



CIHI PROMs Program: Registration Form

EQ-5D-5L Licence

This registration form is used to confirm intent to collect data from patients in routine care using the EQ-5D-5L, paper and/or REDCap electronic versions, under the Canadian Institute for Health Information's (CIHI's) national licence for this instrument. If another version of the EQ-5D (e.g., EQ-5D-3L, EQ-5D-Y) is required, email proms@cihi.ca.

By completing and signing this registration form and the attached CIHI PROMs Program EQ-5D-5L Licence Terms of Use ([Appendix A](#)), the requestor, on behalf of the organization identified in this registration form, agrees to abide by the CIHI PROMs Program EQ-5D-5L Licence Terms of Use. Upon approval of this request, instructions will be provided on how to print official paper versions of the EQ-5D-5L, as well as how to upload the REDCap electronic version.

Except as otherwise permitted in the CIHI PROMs Program EQ-5D-5L Licence Terms of Use, use of the EQ-5D-5L for research purposes or for the creation of an electronic version of the EQ-5D-5L is not permitted. Email proms@cihi.ca for information on obtaining licences for these purposes.

Please complete the following information and submit to CIHI at proms@cihi.ca.

Contact information

Organization:

Site(s):

List all applicable sites/campuses.

Department:

Name of requestor:

Position:

Phone:

Email:



Canadian Institute
for Health Information

Institut canadien
d'information sur la santé



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Use of the EQ-5D-5L

1. Will data be collected on patients for routine care purposes only?

Yes

No If no, please specify purpose:

2. Provide a brief description of your PROMs initiative.

3. Identify the patient population(s) for your PROMs initiative.

4. What is the source of funding for your initiative?

If this is part of the practice in your setting, state "Internal funding." If there is no funding for your project, state "Not applicable."

5. Number of patients that will be surveyed

This number should reflect unique patients surveyed annually (i.e., a patient who is administered the instrument more than once is considered 1 unique patient). This information will be reported to the EuroQol Research Foundation and will also be used to determine licensing fees, if applicable.

6. Start date of initiative

7. End date of initiative

If collection will be ongoing, state "Not applicable."



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8. Indicate how patients will self-complete the EQ-5D-5L.

Select all that apply. If you require an option that is not listed (e.g., proxy, face-to-face), select "Other" and provide details.

Paper

Telephone

Digital (tablet) — includes iPads

Digital (web) — includes computer and kiosk

Digital (PDA) — includes phone

Other (please specify):

9. If collecting electronically, specify the vendor/software/platform that will be used or that are being considered.

10. Language(s)

Select all that apply.

English (Canadian)

Chinese (simplified Malaysia)

Hindi

Spanish

French (Canadian)

Chinese (simplified Singapore)

Italian

Tagalog

Arabic

Farsi

Polish

Tamil

Chinese (Cantonese/traditional)

German

Punjabi

Urdu

Chinese (simplified China)

Korean

Russian

Vietnamese

11. Do you acknowledge and agree that this information may be published in EuroQol reports regarding usage of the EQ-5D?

Note that only anonymized information will be published.

Yes

No



Appendix A: CIHI EQ-5D-5L Licence — Terms of Use

CIHI Patient-Reported Outcome Measures (PROMs) Program EQ-5D-5L Licence

Terms of Use

The terms in this agreement govern the use of the EQ-5D-5L questionnaire paper version (“**EQ-5D-5L**”), as well as the REDCap electronic version (“**REDCap**”), both of which are owned by the EuroQoL Research Foundation, by the organization identified in the CIHI PROMs Program: Registration Form to which this agreement is attached (the “**Licensee**”). The EQ-5D-5L and the REDCap are collectively referred to as the “**Questionnaires**” in this agreement.

CIHI has licensed the use of the Questionnaires from their owner.

The Licensee

1. (a) The Licensee represents and warrants that it is a Canadian publicly funded, not-for-profit health care organization, such as a hospital, community care access centre, regional health authority, local health integration network, or provincial or territorial ministry or department of health.
(b) For clarity, only an entity that is the Licensee may use the Questionnaires under this agreement.

Start of Term

2. The agreement is effective as of the date on which this agreement is signed by the Licensee (the “**Effective Date**”).

Permitted Uses

3. The permitted uses of the Questionnaires are for data collection in routine care as part of CIHI’s PROMs Program and, to that end, include:
 - a) Administering the EQ-5D-5L to Canadian patients to evaluate health status and outcomes in Canada and informing clinical and health system decision-making and evaluation in publicly funded health care in Canada;
 - b) Administering the REDCap to Canadian patients to evaluate health status and outcomes in Canada and informing clinical and health system decision-making and evaluation in publicly funded health care in Canada;
 - c) Administering the EQ-5D-5L via telephone to Canadian patients to evaluate health status and outcomes in Canada and informing clinical and health system decision-making and evaluation in publicly funded health care in Canada; and
 - d) Submitting collected PROMs data directly or indirectly (through a licensed software vendor, for example) to CIHI (collectively, the “**Permitted Uses**”).



