

Supplement table S1: Composition of the working group for the development of the standardised PCD follow-up form (FOLLOW-PCD) in alphabetical order

Name	Country	Specialty
Amirav Israel	Israel	Paediatric pulmonologist
Barben Juerg	Switzerland	Paediatric pulmonologist
Baynton Laura	United Kingdom	Nurse
Boon Mieke	Belgium	Paediatric pulmonologist
Casaulta Carmen	Switzerland	Paediatric pulmonologist
Castillo Sylvia	Spain	Paediatric pulmonologist
Clement Annick	France	Paediatric pulmonologist
Dehlink Eleonora	Austria	Paediatric pulmonologist
Eber Ernst	Austria	Paediatric pulmonologist
Escribano Amparo	Spain	Paediatric pulmonologist
Escudier Estelle	France	Diagnostic scientist
Georgy Huda	Israel	Paediatric pulmonologist
Goutaki Myrofora	Switzerland	Epidemiologist
Halbeisen Florian	Switzerland	Epidemiologist
Harris Amanda	United Kingdom	Nurse
Hogg Claire	United Kingdom	Paediatric pulmonologist
Honore Isabelle	France	Adult pumonologist
Jackson Claire	United Kingdom	Diagnostic scientist
Jung Andreas	Switzerland	Paediatric pulmonologist
Karadag Bülent	Turkey	Paediatric pulmonologist
Koerner-Rettberg Regula	Germany	Paediatric pulmonologist
Kuehni Claudia E.	Switzerland	Epidemiologist
Lazor Romain	Switzerland	Adult pumonologist
Legendre Marie	France	Diagnostic scientist
Lucas Jane S.	United Kingdom	Paediatric pulmonologist
Marsh Gemma	United Kingdom	Physiotherapist
Maitre Bernard	France	Adult pumonologist
Moya Eduardo	United Kingdom	Paediatric pulmonologist
Moreno Antonio	Spain	Paediatric pulmonologist
Nielsen Kim G.	Denmark	Paediatric pulmonologist
Papon Jean-François	France	Otolaryngologist
Price Mareike	Germany	Paediatric pulmonologist
Romero Teresa	Spain	Paediatric pulmonologist
Rubbo Bruna	United Kingdom	Epidemiologist
Rumman Nisreen	Palestine	Paediatric pulmonologist
Schwerk Nicolaus	Germany	Paediatric pulmonologist
Schofield Lynn	United Kingdom	Physiotherapist
Shoemark Amelia	United Kingdom	Diagnostic scientist
Thouvenin Guillaume	France	Paediatric pulmonologist
Wilkins Hannah	United Kingdom	Physiotherapist
Zivkovic Zorica	Serbia	Paediatric pulmonologist

Supplementary information: DATA TRANSFER AGREEMENT template

DATA TRANSFER AGREEMENT

between

University of Bern
Institute of Social and Preventive Medicine, 3012 Bern
Switzerland

(hereinafter referred to as "University")

and

(hereinafter referred to as "Partner")

Preamble

In the framework of the EU FP7 funded research project "BESTCILIA" (GA nr. 305404), University developed the international PCD Cohort (iPCD Cohort) ("Project"). Among University's tasks in the Project is the preparation of a joint dataset for analysis out of different datasets collected by several partners from within or outside the Project, the evaluation and interpretation of certain epidemiological and clinical data. For the collection of standardised prospective clinical and patient-reported data, University has developed a data collection form linked to the iPCD Cohort, FOLLOW-PCD. The Partner is willing to provide patient related data relevant for the Project ("Data") using FOLLOW-PCD, subject to the terms and conditions of this Agreement.

The parties thus agree as follows:

- 1) The Data shall remain the property of the Partner. University shall treat the Data confidential and not distribute the Data to third parties, except that University shall be allowed to transfer extracts of datasets to the partners contributing data within and outside of collaborator of the iPCD Cohort, according to Art. 5 below and upon consent of Partner. In the event Partner should decide to withdraw his consent to the use of his Data as described herein, it shall have the option to terminate this Agreement. University will then return and not further use the Data.
- 2) The Partner shall be responsible for ensuring that sent Data are strictly pseudo-anonymized (as described in Exhibit B) and is provided in accordance with applicable national/local data protection laws.
- 3) The Partner shall adhere to safe data transfer procedures as will be defined by University.
- 4) In the event University sees potential to scientifically publish findings derived from/related to the Data, University will provide to Partner a concept sheet for such publication. The Partner shall have the right to provide input to the concept sheet and the planned publication overall. Once the parties agree on the modalities regarding such publication they shall conclude a separate publication agreement along the lines of the template attached hereto as Exhibit A. For clarity, the Partner shall have no obligation to enter into a

publication agreement with University. If the Partner opposes to a publication pursuant to this Article, University will not use the Data for this specific publication.

- 5) Publications: For the firstline papers, essential for grant funding the iPCD Cohort, University will take the lead. Concept sheets on other topics ("Additional Papers") can be proposed by all partners contributing data. All concept sheets have to be approved by all partners contributing data to the proposed paper under question.

