

DATA PROTECTION AND PRIVACY POLICY

Data Protection and Privacy Policy in accordance with the General Data Protection Regulation (GDPR) for APST Research GmbH and its mobile applications.

1. General purpose of data processing

These data protection and privacy policies apply to the use of services provided by the APST Research GmbH (hereinafter referred to as "APST Research") and the use of the APST research mobile software applications, including the "ALS App", "SMA App" "ALS Research App", "Neurofilament App" and other mobile applications (hereinafter referred to as "APST Research Apps"). APST Research processes personal data to operate its mobile applications. The APST Research Apps enable the structured collection of research-related data in neurological and neuromuscular diseases, particularly ALS and SMA. Data processing supports patient participation, workflow organisation, platform functionality, security, and quality assurance. APST Research processes personal data in compliance with the General Data Protection Regulation (GDPR) and applicable national data protection laws.

2. Responsibilities

(1) APST Research is responsible for data protection and data security when using the APST Research website, APST Research Apps or other services. On behalf of APST Research, personal data are stored on servers that meet the particular and most stringent data security and data privacy standards for health data. APST Research is the contracting party of hosting services of Ambulanzerpartner Soziotechnologie APST GmbH (hereinafter "APST") and the responsible entity pursuant to the General Data Protection Regulation (GDPR), and the 235.1 Federal Act of 19 June 1992 on Data Protection (FADP).

(2) The personal data captured and used via the APST Research are sensitive data protected with effective and reliable data privacy and data security measures. Together with APST, APST Research ensures compliance with data privacy laws and is reportable to the County of Berlin Data Protection Authority. At APST Research, equal priority is given to data privacy and protection within the company. Employees are bound by discretion and obligated to act in conformity with applicable data privacy laws.

(3) You can contact our data protection officer at dataprivacy@apstresearch.com or by post at our address with the addition "the data protection officer".

3. Data processing relating to research

3.1. Principle of purpose limitation, legal basis

(1) APST Research shall process your personal data only to the extent necessary for the rendering of research services (see Table 1 in Section 3.3). Transferring your personal data to third parties outside the APST research network shall require your explicit consent. Moreover, transfers to state organizations and authorities entitled to receive information shall occur only beyond APST Research's statutory reporting duties if a court order obliges APST Research to do so.

(2) The legal basis for data processing for research purposes shall be the current contractual relationship (Art. 6 Section 1 p. 1 lit. b GDPR) as well as the patient's consent (Art. 6 Section 1 p. 1 lit. a GDPR) and the patient's signed consent form for research (Art. 6 Section 1 p. 1 lit. a GDPR).

3.2. Research

(1) Data generated in the context of research will be used for systematic analysis of data, provided you have given your consent. The digitisation of research data through APST Research's services thus enables research.

(2) The data collected via APST Research Apps in the context of research (see **Table 1** in Section 3.3) will be processed for scientific analyses. Such use of the data for research, publication, or teaching purposes shall only take place in pseudonymised and/or anonymised form, provided you have consented to this use. Depending on your consent, your pseudonymised and/or anonymised data will be used for the following purpose:

- Evaluation of data for healthcare research in cooperation with academic institutions to promote the further development of medical research and treatment.

3.3. Scope and extent of data use

(1) Data processing by APST Research shall serve research purposes.

(2) Personal data, i.e., individual information on a specific or identifiable patient's personal and factual situation, shall be used solely for the purpose of realizing data analysis.

(3) Table 1 illustrates pseudonymized and anonymized data used within the APST Research network for research purposes.

Table 1: Data used for research purposes– in pseudonymized and/or anonymized form.

