



IDDO - Visceral Leishmaniasis (VL) Data Platform Terms of Submission (the “Terms of Submission”)

1. BACKGROUND AND INFORMATION

Making health research data available for secondary analysis can increase the impact of the data to improve health and optimise use in the long-term. These Terms of Submission set out the conditions under which data are submitted to the IDDO-VL Data Platform, how the data will be handled and how access will be managed. Please read these terms carefully before submitting data to IDDO: By submitting data to IDDO, you indicate that you accept these terms and you agree to abide by them.

In these Terms of Submission:

The [Infectious Diseases Data Observatory](#) (IDDO) is an international collaboration and is hosted by the University of Oxford. IDDO has a focus on data for neglected poverty-related diseases and emerging pathogens. The IDDO - Visceral Leishmaniasis (VL) Data Platform (the “**Platform**”) is a platform specifically for Visceral Leishmaniasis data and is part of the IDDO project.

“**Data Contributors**” or “**you**” are the institutions and their authorised representatives responsible for submitting anonymised data including individual patient data and meta-data, (the “**Data**”) to the Platform.

The “**Data Inventory**” refers to an aggregated listing of the type, volume and source of data held on the Platform.

The “**Website**” refers to the IDDO website at www.iddo.org, which hosts information about the Platform. These Terms of Submission form part of the IDDO website [Terms of Use](#) and prevail over the website Terms of Use in the event of inconsistency. The website Terms of Use should be read in conjunction with these Terms of Submission. Note that Data are uploaded via the IDDO website to the Platform. Data submitted to the Platform are not part of the website content.

2. YOUR RIGHTS

- 2.1 The Platform is dependent on the submission of Data by Data Contributors. IDDO respects the rights of Data Contributors over the Data shared with the Platform.
- 2.2 Neither IDDO, nor the University of Oxford will claim any rights of ownership (including intellectual property rights) over the Data submitted. Data Contributors will continue to own and have full control over the Data they submit (subject to delegation to a Data Access

Committee as set out in section 4.4). However, in order to allow IDDO to operate, you hereby grant to IDDO the right to display summary data and to use, copy, translate, reformat, and make derivative works of your Data in accordance with these Terms of Submission.

- 2.3 All Data submitted will be accessed and used by the [IDDO Team](https://www.iddo.org/about-us/iddo-team) (<https://www.iddo.org/about-us/iddo-team>), which may change from time to time, only in accordance with these Terms of Submission, and for the purposes described in section 4.
- 2.4 In the event that IDDO is transferred from the University of Oxford to another entity, the rights you grant under section 2.2 will be transferred to that entity.
- 2.5 You may at any time withdraw the right of IDDO to use your Data, and/or request that IDDO destroy the Data you have submitted, but you accept that the reports, analyses and data made publicly available prior to that point cannot be withdrawn. The Data Inventory will be amended to reflect any changes to the Data held on the Platform.

3. YOUR OBLIGATIONS

- 3.1 In order to ensure compliance with its legal and ethical obligations, IDDO requires that all submitted Data have been obtained in accordance with any laws or regulations governing the collection and any other processing of Data that are applicable, including without limitation those in the country of Data origin.
- 3.2 IDDO requires that you anonymise the Data before submitting it to the Platform so that it does not include information which alone or in combination with other publicly available data can be used to identify the individual(s) to which it relates (i.e. personal data as defined under the UK Data Protection Act 2018, as it may from time to time be amended, modified, consolidated or re-enacted).
- 3.3 You must have the authority and all necessary rights and licences to submit the Data to be used in accordance with these Terms of Submission.

