

Information on Data Protection

Experiences with Clinical Trial Information and Participation Survey

1. Roles for processing your personal data under General Data Protection Regulation (GDPR)

For the purposes of this project, **argenx BV** (argenx) is the data controller (Art. 4(7), Art. 24 GDPR). admedicum GmbH & Co. KG (admedicum) processes personal data on behalf of argenx as argenx's data processor (Art. 4 (8), Art. 28 GDPR).

Data Controller: argenx BV

Industriepark-Zwijnaarde 7, 9052 Zwijnaarde, (Ghent) Belgium - www.argenx.com

Privacy contact / argenx Data Protection Officer (DPO): privacy@argenx.com.

Data Processor: admedicum GmbH & Co. KG

Industriestraße 171, 50999 Köln, Germany

Email (project contact): pabpnsmaastricht2026@admedicum.com

admedicum Data Protection Officer (DPO): Jasmin Mumenthaler-Sturm, Datenbeschützerin GmbH, Unterer Sand 9, 94209 Regen, Germany, dataprotection@admedicum.com, +49-9921-88229000

2. Purpose of the project and processing your personal data

On behalf of argenx, admedicum conducts the online anonymous survey on **Experiences with Clinical Trial Information and Participation**. This short survey aims to understand what helps or hinders people with CIDP, GBS, or MMN in becoming aware of, understanding, and navigating clinical trials.

No products will be discussed, promoted, or recommended.

3. Legal Basis for processing

The legal basis for these activities is Art. 6(1)(a) GDPR. Where you provide health-related information, admedicum processes on behalf of argenx such special category data based on your explicit consent (Art. 9(2)(a) GDPR). Participation is voluntary; you may decline or withdraw without disadvantages.

4. What personal data we collect

The survey is conducted anonymously. The following categories of personal data may be processed; however, no direct identifiers are collected, and the data is not used to identify individual respondents:

- Demographic information (e.g., age, gender, country).
- Your status (patient or relative/caregiver).
- Information relating to the disease and treatment of the family member affected (health data; special category data under Art. 9 GDPR) – only to the extent you choose to share it.
- Information on your preferences regarding clinical trials information and access and regarding on potential future treatment.

5.4 Sub-processors (service providers)

To execute the project, admedicum may use the following sub-processors on behalf of argenx:

- SurveyMonkey Europe UC, 5 School House Land East, Dublin 2, D02 N279, Ireland (SurveyMonkey). SurveyMonkey stores your responses but can only access them under specific circumstances.

The use of sub-processors is governed by contractual arrangements ensuring appropriate safeguards and confidentiality.

6. International transfers (outside the EU/EEA)

argenx is established in the United States. Where your data is transferred to argenx in the USA, your data may be transferred to a third country. In such cases, appropriate safeguards under Chapter V GDPR will be used (e.g., Standard Contractual Clauses under Art. 46(2)(c) GDPR). You may request a copy of the safeguards from argenx via the controller contact details above.

7. Storage duration

As the survey is anonymous, responses may be stored without a fixed deletion period for analysis and documentation purposes.

8. Automated decision-making

No automated decision-making (including profiling) within the meaning of Art. 22 GDPR is carried out. Selection for the focus group (if applicable) is based on predefined criteria and performed by humans.

9. Your rights

Please note, as the survey is conducted anonymously and no personal data is collected, the rights under the GDPR, such as the right to revoke consent to the storage and use of personal data, are not applicable in this case.

Generally, the processing of your personal data gives you the following rights:

- a. Right to information (see Art. 15 GDPR)
- b. Right to rectification (see Art. 16 GDPR)
- c. Right to erasure (see Art. 17 GDPR)
- d. Right to restriction of processing (see Art. 18 GDPR)
- e. Right to data portability (see Art. 20 GDPR)
- f. Right to object (see Art. 21 GDPR and Section 10 below for further details)
- g. Right to complain (see Art. 77(1) GDPR and Section 11 below for further details)

To exercise your rights, please contact argenx (controller) using the contact details above. You may also contact admedicum, which will forward your request to argenx and support its handling.

10. Right to object

If the processing is based on Art. 6 GDPR paragraph 1 letter a or Art. GDPR 9 paragraph 2 letter a, you have the right to withdraw your consent at any time. For legal reasons, we must reserve the right to receive data under certain conditions regulated by law, for example if such data is required as evidence in a legal dispute. We will then consult you accordingly to respond to your request as far as possible.

Data processed prior to the withdrawal remains unaffected by the withdrawal.

11. Right to complain

If you believe that we process your personal data unlawfully, you can lodge a complaint with a data protection supervisory authority. You can do so in particular with the authority in the Member State of your habitual residence, your place of work, or where the alleged infringement took place.

For your convenience, please find here the supervisory authorities in the following countries:

- United States: Federal Trade Commission (FTC), 600 Pennsylvania Avenue NW, Washington, DC 20580 - <https://www.ftc.gov>
- United Kingdom: Information Commissioner's Office (ICO), Wycliffe House, Water Lane, Wilmslow, Cheshire SK9 5AF - <https://ico.org.uk>
- Ireland: Data Protection Commission, 21 Fitzwilliam Square South, Dublin 2, D02 RD28 - <https://www.dataprotection.ie>