Data category	Data fields
Study center	<ul style="list-style-type: none"> • Contact data • Contact person
Demographic Data	<ul style="list-style-type: none"> • Age • Gender
Diagnosis and classification	<ul style="list-style-type: none"> • Main diagnosis • Secondary diagnosis • International Classification of Disease (ICD) • Disease onset (MM-YYYY)
Clinical characteristics and symptoms	<ul style="list-style-type: none"> • Symptoms • Symptom onset (MM-YYYY) • Symptom severity • Variations of course
Measurement parameters, biomarker findings, genotype (if applicable)	<ul style="list-style-type: none"> • Body mass index (BMI) • Slow vital capacity (SVC) • Peak Cough Flow (PCF) • Neurofilament light chain (NfL) in cerebrospinal fluid (CSF) • Neurofilament light chain (NfL) in serum • Other biomarkers related to the principal diagnosis or genotype with respect to the principal diagnosis
Ventilation Therapy (if applicable)	<ul style="list-style-type: none"> • Non-invasive ventilation (start: MM-YYYY) • Invasive ventilation (start: MM-YYYY)
Nutritional Therapy (if applicable)	<ul style="list-style-type: none"> • Non-invasive nutrition therapy (start: MM-YYYY) • Invasive nutrition therapy (start: MM-YYYY)
Survey (if applicable, optional)	<ul style="list-style-type: none"> • ALSFRS-r – ALS Functional Rating Scale-Revised • ALSFRS-EX – ALS Functional Rating Scale-Extended • Amyotrophic Lateral Sclerosis Functional Rating Scale revised-self-explanatory (ALSFRS-R-SE) • Health-related quality of life questionnaire EQ-5D-5L • MYMOP – Measure Yourself Medical Outcome Profile • NRS – Numeric Rating Scale • NPS – Net Promotor Score • SMA-FRS – SMA Functional Rating Scale • TSQM-9 – Treatment Satisfaction Questionnaire for Medication-9 • ALS relevance
Applications	<ul style="list-style-type: none"> • Disease progression rate of ALS and SMA

4. Data processing when visiting our websites

(1) When using our websites merely for the purpose of gaining information, i.e., when no request or personal information is submitted and no login is performed, we shall process the data your browser sends to our server, and those data technically required to display our website to you and to safeguard stability and security:

- IP address
- Date and time of inquiry
- Duration of a website visit
- Time zone difference to Greenwich Mean Time (GMT)
- Content of inquiry (precise page)
- Access status/http status code
- Data volume transferred each time
- Website this inquiry is coming from
- Our websites that you visit
- Internet service provider
- Browser type
- Server Log Files
- Operating systems and their interface
- Language and version of the browser software

(2) The relevant legal basis is Art. 6 Section 1 p. 1 lit. f) GDPR, i.e., our legitimate interest in displaying the websites that are accessed.

4.1 Cookies

(1) When using our websites for purely informational purposes, i.e., if you do not make any enquiries, do not log in or otherwise provide us with personal information, our websites use so-called "cookies". The APST Research itself does not use cookies. Cookies are small text files and do not cause any damage to your device. They are either stored temporarily for the duration of a session (session cookies) or permanently (permanent cookies) on your device. Session cookies are automatically deleted at the end of your visit. Permanent cookies remain stored on your device until you delete them yourself or your web browser automatically deletes them.

Cookies have various functions. Numerous cookies are technically necessary, as certain website functions would not work without them (e.g., video display). Other cookies are used to evaluate user behaviour or to display advertising. Cookies that are necessary for the electronic communication process (essential cookies) or for the provision of certain functions requested by you (functional cookies, e.g., for displaying videos) or to optimise the website (e.g., cookies for measuring the web audience) are stored on the basis of Art. 6 para. 1 lit. f GDPR, unless another legal basis is specified. The website operator has a legitimate interest in storing cookies for the technically error-free and optimised provision of its services. If consent to the storage of cookies has been requested, the storage of the cookies in question is based exclusively on this consent (Art. 6 para. 1 lit. a GDPR); consent can be revoked at any time.

(2) You can set your browser so that you are informed about the setting of cookies and only allow cookies in individual cases, exclude the acceptance of cookies for certain cases or in general, and activate the automatic deletion of cookies when closing the browser. If you deactivate cookies, the functionality of this website may be limited. If cookies from third-party companies or for analysis purposes are used, we will inform you separately in this privacy policy and, if necessary, request your consent.