4. USE OF THE DATA

- 4.1 IDDO reserves the discretionary right to delete any Data from the Platform or to cease to host any Data submitted, in whole or in part, at any time.
- 4.2 IDDO only accepts anonymised Data and will take appropriate technical and organisational measures to protect the security and confidentiality of Data. IDDO reserves the right to omit from the Platform any Data if it contains information that may pose a risk to an individual or a community in whole or in part, or if it contains any information that would identify an individual.
- 4.3 IDDO may use Data and information that is provided for any or all of the following purposes:
 - a) For data curation, which includes data cleaning, translation, incorporation of meta-data in relation there to, standardisation and migration, as it sees fit for preservation, utility and accessibility;

- b) To create publicly available maps, displays of the summary analysis, reports and a Data Inventory which demonstrate the type, volume and source of data held on the Platform. These tools are for the purpose of informing the public about the Platform and to promote engagement of the scientific community via the Platform website.
- c) To make the Data accessible for research in accordance with the procedure set out in section 4.4.
- d) Other uses explicitly approved by the relevant Data Contributor.

4.4 Process for providing access to the Data to third party researchers:

- a) Data Contributors may delegate decisions regarding access to Data by third parties to an independent Data Access Committee (DAC), the membership and details of which may change from time to time. The DAC is intended to help researchers meet the demands of funders and journals by providing an option for how they make data accessible for re-use. The DAC will provide controlled access to third party researchers whose applications for Data held within the IDDO repository are approved by the DAC in accordance with specific Data Access Guidelines.
- b) For a period of five years from submission of the Data (see c below), Data Contributors may opt not to delegate decisions regarding data access to the DAC. In this case all requests for Data access will be forwarded to the relevant Data Contributor for consideration. Requests will include the intended purpose, analysis plan and publication plan for the feedback and consideration of the Data Contributor. During this period of five years, Data will be made accessible by IDDO for research use only with the agreement of the Data Contributor unless the Data Contributor chooses to delegate decisions to the DAC as set out in paragraph (a) above.
- c) After the period ending 5 years from submission of the Data, all requests for access to the Data from third parties shall automatically be delegated to DAC as set out in paragraph (a) above. If you do not wish for this to happen, you may at any time withdraw the right of IDDO to use your Data in accordance with section 2.5 above.

4.5 The University of Oxford shall not be entitled to use or transfer the Data submitted by any Data Contributor to any other entity other than pursuant to its role within the IDDO as specifically laid out in these Terms of Submission.

5. ACKNOWLEDGEMENTS AND PUBLICATION

- 5.1 Submission of Data to the Platform does not affect the Data Contributor's right to publish the Data, which may occur entirely at the Data Contributor's own discretion and without consent from or reference to the Platform
- 5.2 IDDO supports the due acknowledgement of Data Contributors in the production of publications and research outputs that use Data from the Platform. Authorship of any manuscripts resulting from use of Data should be decided in accordance with the guidelines

of the [International Committee of Medical Journal Editors](#) (ICMJE). Where Data Contributors are not involved in analysis and manuscript production at the level of the criteria for authorship, Data Contributors should be named as collaborators consistent with MEDLINE [citable acknowledgement](#).

6. LANGUAGE

These Terms of Submission were drafted in English. They have been translated into other languages for convenience only, and the English language text shall prevail in the event of any conflict or inconsistency.

7. QUESTIONS OR CONCERNS

If you have any questions about these Terms of Submission, please contact data@iddo.org.

By clicking “I accept the Terms of Submission” below, you acknowledge that you are bound by these Terms of Submission and [The Platform website Terms of Use](#) (<https://www.iddo.org/terms-of-use>).

I accept the Terms of Submission and I wish to delegate decisions regarding access to the submitted Data to the IDDO independent Data Access Committee (DAC). I acknowledge that researchers approved for access to this data will be given a copy of my name and email address for the purpose of inviting collaboration, and I understand it is my responsibility to keep my contact details up-to-date.

I accept the Terms of Submission and I do NOT wish to delegate decisions regarding access to the submitted Data to the IDDO independent Data Access Committee (DAC) at this time. I understand that after five years following submission of this Data, decisions about access to this Data will automatically transfer to the DAC.

