



Guidance for conducting „Patient education” – Checklist

<input type="checkbox"/>	Announcement of Patient Education (e.g. by the healthcare professionals or nursing staffs)
<input type="checkbox"/>	Prevalent cases started with baseline evaluation questionnaires before visit Incident cases started with the list of issues
<input type="checkbox"/>	Next, list of subjects fill in before visit
<input type="checkbox"/>	Collect baseline evaluation questionnaires and list of issues (before visit)
<input type="checkbox"/>	Patient education preparation
<input type="checkbox"/>	Definition of the most important information needs Patient Education
<input type="checkbox"/>	Conduct the Patient education session
<input type="checkbox"/>	Involve the Information booklet
<input type="checkbox"/>	Post assessment: questionnaire fill in by patients and caregivers directly after patient education session
<input type="checkbox"/>	Assessment of physicians: fill in after conduct one patient education session at least
<input type="checkbox"/>	Documentation of medical variables from the register or worksheets
<input type="checkbox"/>	Mailing self-efficacy questionnaires for re-assessment (between 4 to 6 weeks after patient education session)



How to educate patients? – Detailed Information about implementation and evaluation

Clinics for Pilot testing:

- 1 Munich
- 2 Hannover

Criteria for inclusion for Pilot testing:

Criteria for inclusion of patients:

- (1) interstitial lung disease (chILD) is clinical suspected
- (2) age of children and adolescents is between 0 to 18 years
- (3) sufficient German language knowledge to answer the questionnaires and fill in the list of topics as well to understand the information of the patient education session and information material

Criteria for inclusion of parents:

- (1) presence of a child/foster child (≤ 18 years) with the medical reasonable suspicion if interstitial lung disease (chILD)
- (2) sufficient German language knowledge to answer the questionnaires and fill in the list of issues as well to understand the information of the patient education session and the information material

Conduct Patient education

The subsequent section give practical advice for a possible design of a patient education session.

1. Step: Patient information about the programme and baseline assessment

Patients and/or their caregivers should point to the methodology of the programme and its evaluation, before they start with the patient education session.

Prevalent cases start with the baseline assessment. Subsequently, they fill in the list of issues. **Incident cases** start with the list of issues. All patients 8 years and above and his/her caregiver should complete the evaluation questionnaires and list of issues.

2. Step: Provide the list of issues for Patient education

To assess patients' needs, all patients of 8 years and above and caregivers are filled in the list of issues prior consultations and clinical visits. In a free text, the patient and/or his/her caregiver has the possibility to specify further questions. This list of issues should be filled from patient and/or his/her caregiver before clinical visits. It should be chosen a maximum of 3 items. These items should be prioritized from 1 to 3.



Before consultation, the physician should be oriented to questions of the patient and/or his/her caregiver.

Patients should make a note of the time before beginning and at the end of the patient education session.

3. Step: Targeted individually Patient education session

Before the education session starts, questionnaires and list of issues will be collected. Patient education should basically happen during clinical visits. For the scheduling, a timeslot of 30 minutes should be reserved at least, to assess the information needs, to conduct the educational session, and to evaluate this session.

Incident cases have probably more information needs and a larger time frame shall be provided.

Questions and needs should have priority in this treatment. Patient education should be conducted based on the prioritized items of the list of subjects. Patient education should be structured and individualized. Relevant chapters of the patient information booklet should be integrated into the educational session. Provided images and illustrated examples of patients affected with chILD should be used, to illustrate medical issues. The use of flipcharts or adhoc produced graphics is useful to illustrate medical information.

Questions of the patient and/or his/her caregiver are arising during the patient education session, but not related to the actual subject, should be noted and picked up at the end of the session or during another visit.

Existing knowledge, age, developmental stage and medical background should be considered. A patient- and family-centered communication is recommended. For patient education with **younger children** we recommend a child-centered approach and the integration of the caregivers. Patients who have reached **school age** should already be treated as experts of their illness. As early as possible they should become the focus person in therapy, parallel to their caregivers. Education for **adolescents** should primarily work with the patients, caregivers can be secondarily integrated and should be informed after the educational session with their child about learning contents.

4. Step: Examination of goal-attainment

An evaluation of the patients' satisfaction with his/her received education is performed immediately after the session. The assessment of the patient information materials as well as self-efficacy should be conducted between 4 to 6 weeks after the educational session.



The assessment of the healthcare professionals should be conducted once they have conducted at least one educational session.

5. Step: Patient education as continuous process

Previous steps can be repeated if necessary with the scope of further appointments in the clinic.



Checklist for parents of patients with chILD

Hello,

Your child has a interstitial lung disease. This forms of diseases called chILD. Please read the following list of subjects. For our today's consultation we will ask you to circle 3 chosen subjects, such you need more informations (**a maximum of 3**). Please specify how important this subject is for you, to marke with numbrs from 1 to 3. **1 (= "That is particular important for me to get further information!")**, **2 (= "That is important to me to get further infmration!")**, **3 (= "That is less important for me to get further infomration!")** You can write down your own questions if you needed. If you filled this list of subjects, we are requested to return this list to the healthcare rofessionals.

Thank you very much!

Please make a note of the:
time for beginning: _____
time for the end: _____

Structure and function of the respiratory tract	

What is chILD?	
What are the symptoms of chILD?	
What are the forms of chILD	
Which degrees of severity there are?	
What are the causes of chILD?	

Diagnostic	
How the diagnosis is made?	
How I can prepare my child for consultation in the clinic?	
It may something else as chILD?	
Which diagnostic tests my child must unerwent?	
The diagnosis is definit, and now?	

chILD-treatment	
Who is involved in my treatment?	
Oxygen therapy	
treatment by medication	
Additional non-medicational treatment	

Everyday life with chILD	
Feeding and nutrition	
By which I perceive impairment?	
avoid complications	
emergency procedures	
School/kindergarten/free time	
Traveling on holidays	

Social and emotional support	
Self-help groups	
Stress-management (handling stress, anxiety and negative thoughts)	
Familie life	
social law	

If you have any questions? Please specify!



Checklist for patients with chILD (< 8years)

Hello,

you have a interstitial lung disease. This forms of diseases called chILD. Please read the following list of subjects. For our today's consultation we will ask you to circle 3 chosen subjects, such you need more informations (**a maximum of 3**). Please specify how important this subject is for you, to marke with numbrs from 1 to 3. **1 (= "That is particular important for me to get further information!")**, **2 (= "That is important to me to get further infmation!")**, **3 (= "That is less important for me to get further infomration!")** You can write down your own questions if you needed. If you filled this list of subjects, we are requested to return this list to the healthcare rofessionals.

Thank you very much!

Please make a note of the:

time for beginning: _____

time for the end: _____

Structure and function of the respiratory tract

What is chILD?

What are the symptoms of chILD?

What are the forms of chILD

Which degrees of severity there are?

What are the causes of chILD?

Diagnostic

How the diagnosis is made?

How I can prepare for consultation in the clinic?

It may something else as chILD?

Which diagnostic tests I must unerwent?

The diagnosis is definit, and now?

chILD-treatment

Who is involved in my treatment?

Oxygen therapy

treatment by medication

Additional non-medicalational treatment

Everyday life with chILD

Feeding and nutrition

By which I perceive impairment?

avoid complications

emergency procedures

School/kindergarten/free time

Traveling on holidays

Social and emotional support

Self-help groups

Stress-management (handling stress, anxiety
and negative thoughts)

Familie life

social law

If you have any questions? Please specify!