(3) Cookie consent with Usercentrics: This website uses Usercentrics' cookie consent technology to obtain your consent to the storage of certain cookies on your device or to the use of certain

technologies and to document this in accordance with data protection regulations. This technology is provided by

Usercentrics GmbH, Rosental 4, 80331 Munich, website: <https://usercentrics.com/de/> (hereinafter "Usercentrics"). When you visit our website, the following personal data is transferred to Usercentrics:

- Your consent(s) or the revocation of your consent(s)
- Your IP address
- Information about your browser
- Information about your device
- Time of your visit to the website
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(4) Furthermore, Usercentrics stores a cookie in your browser in order to be able to assign the consents you have given or their revocation. The data collected in this way is stored until you request that it be deleted, delete the Usercentrics cookie yourself, or the purpose for which it was stored no longer applies. Mandatory legal retention obligations remain unaffected. Usercentrics is used to obtain the legally required consent for the use of specific technologies. The legal basis for this is Art. 6 (1) (c) GDPR.

4.2 Analysis tools and advertising

(1) When using our websites for purely informational purposes, i.e., if you do not submit any enquiries, log in or otherwise provide us with personal information, our websites use functions of the web analytics service Google Analytics. The provider is Google Ireland Limited ("Google"), Gordon House, Barrow Street, Dublin 4, Ireland.

(2) APST Research, on the other hand, does not use any functions of the web analysis service Google Analytics.

(3) Google Analytics enables the website operator to analyse the behaviour of website visitors. In doing so, the website operator receives various usage data, such as page views, length of stay, operating systems used and the origin of the user. This data may be summarised by Google into a profile assigned to the respective user or their end device.

(4) Google Analytics uses technologies that enable the recognition of the user for the purpose of analysing user behaviour (e.g., cookies or device fingerprinting). The information collected by Google about the use of this website is usually transferred to a Google server in the USA and stored there.

(5) The use of this analysis tool is based on Art. 6 para. 1 lit. f GDPR. The website operator has a legitimate interest in analysing user behaviour to optimise its website and advertising. If consent has been requested (e.g., for the storage of cookies), processing is carried out exclusively based on Art. 6 para. 1 lit. f GDPR, consent can be revoked at any time. Data transfer to the USA is based on the EU Commission's standard contractual clauses.

Details can be found here: <https://privacy.google.com/businesses/controllerterms/mccs/>.

(6) We have activated the IP anonymisation function on this website. This means that Google will truncate your IP address within the member states of the European Union or in other states party to the Agreement on the European Economic Area before it is transmitted to the USA. Only in exceptional cases will the full IP address be transmitted to a Google server in the USA and truncated there. On behalf of the operator of this website, Google will use this information to evaluate your use of the website, to compile reports on website activity and to provide other services relating to website activity and internet usage to the website operator. The IP address your browser transmits to Google Analytics will not be merged with other Google data.

(7) You can prevent Google from collecting and processing your data by downloading and installing the browser plugin available at the following link:

<https://tools.google.com/dlpage/gaoptout?hl=de>.

For more information on how Google Analytics handles user data, please refer to Google's privacy policy: <https://support.google.com/analytics/answer/6004245?hl=de>.

(8) Data stored by Google at the user and event level that is linked to cookies, user IDs (e.g., user ID) or advertising IDs (e.g., DoubleClick cookies, Android advertising ID) is anonymised or deleted after 14 months. Details can be found at the following link: <https://support.google.com/analytics/answer/7667196?hl=de>

5. Data processing when contacting us

When you contact us by email, telephone, or via a contact form, we process the data you provide (e.g., email address, name, telephone number, or the content of your enquiry) to answer your questions and/or process your request. The legal basis for this is Art. 6 (1) (b) GDPR.

6. Data processing when sending newsletters (where applicable)

(1) We send emails and other electronic notifications with promotional information (hereinafter "newsletters") only with your consent (Art. 6 (1) (a) GDPR) or with legal permission. The newsletters contain information about our projects, events, company, and network. By subscribing to our newsletter, you agree to receive it.

(2) The use of a mailing service provider, the performance of statistical surveys and analyses, and the logging of the registration process are based on our legitimate interests pursuant to Art. 6 (1) lit. f GDPR. Our interest is in using a user-friendly and secure newsletter system that serves both our business interests and meets your expectations.