Once the parties agree to publish, the following general publication rules shall apply:

- general authorship rules of the International Committee of Medical Journal Editors will be adhered to
- the first and last author will usually be from the institution which is responsible for the specific paper.
- whenever possible, all partners contributing data on a significant number of subjects will be offered a co-authorship. Depending on the topic of the publication, target journal and number of involved data providers, this general rule might need to be adapted for some publications.
- second and second last co-authorship will be offered to co-authors who have a major input in data analysis or writing, or who provided data on a very large number of subjects
- remaining co-authors will be listed alphabetically
- all partners contributing data shall be duly acknowledged

For Additional Papers, University will extract the appropriate anonymous dataset ("Dataset") and send it to the relevant partner ("Recipient"). Such transfer of data needs to be approved by the data provider(s) concerned. When possible (depending on funding), University can offer to perform the statistical analysis for the partner having proposed the publication. The funding necessary for analysis and writing of Additional Papers will be organized by the institution which is responsible for the specific paper. The Recipient agrees to use the Dataset only for the agreed publication and will otherwise warrant confidentiality of the Dataset and will destroy all copies of the Dataset in his possession within 3 months after this publication is accepted.

For University:

For Partner:

Bern, Date: _____

Place, Date: _____

Prof. Dr. Claudia Kuehni
Principal Investigator

Collaborator

Exhibit A: Template for Publication Agreement

Exhibit B: Anonymization of Data and safe Data transfer procedures

Exhibit A: Template for Publication Agreement

PUBLICATION AGREEMENT

between

**University of Bern
Institute of Social and Preventive Medicine,
3012 Bern, Switzerland**

(hereinafter referred to as "University")

and

(hereinafter referred to as "Partner" or in the event of several partners as "Partners", as the case may be)

Preamble

WHEREAS, University is the lead centre for the iPCD Cohort. Among University's tasks in this project is the preparation of a joint dataset for analysis out of different datasets collected by several partners from within or outside the project, the evaluation and interpretation of certain epidemiological and clinical data;

WHEREAS, University and Partner(s) have concluded a Data Transfer Agreement on _____ [execution date] and Partner has provided data to University for evaluation within the iPCD Cohort ("Data");

WHEREAS, the University and Partner intend to publish certain findings based on the Data.

The parties thus agree as follows:

Article 1: Publication

- 1.1 The parties intend to jointly publish, based on a concept sheet and an analysis dataset provided by University, the following scientific findings _____ [working title] in _____ [Journal] ("Publication"). If the manuscript is rejected by the journal of choice, the choice of alternative journals will be made in discussion between University and all Partners.
- 1.2 As agreed in the Data Transfer Agreement, the following publication rules in accordance with the regulations of the International Committee of Medical Journal Editors shall apply:
 - the first and last author will be from the institution which is responsible for the specific paper.
 - all partners contributing significant numbers of datasets will be offered a co-authorship.
 - second and second last co-authorship will be offered to co-authors who had a major input in data analysis or writing, or who provided a very large number of datasets
 - remaining co-authors will be listed alphabetically
 - all partners contributing data shall be duly acknowledged

Thus, the parties now agree upon the following authorship for publication:

- First author: _____
- Last author: _____
- Second author: _____
- Second last author: _____
- Co-authors or contributing partners defined according to the criteria of the International Committee of Medical Journal Editors; from University and from Partner(s):

...

1.2 The planned timeline of the publication is as follows:

- dataset delivered from University to the partner responsible for this publication:

- results (tables) circulated by the responsible partner to all co-authors and data providers: _____
- first draft of the publication circulated by the responsible partner to all co-authors and data providers: _____
- final draft of the publication circulated by the responsible partner to all co-authors and data providers: _____
- latest possible date for submission of the publication to the target journal:

1.3 If these deadlines are not kept and the manuscript is not submitted to the target journal 2 years after receipt of the data at the very latest, the responsible partner loses its leadership and the topic is again open for other data providers (upon circulation and acceptance of a concept sheet).

Article 2: Miscellaneous

No agreements altering or supplementing the terms may be made except by a written document signed by the duly authorized representatives of the parties.

For University:

For Partner:

Bern, Date: _____

Place, Date: _____

Prof. Dr. Claudia Kuehni
Principal Investigator

Collaborator

Exhibit B: Anonymization of Data and safe Data transfer procedures

Anonymization of Data

Before uploading the Data, make sure it is pseudo-anonymised:

1. Assign each patient a unique patient identification code.
2. You should keep a list of the codes corresponding to each patient, so you can in case you need to get further detail out of the patient charts later. This list is for your own internal use, never send it to us.
3. Do not enter any names of your patients in the dataset.
4. Do not enter any contact details (address, phone numbers, e-mail).
5. Do not enter any other type of identifying data (e.g. social security number, health insurance number, official patient number in the hospital).
6. If it is required in your country to not include date of birth into pseudo-anonymized data, replace the day of the date of birth by 15.

Safe data transfer procedures

(This is a draft. It will be personalized in the final version).

1. For the transfer of the data the program REDCap will be used, which is a safe online platform hosted by the University that allows to the Institution to enter anonymized cross-sectional and longitudinal data and also extract them directly into various format.
2. University has created detailed instructions for the use of REDCap and will offer support to Institution when needed. Institution will have personalized accounts for its collaborators entering the data and has the obligation to keep the passwords for accessing REDCap strictly confidential.