

DATA ACCESS, USE AND DISTRIBUTION AGREEMENT

The purpose of this Data Access, Use, and Distribution Agreement (this “Agreement”) is to establish terms and conditions which the Approved Requestor understands and agrees to follow, including but not limited to those set forth in MDA’s Data Governance Policy (the “Policy”), prior to and as a condition precedent to, MDA sharing MOVR Data and MDA agrees to maintain confidentiality on scientific findings prior to manuscript publication and/or presentation.

This Agreement clearly defines the scope of the Approved Requestor’s project and guidelines around permitted MOVR Data use and distribution, including publications and presentations. By signing this Agreement, the Approved Requestor agrees to these terms, which are legally binding.

Any capitalized terms in this Agreement shall have the same meanings as defined in the Policy.

By executing this Agreement, I, [*Name of Requestor*], on behalf of myself and the company or organization by whom I am employed (the “Approved Requestor”), confirm I have completed the following requirements:

1. Review of the Policy.
2. Submission of the Data Request Form describing the scope of the project.
3. Receipt of written approval from MDA in response to the Data Request Form.

As written in the Data Request Form, the scope of the project includes:

4. [*Insert project scope*]
5. I understand and acknowledge that MOVR data will be available via
 - Data Download Report
 - CDISC Expert Statistical De-Identification
 - MOVR’s Visualization and Reporting Platform

I acknowledge that the below are not required by MDA but are encouraged, and I intend to do the following to give back to the community (OPTIONAL; Approved Requestor chooses options):

6. I will submit an electronic form to PubMed Central once the final peer-reviewed manuscript is accepted for publication, so it can be made available to the public. MDA will keep a repository of published manuscripts available to the public.

7. I will provide a summary of the results in lay terms to MDA, so they are able to share back to MOVR participants.
8. I will present scientific findings at the Annual MDA Scientific and Clinical Conference.

I am requesting access to MOVR Data in MDA's MOVR Data Hub[®] for scientific and educational purposes and agree to the terms of the Policy, which are incorporated by reference into and form an integral part of this Agreement:

9. I acknowledge that re-identification of MOVR Data is expressly prohibited.
10. In the event MOVR Data is re-identified (which is explicitly prohibited), I am responsible for immediately notifying MDA of any improper data use, distribution, and/or breaches of HIPAA immediately upon becoming aware of this incident.
11. I will ensure that MOVR Data is stored securely using software that is compliant with current laws and regulations and is kept up to date with all then-current legal or regulatory requirements.
12. I will notify MDA immediately in the event of a breach of security that leads to the accidental or unauthorized disclosure of, or access to, MOVR Data.
13. I will not communicate directly with MOVR principal investigators or staff at MOVR Sites regarding certain outcomes of individual participants.
14. I will not share or sell MOVR Data and/or research findings to any third parties unless I receive expressed written approval from MDA.
15. To the extent I share MOVR Data with individuals on my research team that have a need to know, I will ensure they agree to and comply with the terms of this Agreement.
16. I will provide to MDA current contact information for those team members who have access to MOVR Data.
17. I will respond within 30 days to annual requests for information updates. Progress updates will include published or unpublished (e.g., regulatory submission) scientific findings on the project, patent development, program development, and submission of conference abstracts and/or presentations of findings.
18. I will follow my institution's rules and regulations and its Institutional Review Board (IRB) in requesting access to MOVR Data. I will provide a copy of IRB approval upon MDA's request.
19. I will not use MOVR Data in pursuit of litigation or any of the Non-Authorized Uses, which is defined in the Policy.
20. I will inform subject companies if my research project involves Comparative Effectiveness Research/Analysis, and I intend to make findings public.
21. I understand that regardless of any analysis, data transformation, or combination of MOVR Data with other datasets, MOVR Data remains under MDA ownership.
22. I will ensure that appropriate administrative, physical, and technical precautions are implemented by me and/or anyone on my team who uses MOVR Data to avoid usage and data distribution beyond what is stated in the Data Request Form.

23. I acknowledge that MDA fairly calculated service fees and/or license fees based on the complexity of my request.
24. I will destroy any copy of MOVR Data files upon completion of the project and send MDA a written confirmation when MOVR Data has been destroyed and the project is completed.

I agree to the following if I submit abstracts with MOVR Data:

25. I will cite MDA as the source of MOVR Data and any applicable MDA funding sources as space allows in the abstract.
26. I will not mention MDA in the authorship line of the abstract.
27. I will present any analysis of MOVR Data in the de-identified aggregate form only.

