



## Terms of Use of the MSDA Catalogue

**Last update 03 May 2022**

The Multiple Sclerosis Data Alliance (“**MSDA**”) is a global multi-stakeholder non-profit collaboration that strives to overcome the sociological and technical challenges that arise when scaling-up real-world MS data. The MSDA is acting and operating via the European Charcot Foundation (“**ECF**”), an independent non-profit organization, organized and existing under the laws of Belgium, having its registered office located at Vaartdijk 3, bus 2, 3018 Leuven, Belgium and with company number (RLE Leuven) 0547.995.164.

Finding real-world MS data sources that have the potential to address urgent needs within the ecosystem is challenging and time-consuming. To overcome this challenge, the MSDA strives towards developing and implementing tools to reduce the time needed to find and assess real-world MS data sources and data acquisition systems. Since 2019, the MSDA has developed and maintained a metadata catalogue (“**MSDA Catalogue**”). The MSDA Catalogue allows metadata providers (“**Metadata Providers**”) to make available metadata profiles (“**Metadata**”) that can be browsed, filtered, ordered and exported by end-users, including but not limited to Metadata Providers (“**Users**”).

The present Terms of Use govern the use of the MSDA Catalogue and MSDA Services (as defined hereinafter) (“**Terms**”).

**BY REGISTERING AND USING THE MSDA CATALOGUE, THE USER ACKNOWLEDGES THAT HE/SHE HAS READ THESE TERMS CAREFULLY AND THAT HE/SHE IS LEGALLY COMPETENT TO AGREE WITH THESE TERMS WITHOUT RESERVATION.**

### 1. Description of the MSDA Catalogue

The MSDA Catalogue is made available through a platform accessible via the following url: <https://msda.emif-catalogue.eu/>.

The MSDA shall use its best endeavours to provide the User access to and use of the MSDA Catalogue (“**Access and Use**”) in accordance with the standards that may be expected from a similar service provider delivering similar services. Access and Use shall include, but is not limited to, the right to browse, compare, filter, ordered and/or export the Metadata, and/or, for Metadata Providers only, certain editing rights on their own Metadata.

The MSDA Catalogue is provided to the Users “AS IS”.

The Users accept and acknowledge that the MSDA Catalogue is dependent on software, which means that flawless operation and permanent availability cannot be assured.

Access and Use is granted after registration and are free of charge. Access and Use is granted and allowed for the purpose to acquire and browse the Metadata on multiple sclerosis real-world data sources and acquisition tools (“**Scope**”).

Any responsibility and/or liability of the MSDA outside the Scope shall be excluded.

During the registration process, Users will be asked to accept these Terms, which is a mandatory requirement before Access and Use shall be granted.

After the registration process, the User can Access and Use the MSDA Catalogue for its intended purposes via his/her personal account (“**Account**”).

The MSDA reserves the right to change the functionalities and availability of the MSDA Catalogue at all times and at its own discretion. Insofar as reasonably possible, any major expected change in availability of the MSDA Catalogue shall be communicated in advance via the MSDA Website ([www.msdataalliance.com](http://www.msdataalliance.com)); hereinafter: “**MSDA Website**”).

The MSDA Catalogue is not intended and shall not be construed as a medical device and/or as generating personalized medical advice in terms of the applicable legislation and/or regulations, including EU or national legislations and/or regulations.

### 2. Description of the MSDA Services

The MSDA shall use its best endeavours to provide the following support and maintenance services in relation to the MSDA Catalogue (“**MSDA Services**”): (i) Maintenance (as defined hereinafter); and (ii) Support (as defined hereinafter).

For the purpose of these Terms, “**Maintenance**” shall mean: corrective maintenance only, with the exclusion of evolutive maintenance. Hence, maintenance does not include software updates nor new features, but is aimed at providing uninterrupted service delivery on a best-efforts basis only for the duration of the Access and Use.



For the purpose of these Terms “**Support**” shall mean: assistance for resolving any software issues (such as bugs) or other types of malfunctions or defects, but shall not include personalized training on how to use the MSDA Catalogue. Support will be offered via email ([info@msdataalliance.com](mailto:info@msdataalliance.com)) and documentation on the MSDA website only. Requests via email will be handled during normal business hours (from 9 AM to 5 PM) on a best-efforts basis only, without any warranty or representation with regard to specific response or resolution times.

If a User requires more customized services, he/she should contact the MSDA ([info@msdataalliance.com](mailto:info@msdataalliance.com)).

### **3. Terms Specific for Metadata Providers**

The Metadata Provider represents and warrants to the MSDA that the Metadata are (i) correct; (ii) shall only consist of or contain metadata; (iii) shall in no event consist or contain patient-level data; (iv) may be included in the MSDA Catalogue; and (v) be made available to other Users without any restriction and/or without infringing any third-party rights.

The Metadata Provider remains at all times holder of all rights (including but not limited to Intellectual Property Rights (as defined hereinafter)) related to his/her Metadata. This includes the Metadata Provider’s right to adapt, modify and/or delete his/her Metadata at any time.

Without prejudice to any contradicting requirements under applicable data protection or professional secrecy laws, the Metadata Provider hereby grants the MSDA an exclusive, worldwide, irrevocable, sublicensable, royalty-free and everlasting right to use its/her Metadata, insofar the MSDA makes use of this content in the framework of delivering or improving the MSDA Catalogue, MSDA Services and/or MSDA Website or for promotional, academic or educational purposes. If and where applicable, any such use shall properly acknowledge the Metadata Provider concerned to the extent reasonably possible. Such use shall include the right to reproduce, to communicate to the public, to distribute, rent, adapt or translate.

