

MULTI-ACT DIGITAL TOOLBOX

Multiple Sclerosis Care Unit Survey

TERMS AND CONDITIONS

You are about to create an account in the **MULTI-ACT Digital Toolbox** in order to complete the **Multiple Sclerosis Care Unit (MSCU)** Survey and you are subject of the following Rights and Conditions.

Rights of users

The creation of this account will enable you to:

- Create a profile, as an individual or as an organization, where you portray your interests and background
- Upload resources into the Digital Toolbox, such as data and information

Conditions for users

By signing up to the MULTI-ACT Digital Toolbox, you agree to the following conditions:

1. Behaviour of users

When using the Digital Toolbox for the MSCU survey, you will be compliant to the following behaviour:

- **Responsibility** – You take responsibility for your edits (MULTI-ACT Digital Toolbox only hosts your content).
- **Lawful Behaviour** – You do not violate copyright or other laws; **you acknowledge that all contents¹ uploaded by you are yours or you have permission from the authors/owners and from people, if any, to upload them and license them under the site conditions** (see “Licensing of Contents” below)
- **No Harm** – You do not harm MULTI-ACT Digital Toolbox technology infrastructure.

2. Revision and edition of contents (non-personal data)

- You agree to subject the information you are uploading to an analysis by the Digital Toolbox, the analysis is defined according to Per Soelberg Sorensen et al.² (2019). .

¹ This apply also to any image and photographs that may appears in reports

² Soelberg Sorensen P, Giovannoni G, Montalban X, Thalheim C, Zaratin P, Comi G. The Multiple Sclerosis Care Unit. Mult Scler. 2019;25(5):627–636. doi:10.1177/1352458518807082.

3. Licensing of Contents (non-personal data)

Unless otherwise stated, all materials created by the MULTI-ACT consortium are licensed under a [CREATIVE COMMONS ATTRIBUTION 4.0 INTERNATIONAL LICENSE](#).

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You are free to:

- **Share** — copy and redistribute the material in any medium or format
- The licensor cannot revoke these freedoms as long as you follow the license terms.

Under the following terms:

- **Attribution** — You must give [appropriate credit](#), provide a link to the license, and [indicate if changes were made](#). You may do so in any reasonable manner, but not in any way that suggests the licensor endorses you or your use.
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- **NoDerivatives** — If you [remix, transform, or build upon](#) the material, you may not distribute the modified material.
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- You do not have to comply with the license for elements of the material in the public domain or where your use is permitted by an applicable [exception or limitation](#).
- No warranties are given. The license may not give you all of the permissions necessary for your intended use. For example, other rights such as [publicity, privacy, or moral rights](#) may limit how you use the material.

Any dissemination or communication means resulted from the use of the Digital Toolbox should display the sentence “*The [organization’s name] has used the MULTI-ACT Digital Toolbox that has received funding from the European Union’s Horizon 2020 research and innovation programme under grant agreement No 787570*” as per the Article 38 of the Grant Agreement which is regulating the visibility of the EU funding.”

4. Personal data processing and protection and Privacy Policy

The data provided via this form are collected in the context of the collaboration between the EUROPEAN CHARCOT FOUNDATION (**ECF**), Coordinator of the Multiple Sclerosis Care Unit (MSCU) Initiative, and the FONDAZIONE ITALIANA SCLEROSI MULTIPLA ONLUS (**FISM**), Coordinator of the European project MULTI-ACT (Contract Number GA n.787570, May 2018 – April 2021), under the conditions included in the Memorandum of Understanding signed by the two entities (ECF and FISM).

By accepting these Terms and Conditions, users automatically accept the [Privacy Policy](#) of the website [MULTI-ACT](#).

