

Privacy Notice Neurokeys App and Website & Procedure for Filing a Complaint

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PRIVACY NOTICE: NEUROKEYS APP OF NEUROCAST

1. Summary

- It's our objective to fight chronic diseases worldwide

Neurocast has the ambition to provide researchers, doctors and the industry in the field of chronic diseases with better information that can help them do their job more effective and efficiently. Ultimately this should lead to solutions for patients to better manage their lives. Since the course of chronic diseases is hard to track, there is a strong urge for 24/7 real world evidence. With our Neurokeys App we are able to unobtrusively collect and analyze data from patients, for patients in a real-world setting. In everything we do we try to meet the highest privacy standards available. No data is stored that could directly lead to individuals.

- You generate valuable research data for doctors and yourself, without knowing it
Our Neurokeys App is an intelligent smartphone keyboard aimed at providing individual and group level insights into patients' fatigue. This is done by analyzing typing behavior, under the assumption that people will type different on days when they feel less energetic compared with days when they are full of energy. This is valuable information for doctors and researchers since fatigue is a good indicator for the status of a patient. The interesting part is the fact that the data is collected in a 24/7 real world setting since smartphones are always nearby.

- You can help doctors and researchers developing better treatments and medication
In the nearby future the App will have the possibility to share your data with your doctor. We are working on a set up where you decide which data you share with which doctors and when. This allows your doctor to get better insights into your status and they can use this information when constructing a treatment plan. For now, researchers can use the anonymous aggregated data within their research projects to start predicting the course of diseases. Hopefully your data will bring them one step closer to insights into the causes of chronic diseases such as MS, Alzheimer, Parkinson's, various kinds of cancer, diabetes and for instance COPD.

- You are unknown to us and we do not see what you type
We do not store profile information of our users that can be directly linked to individuals. For instance, we do not store email addresses, names, nicknames whatsoever. We just ask you to share your gender, year of birth and which disease is diagnosed. It is up to you if you want to share this data. Furthermore, we only know our users by their anonymous ID and the randomized password is unknown to us. We are not interested in what people type, only how they type. Since alpha numeric keystrokes are not logged nor stored in the database, the content of what's being typed cannot be reproduced.

- Check out any time you like, without leaving a trace
Quitting the Neurokeys service is easy. Just remove your Neurokeys App from your Smartphone. To prevent you from unintended loss of your history, we will ask you to confirm once. Since we do not know who you are and the profile linked to your ID is removed in our database, you can leave the service without leaving a trace.

2. About Neurocast

- The overall purpose and objective of collecting your data

Neurocast has the ambition to provide researchers, doctors of patients with chronic diseases and the industry with better information that can help them do their job more effectively and efficiently.

Since the course of chronic diseases are hard to track, there is a strong urge for 24/7 real world evidence data. Since your smartphone is really smart, we found out that this device can generate millions of interesting data points for researchers to investigate and you carry your mobile phone with you everywhere you go. We can see patterns just by analyzing the way you type. The number of messages, words and typos for instance give us an indication of how you perform from day to day.

We've set up our systems in such a way that we are unable to see what you type. Your privacy is a part of our DNA.

Given the complex nature of chronic diseases, we collaborate with industry leaders worldwide and approach solutions from various angles of interest. Amongst our partners are the MS Center (VU Medical Center Amsterdam), patient organizations in Europe, the USA and researchers from various universities and pharmaceutical companies. The anonymous and aggregated data will be open for researchers to start helping us to help you with better treatments and medication.

– Privacy first

In everything we do, we try to meet the highest privacy standards available. We do our utmost to be as transparent as possible with what data we collect, why we collect it and what we actually do with your data. Again, you should be aware of the fact that we do not know who you are, we do not need your email address nor other personal data that can lead us to you as an individual. We do not store personal data other than what you decide to share with us. However, you should notice that we cannot share results and analyses with you that is based on data that you did not provide to us. It is your data and it is your choice what to share with us. We try to be as open as possible in helping you decide what to share with us by telling you for what reason we collect the data. Feel free to contact us by sending an email to privacy@neurocast.nl.

– Ease of stopping, without leaving a trace

Participating is easy and it just takes one minute of your time to start collecting the data. Stopping is just as easy. Just delete the Neurokeys App from your smartphone and we stop gathering your data. We will ask you to confirm once, just to be sure that you did not press buttons unintentionally. If you are out you're out.

If you withdraw your consent no further data will be collected, but analyses performed on your anonymous data in the past may still be used. The profiling model that may have been built using your data will not be able to 'unlearn' from your data.

In the case you participate in a closed (third-party) study, the study initiator or sponsor will be appointed Data Controller. After the study ends and users choose to cease using the Neurokeys app, no further data will be collected. The profiling model that may have been build using your data will not be able to 'unlearn' from your data.

In both cases, the data will still be in the Neurocast Database until the end of the retention period established by the Data Controller/Sponsor. In this case: at least 1 year, up to a maximum of 15 years after the clinical trial finishes. In the case that Neurocast ceases to exist or is not able to retain the data, the data will be transferred to the VU medical center's internal systems.

– Contact information

If you have any questions, please feel free to drop us an email at privacy@neurocast.nl. Besides answering your questions, you help us to be more precise and transparent in our communication.

3. The reason why the data is being collected

It is our intention to come up with the largest reference database with anonymous data of patients suffering from chronic diseases like MS, Parkinson's, Alzheimer's, various forms of oncology related illnesses and for instance COPD. We want to share this anonymous data with researchers to start predicting the disease course and help investigate the possible causes of these diseases.

