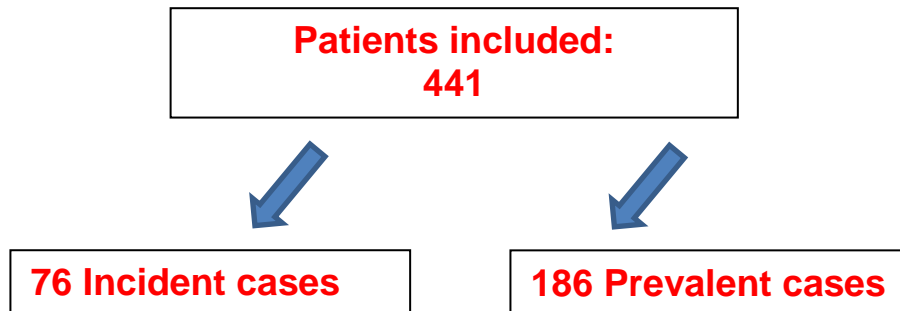




Observational trial



Completed cases: 113

Peer reviewed, but lost of follow up: 94

Peer review pending: 15

Working on data: 81

PROs available in 146 cases

Blood sent to the Biobank in Munich in 199 cases

High data quality is a hallmark of the register! Therefore in general:

1. Please always complete the PROs and fill them out for the appropriate visit. After that, please send the sheets via mail or post to Munich for the double data entry.
2. If you are not able to upload DICOM images, we can do that for you. Please send us the images via CD.
3. We need EDTA and Tempus blood from every patient and their parents. Moreover we need stained slides or wax block, if a lung biopsy was done.
4. Please note, that we primarily want to collect prospective data. Therefore the follow up data is the most important point to analyse this “real time” information.

Complete cases make a lot of fun and give satisfaction



Observational trial – News I

chILD EU meeting in Ankara

It was a wonderful and superb ILD meeting in Ankara. It took place from 15th to 16th January 2016. The broad range of faculty including rheumatologist, immunologist and adult physicians gave a broad input of knowledge. Thanks again to Nural Kiper, her team, and all participants!



Observational trial - News II

PROs: Patient Reported Outcomes (= Health economics and Quality of Life (QOL)):

Changes to make it more convenient:

- QoL added to all visits
- One questionnaire for all patients
- Only difference: incident cases fill in the questionnaire also after 3 months (Table 1)
-

Remember:

- Incident cases = patients with newly diagnosed diseases, presenting to the referring center
- Prevalent cases = patients with already diagnosed disease, known to the referring center

Table 1a: Observational trial – incident cases

	Baseline	1 month	2 months	3 months	6 months	12 months	annual y
Basic data	x			x	x	X	x
Healthcare utilisation	x			x	x	X	x
Quality of life	x			x	x	X	x



Observational trial

Table 1b: Observational trial – prevalent cases

	Baseline	1 month	2 months	3 months	6 months	12 months	annually
Basic data	x				x	x	x
Healthcare utilisation	x				x	x	x
Quality of life	x				x	x	x

Updated download area for PROs in Secutrial

Download area

chILD-EU: Observational study

- [1. Short introduction to the database](#)
2. Consent forms (Please download directly from ChILD EU-website). These and other pat
- [3. Worksheets for visits](#)
 - [Worksheets chILD baseline-visit](#)
 - [Worksheets chILD follow up-visit](#)
 - [Worksheets chILD Baseline-Visit \(deutsch\)](#)
 - [Worksheets chILD Follow Up-Visit \(deutsch\)](#)
- [4. PROs \(=Health economics and Quality of Life\) Baseline, 3, 6, 12 months, annually:](#)
3 months only incident cases, 6 and 12 months and annually all;
*incident=patients with newly diagnosed diseases, presenting to the referring center / *prevalent=patients with
5. Peer reviewers' Handouts
 - [Discussion Panel](#)
6. Information for National Coordinators

Click on the 4.PROs-Link and download the file (it takes about 20 sek)

Open the file and click on the next file then choose your language:


- 1_1_German-Baseline-3-6-12months-annually
- 1_2_English-UK(only)-Baseline-3-6-12months-annually
- 1_3_English-notUK-Baseline-3-6-12months-annually
- 1_4_French-Baseline-3-6-12months-annually
- 1_5_Italian_Baseline-3-6-12months-annually
- 1_6_Turish-Baseline-3-6-12months-annually
- 1_7_Polish-Baseline-3-6-12months-annually

Open the file for your PDF-version

NEW PROs in Polish available: many thanks to Dr Lange and Dr Krenke from Warszawa!



Observational trial

-  Manual_SOP_English.pdf
-  PRO_37_Polska_1.-12. months-completed.pdf
-  PRO_38_Polska_13-24 months-completed.pdf
-  PRO_39_Polska_2-4 lat-completed.pdf
-  PRO_40_Polska_5-7 lat-completed.pdf
-  PRO_41_Polska_8-12 lat-completed.pdf
-  PRO_42_Polska_13-18 lat-completed.pdf

Always IMMEDIATELY decide on the observational type and generate “more visits”. This will activate a single reminder for upcoming visits.

If you have any questions give notice to chILD-EU.register@med.uni-muenchen.de.
Send YOUR news for this newsletter to meike.hengst@med.uni-muenchen.de.