

External privacy statement for the KLIK website of the AMC and the other affiliated hospitals in the Netherlands.

Online privacy statement on the KLIK website, last amended on 1 March 2024

1. Introduction

This KLIK website has been developed by the Academic Medical Center (Academisch Medisch Centrum). The Academic Medical Center, hereinafter 'AMC', is located at Meibergdreef 9, 1105 AZ in Amsterdam and is an entity governed by public law, acting under the name 'AMC', occasionally also under the name 'Amsterdam UMC - AMC site', registered with the Chamber of Commerce under number 34362777.

2. Objective of the KLIK website

KLIK is a method that makes it possible to systematically map out the quality of life, psychosocial functioning and symptoms of children undergoing or discharged from hospital, their parents and adult patients.

The primary objective of this KLIK website is to provide children, parents and adult patients with a tool to prepare for the discussion with their practitioner. This is done by giving them an opportunity to complete questionnaires on how they are doing on this KLIK website, prior to the outpatient appointment. During the outpatient appointment, the practitioner will load the KLIK website and discuss the answers.

Aside from the primary purpose of KLIK, to discuss the quality of life in the consulting room, it is possible to use the KLIK portal for research purposes. Participants in the study, who have provided their consent, are asked to complete questionnaires, as part of which the answers to the questionnaires are definitely not shared with the practitioner.

In addition, you can give your consent for the answers to the questionnaires completed before the outpatient consultation are used for research purposes, with the objective of mapping out the quality of life and psychosocial functioning of children, their parents and adult patients.

3. Responsibility for the personal data collected and processed (further) via this KLIK website.

Apart from the AMC, several other hospitals in the Netherlands also use this KLIK website for the purposes indicated under point 2. That is why you can consider 'your hospital' to refer to the name of the hospital where you or your child have/had been treated or are/is still being treated. If you would like to know whether your hospital also uses this KLIK website, you can check the list of 'affiliated hospitals' under point 13.

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In order to serve you better via the KLIK website, it is necessary for your hospital to process (collect, store or use in any other way) your personal data. Personal data is data that can be traced back to an individual, for example your date of birth and your email address are your personal data. Based on the General Data Protection Regulation (GDPR), your hospital is the controller of your personal data and the personal data of other visitors to the KLIK website, which your hospital collects via the KLIK website for further use. In this context, your hospital is responsible for observing due care when collecting and processing this personal data, in conformity with the GDPR and other applicable privacy and health regulations. In this online privacy statement, you and any other visitor of this KLIK website can read how your hospital handles the data that it collected through this KLIK website. Furthermore, you and the other visitors to this KLIK website are informed about your rights with regard to processing your personal data and how you can exercise those rights.

4. Personal data that is collected through this KLIK website and the retention periods

With this website, your hospital only collects the personal data if this is necessary for enabling you to use this KLIK website and of the services offered via this KLIK website. Your personal data is not used for other purposes than the purposes for which you provided it to the hospital. This is different if your hospital obtains your specific consent for using your personal data for another purpose, if your hospital needs to fulfil statutory regulations or if your hospital needs the personal data to look after your hospital's legitimate interests. Below, we will explain in greater detail how personal data is collected and processed via this KLIK website.

a) The following personal data is collected and processed, in preparation of the discussion in the surgery about the quality of life.

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Personal data	Purpose of processing
<p>1. Initials (first two letters of first name and first two letters of surname)*, email address of patient and parents (for children), patient group (combination of centre and condition), primary practitioner.</p> <p>* Exceptions: Neonatology (first name), HIPPO study (surname)</p>	<p>To enable you to log into the KLIK website, to complete questionnaires, to ask a question of the KLIK team, to send you mails if you can complete questionnaires on the KLIK website, or to contact the KLIK team.</p>
<p>2. Patient's date of birth</p>	<p>To present you or your child age-appropriate questionnaires.</p>
<p>3. Dates of appointments and consultations</p>	<p>To enable you to complete the questionnaires in advance, before your appointment in your hospital.</p>
<p>4. Initials (first two letters of first name and first two letters of surname)*, patient number of your hospital (only applicable to the Amsterdam UMC and the Prinses Maxima Center), patient's date of birth, patient group (combination of centre and condition), primary practitioner, sex and dates of questionnaires completed. The questions concerned may relate to well-being, quality of life, symptoms, executive functions, general health, daily functioning, productivity, care consumption, behavioural problems, emotional problems and hearing impairments.</p> <p>* Exceptions: Neonatology (first name), HIPPO study (surname)</p>	<p>For the purpose of the outpatient consultation.</p>

