



IDDO/WWARN Policy on Data Use, Publication and Credit

The Infectious Diseases Data Observatory (IDDO) and the WorldWide Antimalarial Resistance Network (WWARN), part of IDDO, respect the rights of researchers and institutions who collaborate and share data for further reuse with IDDO. This document, which explains our Policy on Data Use and Publication, should be read in conjunction with the IDDO Terms of Submission and the IDDO Data Use Agreement. Further information can also be found on the frequently asked questions section of the IDDO website. IDDO policies apply for all disease themes, including WWARN.

If you have a query or would like access to IDDO's legal documentation relating to data submission or data access, please email the team at info@iddo.org



Table of Contents

IDDO/WWARN Policy on Data Use, Publication and Credit	1
1. Data Contributors: rights and obligations	3
1.1 Your obligations	3
1.2 Your rights	3
1.3 IDDO usage	4
2. Data Users: rights and obligations	4
2.1 Your obligations	4
2.2 Your rights	4
2.3 IDDO Usage	4
3. How IDDO publishes and refers to data contributed to IDDO	4
3.1 Study Summaries in WWARN data visualization tools	5
3.2 Data Inventory	5
3.3 Summary Data	5
4. Study Group Individual Participant Data Meta-analyses	5
4.1 Study group data access	5
4.2 Authorship on IDDO study group publications	5
4.3 Acknowledgements	6
5. Data integrity, study group governance and ethics	6
Appendix	6
1. Byline Authorship	6
2. Collaborators	7



1. Data Contributors: rights and obligations

1.1 Your obligations

- Please acknowledge the use of specific IDDO analysis tools (including usage to analyse data that you are the data controller for) in any publication by mentioning the name of the tool and the organisation (WWARN/IDDO), for example:
 - “Estimation of the parasite clearance rate and lag phase duration was done using the Parasite Clearance Estimator developed by the WorldWide Antimalarial Resistance Network (WWARN), part of the Infectious Diseases Data Observatory (IDDO).” Please also cite the corresponding reference wherever available, for example: Flegg JA, Guerin PJ, White NJ, Stepniewska K. Standardizing the measurement of parasite clearance in falciparum malaria: the parasite clearance estimator. *Malar J.* 2011 Nov 10;10:339. doi: 10.1186/1475-2875-10-339.
 - Or “*The data presented in X was analysed using tools developed by the WorldWide Antimalarial Resistance Network (WWARN), part of the Infectious Diseases Data Observatory (IDDO).*”

Please replace the tool name cited above with the specific tool you use, and please mention the specific organisation which has developed the tool (IDDO or WWARN) as applicable.

1.2 Your rights

- Data Contributors continue to retain the right to publish data that you have contributed to IDDO: your data may be published without any involvement of IDDO.
- We will ask data requestors to cite the digital object identifier (DOI) we assign one to your dataset in any publications that result from/use your dataset. This means that the usage of dataset and its impact can be tracked, cited and evidenced as a contribution of your work and of your institution.
- We will ask data requestors (including IDDO-facilitated study groups; see section 4) to ask to engage and offer to collaborate with you on any meta-analysis that include data that you have contributed. You are however not obliged to participate in these collaborations.
- If you do participate in these invited collaborations, you may be invited as an author on any resulting publication. The authorship is decided on the basis of the intellectual contribution to the publication: the criteria for this decision are based on independently agreed on guidelines used in academic research, and are described in more detail in the Appendix, section 1.
- If your data is included in a publication from an IDDO-facilitated study group (see section 4), this will be acknowledged in the publication byline, as described in the US National Library of Medicine MEDLINE® authorship fact sheet. IDDO Study Group collaborators may cite any such publication in their CV and their name is indexed in Medline for the corresponding publication.

See Appendix 1 and 2 for more information on authorship and collaboration status. See Section 4 for examples of how authorship and collaboration is managed by IDDO study groups.



1.3 IDDO usage

IDDO provides a limited overview of the data it holds in its repositories in study summaries, visualisation tools and data inventories. These overviews are instrumental in allowing researchers to discover relevant datasets, form hypotheses, and test research questions therefore improving findability and maximising data reuse. We do not provide publication credit for information used in this way, as the information disclosed is limited (similar to that published in a meeting abstract) and does not prevent the data from being published elsewhere. More information on the ways in which we publish information about datasets held in the IDDO repositories is included in section 3.