(3) You may revoke your consent to receive our newsletter at any time.

7. Your rights

(1) You have the following rights with regard to your personal data:

- Right to information (Art. 15 GDPR),
- Right to rectification and erasure (Articles 16 and 17 GDPR),
- Right to restriction of processing (Art. 18 GDPR),
- Right to object to processing (Art. 21 GDPR),
- Right to data portability (Art. 20 GDPR).

(2) You also have the right to complain to the data protection supervisory authority about our processing of your data.

(3) We would like to point out that you can revoke any consent you may have given us under data protection law at any time with effect for the future. The same applies to consent for advertising purposes. To do so, please send an informal email to: dataprivacy@apstresearch.com. The respective revocation may mean that our offers can no longer be made available to you, or only to a limited extent.

(4) Insofar as we base the processing of your personal data on a balancing of interests (Art. 6 (1) (f) GDPR), you may object to the processing. When exercising such an objection, we ask you to explain the reasons why we should not process your personal data as we have done. In the event of your justified objection, we will examine the situation and either cease or adapt the data processing or point out to you our compelling legitimate grounds for continuing the processing.

8. Data security and data deletion

(1) Data accessible by APST Research are sensitive and shall thus be subject to the most stringent and state-of-the-art security standards.

(2) You may only access your data after entering an individual username and password. We generally recommend safeguarding your access data (username, password) as if they were valuable and refrain from writing them down and keeping them somewhere. You shall personally be responsible for the safety and security of your own computer and software, and you are under an obligation to ensure adequate protection.

(3) Access to personal data shall be subject to access authorization as specified below:

Patient

- Personal contact details
- Personal social profile
- Personal medical profile
- Personal ratings

Medical partners

Access to all the data available on the APST Research website and research Apps for the patient for whom they have a mandate for treatment or provision (no data available for patients for whom they do not have a mandate for action)

Data managers and administrators of APST Research

- Full data set with all patient-related data
- Full data set for all medical partners
- Full data set for all patient ratings (survey administration) and participating parties (participant administration)

(4) Data shall be encoded for transfer from the user's computer to the server and vice versa.

(5) The personal data processed by APST Research will be deleted as soon as the contractual relationship has ended and there are no legal retention obligations preventing deletion. Data processing will continue even after the patient's death if the contractual relationship is not terminated by the patient's legal successor(s) or the patient's consent(s) is not revoked. If the data is not deleted because it is required for other, legally permissible purposes (e.g. billing data is subject to the commercial/tax law obligation to retain data in accordance with Section 257 (1) of the German Commercial Code (HGB) and/or Section 147 (1) of the German Fiscal Code (AO)), its processing will be restricted. This means that the data will be blocked for operational use.

9. Final provisions

- (1) APST Research uses technical and organisational security measures to protect the processed data, in particular against accidental or intentional manipulation, loss, destruction or attacks by unauthorised persons. The security measures are continuously improved in line with technological developments.
- (2) If we use subcontractors to provide our services, we take appropriate legal, technical and organisational measures to ensure the protection of personal data in accordance with the relevant legal requirements. These are, in particular, technical service providers who support us in providing services.
- (3) APST Research will update the privacy policy from time to time due to technical progress and the further development of APST Research's offerings. Unless the change to the privacy policy affects the use of your existing data, the new privacy policy will apply from the date of its update. Any change to the privacy policy that affects the use of your already collected data will only be made if it is reasonable for you. In such a case, we will notify you in good time. You have the right to object to the validity of the new privacy policy within four (4) weeks of receiving the notification. In the event of an objection, we reserve the right to terminate the user agreement in accordance with Section 4 of the General Terms and Conditions. If no objection is made within the specified period, the amended privacy policy shall be deemed to have been accepted by you. We will inform you of your right to object and the significance of the objection period in the notification.
- (4) APST Research shall be available to answer any further questions and provide information on data protection and the processing of your personal data via the contact address in the APST Research legal notice. If you have any questions, suggestions, or require information on data protection, you can also contact APST Research's external data protection officer at dataprivity@apstresearch.com.

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