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5. Your IP address. An IP address is a number assigned to your computer when you gain access to the Internet.	To enable communication between your computer or phone and the KLIK website.
6. All personal data indicated under 1 to 4 above.	For meeting statutory obligations and for your hospital's legitimate interests: finalisation, complaints and (legal) claims.
<p>Legal basis: the personal data in preparation of the conversation about the quality of life in the surgery is collected and processed to carry out the medical treatment contract between you on the one hand and the attending physician and hospital on the other hand. If you no longer wish your hospital to process your personal data, you can revoke your consent. Your hospital will then cease to process your personal data, unless this is prohibited by law or a legitimate interest of your hospital or a third party. In addition, the (personal) data in your medical file is governed without prejudice by the rights arising from the Medical Treatment Contract Act.</p> <p>If your hospital stops processing your personal data at your request, it may mean that you will no longer be able to access this KLIK website and the associated services.</p>	

b) The following personal data is gathered through this KLIK website and processed in the context of research

Personal data	Purpose of processing
<p>1. Initials (first two letters of first name and first two letters of surname)*, email address of patient and parents (for children), patient group (combination of centre and condition), primary practitioner.</p> <p>* Exceptions: Neonatology (first name), HIPPO study (surname)</p>	To enable you to log into the KLIK website, to complete questionnaires, to ask a question of the KLIK team, to send you mails if you can complete questionnaires on the KLIK website, or to contact the KLIK team.

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2. Patient's date of birth	To present you or your child age-appropriate questionnaires.
3. Initials (first two letters of first name and first two letters of surname)*, patient number of your hospital (only applicable to the Amsterdam UMC and the Prinses Maxima Center), patient's date of birth, patient group (combination of centre and condition), primary practitioner, sex and dates of questionnaires completed. The questions concerned may relate to well-being, quality of life, symptoms, executive functions, general health, daily functioning, productivity, care consumption, behavioural problems, emotional problems and hearing impairments. * Exceptions: Neonatology (first name), HIPPO study (surname)	For realising the research objectives.
4. Your IP address. An IP address is a number assigned to your computer when you gain access to the Internet.	To enable communication between your computer or phone and the KLIK website.
5. All personal data indicated under 1 to 3 above.	For meeting statutory obligations and for your hospital's legitimate interests: finalisation, complaints and (legal) claims.
Legal basis: your hospital will always seek your specific consent in advance for gathering and processing personal data for research purposes. Your hospital will only gather and process your personal data for research purposes if you gave your specific consent for it. If you no longer wish your hospital to process your personal data for research purposes, you can revoke your consent. Your hospital will then cease to process your personal data, unless this is prohibited by law or a legitimate interest of your hospital or a third party. If your hospital stops processing your personal data at your request, it may mean that you will no longer be able to access this KLIK website and the associated services.	

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c) **Retention periods.** Your hospital will not retain your personal data for longer than necessary for the purpose for which you provided the data, unless a longer retention period is required to meet a statutory obligation or to protect your hospital's legitimate interest. A retention period of 15 years applies to (personal) data that form part of your medical file. Further information regarding your medical file, including other retention periods with regard to the file, can be found on your hospital's website. In relation to your personal data gathered by your hospital via this KLIK website and used for research, you will be informed about the specific study - prior to being asked for your consent - about the applicable retention period.