Based on these analyses we provide individual users of the Neurokeys App with insights in their energy levels over time, since this can be a good indicator of their well-being and possibly how the chronic disease reveals itself. We have made it easy for patients to share this information with their doctors. The access to the data can be withdrawn at any time.

Any interesting and medically validated report will be shared on our website. The same applies to research projects in which we participate.

4. The data that is being collected

The data that we collect with the Neurokeys App can be divided into four categories:

- Keystroke Data
All keystrokes on your smartphone are timestamped and stored in the Neurokeys database. The alphabet and number keys are all stored under unidentifiable labels (i.e. "A keystroke" or "A number"). For example, we cannot see the difference between for instance the letter "a" and "e" and numbers "5" and "9".
- Profile Data
When installing the Neurokeys App you are asked to share non-identifiable data about yourself with us: Gender, age and diagnosed disease if any. This helps us in analyzing your data in the right context.
- Sensor Data
Your Smartphone has built-in sensors that provide valuable information. The Neurokeys App collects among other sensors the accelerometer, screen lux and GPS location on an accuracy level of hundreds of meters.
- Optional Data
During the installation of the Neurokeys App you will be asked to provide access to your HealthKit data. If you allow us access to this data we will use it to provide you with more interesting feedback, based on the analyses we make. Some examples of additional insights we can provide with this data are given on our website. Sharing your GPS location is optional, we encourage you to do so as this enables us to couple open datasets such as weather data or air quality data to our database.
- Smart Panel Data
This is an option too. To train our data science models and to better understand how you feel we can ask you a couple of (easy to answer) questions per day. Again, we cannot see who you are but this helps us to see if we interpret your data correctly.

5. The way the data is collected

The data is collected once you have installed the Neurokeys App. This App replaces the standard keyboard on your smartphone with the intelligent Neurokeys Keyboard. Every time you open an App on your smartphone and input is wanted, the Neurokeys Keyboard pops up. One remark for people using Apple iPhones, whenever an App asks for user id's or passwords, the native keyboard automatically takes over. This way Apple protects its users from software vendors that try to log password information. Safety first, we could not agree with them more.

6. How the data will be used

The data is stored in a secure cloud environment (Amazon Web Services in Frankfurt, Germany). The data will solely be used in models that provide insights into patients' energy levels as an indicator for the course and/or cause of their disease.

7. With whom the data is shared and under which circumstances

The data will be shared with the respective individuals using the Neurokeys App. With their unique and anonymous combination of user id and password they can access their data in-app and web-based via a secured link. They themselves can decide to share the data with third parties such as treating doctors. They can withdraw access at any time.

Aggregated anonymous data will be shared with researchers upon request. These requests will be evaluated based on the curriculum of the institution and/or researcher, his/her intention, the research objectives, contribution to the overall Neurocast goal, and scientific substantiation.

8. The conclusions that can be drawn by analyzing the data

With the Neurokeys App we want to provide individual users an objective indication of their energy level. At this point in time the outcomes are not medically validated and it should be interpreted as such. Several universities and research institutes, the VU Medical Center Amsterdam being one of them, are working with us on validating the underlying Neurokeys models. Any progress made is communicated on the website of Neurocast. (www.neurocast.nl).

9. Where you can benefit from sharing your data

By providing access to your Neurokeys data, smart researchers will get closer to more effective and efficient ways to treat patients with chronic diseases worldwide. You do not need to be a patient yourself since the data of people that do not suffer from a specific disease can be compared with people that do. It is a joint effort of scientists, researchers, doctors, patients and people that just care about people.

10. Filing a complaint

You may file a complaint with our Data Protection officer, see the appendix: "Procedure for filing a privacy complaint" attached to this document. In case you may have a serious concern regarding data privacy, you may always contact "Autoriteit Persoonsgegevens" (<https://autoriteitpersoonsgegevens.nl>), or the Data Privacy Agency/Authority of your respective country.

Appendix: Procedure for filing a privacy complaint

File a privacy complaint

We take your privacy seriously and have created a process by which you can formally file a complaint with our Data Privacy Officer.

Privacy complaints we can help with

We accept written complaints about:

- How the Neurocast BV (Neurocast), the legal entity behind the Neurokeys App collects or uses personal information;
 - How, when, and with whom Neurocast shares personal information;
 - The type(s) and/or amount of personal information Neurocast collects; and
 - Any other concern(s) you may have about how Neurocast handles personal information and/or its impact(s) on personal privacy.

Complaints about the privacy of a business entity, a corporation, or any entity other than a person are not covered by our privacy complaint procedures. Please keep in mind that filing a complaint does not negate or replace your right to seek judicial relief under GDPR for violations of individual privacy rights.

Submit a privacy complaint

To submit a complaint, you can write a letter that includes:

- Your name
- A summary of your complaint or a written description of the specific circumstances
- A summary of other steps taken, if any, by you or Neurocast to resolve this complaint
- A preferred method of contact about your complaint – a mailing address, telephone number or email address

Send us the letter by email or mail:

privacy@neurocast.nl
Neurocast BV
Attention: Data Privacy Officer
Homeruslaan 31
3707 GN ZEIST
The Netherlands

Evaluation procedure

- We will send you an acknowledgement letter within 5 business days of our receipt of your complaint.
- We will review and categorize the complaint as: Process and procedural, redress, operational or referral
- The Chief Privacy Officer will recommend any necessary actions in response to the complaint. We'll let you know once your complaint is closed and, in general, include what, if any, action we're taking in response to the complaint.

Our goal is to review and close complaints within 20 business days. For complaints that we'll need more than the normal time to close, we'll contact you to give a status update.