

## **Registry Publication Guidelines**

for the publication of results from the German CF-Registry of the  
German Cystic Fibrosis Association (Mukoviszidose e.V.)  
[Publikationsordnung des dt. Mukoviszidose-Registers]

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This guideline was created and adopted in collaboration with the “CF-Registry working group”, the “Head Committee” of the CF-Registry and the Mukoviszidose Institute gGmbH (MI), in order to ensure that:

- access to data from the German CF-Registry takes place in a regulated way;
- the German CF-Registry is mentioned in a standardized way in publications;
- the quality of publications is improved; and
- (co)authorship is clearly regulated.

### **1. Who can request, evaluate and publish results from the German CF-Registry?**

After entering data into the German CF-Registry, each hospital department/clinic has the right to access their own data, i.e. they have unrestricted access to their own data for their use and publishing. Consultation with members of the “CF-Registry working group”/with the “Head committee” is not a requirement, but is recommended.

Beyond this internal use of own data, CF-Registry data may be requested by the following people/groups:

- Registry participants
- The benchmarking group
- Non-commercial research groups
- Commercial applicants

The “CF-Registry working group”/“Head committee” of the German CF-Registry can process and publish selected queries in cooperation with the centres involved.

Data accumulated from the annual reports are valid as published data. When these data are used, the source must be cited (for example: Annual report of the German CF-Registry; PDF; [www.muko.info.de](http://www.muko.info.de))

A publication in peer-reviewed journals should be strived for.

### **2. How are applications for analysis requests created and handled?**

Analysis requests can be directed to the “Head committee” of the CF-Registry through the “Registry Query Request Form” on the MI homepage. The enquiry process is regulated by the jointly valid document “Rules of Procedure for Registry Queries”

### **3. Internal Review Board**

BEFORE submission of an article to a journal or submission of an abstract to a congress, an internal review is carried out by the “Head committee”/“CF-Registry working group”, in order to:

- improve the methodological quality of the paper;
- to verify the consistency of any statements made (also for Articles published from the German CF-Registry);
- to check the statistical methods;
- to clarify formalities in writing (e.g. citation method); and
- to point out any possible limitations.

It is NOT the aim of this internal review to reject any given paper; on the contrary, support should be given during the publication process. The author is responsible to take the reviewer comments into account; obvious disregard of important points may, however, have an effect on future publications.

The “CF-Registry working group” appoints an internal review board of 4 members, with 1 member from the data management department, and the 3 remaining members being involved in active publishing. This board undertakes to carry out reviews within a 6-week time frame. Submission and feedback are carried out centrally through the MI.

#### **4. Citations and Co-authorship**

Where the German CF-Registry is relevantly involved in any results, the Registry must be cited as a co-author (see below for citation method).

- In German:  
AG Register - Deutsches Mukoviszidose-Register
- In English:  
Registry working group of the German CF-Registry

#### **Co-authorship**

Individual members of the “CF-Registry working group” are only to be cited as co-authors if they have been substantially involved in working on the paper.

In connection with this, the “CF-Registry working group” supports the „Uniform requirements for manuscripts submitted to biomedical journals“ of the International Committee of Medical Journal Editors (ICMJE)  
cf. C. Baethge: „Gemeinsam veröffentlichen oder untergehen“ [publishing or founding in collaboration] Dt. Ärzteblatt 2008; 105: 380-283) [Medical journal 2008; 105: 380-283]

#### **5. Citation of sites**

For citation of hospital departments/medical centres in publications, which have contributed data to the German CF Registry, there are two possibilities:

- a) Citation of the complete or selected list of sites and the medical staff to be credited e.g. in an appendix. This should be done as part of a study group, such that all medical staff to be credited are clearly indicated as "collaborators" with this publication. The complete list of sites should be cited as „AG Register des Deutschen Mukoviszidose-Register“(German), or "Registry working group of the German CF-Registry" (English). The current list can be found on the homepage of the MI. For the benchmarking group, a separate list is presented.
- b) as a reference to the MI homepage.

#### **6. On approval of the publication**

In order to record the dissemination of the scientific results of the German CF-Registry, a list is compiled of all publications coming from the Registry, which is updated on a yearly basis and published on the MI homepage. Authors are therefore requested to inform the MI when papers are approved, and to make a copy/file of the publication available to the Institute.

#### **7. Non-compliance with the Publication Guidelines**

If the rules as laid out above are not complied with, the CF-Registry will be convened and the author may be excluded from future data analyses by the German CF-Registry.

## **8. Validity of this Guideline**

This publication guideline is valid from 01.10.2016 until further notification of a new version. The guideline is to be followed for all publications in which data is used from the German CF-Registry. Only manuscripts that can be shown to have been submitted before 01.10.2016 are excluded.

## **9. Jointly Valid Documents:**

- General Rules and regulations of the German CF-Registry [Geschäftsordnung dt. Mukoviszidose-Register]
- Rules of Procedure for Registry Queries [Verfahrensordnung Registerstudien]
- Register Queries Schedule of Fees (in preparation) [Gebührenordnung Registerstudien (in Bearbeitung)]