

BURDEN Initiative **Bronchiectasis Understanding & Research on Daily Experiences & Needs**

Information on data protection

Your participation in the online survey with admedicum GmbH & Co KG (admedicum).

For maximum security of your data, the online survey is completely anonymous and of course voluntary. admedicum is acting as the data controller according to Art. 4.7 of the European General Data Protection Regulation (EU GDPR) or the equivalent under other applicable data protection laws.

We guarantee compliance with the protection standards of the EU GDPR, which are very strict and are also covering all rights under national and regional laws in the United Kingdom (UK), United States of America (USA) and Japan (JP). If you reside in the UK, USA, or JP, you may claim all your rights under local laws; however, we herewith agree to hold your data protection rights towards us also according to EU GDPR.

As such, we ask you to read and accept the following privacy policy before starting the online survey. The legal basis for the collection of data by admedicum results from art. 6.1 a and 9.2 a of the EU GDPR.

Purpose of the online survey

The online survey is as part of the BURDEN initiative to learn more about the impact of Non-Cystic Fibrosis Bronchiectasis (NCFBE) on everyday life of people living with bronchiectasis (without having cystic fibrosis)/NCFBE and their caregivers. The goal of the online survey is to gain a better understanding of the burden of disease from a larger group of affected people, including their needs and experiences in their daily, social and work lives.

The objectives of the BURDEN initiative are:

- Increasing awareness on the impact of bronchiectasis on the lives of those affected.
- Enhancing quality of research, care, and information materials.
- Empowering the bronchiectasis community.
- Generating patient relevant insights/ evidence that may be considered by health care decision makers globally.
- Demonstrating disease burden to healthcare decision-makers globally by sharing information delivered by people living with bronchiectasis and those who care for them.

The sponsor for this research initiative is Insmmed Incorporated, a global biopharmaceutical company committed to focusing on serious or rare diseases. admedicum organizes this research. In no case will our work with you describe or directly or indirectly recommend any products.

Data Processor

The survey is conducted via an online data collection platform. The name of this company and therefore the data processor is:

SurveyMonkey Europe UC
Ella House, Suite 40.4
40 Merrion Square East
Dublin 2
D02 NP96
Ireland

SurveyMonkey's privacy policy can be viewed in detail here:

<https://www.surveymonkey.com/mp/legal/privacy-basics/>

Will personal data be collected during the online survey?

No personal or identifiable data will be collected. Even your IP address will not be tracked when participating in the online survey. There is no way to trace your data entries back to you.

At the end of the online survey, we will offer to send you a summary of the online survey results when they become available. If you choose so, you will be asked to provide personal contact information in a separate contact form which disconnects this information from your answers you have previously provided in the online survey. Therefore, your answers in the online survey and personal contact information cannot be combined. Before you decide to provide such information, you will be asked to agree to a separate privacy policy.

How do we use the anonymous online survey results?

The anonymous, individual results of the online survey will be analyzed by admedicum. They may be published in aggregated form by admedicum and/or third parties such as patient associations, physicians, and pharmaceutical companies.

What rights do you have regarding your data?

Your participation in the online survey is entirely voluntary. However, once you answer a question in the online survey, you cannot revoke your consent to use the data collected. Because the data is anonymous, we cannot trace back and single out which data belongs to you.

If you have any questions regarding data protection, please contact our **data protection officer**:

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In addition, according to Article 77 of the GDPR, data subjects in the EU/EEA have the right to lodge a complaint with a supervisory authority, usually the respective data protection authority of the local jurisdiction in which you reside. A list of the competent supervisory authorities can be found [here](#).

In the UK this would be the Information Commissioner's Office (ICO) icocasework@ico.org.uk and for Japan this would be the Personal Information Protection Commission (PPC)

<https://www.ppc.go.jp/en/contactus/>.

If you reside in the US, you may file an online complaint at the Office of Human Rights at

<https://ocrportal.hhs.gov/ocr/smartscreen/main.jsf>.