I agree to the following if I publish manuscripts with MOVR Data:

28. I will acknowledge MDA as the source of MOVR Data contained in any such publication with the following attribute: Muscular Dystrophy Association's neuroMuscular ObserVational Research (MOVR) Data Hub®.
29. I will include some variation of the language shown below in the conflict of interest and disclosure statement:

MOVR Data used in this article was captured by MDA's MOVR Data Hub®. As such, principal investigators who contributed to MOVR Data and/or participated in the design and implementation of MOVR did not provide any work to analyze or write this report.

30. I may only publish findings and conclusions related to my analysis of MOVR Data or a subset thereof, provided that I appropriately reference MOVR in the manuscript. I acknowledge it is mandatory to include some variation of the language shown below:

This study was conducted using data from the Muscular Dystrophy Association's neuroMuscular ObserVational Research (MOVR) Data Hub®. MOVR is operated through participating MDA Care Centers with the support of participants, MOVR Site PIs, coordinators, and staff.

31. I will appropriately acknowledge MOVR in the method section, if analysis was done by MDA staff and will include some variation of the language below:

Data in this article were analyzed by Muscular Dystrophy Association staff using MOVR Data from the MOVR Data Hub®.

I agree to the following if I give an oral and/or poster presentation using MOVR Data:

32. I will acknowledge MDA as the source of MOVR Data and any applicable MDA funding sources as space allows on the slide and/or poster with the following attribute: Muscular Dystrophy Association's neuroMuscular ObserVational Research (MOVR) Data Hub®.
33. I will appropriately reference MOVR in the acknowledgements slide and/or poster. I acknowledge that it is mandatory to include some variation of the language shown below:

This study was conducted using data from the Muscular Dystrophy Association's neuroMuscular ObserVational Research (MOVR) Data Hub®. MOVR is operated through participating MDA Care Centers with the support of participants, MOVR Site PIs, coordinators, and staff.

I agree to MDA's Publication Guidelines:

34. I will immediately notify MDA if my method of analysis has changed, or an additional analysis was added.
35. I will follow submission guidelines of my journal of choosing and will provide MDA the journal name. I understand that each journal will have its own specific requirements.
36. I will provide names of the authors of the manuscript, along with their roles and contributions, to MDA.
37. In the event I provide the journal with names of suggested reviewers for the manuscript, I will provide those names to MDA. I will choose reviewers who are experts on the topic or in the field and who can provide an objective assessment on the manuscript. I am responsible for avoiding possible conflicts of interest when recommending reviewers.
38. I will follow ethical publication standards such as, but not limited to, Good Publications Practice, International Committee of Medical Journal Editors and EQUATOR recommendations to ensure high-quality publications of scientific findings, public trust in the research, and to appropriately acknowledge contributors to the project.
39. I acknowledge MDA takes plagiarism seriously and any violation to manuscript publication may result in termination of future access to MOVR Data.
40. I am responsible for ensuring that all authors are in agreement on the final manuscript draft prior to sending a copy to MDA for review.
41. I will send all manuscripts to the MOVR Publication Committee at least 30 days prior to journal submission to ensure that MOVR is properly cited and acknowledged, and that the data is compliant with the initial research scope as stated this Agreement. The MOVR Publication Committee will keep scientific findings in the manuscript confidential and will complete its review within 2 weeks. An approval can be assumed if no response is given within 2 weeks.
42. I understand that MDA does not have final decision on publication submission and thus the decision to publish is mine and my co-authors.

The table below lists the individuals who will have access to MOVR Data and help achieve the research goals/objectives detailed in the Data Request Form:

Name	Job Title	Institution	Email

MDA will make MOVR Data available to researchers in a timely manner, unless more time is needed due to the complexity of the request. I also acknowledge that I am responsible for familiarizing myself with the methods of analysis before submitting them for manuscript publications or other scientific purposes.

I acknowledge that access to MOVR Data is provisional, and any violation of the terms of this Agreement will result in termination of my privileges to access and use MOVR Data, effective immediately.

The Approved Requestor represents and warrants that the undersigned is authorized to execute this Agreement on behalf of his/her/their employer company or organization.

Electronic Signature of Approved Requestor

Name

Signature



Muscular
Dystrophy
Association

Date

Electronic Signature of MDA Representative

Name

Signature

Date

Questions? Contact MDAMOVR@mdausa.org