Terms of Use Non-commercial

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These Terms of Use of the **STICHTING EUROQOL RESEARCH FOUNDATION**, also trading as **EUROQOL RESEARCH FOUNDATION**, a registered charity incorporated under the laws of The Netherlands, having its registered office in Rotterdam, and its principal place of business in (3068 AV) Rotterdam at the Marten Meesweg 107, The Netherlands (hereinafter '<u>EuroQol</u>') should be accepted for the use of the EQ-5D in a Non-Commercial study or ROM/PROMS project, including registries (hereinafter '<u>Study' or 'ROM/PROMS Project</u>').

By registering the Study or ROM/PROMs Project at the EuroQol website (<u>https://euroqol.org/</u>) and explicitly confirming acceptance of these Terms of Use, the registered natural person or legal registered person becomes a User ('<u>User</u>').

Article 1 - Permission

- 1. User is allowed to use the EQ-5D version(s) requested for the Study or ROM/PROMs Project registered on EuroQol's website:
 - The EQ-5D Paper versions are to be filled out on paper by pen(cil) (hereinafter 'EQ-5D Paper').
 - The EQ-5D REDCap, LimeSurvey or Qualtrics versions are ready-to-use digital surveys to be used for collecting EQ-5D data electronically on the supported Electronic Data Capture (EDC) platform (hereinafter '**EQ-5D module**').
 - The EQ-5D Digital versions are to be implemented by User on an unsupported digital platform of the User's choice, compliant with the provide documentation for correct digital implementation of the EQ-5D Digital (hereinafter '**EQ-5D Digital**').
- 2. Considering that the registered Study or ROM/PROMs Project is non-commercial, EuroQol grants permission to use the full version (*descriptive system*, *Visual Analogue Scale and copyright statement*) of the EQ-5D **free of charge** for the duration of the registered Study.
- 3. To request use of the EQ-5D in a new study/project, a new registration should be made on the website of EuroQol.
- 4. Separate permission is required if the Study or ROM/PROMs Project is funded by a pharmaceutical company, medical device manufacturer or other profit-making stakeholder.
- 5. Separate permission is required when the intention is to charge a fee for third party access to collected EQ-5D data in the Study or ROM/PROMs Project.
- 6. The permission to use the EQ-5D is restricted to:
 - $\circ~$ A maximum of 10,000 unique respondents when used in a Study or Registry;
 - A maximum of 100,000 unique respondents when used in a ROM/PROMs Project;
 - 10 years from the date of acceptance of the Terms of Use when used in a ROM/PROMs project or Registry.
- 7. Upon acceptance of these Terms of Use, EuroQol will make the requested available EQ-5D language versions accessible to User by means of the online customer portal.
- 8. The provided EQ-5D language version(s) may not be distributed to third parties other than clinical sites, administrative third parties involved in the study, participating partners without prior approval of EuroQol. Distribution includes, but is not limited to, making available on the internet and/or providing the EQ-5D language versions to third parties other than administrative third parties involved in the study, participating partners, respondents or clinical sites.
- 9. The provided EQ-5D may only be used for the designated purpose and in accordance with the written instructions of EuroQol as set out in the corresponding user guide (https://euroqol.org/information-and-support/documentation/user-guides/).

<u> Article 2 – Use</u>

- 1. The **EQ-5D Paper** may only be provided as-is to respondents to be filled out on paper with a pen(cil). Implementation of the provided **EQ-5D Paper** into an online survey, app or an electronic device is not allowed.
- 2. For the proper use of the **EQ-5D module**, a separate manual can be found on the customer portal, together with the EQ-5D module. Implementation of the provided **EQ-5D module** onto other (EDC) platform(s) than for which it is developed, is not allowed.
- 3. For the proper use of the **EQ-5D Digital**, the Digital Representation Design Guidelines (detailed instructions on how to implement the EQ-5D on a digital platform) and the EuroQol Office

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Representations (example screenshots of digital EQ-5D reproductions for every requested language, which comply with the Digital Representation Design Guidelines), together with the EQ-5D Digital Excelfile source file(s) can be found on the customer portal.