5. Dissemination

Dissemination activities deriving by using the MSCU Survey in the MULTI-ACT Digital Toolbox include but are not restricted to publications and presentations. In addition to the licence features (see paragraph n.3 above), dissemination activities must be compliant with the conditions included in the Memorandum of

Understanding signed between ECF, as coordinator of MSCU Initiative, and FISM, coordinator of MULTI-ACT,, and with the procedure prescribed by the MoU between ECF and FISM, in line the Article 29.1 of the MULTI-ACT Grant Agreement and subject to the provisions specified in the MULTI-ACT Consortium Agreement:

- Prior notice of any planned publication that results by using the MSCU Survey shall be given to the ECF and FISM at least 30 calendar days before the publication. Any objection to the planned publication shall be to the Party proposing the dissemination within 30 calendar days after receipt of the notice. If no objection is made within the time limit stated above, the publication is permitted.
- Any dissemination or communication means resulted from the use of the Digital Toolbox should display the sentence *“The [organization’s name] has used the MULTI-ACT Digital Toolbox that has received funding from the European Union’s Horizon 2020 research and innovation programme under grant agreement No 787570”* as per the Article 38 of the Grant Agreement which is regulating the visibility of the EU funding.”

Validity of information and contents

These conditions have been valid since the site was last updated. ECF and FISM reserves the right to modify them at any time, in which case they will come into force on the date of their publication and will be applicable to all users of the portal from that date.

The contents of the portal do not constitute any kind of binding offer, except when this is expressly indicated. ECF and FISM reserves the right to introduce modifications to the current contents of the portal and partially or totally omit them when it considers it appropriate, and to impede or restrict access to the site temporarily or permanently.

The website may allow users to introduce contents. ECF and FISM reserves the right to leave unpublished, withdraw or delete any comments whose content it considers incorrect, imprecise or contrary to this Disclaimer.

Users may not post content on the website about religious beliefs or political ideas (including statements from political parties and religious organizations or their symbols). Nor may they include content that is antisocial, offensive to cultural or religious values, provocative, disrespectful, violent, obscene or sexual, or which refers to groups that are socially unacceptable or illegal, or any other content which may damage the sensitivity of third parties, infringe fundamental rights and public liberties recognized under current legislation and/or those enshrined in law concerning consumer and user rights and the protection of minors, or which constitute or represent a violation of personal or family privacy in the case of natural persons, or are in contravention of third parties’ right to honour or privacy of communication. Under all circumstances, the user will be the sole responsible for opinions given in comments, as also for the veracity, accuracy and/or lawfulness of such comments.

The inclusion of contents subject to copyright and/or image rights is subject to the user in question having sufficient claim to the use of such content by said user or obtaining such authorization as may be necessary for the content to be used both by said user as well as by others, under the terms set out in these Conditions of Use, and to the use of content involving no infringement of any legal provision, contract, right or ownership by third parties, nor in any way representing unfair competition.

In consequence, by virtue of including contents on the website, it will be understood that the user has the legal grounds to do so.

Responsibilities

ECF and FISM do not guarantee continued access or the correct visualisation, download or use of the elements and information contained in the pages of its website, which may be impeded, obstructed or interrupted by factors or circumstances beyond its control.

ECF and FISM are not liable for the information and other content in spaces or web pages belonging to third parties accessible from their portal by means of hyperlinks or links, nor for the information and other content in spaces or web pages belonging to third parties which can be accessed by means of links or hyperlinks to their websites or any of their pages, nor the information and contents of any web page belonging to third parties and presented with the appearance or distinctive signs of MULTI-ACT Consortium , except with the express authorization of the latter.

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IPR RIGHTS

It is understood that all intellectual property rights on the platform, the databases of this tool as well as all related technical documentation, both paper and electronic, remain property of the legitimate owners.

The User will not acquire any rights other than those provided for in this terms and conditions.

The User acknowledges that this platform is protected by laws, decrees, regulations and any other applicable national provisions, in particular by the rules on copyright and intellectual property, as well as by community rules and international conventions, as applicable.

The software, every copy and every part or element of it (including, by way of example and not exhaustive: every image, icon, photograph, animation, video), any text or image, electronic and "on-line" documentation relating to it, are the exclusive property of the Owners and cannot be reproduced by the User in any form or manner. All rights on trademarks, product names and any other distinctive signs are reserved to the Owners.