5. Your rights

You have the following rights with regard to your personal data collected by your hospital through this KLIK website and processed:

- a) Access: you can ask your hospital to view the personal data that your hospital processes in relation to you and for a copy of it;
- b) Correction: if the personal data that your hospital processes is not correct, you can ask your hospital to correct it;
- c) Deletion: if you no longer agree to it that your hospital processes your personal data, or if you are of the opinion that your hospital no longer needs to process your personal data for the purpose for which you provided the hospital with the data, or that the data is being unlawfully processed, you can ask the hospital to delete the personal data concerned. The KLIK team forwards this request to the attending physician and will follow the attending physician's instructions;
- d) Restriction: if you dispute the accuracy of the processing of your personal data or if you object to it, you can ask your hospital not to take any action with the data other than retain it for the duration of the dispute;
- e) Objection: if you doubt that your hospital is processing your data in a lawful manner, you can object to your personal data being processed;
- f) Data portability: if you have provided data to your hospital and your hospital processes the personal data in a digital format, you can ask your hospital to make the personal data concerned available to you in a digital format.

You can exercise the aforementioned rights by submitting a written request to your hospital (see point 13 for your hospital's contact details). Your hospital will carry out your request within the statutorily defined period. Your hospital will carry out your request, if and insofar you are entitled to it in the circumstances. Your hospital has appointed a Data Protection Officer whose contact details are indicated under point 13 of this online privacy statement.

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6. Other visitors to this KLIK website

For other visitors to this KLIK website who do not make any other use of the services offered by this KLIK website, only the personal data referred to under 4a, bullet point 5, can be collected of them through this KLIK website, for the purposes set out under 4a, bullet point 5. The rights referred to under point 5 of this KLIK website also apply insofar as applicable to these other visitors to the website.

7. Sharing and forwarding of your personal data

Your hospital will ensure that your personal data are not provided to third parties or that third parties cannot access your data without your prior consent, unless: **(1)** it is necessary for the provision of a service that you use in your hospital; **(2)** it is required to safeguard a legitimate interest of your hospital, in which case you will be informed of it in advance; **(3)** there is a mandatory requirement; **(4)** it concerns a supplier to your hospital and solely insofar as necessary in the context of the support services provided by the supplier concerned to your hospital. In the latter case, your hospital ensures that it makes the necessary contractual arrangements with the supplier concerned to ensure that the supplier uses the same level of protection and confidentiality as the level applied by your hospital. If in the context of your use of this KLIK website, or in the context of services provided to you, your personal data is forwarded via this KLIK website to parties in countries outside the European Economic Area that do not provide suitable protection for processing your personal data, your hospital will take the necessary measures to ensure that your personal data is processed in conformity with the requirements of the European privacy regulations.

8. Confidentiality and security

Your hospital has taken appropriate technical and organisational measures to protect your personal data against loss, unauthorised access or any form of unlawful processing. However, despite the far-reaching efforts of your hospital, your hospital cannot guarantee protection against every possible threat. Your hospital will strictly limit the access to your personal data to those who are involved in providing services to you on behalf of your hospital or who are entitled to access within the context of the privacy and healthcare regulations in some other way. The individuals with access to personal data are required to keep your personal data confidential.

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9. Cookies

Only one functional cookie is used in relation to this KLIK website, as indicated in the matrix below. The 'cookie' is small piece of data that is stored in the browser of your device (for example, your computer or smartphone). The cookie is automatically stored when you visit this KLIK website with your device. The purpose of the cookie is indicated in the matrix shown below.

Name of cookie	Purpose	Duration
PHPSESSID	The purpose of the cookie is to retain your login session, i.e. to ensure that you remain logged in while browsing the KLIK website until you log out or close the browser.	<p>The cookie disappears from your device (computer, smartphone, etc.) when the browser is closed.</p> <p><i>A browser is a program that makes it possible to visit websites on the Internet. The most common browsers are Google Chrome, Microsoft Edge, Internet Explorer, Safari (Apple).</i></p>

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10. Links to other websites

Be aware of it that the KLIK website may redirect you to other websites, including websites maintained by other entities not subject to this online privacy statement, but by other privacy statements with a potentially different content. We advise you to assess the privacy policy of every website you visit before providing your personal data.

11. Validity of this version

Your hospital may amend this privacy statement if it considers it necessary. This KLIK website will always carry the most recent version of your hospital's online privacy statement, with reference to the date it was most recently amended at the top of the page. We recommend that you regularly check this KLIK website, in order to be informed of any changes.

