

General terms and conditions

for the use of "ALS-App", "ALS Research App", "SMA-App", "Neurofilament-App" and other mobile applications

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There is a great need for research on people with neurological diseases, especially amyotrophic lateral sclerosis (ALS), spinal muscular atrophy (SMA), and other neurodegenerative and neuromuscular diseases. This necessary research serves to develop effective therapies and to improve existing forms of treatment. A paramount concern of modern medical science is the direct involvement of patients in research - by systematically collecting their treatment data or by interviewing them about their therapy experiences. A critical moment in research is the coordination of data collection, and coordination of the partners (stakeholders) involved, not limited to, especially patients, physicians, study assistants, persons at scientific institutions, laboratories or logistics companies. APST Research GmbH addresses these needs and embodies a digitally-supported research organization. It supports medical research projects by providing coordinative services, mobile applications ("Apps"), with which research-related data are digitally mapped and recorded.

1. Scope

1.1 These general terms and conditions of use (GTC) apply to the use of services of APST Research GmbH (hereinafter referred to as "APST Research"), and the use of mobile software applications, including the "ALS-App", "ALS Research App", "SMA-App" and "Neurofilament-App" and other mobile applications (hereinafter referred to as "APST Research Apps").

1.2 The services of APST Research support patients (and their relatives) with chronic, serious or rare diseases to participate in medical research projects. Patients are authorized as users of APST Research Apps, and receive individual user accounts. The legal basis for this is derived from the individual agreements made upon the conclusion of the contract and these GTC. In addition, the use of the APST platform by medical partners (physicians, medical assistants, study coordinators, and scientific staff) is also provided for and is regulated in separate GTC for medical partners.

1.3 By registering with APST Research, the patient (or legal representative) agrees to the terms and conditions and the privacy policy. The APST Research reserves itself to change, if necessary - particularly for factual and/or legal reasons - these GTC under reference to these reasons. The amended terms and conditions will be sent to the patient (or legal representative) by e-mail one month before they come into effect, to the e-mail address last provided to APST Research and stored on the APST platform. If the patient has not objected within 14 days of receipt of the e-mail, the amended terms and conditions shall be deemed accepted and shall govern the future contractual relationship between the patient and APST Research. If the patient (or his legal representative) objects, the contract ends according to the provisions from clause 4.2.

1.4 The Patient may not assign the rights and obligations under this agreement. Therefore, the assignment of rights is excluded.

2. Subject matter of the contract and services

2.1 APST Research provides services for research coordination and networking between the patient, medical partners and academic institutions. The framework of these services is referred to as the "Research Organization" and includes the following components.

- Coordination of the partners involved
- Provision of the necessary participation documents (e.g., questionnaires)
- Provision of technical requirements for data collection at home or in medical facilities (through APST Research Apps or study software)
- Conduct patient surveys via APST Research Apps, by phone, or by mail.
- Coordination of the shipment and analysis of biospecimens

The components of the research organization can be used together or separately.

2.2 APST Research provides the APST Platform to patients for optional use. The APST platform is a structured database with an associated digital platform that allows electronic capture, storage and processing of patient- and research-related data and digital support of research processes. The APST platform and the associated applications are software products of Ambulanzpartner Soziotechnologie APST GmbH, which APST Research licenses for research. For this purpose, separate license agreements have been made between APST Research and Ambulanzpartner Soziotechnologie APST GmbH, both located in Berlin, Germany,

2.3 Access to APST Research Apps is done with a personal username and password combination. Those credentials also enable patient authentication for the use of APST Research Apps. The features of APST Research Apps, the data collected, the user roles and authorizations, and the terms of use can be found in the privacy policy.

2.4 APST Research shall provide the patient with APST Research Apps that allows participation in surveys and evaluation of disease symptoms, symptom progression and treatment experience.

2.5 The APST Research supports the patients or their legal representatives and other users authorized by the patient to use of APST Research Apps. APST Research offers a free telephone briefing before using the APST Research Apps and, if required, further free training sessions, which are agreed upon individually.

2.6 Medical partners are allowed or liberated to view, process, and use the patient's data with the patient's written consent. The patient is free at any time to revoke an initially declared consent without reasons with immediate effect. APST Research shall ensure that the corresponding declaration of consent meets all legal requirements, particularly those relating to data protection.

2.7 The Internet connection and the web browser are not subject to the contractual relationship between the patient and APST Research.

3. Conclusion of the contract

3.1 The use of the services mentioned in 2.1 as well as the software of APST Research Apps requires the conclusion of a user contract. This contractual relationship comes about through comprehensive information about the patient and the signing of a consent. For this purpose, the patient will be sent or handed the following documents:

- privacy policy of APST Research for research coordination and the use of APST Research Apps and other study software for the purpose of data capture, assessment, aggregation and analysis.
- informed consent to participate in research coordination and to use APST Research Apps

The patient completes the necessary information (address, e-mail address) on the consent form. By signing the consent form on the signature field, the patient declares consent to the GTC and the data protection policy. The patient sends the signed consent form by mail or e-mail (with an attachment of the signed document) to the following address:

APST Research GmbH
Area F, Verwaltungsgebäude
Westhafenstr. 1
13353 Berlin
Germany

or e-mail: info@apst-research.de

After receipt of the signed consent form, the patient receives an e-mail with a registration link for the selected APST Research App. The patient himself or herself assigns the username and password.