It is forbidden to copy, decompiling in all or in part the present platform, and/or use it for any use different from the use proper object of the present terms and conditions. Any infringement will be prosecuted under the laws.

PRIVACY POLICY

The organisations responsible for the processing of your personal data in relation to the MULTI-ACT Digital Toolbox Multiple Sclerosis Care Unit Survey are:

- EUROPEAN CHARCOT FOUNDATION (ECF), as Coordinator of the Multiple Sclerosis Care Unit (MSCU);

- FONDAZIONE ITALIANA SCLEROSI MULTIPLA ONLUS (FISM), as Coordinator of the European project MULTI-ACT (Contract Number GA n.787570, May 2018 – April 2021);

They are considered the “joint data controllers” in the terms used in the GDPR.

The data controllers, ECF and FISM, who have already signed an MoU, agree to ensure that all the organisations involved will develop an effective privacy compliance regime ensuring all those who may come in contact with personal information as part of the integration effort are competent to meet privacy requirements. This includes collectors/owners of personal information, service providers and agents.

ECF and FISM fully comply with the legislation in force regarding protection of personal data. They have adopted the technical measures necessary to maintain the required level of security, according to the nature of the personal data held and the way in which it is used, doing everything possible, within the limitations of current technology, to prevent the alteration or loss of such data, and unauthorized access to or use of it.

Any user of the toolbox has a fundamental right to privacy and to data protection. That means that any organisation processing your personal data is obliged by law to do so only under certain conditions and only with your permission. Personal data is protected in EU law by the General Data Protection Regulation (GDPR). When we process your personal data in MULTI-ACT Digital Toolbox, we process it in full compliance with the GDPR. The legal basis for processing your personal data is that you will have consented to that processing.

MULTI-ACT Digital Toolbox data collection and processing

During the use of the Digital Toolbox and participation in the MSCU survey, personal data about you will be collected and processed (i.e. used). This section explains what this involves. In particular, it explains what personal data is, what personal data of yours is processed/used, why we need to process it, how we process and store it, how we keep it safe, what we do with it when the project is finished, what your rights concerning this personal data are, and how you can exercise your rights.

Type of personal data that will be processed:

- All data that you enter in the Digital Toolbox when answering to the survey.

When you participate in the MULTI-ACT Digital Toolbox we will collect the following personal data:

- Your name
- Your contact details
- Your answers to the questionnaire

Your data will be used only for the purposes that are described in this section. If it should happen in the future that we would want to re-use your data, we will seek your consent for new processing and we won't proceed with the processing without your consent.

Processing for management purposes:

The MULTI-ACT Digital Toolbox will process your data to manage the analysis and handling of information resulting from the survey.

The MULTI-ACT Digital Toolbox is authorised to perform the aforementioned processing of your data since it is necessary to comply with the analysis of the survey.

Processing for regulatory purposes:

The MULTI-ACT Digital Toolbox will also process those personal data **required to comply with its legal and/or regulatory obligations**, such as those established by the prevention of money laundering and terrorist financing regulations or tax regulations to the extent required. Likewise, your data can be notified to the tax authorities and the Italian, Belgium and European control authorities, to ensure compliance with those legal and/or regulatory obligations required.

Automated individual decisions:

The MULTI-ACT Digital Toolbox is based **exclusively on the automated processing of your data**.

Data conservation:

Your personal data will be conserved while you hold a relationship with the MULTI-ACT Digital Toolbox and following termination of such relationship for any cause, during the applicable legal limitation periods. In this case, they will be processed solely for the purposes of accrediting compliance with our legal or contractual obligations. Once such limitation periods have ended, your data will be eliminated or, alternatively, anonymised.

Personal data assignments to third parties:

The MULTI-ACT Digital Toolbox will not share with/transfer data to third parties without obtaining your prior consent, with the exception of those required to comply with the legal obligations to which the MULTI-ACT Digital Toolbox is subject at all times due to its nature and activity.