Appendix A: CIHI EQ-5D-5L Licence — Terms of Use

Licence and Fees

4. (a) CIHI hereby grants the Licensee a non-exclusive, non-transferable licence to reproduce and use the Questionnaires to make Permitted Uses of the EQ-5D-5L questionnaire during the Term (defined below), subject to the terms of this agreement.
- (b) CIHI may charge cost-recovery fees to the Licensee for the use of any or all of the Questionnaires. CIHI will invoice the Licensee in respect of these fees and the Licensee will pay in accordance with the invoice.

Limitations

5. (a) The Licensee may not, without express written authorization from CIHI and the EuroQol Research Foundation,
- (i) Make any commercial use of the Questionnaires;
 - (ii) Remove or alter any copyright notice or similar notices on any copy of all or part of the Questionnaires;
 - (iii) Create electronic tools (for example, an internet or other digital version of the questionnaire or an Interactive Voice Response System) using the Questionnaires;
 - (iv) Translate or modify the Questionnaires;
 - (v) Publish or distribute the Questionnaires in any manner which may be seen as contrary to this agreement;
 - (vi) Sublicense the Questionnaires or otherwise provide a copy to other legal entities for those other entities to administer;
 - (vii) Use the Questionnaires for research purposes;
 - (viii) Use the Questionnaires for purposes unrelated to CIHI's PROMs Program;
 - (ix) Use less than the full Questionnaires;
 - (x) Depart from or modify any telephone script provided by CIHI for administering the EQ-5D-5L via telephone; or
 - (xi) Use a third party in the reproduction or use of the Questionnaires, or in the distribution of the Questionnaires to patients.
- (b) The Licensee may direct any questions regarding acceptable activities under this agreement to CIHI at proms@cihi.ca.



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(c) The Licensee

- (i) Will ensure that its employees who use the Questionnaires are aware of the terms of this agreement;
- (ii) Will ensure that any third parties approved by CIHI and the EuroQol Research Foundation to be used by the Licensee in the reproduction, use or distribution of the Questionnaires have agreed to terms no less stringent than this agreement; and
- (iii) Accepts responsibility for all uses of the Questionnaires by its employees and third parties as if those uses were the Licensee's own.

Ownership of Modifications

- 6. (a) In the event CIHI and the EuroQol Research Foundation, as applicable, grant the Licensee permission to modify or translate the Questionnaires, the Licensee hereby assigns all modifications and translations it makes to the Questionnaires to CIHI or the EuroQol Research Foundation, as directed by CIHI, and waives moral rights in those modifications and translations in favour of CIHI or the EuroQol Research Foundation, as directed by CIHI, and its assigns unless CIHI expressly agrees otherwise in writing.

(b) The Licensee will promptly take all necessary steps to ensure the assignment and waiver upon CIHI's request.

Licensee Tracking

- 7. (a) The Licensee will inform CIHI of its intention to collect PROMs data by email directed to proms@cihi.ca so that CIHI may register the Licensee with the EuroQol Research Foundation.

(b) The Licensee will, to the best of its ability, track the number of patients to which it administers the Questionnaires and share those numbers with CIHI annually in accordance with a schedule communicated by CIHI.

Trademarks and Names

- 8. (a) The Licensee will not use the name, trade name, trademark or any other identifier of the EuroQol Research Foundation for advertising, promotion, press, media or any other public purpose without CIHI's prior written authorization.

(b) Every copy of the Questionnaires will incorporate the following wording: © *EuroQol Research Foundation. EQ-5D™ is a trade mark of the EuroQol Research Foundation.*

(c) The Licensee may use CIHI's name to state that the Licensee has sublicensed the Questionnaires from CIHI.



Appendix A: CIHI EQ-5D-5L Licence — Terms of Use

Ownership

9. (a) The Licensee acknowledges ownership of the Questionnaires by the EuroQol Research Foundation.
(b) The Licensee obtains no rights in the Questionnaires other than those rights expressly granted by this agreement.

Disclaimer of Warranties

10. THE QUESTIONNAIRES ARE PROVIDED AS IS AND WITHOUT WARRANTIES OF ANY KIND, INCLUDING WARRANTIES OF FITNESS FOR A PARTICULAR PURPOSE AND NON-INFRINGEMENT.