2. Data Users: rights and obligations

Please see the IDDO Data Use Agreement (obtainable by emailing info@iddo.org) for a full description of the conditions and processes under which IDDO releases data deposited in their repository.

2.1 Your obligations

- Data submitted to IDDO are curated and standardised into [STDTM standards](#). IDDO should be acknowledged if any outputs from the data using the wording set out in the IDDO Data Use Agreement document.
- IDDO/WWARN also provide a number of tools and resources, and these should be acknowledged using the wording set out in 1.1.
- Where IDDO has assigned digital object identifiers (DOIs) to individual datasets in its inventory, any publication resulting from analyses of these datasets or using these datasets needs to cite the DOI for that dataset/s in the reference list of the publication.
- Data requestors are also obliged to invite data contributors to collaborate on any data reuse of that dataset, and if applicable, include them as authors or in acknowledgements (see Appendix 1 for more on this).
- Researchers requesting access to COVID-19 data are encouraged but not obliged to invite all data contributors, but should cite DOIs/acknowledge use.

2.2 Your rights

Authorship claims on any publications resulting such analysis are decided on the basis of the intellectual contribution to the publication: the criteria for this decision are based on independently agreed on guidelines used in academic research, and are described in more detail in section the Appendix, section 1. See section 4 for an explanation of how authorship on publications by IDDO-facilitated study groups is managed.

2.3 IDDO Usage

If your data request is successful, IDDO may publish the title, institutional affiliation and the summary included in your application on the iddo.org website, in order to provide researchers with examples of successful data reuse applications.

3. How IDDO publishes and refers to data contributed to IDDO

IDDO uses data in its Data Repository to produce several types of outputs:



3.1 Study Summaries in WWARN data visualization tools

The Study Summary provides a limited overview of the data and thus this will not influence the ability of a Contributor to publish the data elsewhere, since the results shown are similar to those usually published in a congress/conference abstract. Detailed re-analyses of individual studies are not published.

We may use any relevant summary data suitable for presentation on interactive visualisation tools such the WWARN Surveyors. Data Contributors retain the right to decline permission for the Study Summary to be presented on IDDO data visualisation tools.

3.2 Data Inventory

Studies shared with IDDO will be listed in the appropriate research theme, which includes the study title and, if available, the associated publication PubMedID or other database identifiers (e.g. web of science). The inventory will also include the level of control preferred by the controller at the time of contribution (e.g., Data Access Committee control versus Contributor Control). This information is crucial in enabling data reuse, and as such, this listing is not optional.

3.3 Summary Data

We also regularly present summary data about the datasets included in our inventories, and in descriptions of the work that IDDO does. Summary data can include details of the submitted study/data such as: country, year, total patients enrolled and number of sample assays and high level calculations (such as IC50 values, treatment success/failure).

4. Study Group Individual Participant Data Meta-analyses

4.1 Study group data access

We regularly facilitate the formation of study groups to conduct specific individual patient data meta-analyses in relation to a particular drug, patient group, time span, etc.

If you agree to be part of the Study Group, the data you have contributed will be included in the pooled analysis (assuming it is eligible). You are not obliged to agree to this request: the study group making the approach will also provide refusal instructions in their contact email.

If you have chosen to delegate decisions on requests to access your data to the independent [IDDO data access committee](#) (DAC), Study Group members will follow the standard [data access procedures](#). As with contributor-controlled data, you will also be offered the opportunity to actively participate in the Study Group, but you are not obligated to do so.

4.2 Authorship on IDDO study group publications

We offer all contributors whose data are included in the Study Group analysis the opportunity to participate in the IPD meta-analysis, including contributing to the development of the statistical analysis plan, and writing and/or editing any resulting manuscript/s. The Study Group team are responsible for making the decision on the total number of authors to be included on the resulting manuscript at the outset of the collaboration.

Usually, the Data Contributor of each dataset used by a Study Group nominates two individuals to contribute, although the inclusion of additional individuals may be justified in large, complex, multi-centre studies. Those who fulfil the International Committee of Medical Journal Editors



(ICMJE) guidelines for authorship will be listed as authors on any publication that results from the study (see Appendix 3.1).