12. Questions, complaints, comments and objections

If you have any questions, complaints or comments about this privacy statement or if you object to your personal data being processed, please inform the Data Protection Officer at your hospital. Your hospital will endeavour to serve you as well as possible. In addition, we inform you of your right to lodge a complaint with the Dutch Data Protection Authority if your hospital did not process your data in accordance with the prevailing privacy regulations in your opinion.

13. Affiliated hospitals

The following hospitals make use of this KLIK website and are therefore responsible for the personal data they collect and process via this KLIK website

<i>Naam ziekenhuis</i>	<i>Contactpersoon/afdeling</i>	<i>Contactgegevens</i>
Albert Schweitzer	Data Protection Officer	privacy@asz.nl

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Amphia Ziekenhuis	Data Protection Officer	functionarisgegevensbescherming@amphia.nl
Amsterdam UMC, locatie AMC	Data Protection Officer	fg@amc.nl
Amsterdam UMC, locatie VUmc	Data Protection Officer	privacy@vumc.nl
De Hoogstraat - Revalidatie	Data Protection Officer	functionarisgegevensbescherming@dehoogstraat.nl
Dijklander Ziekenhuis	Data Protection Officer	privacy@dijklander.nl
Erasmus MC	Data Protection Officer	functionaris.gegevensbescherming@erasmusmc.nl
Flevoziekenhuis	Data Protection Officer	functionarisgegevensbescherming@zgv.nl
Groene Hart Ziekenhuis	Data Protection Officer	winke.uytdehaage@ghz.nl
Haaglanden Medisch Centrum	Data Protection Officer	fg@haaglandenmc.nl
Isala	Data Protection Officer	privacy.functionaris@isala.nl
Jeroen Bosch Ziekenhuis	Data Protection Officer	fg@jbz.nl
Juliana Kinderziekenhuis/Haga ziekenhuis	Data Protection Officer	fg@hagaziekenhuis.nl
Kempenhage	Data Protection Officer	FG@kempenhaeghe.nl
Kindertand	https://www.kindertand.nl/privacy/	info@kindertand.nl
Laurentius Ziekenhuis	Data Protection Officer	FunctionarisGegevensbescherming@lzt.nl
Leids Universitair Medisch Centrum	Data Protection Officer	infoavg@lumc.nl
Maasstad Ziekenhuis	Department of Legal Affairs / Data Protection Officer	privacy@maasstadziekenhuis.nl
Maastricht UMC	Data Protection Officer	fg@mumc.nl
Maxima Medisch Centrum Veldhoven	Data Protection Officer	gegevensbescherming@mmc.nl
Meander Medisch Centrum	Data Protection Officer	FunctionarisGegevensbescherming@meandermc.nl

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Noordwest Ziekenhuisgroep	Data Protection Officer	privacybescherming@nwz.nl
OLVG	Data Protection Officer	fg@olvg.nl
Prinses Maxima Centrum voor kinderoncologie	Data Protection Officer	fg@prinsesmaximacentrum.nl
Radboud UMC	Data Protection Officer	gegevensbescherming@radboudumc.nl
Reade	Data Protection Officer	l.creemers@reade.nl
Regionaal Astma en Allergiecentrum voor kinderen / Canisius-Wilhelmina Ziekenhuis	Data Protection Officer	FG@CWZ.NL
Rijnstate Ziekenhuis	Data Protection Officer	privacy@rijnstate.nl
Sint Maartenskliniek	Data Protection Officer	privacy@maartenskliniek.nl
Spaarne gasthuis	Data Protection Officer	fg@spaarnegasthuis.nl
St Jansdal Ziekenhuis	Data Protection Officer	sa.hazekamp@stjansdal.nl
Universitair Medisch Centrum Groningen	Data Protection Officer	privacy@umcg.nl
Universitair Medisch Centrum Utrecht / Wilhelmina Kinderziekenhuis	Data Protection Officer	privacy@umcutrecht.nl
VieCuri Medisch Centrum	Data Protection Officer	FG@viecuri.nl
Zuyderland	Data Protection Officer	privacycare@zuyderland.nl