



## RD-Connect Publication Policy





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## Overview

The purpose of this document is to describe the publication and acknowledgement rules relevant to work generated in connection with RD-Connect. These guidelines are designed to encourage publications acknowledging RD-Connect while maintaining the highest quality of such publications and safeguarding the legitimate interests of RD-Connect and its partners. They also serve to increase the profile of RD-Connect among the rare disease community and the general public.

## Non-academic publications

Non-academic publications include press conferences, newspapers, articles and websites. Where possible, authors should acknowledge the RD-Connect project by referring to the website address, adding the RD-Connect logo and mentioning that the research received funding from the European Union Seventh Framework Programme. Press conferences should contain a full acknowledgement, like the academic publications (see below). Posts in social media should contain RD-Connect handles, where possible.

## Academic publications

### (i) Acknowledgement of EU funding

All publications shall include the following statement to indicate that the study was generated with the assistance of financial support from the European Union:

**The research leading to these results has received funding from *the European Union Seventh Framework Programme (FP7/2007-2013)* under grant agreement No. 305444**

### (ii) Acknowledgement of RD-Connect

To acknowledge scientific publications where a large proportion of the work is directly related to RD-Connect, for example workshop reports or publications describing an RD-Connect resource, “RD-Connect” should be mentioned in the title of the publication. Alternatively, the author line should conclude with the statement “on behalf of RD-Connect\*”; the asterisk (\*) refers to the RD-Connect website address as a footnote on the first page of the manuscript ([www.rd-connect.eu](http://www.rd-connect.eu)).

To acknowledge scientific publications where authors agree that RD-Connect funding or the RD-Connect collaboration more generally has contributed to the work, or if a publication policy does not allow the above statement, then RD-Connect should be duly acknowledged in the Acknowledgements section of the manuscript, including the EC contract number (as above).



## (iii) Authorship

As a general rule, RD-Connect papers must follow the standard rules on Authorship established in the International Committee of Medical Journal Editors: 'Uniform Requirements for Manuscripts Submitted to Medical Journals' ([www.icmje.org](http://www.icmje.org)). It is the responsibility of the first and last authors to ensure sufficient recognition in the author list of those persons who contributed to the publication, from RD-Connect and/or NeurOmics, EUREnOmics or other IRDiRC funded projects. Where publications make use of data coming from the RD-Connect platform, it should be acknowledged.

## Notification of publications

It is a requirement of the Consortium Agreement that prior notice is given of all planned publications in order to give partners the opportunity to comment on intellectual property (IP) issues (see Appendix). In addition, to ensure consistency across manuscripts written in the context of RD-Connect as well as to verify the appropriate implementation of this policy, all RD-Connect publications should, where possible, be reviewed by the Executive Management Committee (EMC). Notification of "intention to submit" should be circulated to ([partners@rd-connect.eu](mailto:partners@rd-connect.eu)) 45 days prior to submission.

## Deposit

The lead author should ensure that an electronic copy of the publication is made available to all RD-Connect partners, via the Coordination Office, as soon as it becomes electronically available. Where possible, an open access version should also be made available for dissemination through the RD-Connect website.



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## Appendix:

### Dissemination and Publication clauses from the RD-Connect Consortium Agreement, final version 2012-08-20, for reference

#### 8.3 Dissemination

##### 8.3.1. Publication

8.3.1.1 Dissemination activities including but not restricted to publications and presentations shall be governed by the procedure of Article II.30.3 of the EC-GA subject to the following provisions.

Prior notice of any planned publication shall be made 45 days before the publication and should be circulated to [partners@rd-connect.eu](mailto:partners@rd-connect.eu). Any objection to the planned publication shall be made in accordance with the EC-GA in writing to the Coordinator and to any Party concerned within 30 days after receipt of the notice. The proposed publication shall not take place until the expiry of the above period of 45 days. If no objection is made within the time limit stated above, the publication is permitted.

8.3.1.2 An objection is justified if based of the following grounds: (i) that the objecting Party considers the protection by intellectual property rights of its Foreground would be adversely affected by the proposed publication, (ii) that the proposed publication includes Confidential Information of the objecting Party, or (iii) the publication of such information would result in disproportionately great harm to the legitimate interests of the objecting Party.

The objection has to include for each part of the publication objected to, the grounds of the objection for each objection, indicating which part of the publication the objection is aimed at (individual paragraphs or sentences) and a precise request for necessary modifications (including deletions).

8.3.1.3 In the event that an objection is raised in accordance to the above, the Party proposing the publication and the Party objecting shall seek in good faith to agree to a solution whereby the Parties objecting give permission to publish the proposed publication.



In the event parts of a publication are objected to on ground (i) the publication will be permitted after expiry of a period of three (3) calendar months following the first submission of the proposed publication in accordance to 8.3.1.1.

In the event parts of a publication are objected to on grounds (ii) or (iii) the objection(s) will be deemed withdrawn in the event the Party proposing the publication removes the parts objected to from the intended publication.

Authorship on publications will be based on academic standards and custom.

### **8.3.2 Publication of another Party's Foreground or Background**

For the avoidance of doubt, a Party shall not publish Foreground or Background of another Party, even if such Foreground or Background is amalgamated with the Party's Foreground, without the other Party's prior written approval. For the avoidance of doubt, the mere absence of an objection according to 8.3.1 is not considered as an approval.

### **8.3.3 Cooperation obligations**

The Parties undertake to cooperate to allow the timely submission, examination, publication and defense of any dissertation or thesis for a degree which includes their Foreground or Background subject to the confidentiality and publication provisions agreed in this Consortium Agreement.

### **8.3.4 Use of names, logos or trademarks**

Nothing in this Consortium Agreement shall be construed as conferring rights to use in advertising, publicity or otherwise the name of the Parties or any of their logos or trademarks without their prior written approval