- 4. The fundamental design guidelines for the EQ-5D Digital are:
 - The digital reproduction of EQ-5D Digital should be responsive and should not require scrolling at any point during the completion of the EQ-5D.
 - Every dimension of the EQ-5D should be displayed on a separate screen with the instruction above the dimension and the levels listed below each other.
 - \circ $\;$ The copyright line should be displayed on every screen.
 - The VAS should be vertical with the VAS instructions next to the scale.
- 5. User is responsible for implementing the EQ-5D Digital on the platform of choice based on the Digital Representation Design Guidelines and the EuroQol Office Representations. Any deviation from the Digital Representation Design Guidelines and the EuroQol Office Representations is at User's own risk.

Article 3 - Intellectual Property Rights

- 1. All intellectual property rights in, or in connection with the EQ-5D are vested in EuroQol.
- 2. User is not allowed to modify, alter, amend the provided EQ-5D or develop any (new) Language of the provided version(s), without permission of EuroQol.
- 3. User shall include the copyright statement located in the footer of each EQ-5D.
- 4. User is responsible for the correct representation of EQ-5D in the Study or ROM/PROMs Project. The EQ-5D should be represented as shown in the demo pages that can be found on the EuroQol website: https://euroqol.org/eq-5d-instruments/sample-demo/).
- 5. User is responsible for any license required for the use of the EDC platform if applicable.
- 6. The provided EQ-5D may not be reproduced in a publication or on the internet without written permission.

Article 4 - Study or ROM/PROMs Project data

- 1. User is proprietor with regard to all personal and other data which is collected in connection with the use of the requested version.
- The EuroQol Office shall not request nor receive any collected data from User. Therefore, User will be solely responsible with regard to the compliance with all applicable laws and regulations in respect of the protection of the collected (personal) data.

Article 5 - Liability

- 1. User is solely responsible for the use of the EQ-5D and the data resulting from such use.
- 2. For the avoidance of any doubt, EuroQol is not liable towards User for any damage resulting from the use of the EQ-5D in the Study or ROM/PROMs Project, except in case of gross negligence or willful misconduct by EuroQol.
- User shall indemnify EuroQol and hold EuroQol harmless against any and all damages, claims, liabilities, costs and expenses, which may arise out of or are related to the (mis)use and/or reproduction of the content of the EQ-5D provided by EuroQol to User, except in case of gross negligence or willful misconduct by EuroQol.

Article 6 - Miscellaneous

- 1. In case of questions regarding data analysis, User is requested to complete the Support Form on the website (<u>https://customer.euroqol.org/support</u>). Please refer to the Tracking ID number.
- 2. Frequently asked questions relating to the EQ-5D are answered on EuroQol's website 3. (https://euroqol.org/support/faqs/).

Article 7 - Governing law

1. These Terms of Use shall be governed by, and construed in accordance with, the laws of the Netherlands

Article 8 - Dispute Resolution

1. If any dispute arises out of or in connection to these Terms of Use, parties shall strive to amicably settle the dispute.

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- 2. Should it not be possible to resolve any dispute arising hereunder through good faith discussions and negotiations, the below applies:
 - \circ If User is vested outside the EU:
 - any dispute arising out of or in connection with these Terms of Use, including any question regarding its existence, validity or termination, shall be referred to and finally resolved by arbitration conducted in accordance with the International Chamber of Commerce Rules for Arbitration ("ICC Rules") for the time being in force, which rules are deemed to be incorporated by reference.
 - The number of arbiters shall be one (1) and shall be appointed by the Court of Arbitration. In principle, the arbiter shall not have the nationality of either of the parties. The place of arbitration shall be Rotterdam. The arbitral procedure shall be conducted in the English language. The arbitral court shall decide in accordance with the rules of law.
 - Notwithstanding the foregoing, nothing shall affect either party's right to seek an immediate remedy of an injunction, specific performance or similar court order to enforce the defaulting party's obligations.
 - These Terms of Use shall be governed by and construed in accordance with the laws of the Netherlands.

• If User is vested in the EU:

- these Terms of Use shall be governed by, and construed in accordance with, the laws of the Netherlands.
- All disputes arising out or in connection with these Terms of Use shall be finally settled by the competent court in Rotterdam, the Netherlands.