Terms of Use for EORTC Datasets

Acceptance of Terms of Use

1. By accessing and using the datasets provided by the European Organisation for Research and Treatment of Cancer (“EORTC”) in the scope of specific project(s), you shall be deemed to have accepted to be legally bound by these terms (hereinafter referred to as “Terms of Use”). If you do not agree to these Terms of Use, do not use and delete the datasets (unless datasets are to be kept to comply with the archiving periods legally required by the legislation applicable to the previously approved project(s)).

2. These Terms of Use are standardly available on the EORTC website (link provided through the data request form) and may change between the time of request and data transfer. In case of major update and prior to the transfer, EORTC may ask you to agree on the updated terms of use.

3. In addition, EORTC may require that you are bound by additional project-specific terms of use (these may be notified in writing to the requestor at the time of the approval of the request). Your use of such datasets will be subject to those additional terms of use. In case there is a change to such additional terms of use, you will be notified in writing. EORTC may also request to execute a formal agreement in some particular cases of which you will be prospectively notified in writing.

Conditions of Use

4. Subject to these Terms of Use, EORTC grants you a royalty-free, non-exclusive, non-transferable, non-assignable license to use the data for the following purposes:
   a. use of the data specifically for the project(s) for which the data has been released by EORTC (referred to hereinafter as “Projects”);
   b. modification or adaptation of the datasets to suit the needs of Projects;
   c. publication of results of Projects.

5. Subject to these Terms of Use and without prior written authorization by EORTC, are prohibited:
   a. further copying, distribution or transmission of the datasets to any third party that was not declared to and accepted by EORTC at the time of the data request;
   b. posting data on a public data repository/website, unless in a form of results and/or otherwise agglomerated data;
   c. further sharing or commercialization of the applications or any other material that you might develop using the datasets;
   d. any attempt to identify data subjects or any action which is likely to lead to subject identification;
   e. publication of individual patient data (except when fully anonymized or agglomerated) or any other type of data that puts data subjects under the risk of potential intentional or unintentional identification, unless specifically and explicitly authorized by data subject;
   f. use of the data for other purposes than the Project.
6. You must:
   a. ensure the Project has received, when applicable, an appropriate ethical approval and / or any other approval or that it is otherwise legitimate as per applicable legislation;
   b. ensure all third parties comply with these Terms of Use as applicable;
   c. process the data in a way that will make highly unlikely any inappropriate access to the datasets or any breach to data privacy by, among other measures, using appropriate technical tools;
   d. limit all processing of datasets to entities based within the European Union or inform EORTC about any need to transfer datasets to any party based outside the European Union prior to any transfer or any agreement to transfer as additional constraints may apply;
   e. clearly state in all your communication: “The authors thank the European Organization for Research and Treatment of Cancer for permission to use the data from EORTC studies [list of study numbers] for this research” and “The contents of this publication and methods used are solely the responsibility of the authors and do not necessarily represent the official views of the EORTC.”;
   f. cease to use the datasets once the Project(s) are ended and do not store the data any longer than the archiving time legally required by the legislation applicable to your activities and/or to the Project(s).
   g. provide the information on, modify, correct or destroy datasets or parts of datasets upon specific request of EORTC at any moment, in particular in relation to data subject rights and requests; such actions shall not generate any costs or liability for EORTC;
   h. immediately inform EORTC about any breach to data privacy in relation to datasets you received from EORTC or any breach of these Terms of Use.
   i. send EORTC (datasharing@eortc.org) the reference of any resulting scientific publication within 2 months of the publication.

7. You must not use the data for unlawful purposes or present results in a misleading way. Such instances include, but are not limited to:
   a. presenting the datasets in a misleading or incorrect manner, or misrepresenting the data; or
   b. using the data to promote or support any illegal activities.

8. The breach of any of these Terms of Use shall result in the cancellation of the license to use the datasets granted to you under clause 4. These Terms of Use (except for clause 4) shall survive the cancellation of the license under clause 4.

Data Protection

9. In relation to the processing of the datasets requested by you and provided by EORTC under these Terms of Use, you become a Data Controller on your own. By agreeing with these Terms of Use you confirm to ensure that any personal data processing activities are compliant with the applicable laws, including but not limited to the General Data Protection Regulation 2016/679 (“GDPR”): i) you ensure you assess and decide the legal basis and the lawfulness of personal data processing activities performed in the scope of your Project; ii) you confirm you will process the shared personal data lawfully, fairly and in transparent manner; iii) you will process personal data in a way that ensures appropriately security of personal data and maintains their integrity and confidentiality; iv) you restrict access to the personal data so it is limited to those employees that meet the regulatory compliance obligations; v) you may delegate partially or entirely any of the processing activities to vendors and sub-contractors and in doing so, you shall enter into a written agreement with the processor, as required by the Article 28 of GDPR which imposes the same obligations on the processor to comply to the conditions imposed under these Terms of Use.

10. Although you are responsible to assess and comply with the formalities requested by GDPR for the data breaches and complains that occurs at your side and in relation to the dataset provided by EORTC, EORTC, as the original controller, would like to be informed (dpo@eortc.org) within the shortest delay possible about any risk or high risk data breaches, as this might have impact on EORTC’s reputation or image.
11. In the event of a data subject request, and since you are not in direct contact with the sites from where the patient data shared with you were initially collected nor in the position to identify the data subject, EORTC will provide reasonable assistance so that you complete the data subject request within the timelines and formalities requested by GDPR.

12. For the sake of clarity, these Terms of Use are applicable only when the requester of the data is an European Union entity and there is no genetic data requested. When the requester is a non-EU entity or is requesting access to genetic data, the Terms of Use might not be sufficient and EORTC will need to put in place additional contractual clauses to cover this.

Disclaimers

13. The datasets are provided on an "as is" basis without warranties of any kind. EORTC does not make any representations or warranties whatsoever and, to the fullest extent permitted by the law, hereby disclaim warranties, whether express, implied or statutory, to you or any third party in relation to the use of the datasets, including but not limited to any warranty as to the accuracy, correctness, reliability, timeliness, non-infringement, title, quality or fitness for any particular purpose of the datasets.

14. To the fullest extent permitted by law, EORTC shall not be liable to you or any third party for damage or loss of any kind, including but not limited to direct, indirect, punitive, special or consequential damages, loss of goodwill, loss of business resources, income, revenue or profits, lost or damaged data, or damage to your computer or other property, arising directly or indirectly from your or any third party’s use of, or inability to use, the datasets or the results of Projects.

Indemnity

15. You agree to fully indemnify EORTC and to hold EORTC harmless from any and all claims, demands, losses, liabilities, costs and expenses (including but not limited to legal costs) against EORTC arising directly or indirectly from your use of the datasets or your breach of any of these Terms of Use or your violation of any third party rights; or any claim made by a third party in connection with the third party’s use of the datasets or any derived analyses or applications which you have provided.

Ownership and Intellectual Property

16. You acknowledge you understand and agree that:
   a. you are not the owner of the datasets and their ownership is not anyhow affected by these Terms of Use;
   b. without prejudice to paragraph 5c above, you retain the intellectual property rights exclusively and specifically on data generated by the Projects; any intellectual property rights otherwise related to datasets is not affected by these Terms of Use and remains with EORTC.

Governing Law

17. These Terms of Use shall be governed by and construed in accordance with Belgian laws. You irrevocably agree that Belgian courts shall have exclusive jurisdiction in relation to any dispute arising from or relating to these Terms of Use.