Instructions for use of data from the CLIDIPA Registry for scientific projects

version December 3, 2024

Eligibility of Projects

Researchers who are employees of or otherwise associated with a Partner (affiliated site) are invited to submit their study proposals to access data from the CLIDIPA Registry. Projects eligible to request data from the Registry must focus primarily on using the data as validation cohort for internally developed AI-models. If the data is used for other purposes, e.g., training of a model or challenges, this should be motivated in the proposal. The project must be non-commercial in nature, meaning it cannot have a profit-driven purpose.

Submission of Study Proposals

To apply, please complete a Study Proposal Form and ensure your proposal aligns with our research guidelines. Each submission will be reviewed by the Steering Committee and discussed during one of the Steering Committee meetings.

The proposal (in English) should be submitted via info@clidipa.org.

Procedure After Submission

Notification

Once a proposal has been submitted, it will be reviewed by the CLIDIPA Steering Committee. The proposals will be discussed at the next Steering Committee meeting. If the Steering Committee gives a positive recommendation, each participating center will then decide whether to share its data for the study. After the meeting, feedback will be provided to the applicant by the Chair or Secretary of the CLIDIPA Registry.

The outcome may be one of the following:

- The application is approved without any restrictions.
- The application is approved with restrictions (e.g., data from Center 1 or 2 will not be made available).
- The application is on hold; additional information is required (depending on the reason this may be provided either in writing or presented orally at the next Steering Committee meeting).
- The application is rejected in its entirety.

The applicant will be notified of the outcome as soon as possible after the Steering Committee's decision. Should additional information be required, the applicant will be informed about the next steps.

Study duration and progress
Studies have a maximum duration of 2 years. At the end of the first and second years after approval of the project, a progress report should be submitted which will be discussed by the Steering Committee.
The outcome may be one of the following:

- The project can continue without making adjustments
- The project can continue with making adjustments (the requested adjustments will be specified by the Steering Committee)
- The project cannot continue (the reason(s) for this will be specified)

If additional time is needed for a project, an extension request with motivation must be submitted and approved by the Steering Committee.

Study completion and attribution
Studies utilizing data from the CLIDIPA Registry are required to be submitted as an abstract for the annual EORTC-CLTG meeting.

As part of our commitment to transparency and collaboration, any algorithms or computational models developed and/or validated using data from the CLIDIPA Registry must be made publicly available upon publication of the study, ideally by sharing them through an open-access platform or database (e.g., GitHub · Build and ship software on a single, collaborative platform · GitHub). Publications must be made in an Open Access format.

The CLIDIPA Registry must be acknowledged in all presentations, publications, and other forms of dissemination where data from the Registry has contributed to the outcomes. This acknowledgment can take the form of a footnote, acknowledgment section, or a clear mention in the methods section of the publication, e.g., "This study was conducted using data provided by the CLIDIPA Registry". Steering Committee members of participating centers that contributed data to the Registry utilized for the study must be included as co-authors in publications. This should be in accordance with standard co-authorship guidelines (e.g., as described by the ICMJE or other relevant authorities), requiring that contributions are substantial and appropriately recognized.

Data provided from by the Registry may only be used for the research project for which the application has been approved. For the use of this data in new or follow-up studies, a new application must be submitted. If the nature or scope of the original research project changes, an amendment to the existing application must be submitted and approved before further use of the data.