

Privacy policy

The Narcolepsy Monitor is offered to you by the Center of Sleep Medicine Kempenhaeghe, established in the Netherlands and registered at the Chamber of Commerce under number 41087534. Where reference is made in this privacy policy to 'we' this refers to the Center of Sleep Medicine Kempenhaeghe.

Kempenhaeghe is responsible for the way the Narcolepsy Monitor is build, including the collection and processing of personal data that takes place within this framework. Via this privacy policy we provide information about who we are and what is done with regard to collection and processing of personal data.

Purposes of the data processing

We respect the privacy of the users of the Narcolepsy Monitor and ensure that personal information you provide is handled confidentially.

The personal data is processed in accordance with the European privacy legislation laid down in the General Data Protection Regulation (GDPR). Your personal data will be processed solely for the purpose of scientific research on narcolepsy. The Narcolepsy Monitor will not be used to diagnose a medical disease or to make a medical decision.

Personal data

Kempenhaeghe receives limited personal information (gender, age, education level, work situation and information regarding your narcolepsy). In addition, Kempenhaeghe receives the data that you record over time in the Narcolepsy Monitor. The Narcolepsy Monitor collects data about the subjectively experienced burden of symptoms, notes made by the user, changes in medication entered by the user, and user statistics. The data cannot be traced back to you as a person. The data is used for scientific research on narcolepsy and to evaluate the use of the Narcolepsy Monitor.

There is a possibility to use the Narcolepsy Monitor for yourself only, without sharing your data with Kempenhaeghe. You can do this by not checking the box "I contribute to scientific research into narcolepsy by sharing my data anonymously" when installing the app. In that case no data will be collected from you, but you can use the Narcolepsy Monitor.

Security technologies

The Narcolepsy Monitor is built by Frontwise, a qualified company specialised in the development and building of software.

Kempenhaeghe takes the protection of your personal data seriously and takes appropriate measures to prevent abuse, loss, unauthorized access, unwanted disclosure and unauthorized changes. The storage of data takes place on servers within Kempenhaeghe in Heeze. For logging in to the Narcolepsy Monitor and for data traffic, SSL certificates and cryptographic techniques are used to secure passwords and data during transport as well as during interim storage.

Access to personal data

The data collected by Kempenhaeghe cannot be traced back to you as a person. Only a few employees have access to this anonymous data, namely the researcher and the system administrator. If requested, national and international supervisory authorities (for example, the Healthcare and Youth Inspectorate) will also be granted access. They will handle your personal data confidentially.

Storage of data

The data collected by the Narcolepsy Monitor will be retained for up to 15 years after completion of the study, as required by the rules for scientific research.

Access, rectification, right to object and right to be forgotten

After filing a written request, you have the possibility to inspect your personal data, including the data which is not visible in the symptom visualisation of the Narcolepsy Monitor. If the overview provided by us contains any inaccuracies, you can ask us in writing to amend, supplement or remove the data by notifying us of this via the contact details at the bottom of this privacy policy. You have the right to object to the processing of your personal data and you can have your personal data irrevocably deleted.

Finally

We reserve the right to change this privacy policy. We therefore recommend that you regularly check this statement for changes.

If you have any questions or complaints about the processing of personal data for scientific research, you can contact us at the telephone number (+31) (0) 40-2279202. If you would not be satisfied with the way we handle your complaint you can contact Kempenhaeghe's data protection officer (FG) (FG@kempenhaeghe.nl).

Contact details:

<https://www.kempenhaeghe.nl/>

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