

Agreement, information on data protection, and declaration of consent

Your participation in an interview in the BURDEN initiative
“Bronchiectasis Understanding & Research on Daily Experiences & Needs”
with admedicum

Agreement

between

admedicum GmbH & Co KG
Industriestraße 171
50999 Cologne

- hereinafter called "admedicum" -

and

Name:

Address:

Thank you very much for agreeing to participate in an interview 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 interview will take about one hour without any need for preparation. Your participation will be compensated with £ 70. You will receive the compensation after successful participation in the interview by bank transfer to your account. For this purpose, we would like to ask you to give us your account details below. You can also decide against compensation by simply leaving the fields blank.

Account holder: _____

Bank: _____

IBAN: _____

BIC: _____

With your signature you agree to receive payment by bank transfer. Please note that you are liable to declare this payment in your tax statement. admedicum will NOT be responsible for the appropriate declaration to the tax authorities.

Information on data protection

What standards do we observe when conducting an interview on behalf of a company in the pharmaceutical industry?

At admedicum we take the confidentiality of all information entrusted to us by all participants very seriously. The reliable and responsible handling of what you entrust us with is a non-negotiable basis for our work with you and sponsors. We are 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.

For your maximum data security, we therefore guarantee compliance with the protection standards of the European General Data Protection Regulation (GDPR) to the extent such standards apply to the data we have collected from you. If you reside in the United Kingdom (UK), you may claim all your rights under local laws.

If your data will be transferred for the purpose of this project as described below to a third country outside of the EU, the application of data protection rules may be less strict than in the EU. In such case of transfer, we will apply all rules of chapter 5 of the EU GDPR and the standard clauses provided by the EU commission in accordance with Art. 46.2 of the EU GDPR.

With this in mind, we ask you to read and sign the following declaration of consent carefully before we begin the dialogue with you on behalf of the sponsor. The legal basis for the data collection by the interview results from Art. 6.1 a and 9.2 a of the EU GDPR.

Purpose of the interview

The interviews are being conducted as part of the BURDEN initiative to learn more about the impact of bronchiectasis (without cystic fibrosis) on everyday life of affected people and their caregivers. The findings from your participation will be used to inform the creation of a larger online survey. Your interview participation will help us to consider all relevant topics. The goal of the interview is to better understand the disease burden including the needs and experiences of people living with bronchiectasis (without cystic fibrosis) and people who take care for them in their daily, social and work life.

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 Insmid Incorporated, a global biopharmaceutical company committed to focusing on serious or rare diseases. admedicum organises this research. In no case will our work with you describe or directly or indirectly recommend any products.

What personal data is collected during the interview?

In order to contact you and in preparation of the interview by admedicum, so-called personal data is collected. These include, above all, information about you, such as age, sex, status (patient), disease(s), disease status and history, your address, your telephone number, your account data (to transfer the compensation) and your email address. admedicum will not use your personal data outside of the described project, except for the purpose of contacting you and complying with legal regulations (see below).

Information from the conversation with you will be anonymised and summarised in a report on a total of up to 60 interviews with affected people and those who care for them in Europe, Japan, and the USA. The report includes country, age, sex, disease status and history as well as reported experiences of the interviewed people living with bronchiectasis (without cystic fibrosis) and those who care for them in aggregated form. Individual quotes may be used but will be also anonymised, i.e. no direct personal information such as your name or address, will be mentioned. This means that your contribution to the content of the report cannot be linked to your name or other personal data and your identity remains unknown to the recipients of the report.

Documentation of the interview

The interview, which can be by telephone or online (virtual meeting), will be recorded by admedicum. For technical reasons, not only the sound but also video will be recorded. The video recording is deleted immediately after the interview and will not be used further. You will be informed of this again before the recording starts. If you do not wish to have video recorded, you can switch off your camera for the duration of the recording. The sound recording will only be used for the purpose of documentation and transcription in the context of the project described above. For transcription your sound recording will be transferred to a transcription service provider (see data processor). Under no circumstances will it be passed on to the Sponsor.

Data Processor

The transcription services provider and therefore the data processor is:

Rev - rev.com

- By mail: 1717 W 6th St, Ste 310, Austin, TX, 78703 – USA
- By phone: +1 888-369-0701
- By email: support@rev.com

Rev.com's privacy policy can be viewed in detail here:

<https://www.rev.com/legal/privacy>

Who sees your data?

Employees and representatives of admedicum, that are bound by strict confidentiality obligations, will see your data if and to the extent that this is useful and necessary for the fulfillment of their tasks or because of their participation in the interview. They will also use the data only for the stated purpose.

The anonymised and summarised report will be made available to Insméd Incorporated as well as patient organisations and physicians who are involved in the BURDEN initiative. A future publication of these results is intended.

How and how long do we store your data?