International data transfers:

MULTI-ACT has arranged cloud hosting supplier services (Hertzner) located in Europe (Germany). The arrangement of these services complies with all data protection regulations, applying the guarantees and protection required to the data transfers to preserve your privacy.

For further information regarding privacy guarantees, please contact the Data Protection Office, at the postal or electronic addresses indicated.

Rights:

You can withdraw the consent granted, and exercise your rights of access, rectification, elimination, portability, limitation and/or opposition to processing at the postal or electronic addresses indicated.

If you have any questions, comments, or concerns about the handling of your personal data in MULTI-ACT Digital Toolbox MSCU Survey, you could contact one of them using the details below.

- Name of organisation: **FONDAZIONE ITALIANA SCLEROSI MULTIPLA ONLUS (FISM)**
- Address: VIA OPERAI 40, GENOVA 16149, Italy
- Telephone number: 01-2713247
- Name of person responsible for data protection: FISM Data Protection Officer - Liguria Digitale, with headquarters in Genoa Science and Technology Park, Via Melen 77, 16152 Genoa
- DPO's contact details: paola.zaratin@aism.it, dpofism@aism.it

ECF and FISM commits to provide easy and direct ways of editing, changing or deleting the information uploaded by users and to exercise the rights to access, amend, delete and oppose your data and its usage by sending the appropriate request to the above contacts.

Claims:

If you consider that the processing of your personal data breaches the regulations or this consent, you may file a complaint:

- To our Data Protection Office at the postal or electronic addresses indicated.
- Before the Italian Data Protection Authority (Garante per la protezione dei dati personali), on its website or to its postal address (www.garanteprivacy.it).

Acknowledgment to the MULTI-ACT Consortium Contract Number GA n.787570, May 2018 – April 2021)

1. FONDAZIONE ITALIANA SCLEROSI MULTIPLA FISM ONLUS (FISM), Coordinator, established in VIA OPERAI 40, GENOVA 16149, Italy,

2. UNIVERSITA DEGLI STUDI DI TRENTO (UNITN), established in VIA CALEPINA 14, TRENTO 38122, Italy,

3. ERNST & YOUNG FINANCIAL BUSINESS ADVISORS SPA (EY), established in VIA MERA VIGLI 14, MILANO 20123, Italy,

4. UNIVERSIDAD DE BURGOS (UBU), established in HOSPITAL DEL REY, BURGOS 09001, Spain,

5. TAMPEREEN YLIOPISTO (UTA), established in Kalevantie 4, TAMPERE 33014, Finland,

6. THE EUROPEAN BRAIN COUNCIL AISBL (EBC), established in RUE D EGMONT 11, BRUXELLES 1000, Belgium,

7. INTRASOFT INTERNATIONAL SA (INTRA), established in RUE NICOLAS BOVE 2B, LUXEMBOURG 1253, Luxembourg,

8. EUROPEAN HEALTH MANAGEMENT ASSOCIATION (EHMA), established in RUE BELLIARD 15-17, BRUXELLES 1040, Belgium,

9. FONDATION POUR L'AIDE A LA RECHERCHE SUR LA SCLEROSE EN PLAQUES (ARSEP), established in 14 RUE JULES VANZUPPE, IVRY SUR SEINE 94200, France,

10. DANE-I-ANALIZY.PL SP ZOO (DiA), established in UL KREMEROWSKA 10/22, KRAKOW 31 130, Poland,

11. UNIVERSIDADE CATOLICA PORTUGUESA (UCP), established in PALMA DE CIMA, LISBOA 1649 023, Portugal.

Collaboration under Memorandum of Understanding:

Multiple Sclerosis Care Unit, European Charcot Foundation - Scientific Secretariat, establishes in IRCCS, Ospedale San Raffaele, Via Olgettina, 60, BE - 20132 Milano; **Operational and Administrative Secretariat**, establish at Vaartdijk 3 box 002 BE - 3018 Leuven.

Fondazione Italiana Sclerosi Multipla FISM Onlus, Via Operai, 40 - 16149 Genoa, Italy