MUKOVISZIDOSE
Mukoviszidose Institut gGmbH

# Registry Query Request Form

All requests to the German CF-Registry must be made through use of this form.The cost calculation for the Registry request depends on time and effort.

## Agreement on Data Use

The applicant (evaluator) is obliged:

- to follow the regulations as set out in the Rules of Procedure, Operation and Publication of the German CF-Registry.
- to only use the data made available for the aims described under: III. Project Information.
- to secure the data from unauthorised access and viewing by third parties, according to the data protection regulations in effect.
- to not modify the original data.
- to not establish any links between the data provided and further data sources, which could lead to identification of patients and CF-facilities participating in the CF-Registry through the use of additional data.
  → Exception: if there is a corresponding declaration of consent of the patient for this project.
- to ensure that verification of upholding the agreement in-house can be carried out at any time by the head committee of the CF-Registry, or a nominated representative.
- to inform the head committee of the CF-Registry or a nominated representative (entirely or also partially) about the results of the analysis (in writing/print, by voice, through electronic means, or other forms of presentation).

Date, Place: _____

First name and Surname (Applicant): _____

Signature: _____

## I. Application information

| | |
|---|---|
| Name: | |
| Title: | |
| Institution/Organisation: | |
| Position: | |
| Address: | |
| Email: | |
| Telephone no.: | |

| | |
|---|---|
| Member of the German CF Registry: | ☐ |
| Commercial applicants:<br>(Pharmaceutical companies, health insurance companies, commercial research institutes etc.) | ☐ |
| Non-commercial applicants:<br>(Universities, clinics, non-commercial research groups etc.) | ☐ |

## II. Disclosure/Conflicts of Interest

Please disclose information on any possible conflicts of interest through connections with private companies, especially with pharmaceutical companies (consultancy work, submissions, financial interests etc.):

## III. Project information

| | |
|---|---|
| Project title: | |
| Acronym: | |
| Version number: | |

| | |
|---|---|
| Date of application: | |

Short summary using layman's language (max. 300 words):

Scientific issue, aims, and justification/relevance to CF:

Reason for using the data/benefit of the data analysis (incl. any publications envisaged, reports, presentations, analyses etc.):

Study design:

Time frame for the project:

Start date (DD/MM/YYYY):

End date (DD/MM/YYYY):

Ethical approval available?

Yes ☐ No ☐ In process ☐

*If no, please give reasons:*

## IV. Data requirements

The possible sample size will be generated through our statistical analysis.

Years for analysis (availability 1995-2015):
(not all items are available for all reporting years)

| | |
|---|---|
| From (YYYY): | |
| To (YYYY): | |

Cohort description:

| | |
|---|---|
| I. Core data items (DataDictionary): | |
| II. longitudinal data items (DataDictionary): | |
| III. Additional items outside of the Registry data set (where appropriate, updating of the declaration of consent is required on part of the applicant): | |

## Information

Please send the completed document to the following address:

Email address:
registeranfragen@muko.info

Queries/Information:

Dr. Sylvia Hafkemeyer
shafkemeyer@muko.info