As with any multiple author publication, details of publication authorship will be negotiated within the study group. Typically, authorship names an 'IDDO XX IPD meta-analysis study group', with or without a named writing committee (see Appendix)

4.3 Acknowledgements

Contributors whose data are used in an IPD meta-analysis, but who do not participate actively in the study design, analysis or manuscript preparation will be acknowledged as Study Group Collaborators in the publication byline, as described in the US National Library of Medicine MEDLINE® authorship fact sheet. Study Group collaborators may cite any such publication in their CV and their name is indexed in Medline for the corresponding publication (see Appendix 4). Those who do not wish to be listed as Study Group collaborators may be acknowledged with or without their affiliation, or not acknowledged as preferred.

5. Data integrity, study group governance and ethics

If a publication requires you to note arrangements about data governance/ethics, the following wording may be adapted as needed:

"This study analysed data from the Infectious Diseases Data Observatory (IDDO) data inventory: datasets are owned by the original controllers who are responsible for ensuring that data was collected in accordance with the applicable laws and ethical approval for the countries where the study was conducted.

In addition to the de-identification processes completed by data contributors, IDDO performs additional checks before or during data curation to ensure that data are pseudonymised. This process is conducted before releasing it to data requestors, to ensure full compliance with international regulations such as the UK Data Protection Regulation (UK GDPR), the European Union Data Protection Regulation (EU GDPR), and the Data Protection Act 2018. More information about IDDO's data governance can be found on IDDO's website (iddo.org)."

Please make sure you comply with your local ethics board/committee requirements: many local ethics board (such as the University of Oxford Ethics Committee) do not require review for the use of existing, pseudonymised data as supplied by IDDO, but please check your local requirements and note compliance as required.

Appendix

1. Byline Authorship

The following are some extracts from the website of the [International Committee of Medical Journal Editors \(ICMJE\)](#):

- a. All persons designated as authors should qualify for authorship, and all those who qualify should be listed. The ICMJE recommends that authorship be based on the following 4 criteria:
 - 1) Substantial contributions to the conception or design of the work; or the acquisition,



analysis, or interpretation of data for the work; AND 2) Drafting the work or revising it critically for important intellectual content; AND 3) Final approval of the version to be published; AND 4) Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. In addition to being accountable for the parts of the work he or she has done, an author should be able to identify which co-authors are responsible for specific other parts of the work. In addition, authors should have confidence in the integrity of the contributions of their co-authors. Acquisition of funding, collection of data, or general supervision of the research group alone does not constitute authorship.

- b. When a large multi-author group has conducted the work, the group ideally should decide who will be an author before the work is started and confirm who is an author before submitting the manuscript for publication. All members of the group named as authors should meet all four criteria for authorship, including approval of the final manuscript, and they should be able to take public responsibility for the work and should have full confidence in the accuracy and integrity of the work of other group authors. They will also be expected as individuals to complete conflict-of-interest disclosure forms.
- c. Some examples of WWARN study group authorships models:
 - [Study group](#)
 - [Study group with writing committee](#)
 - [Individual](#)

2. Collaborators

The following is taken from the US National Library of Medicine MEDLINE® authorship fact sheet and adapted to the IDDO context.

- a. When a group name for a specific consortium, committee, study group, or the like appears in an article byline, the personal names of the members of that group may be published in the article text. This is referring to contributors as defined in 3.5.2 and 3.5.4. Such names are entered as collaborator names for the MEDLINE citation.
- b. Collaborator names are entered for a MEDLINE citation only when a group (corporate) author name is present for the citation. Collaborator names are included redundantly even if they have also been included as authors for the citation (because they also appear in the byline or are explicitly identified in the article as the authors). Collaborator names may also appear redundantly in the MEDLINE citation if they appear redundantly in the published article, such as when the collaborators are listed in the article by various subcommittees and an individual is a member of more than one subcommittee.



- c. If a personal name is entered in a PubMed search without a search tag, for example [au], all citations will be retrieved for which the name is an author or collaborator. A group author name entered without a search tag will retrieve citations with that name as an author occurrence as well as citations with the word(s) in any other field of the citation.

Further information on the [‘collaborator’ status in MEDLINE® / PubMed®](#)