3.2 By concluding the contract, the patient declares his or her agreement with these GTC and the privacy policy.

3.3 The patient assures that the information given by him or her in the context of the conclusion of the contract is complete and correct. In case of violation, APST Research is entitled to block the user account of the patient immediately.

4. Term and termination of the contract

4.1 The contractual relationship is concluded for an indefinite period.

4.2 Both contracting parties may terminate the contract at any time with four weeks' notice to the end of a month. The termination must be declared in writing or email to the following address:

APST Research GmbH
Area F, Verwaltungsgebäude
Westhafenstr. 1
13353 Berlin
Germany

or e-mail: info@apst-research.de

4.3 Both contracting parties shall be entitled to extraordinary termination for a good cause, particularly in the event of a material breach of contract in which the continuation of the contract becomes unreasonable for one of the contracting parties.

4.4 The provisions of Section 2.5 and the patient's rights arising therefrom shall remain unaffected.

5. Duties of the patient and safety recommendation

5.1 The patient must protect his access data (user name, password) carefully and like valuables from unauthorized access by third parties. The patient is expressly recommended to use antivirus, antispyware, firewall software and current operating system versions. If the patient uses outdated hardware and/or operating system versions, the correct display of APST Research Apps may be limited. In this case, the patient can obtain information about suitable operating systems and their versions from APST Research.

5.2 The Patient undertakes not to post any illegal content on APST Research Apps or to make it accessible to third parties, for example, through forums, chat rooms, e-mail or spam. Violations of the contractual restrictions on use entitle APST Research to take appropriate remedial action, including blocking the user account. The patient is informed, in this case, immediately about the kind, duration, reason and extent of the blockage.

5.3 The correctness of the data and information provided by the patient influences the value of the contractual services of APST Research. Therefore, the patient exempts the APST Research expressly from claims for compensation of third parties who have trusted in the completeness, correctness and topicality of the data and information.

6. Costs of the use of services and software of APST Research

6.1 The use of APST Research Apps is free of charge for patients and the persons authorized by you.

6.2 The use of APST Research Apps is free of charge for medical partners.

7. Data security, consent to data processing, protection of patient data

7.1 APST Research is subject to the data protection regulations of the Federal Republic of Germany and European Union (EU-GDPR). APST Research is obligated to protect the data of the patient and the other parties involved based on these provisions.

7.2 APST Research takes all organizational and technical precautions necessary according to the currently common standards to meet the requirements of data protection law, particularly to secure the patient data against unauthorized access by third parties. The stored data is transmitted via the World Wide Web from the server to the patient's mobile device and vice versa using the SSL encryption standard.

7.3 The patient expressly declares his consent to the collection, processing and use of his data by APST Research within the scope of the contractually intended purposes and by a separate privacy policy.

8. Liability

8.1 APST Research shall be liable without limitation in case of intent or gross negligence for all damages caused by APST Research and its legal representatives and vicarious agents.

8.2 In case of slight negligence, APST Research shall be liable without limitation for injuries to life, body or health caused by APST Research as well as its legal representatives and/or vicarious agents.

8.3 Liability under the Product Liability Act shall remain unaffected.

8.4 Apart from that, APST Research shall only be liable insofar as a guarantee of quality has been assumed, or an essential contractual obligation (cardinal obligation) has been violated. The term of the cardinal obligation describes here abstractly such obligations whose fulfillment makes the proper execution of the contract possible and on whose observance the patient may trust regularly. In these cases, liability is limited to compensation for the foreseeable, typically occurring damage.

9. Rights of use

9.1 APST Research grants the patient a simple (non-sublicensable and non-transferable) right of use limited to the term of the Agreement.

9.2 The patient shall only be entitled to use the APST Research Apps by the contractual provisions. A transfer of the software to him does not take place.

9.3 The patient is not authorized to make the contractual service available by third parties. Access for relatives of the patient or other persons authorized by the patient is excluded. With the consent of the patient the third person authorized by the patient receives an e-mail from APST Research with a registration link for a selected APST Research App. This person himself or herself does the assignment of the username and password. The patient is not permitted to sublet the software that is the subject of the contract.

10. Ratings

10.1 APST Research provides patients and persons authorized by the patient with software for the evaluation of symptoms, the patient's course of disease, medical devices, drugs, and treatments within the APST Research Apps or other study software. The results of the assessments will be published in aggregated form and without naming the patient on the homepage or subpages of APST Research. The patient agrees to this by the following regulations.

10.2 The evaluations must correspond to the requirement of objectivity and may show no right-violating content. APST Research is not liable for the correctness, quality or completeness of the ratings. The APST Research removes inappropriate or right-infringing evaluations in case of justified hints.

11. Final provisions

11.1 If any provision of the contract is or becomes invalid or void, this shall not affect the validity of all other provisions. Instead, the invalid or void provision shall be replaced by a valid provision that comes as close as legally possible to the purpose pursued by the invalid or void provision. Such practices shall also apply to any loopholes in the contract.

11.2 The law of the Federal Republic of Germany shall apply. The legal regulations for the restriction of the choice of law and for the applicability of compelling regulations, particularly the state, where the patient has his or her usual

stay as a patient, remain untouched. If the patient is a businessman, a legal entity of the public right, or public-legal special property, then the seat of the APST Research is an exclusive area of jurisdiction for all disputes from the contractual relationship.