By storing your data on a cloud service certified with the highest industry standard ISO27018, admedicum ensures that your electronically stored data is safe from loss, destruction, manipulation, or access by unauthorised persons. Written notes and documents are also digitised and electronically secured. Paper originals are also stored in a secure place. Your data will be stored for a period of 5 years, e.g. in the event of a legal dispute, to prove that the work we have done for the sponsor is based on correct data collection and evaluation. Under no circumstances will your data be used for purposes other than those described in this agreement.

You also have the right to revoke the storage and use of your personal data before the work is carried out. Please read the next section.

What rights do you have regarding your data:

You can revoke your consent to participate in the interview or to for us to use the data we have collected before the interview begins and without giving reasons. You then have the right to demand the correction, blocking or deletion of all your information/data stored up to that point. We will comply with your request immediately and inform you of the measures taken. For legal reasons, we must reserve the right to receive data under certain conditions regulated by law, e.g. if this data is required as evidence in the context of a legal dispute. We will then consult with you accordingly in order to meet your request as far as possible.

However, we must point out that after the interview due to the anonymisation of the data and integration into a summarised (aggregated) report about all interviews, correction, blocking or deletion of your personal data is therefore then only possible to the extent that the data is on our server for the purpose of contacting you and for internal documentation (see above).

In case of a revocation, complaints, but also simply in case of questions regarding data protection, please contact our **data protection officer**:

Jasmin Muhmenthaler-Sturm
Datenbeschützerin GmbH
Unterer Sand 9
94209 Regen, Germany.
E-Mail: dataprotection@admedicum.com
Telephone: [+49-9921 88229000](tel:+49-9921-88229000)

Furthermore, according to Art. 77 GDPR, you also have a right of appeal to a supervisory authority. In the UK this would be:

Information Commissioner's Office (ICO) – icocasework@ico.org.uk
Wycliffe House Water Lane
Wilmslow
Cheshire
SK9 5AF

If you agree with the above explanations, we ask you to sign the following declaration of consent. We thank you for your understanding and support.

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DECLARATION OF DATA PROTECTION CONSENT

1. I HAVE READ AND UNDERSTOOD THE ABOVE INFORMATION ON DATA PROTECTION. I AGREE THAT PERSONAL DATA COLLECTED DURING THE INTERVIEW WITH ADMEDICUM OR REPRESENTATIVES OF ADMEDICUM MAY BE RECORDED ON QUESTIONNAIRES AND ELECTRONIC DATA CARRIERS. I ALSO AGREE THAT IN A SUMMARY REPORT MY SEX, AGE AND COUNTRY, AS WELL AS INFORMATION ABOUT MY LIFE WITH BRONCHIECTASIS (NON-CYSTIC FIBROSIS) WILL BE MENTIONED IN AN ANONYMISED FORM AND THAT THIS REPORT CAN BE PASSED ON TO INSMED INCORPORATED AND BE PUBLISHED. OTHER PERSONAL DATA WILL NOT BE FORWARDED OR PUBLISHED BY ADMEDICUM.

2. I AGREE THAT DURING THE INTERVIEW SOUND RECORDINGS WILL BE MADE. SOUND RECORDINGS WILL BE USED EXCLUSIVELY FOR THE PURPOSE OF INTERNAL DOCUMENTATION AND TRANSCRIPTION AT ADMEDICUM, ADMEDICUM REPRESENTATIVES AND THE TRANSCRIPTION SERVICE PROVIDER IN THE CONTEXT OF THE PROJECT DESCRIBED ABOVE.

3. I AGREE THAT DURING THE INTERVIEW VIDEO RECORDINGS WILL BE MADE, AS OTHERWISE NO SOUND RECORDINGS COULD BE MADE FOR TECHNICAL REASONS. THE VIDEO RECORDINGS ARE IMMEDIATELY DELETED AFTER THE INTERVIEW AND WILL NOT BE USED FURTHER.

4. I AM AWARE THAT I CAN WITHDRAW OR CANCEL MY CONSENT TO PARTICIPATE BEFORE THE INTERVIEW IS CONDUCTED AND WITHOUT GIVING REASONS. IF I REVOKE MY CONSENT, I WILL NOT BE ABLE TO PARTICIPATE IN THE INTERVIEW. IN THIS CASE, ADMEDICUM WILL DELETE ALL MY INFORMATION/DATA STORED UNTIL THEN.

5. I HAVE THE RIGHT TO DEMAND THE DELETION OF ALL MY INFORMATION/DATA STORED AFTER THE INTERVIEW HAS BEEN CONDUCTED. I AM ALSO AWARE THAT AFTER ANONYMISATION OF THE DATA CORRECTION, BLOCKING OR DELETION OF ANONYMISED DATA IS NO LONGER POSSIBLE.

6. YES, I WOULD LIKE TO RECEIVE A COPY OF THE SUMMARISED RESEARCH RESULTS AS THEY BECOME AVAILABLE AND I AGREE THAT ADMEDICUM WILL USE MY CONTACT DETAILS TO PROVIDE THIS TO ME.

PLEASE TICK ACCORDINGLY:

YES NO

NAME (USE CAPITAL LETTERS): _____

Date, Location

Signature