The Metadata Provider agrees that the MSDA may, at all times and its sole discretion, transfer his/her Metadata for technical reasons only (e.g. to ship the Metadata to another platform used by the MSDA for the MSDA Catalogue), without the Metadata Provider’s prior consent or approval.

### **4. MSDA RIGHTS**

The MSDA remains at all times holder of all rights (including but not limited to Intellectual Property Rights) related to the MSDA Catalogue, the MSDA Services, MSDA Website and/or any documentation (including but not limited to all appurtenances) related hereto (“**MSDA Rights**”).

The MSDA does not transfer to the User, in any way as part of the Access and Use, any ownership or other rights in and/or to the MSDA Rights. The User shall therefore not copy, analyse, decompile, make public, distribute, transfer to third parties, or change any MSDA Rights beyond what is needed for normal use of the MSDA Catalogue as per his/her Access and Use or unless expressly permitted by the MSDA in writing.

For the purpose of these Terms “Intellectual property Rights” shall mean: all brands, logos, trademarks, internet domain names, models and designs, patents, copyrights (including all rights relating to software) and moral rights, rights relating to databases, semiconductor topographies, knowhow, and other rights, as well as all other industrial and intellectual rights, in any case independent from whether or not they have been registered and with the inclusion of registration applications as well as all equivalent rights or means of protection leading to a similar result anywhere in the world.

### **5. Communication and Publication**

Any User’s publicly accessible materials, such as scientific publications or reports or webpages that contain information directly derived from the MSDA Catalogue (including but not limited to Metadata) and/or MSDA Website must properly acknowledge the MSDA.

The Users may not reproduce the entire MSDA Catalogue and/or MSDA Website or portions thereof for any communication or publication that serves to duplicate the purposes of the MSDA Catalogue and/or MSDA Website.

### **6. Duration – Modifications – Termination**

These Terms shall apply from the moment the User registers with the MSDA Catalogue, until his/her Account is removed.

The MSDA reserves the right to modify these Terms without the Users’ prior consent. Such modifications shall be communicated via the MSDA Website or via their newsletters and social media channels. If the User does not accept the modifications, the User should stop using the MSDA Catalogue and/or the MSDA Services from the moment the modified Terms apply. By continuing to use the MSDA Catalogue and/or MSDA Services after the modifications to the Terms, the User indicated to accept these modifications without reservation.



The User can request to delete his/her account by sending an email to [info@msdataalliance.com](mailto:info@msdataalliance.com). The MSDA will make sure the account is deleted within 5 (five) working days after receiving the request.

Upon removal of the User's Account, all personal details included in his/her Account shall be deleted or destroyed by the MSDA, unless a legal or regulatory obligation or a judicial or administrative order prevents the MSDA to do so.

#### **7. Personal data processing**

For the provision of the Services, the MSDA processes the User's personal data as further stated in the [Privacy Notice](#), the terms of which are herein incorporated by reference and is an integral part of these Terms. In the event of any discrepancy or inconsistency between these Terms and the Privacy Notice, the latter shall prevail.

#### **8. Liability**

The MSDA is not responsible and cannot be held liable for any shortcoming, not even when resulting from a grave error, negligence or fraud in the services of third parties on which the MSDA Catalogue, MSDA Services and/or MSDA Website rely/relies but which are beyond the MSDA's control.

The MSDA can only be held liable for proven damages caused by their grave error or fraud. In any case, for all User's claims and demands for damages, he/she is first to refer to the MSDA by sending an email to [info@msdataalliance.com](mailto:info@msdataalliance.com). The total, aggregate liability of the MSDA with regards to the provision of the MSDA Catalogue, MSDA Services and/or MSDA Website shall in all circumstances be limited to 10.000 euro.

In no event, the MSDA shall be liable for any indirect damage, which shall at least be understood as consequential damages, financial or commercial damages, loss of profit or income, lost opportunities, lost savings, damage due to business discontinuity, reputational damage and damage from legal proceedings initiated by third parties against the User.

#### **9. Miscellaneous**

Any notion starting with a capital shall be defined by explicit reference in these Terms. Where possible given the context, singular words shall be interpreted as also including the plural and vice versa. The language of the Terms and of all interactions between Users and the MSDA in relation to the MSDA Catalogue, MSDA Services and/or MSDA Website shall be in English.

These Terms supersede any other related requests, verbal or in writing, to submit an offer(s) concerning the MSDA Catalogue, MSDA Services and/or MSDA Website as well as any specific terms and conditions of the User (or those of any third party whom the User is affiliated with).

The MSDA is entitled to rely at its own discretion on subcontractors for the fulfilment of its obligations under these Terms. These Terms apply in favour of any subcontractor or third party on which the MSDA relies for the provision of the MSDA Catalogue, MSDA Services and/or MSDA Website.

Where reference is made to certain laws or regulations, such reference shall also include any change, replacement or annulment of said laws or regulations, including any related executive decision. Whenever possible, the provisions of these Terms shall be interpreted in such a manner as to be valid and enforceable under the applicable law. However, if one or more provisions of these Terms are found to be invalid, illegal or unenforceable, in whole or in part, the remainder of that provision and of these Terms shall remain in full force and effect as if such invalid, illegal or unenforceable provision had never been contained herein. Moreover, in such an event, the MSDA shall amend the invalid, illegal or unenforceable provision(s) or any part thereof and/or agree on a new provision, in such a way as to reflect insofar as possible the purpose of the invalid, illegal or unenforceable provision(s).

Users are not allowed to transfer any of their rights and obligations under these Terms to a third party, unless ECF agrees in writing to such transfer.

These Terms are governed by Belgian law. Users agree to try and solve any dispute regarding these Terms through negotiations. Should negotiations fail, then all disputes concerning the validity, interpretation, enforcement, performance and termination of these Terms shall be submitted to the jurisdiction of the courts of Antwerp, Hasselt division.