Term and Termination

11. (a) The term of this agreement (“**Term**”) begins on the Effective Date and continues until terminated in accordance with one of the following termination provisions.
 - (i) If any of CIHI’s rights in the Questionnaires are lost or challenged, CIHI may immediately terminate this agreement by providing the Licensee with notice.
 - (ii) Either CIHI or the Licensee may terminate this agreement for convenience by providing 30 days’ notice to the other.
- (b) The Licensee will permanently delete or destroy all copies, including but not limited to partial copies, of the Questionnaires in its possession or control within 14 days of termination of the agreement and certify the deletion or destruction in writing to CIHI.
- (c) For clarity, the Licensee may not use the Questionnaires after the termination of the agreement without CIHI’s express, prior, written authorization.

Notice

12. (a) Any notice to be given under this agreement must be in writing.
(b) Notice to CIHI will be directed to proms@cihi.ca.
(c) Notice to the Licensee will be directed to the email address identified in the signature block at the end of this agreement.
(d) Each party will promptly notify the other of any change to their contact information.

Intellectual Property Right Infringement

13. If the Licensee becomes aware of possible or certain infringement of intellectual property rights in any of the Questionnaires, the Licensee will promptly notify CIHI and use commercially reasonable efforts to help CIHI protect those rights.



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Data Collection

14. The Licensee will ensure it complies with applicable privacy laws in collecting data using the Questionnaires.

Limitation of Liability

15. NEITHER CIHI NOR THE EUROQOL RESEARCH FOUNDATION IS LIABLE TO THE LICENSEE FOR ANY DAMAGES INCLUDING, WITHOUT LIMITATION, DIRECT, INDIRECT, INCIDENTAL, SPECIAL, OR CONSEQUENTIAL DAMAGES, EVEN IF CIHI OR THE EUROQOL RESEARCH FOUNDATION HAS BEEN ADVISED OF THE POSSIBILITY OF SUCH DAMAGE OR CLAIM, OR IT IS FORESEEABLE. CIHI AND THE EUROQOL RESEARCH FOUNDATION BEAR NO LIABILITY TO THE LICENSEE FOR ANY DAMAGE OR LOSS OF ANY KIND ARISING OUT OF OR RESULTING FROM THE LICENSEE'S POSSESSION, REPRODUCTION OR USE OF THE QUESTIONNAIRES REGARDLESS OF WHETHER SUCH LIABILITY IS BASED IN TORT (INCLUDING NEGLIGENCE), CONTRACT (INCLUDING FUNDAMENTAL BREACH) OR OTHERWISE IN CONNECTION WITH THIS AGREEMENT. THE LIMITATIONS OF THIS SECTION APPLY WHETHER OR NOT THE ALLEGED BREACH OR DEFAULT IS A BREACH OF A FUNDAMENTAL CONDITION OR TERM.

Indemnity

16. THE LICENSEE WILL INDEMNIFY CIHI AND THE EUROQOL RESEARCH FOUNDATION FROM AND AGAINST ALL CLAIMS, DAMAGES, LOSSES, ACTIONS AND OTHER PROCEEDINGS, REASONABLE COSTS AND EXPENSES (INCLUDING LEGAL FEES), HOWSOEVER CAUSED, INCLUDING WITHOUT LIMITATION, BREACH OF CONTRACT, STRICT LIABILITY, TORT (INCLUDING NEGLIGENCE) OR ANY OTHER LEGAL OR EQUITABLE THEORY, RESULTING FROM OR ARISING OUT OF THE LICENSEE'S POSSESSION, REPRODUCTION OR USE OF THE QUESTIONNAIRES.

General Provisions

17. This agreement constitutes the entire agreement with respect to its subject matter. If any provision (in whole or in part) of this agreement is deemed void or otherwise unenforceable by a lawful authority, the rest of the agreement continues in force. The Licensee may not assign this agreement without CIHI's prior, express, written consent. CIHI may amend this agreement in its sole discretion from time to time upon providing written notice to the Licensee. This agreement is governed by and construed in accordance with the laws in force in Ontario without regard to conflicts-of-laws principles. The Licensee agrees any disputes connected to this agreement are to be settled by the courts in Ottawa, Ontario, Canada. The word "will" when used in this agreement means "has a duty under this agreement to." Sections 4(b), 5(c), 6, 7, 9, 10, 11(b), 11(c), 13, 15, 16, and 17 (as well as any other provisions which by their nature are to survive) survive the termination of this agreement.



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AGREED TO AND SIGNED BY THE DULY AUTHORIZED REPRESENTATIVE OF THE LICENSEE

OFFICIAL/LEGAL NAME OF LICENSEE (ORGANIZATION)

Per:

Signature

I have authority to bind the Licensee

Printed Name

Title

Date

Email For Notices Under This Agreement