
gebiedsindeling													
geslacht kind	0												
leeftijd kind	0												
leeftijd ouders	0												
geboorteland kind	0												



	4-8 dg	2 wkn	1 mnd	2 mnd	3 mnd	4 mnd	6 mnd	11 mnd	14 mnd	18 mnd	2 jr	3 jr	3,9 jr
geboorteland ouders	0												
lengte moeder			2										
lengte vader			2										
opleiding vader		1											
opleiding moeder		1											
spreektaal thuis		1											
ouders laag- of niet-geletterd				3									
Zwangerschap & bevalling													
zwangerschapsduur	0	1											
wijze van geboorte	0												
APGAR score 1	0	1											
APGAR score 2	0	1											
roken tijdens zwangerschap	0	1											
alcohol tijdens zwangerschap	0	1											
drugs tijdens zwangerschap	0	1											
meerling		1											
nummer meerling		1											

## 6. Appendix 2 – data collection coreset-plus

Variabele naam	Leeftijd kind bij het uitsturen van de vragenlijst						
	Start deelname	6 mnd	12 mnd	18 mnd	2 jr	3 jr	3,9 jr
<b>Algemeen</b>							
Invuller vragenlijst	x	x	x	x	x	x	x
<b>Demografie</b>							
<b>Huishouden</b>	x						
• soort gezin & aantal kinderen in huishouden							
<b>Lengte en gewicht</b>	x						
• Biologische moeder							
• Biologische vader							
<b>Etniciteit</b>	x						
• geboorteland(en) biologische ouders & grootouders, etnische zelfidentificatie ouder(s)							
<b>Opleidingsniveau</b>	x						
• opleidingsniveau ouder + (eventuele) partner							
<b>Werk</b>	x						
• werk ouder + (eventuele) partner, financiële situatie					x (vanaf 2023)	x (vanaf 2023)	
<b>Gezondheid</b>							
<b>Gezondheid kind (ervaren gezondheid kind)</b>		x	x	x	x	x	x
<b>Gezondheid ouder (ervaren gezondheid ouder, beperkingen, chronische aandoeningen)</b>		x		x		x	

	Start deelname	6 mnd	12 mnd	18 mnd	2 jr	3 jr	3,9 jr
<b>Mentale gezondheid ouder</b> (Kessler Psychological Distress Scale (K6, Kessler et al. 2002) <sup>1</sup> )		x		x		x	
<b>Eenzaamheid ouder</b> (De Jong-Gierveld (6 items, De Jong Gierveld & Van Tilburg, 2006) <sup>2</sup> )		x		x		x	
<b>Voeding</b>							
<b>Melkvoeding</b> (soort, aantal, schema, timing, moment start bijvoeding)		x	x		x	x	x
<b>Voeding kind</b> (groenten, fruit, tussendoortjes, gezoete dranken)			x		x	x	x
<b>Eetgedrag kind</b>							
• Baby Eating Behaviour Questionnaire (BEBQ, Llewellyn et al., 2011) <sup>3</sup>		x					
• Child Eating Behaviour Questionnaire - Toddler (CEBQ-T)			x		x	x	
• Child Eating Behaviour Questionnaire (CEBQ, Wardle et al., 2001 <sup>6</sup> ; Sleddens et al., 2008 <sup>7</sup> )							x
<b>Eetmomenten</b> (aantal, ontbijt, ritme)			x		x	x	x
<b>Slaap</b>							
<b>Duur en Ritme</b> (Brief Infant Sleep Questionnaire (BISQ, Sadeh, 2004) <sup>4</sup> )		x	x	x	x	x	x
<b>Zwangerschap</b>							
<b>Verloop zwangerschap</b> (aandoeningen moeder, gewichtstoename moeder, roken moeder)		x					
<b>Verloop bevalling</b> (wijze, complicaties)		x					

	Start deelname	6 mnd	12 mnd	18 mnd	2 jr	3 jr	3,9 jr
<b>Kinderopvang</b>							
<b>Gebruik kinderopvang</b> (soort en frequentie)		x	x	x	x	x	x
<b>Woning en leefomgeving</b>							
<b>Binnenmilieu</b> (Koken op gas, roken, schimmel & vocht)			x			x	
<b>Tevredenheid</b> (woning, woonomgeving, voorzieningen)			x			x	
<b>Geluid</b> (hinder, stille zijde woning)			x			x	
<b>Woning en buitenruimte</b> (vanaf 2023)			x			x	
<b>Opvoeding</b>							
<b>Belasting</b> (opvoeding Belasting Vragenlijst – verkort (OBVL-k, Vermulst et al. 2013) <sup>5</sup> )			x		x	x	x
<b>Beeldschermgebruik</b>							
<b>Beeldschermgebruik kind</b> (duur & frequentie timing, regels)				x		x	x
<b>Beweging</b>							
<b>Beweeggedrag kind</b> (vervoersmiddelen, buitenspelen, georganiseerde beweegactiviteiten)					x	x	x
<b>Invloed van corona op (2020-2022)</b>							
• slaap		x	x	x	x	x	x
• Voeding		x	x		x	x	x
• Kinderopvang		x	x	x	x	x	x
• Beeldschermgebruik						x	x
coronavirus infectie	x	x	x	x	x	x	x
invloed op welbevinden kind en ouder werksituatie	x	x	x	x	x	x	x
woning en buitenruimte	x	x	x	x	x	x	x

## Bronnen:

- 1 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.
- 2 De Jong Gierveld & Van Tilburg. A 6-Item Scale for Overall, Emotional, and Social Loneliness: Confirmatory Tests on Survey Data. *Res Aging* 2006;28(5):582-98.
- 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.
- 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 Wardle J, Guthrie CA, Sanderson S, Rapoport L. Development of the children's eating behaviour questionnaire. *J Child Psychol Psyc.* 2001;42(7):963-70.
- 7 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.