

Privacy statement

30-10-2024

### **Who are we?**

SPEAKtoCOPD is a site to collect as many voices as possible for research. Eventually we want to develop algorithms to predict lung attacks of COPD with speech. We also collect voices for other research about lung diseases or speech. This research has been set up by Maastricht University.

The SPEAKtoCOPD site has been established by a collaboration between Maastricht University, MUMC+, and MEMIC. Referred to in the rest of the privacy statement as the "SPEAKtoCOPD partners".

Your privacy is important for the SPEAKtoCOPD partners and we handle your data with care. The SPEAKtoCOPD partners are the joint controller of your personal data. How the SPEAKtoCOPD partners ensure your privacy is explained in this privacy statement. This privacy statement is specifically about the SPEAKtoCOPD site.

### **Contact details**

If you have any questions about this privacy statement, if you would like to know more about how the SPEAKtoCOPD partners handle your personal data or if you have a complaint, you can contact the researcher via mail [loes.vanbemmel@maastrichtuniversity.nl](mailto:loes.vanbemmel@maastrichtuniversity.nl). You can also contact the data protection officer of Maastricht University at [fg@maastrichtuniversity.nl](mailto:fg@maastrichtuniversity.nl).

Which personal data do the SPEAKtoCOPD partners process?

To perform the SPEAKtoCOPD study on the site, we are processing these data:

- The data you fill out in the questionnaire on the SPEAKtoCOPD site, including gender, age category, first language, lung disease, other chronic diseases, current situation, current medication and the RSQ questionnaire.
- Your recorded speech on the SPEAKtoCOPD site.
- On what kind of device you access the SPEAKtoCOPD site.
- In which country you visit the SPEAKtoCOPD site.

All your data will be collected directly to the SPEAKtoCOPD partners.

### **Special personal data**

Special personal data are data of sensitive nature. For example, data about your race or ethnical background, political opinions, religion or philosophy, membership of a union or sexual orientation, or data that can derive any of these. Additionally, data about your health, genetic data or biometric data which can identify you (like a fingerprint) are also special personal data.

The SPEAKtoCOPD partners process your special personal data because it is needed for the study. Only data about your health, which you fill in yourself in the questionnaire, are processed. Your voice is a way to possibly identify you and this is also needed for the study. You give explicit informed consent before we process these personal data with the informed consent form on the site.

### **Purposes**

The SPEAKtoCOPD partners process abovementioned personal data with the following purposes:

- Conducting the SPEAKtoCOPD study
- (Optionally, if you give permission) Collecting your data for future research

### **Processing grounds**

When the SPEAKtoCOPD partners process your personal data, then this processing is based on the processing grounds. Processing grounds are the reasons why your personal data is being processed.

The processing of your personal data by the SPEAKtoCOPD partners is to conduct the SPEAKtoCOPD study.

Before the SPEAKtoCOPD partners process your data, you give explicit informed consent for the processing of these personal data.

### **Retention periods**

Personal data collected by the SPEAKtoCOPD partners are, in principle, not retained longer than the specific retention periods according to Maastricht University, which is 15 years. If you choose to add your personal data to the database, your personal data is kept for longer. You can separately choose to give permission for this.

### **Your rights**

The privacy laws give you several rights with regard to your personal data. These rights will be explained shortly below.

- **Right to inspection:** This is the right to obtain a copy of the personal data that we are processing.
- **Right to be forgotten:** This is the right to be “forgotten”. You can ask us to delete your personal data.
- **Right to rectification and addition:** The right to adapt any personal data we process
- **Data portability:** The right to transfer your data to a different party
- **Right for restriction of data processing:** the right to process less data
- **Right to automatic decision making and profiling:** the right to include a human in decision making
- **Right to object to data processing.**

When you want to exercise one of the above rights you can contact [loes.vanbemmel@maastrichtuniversity.nl](mailto:loes.vanbemmel@maastrichtuniversity.nl) with your unique ID code that was shown on the SPEAKtoCOPD site while filling in your data. You can also directly contact the data protection officer via [fg@maastrichtuniversity.nl](mailto:fg@maastrichtuniversity.nl).

When you have a complaint about the processing of your personal data by the SPEAKtoCOPD partners, you can contact the above mentioned emails. You also have the right to submit a complaint to the Dutch Data Protection Authority. On the site of the Dutch Data Protection Authority you can read how to do that.