



# ECORN-CF

- Acronym for „**E**uropean **C**entres **O**f **R**eference **N**etwork for **C**ystic **F**ibrosis“
- Pilot project of the EU (DG SANCO) with 60% EC co-funding for three years (May 2007 – Apr 2010)
- Funding since May 2010 by:

This is one example of a pilot project which has achieved to use the EC funding as start-up money and to get another funding period from the involved patient organizations.

The project has won a prize in Germany as a model project improving patient empowerment – this money helped bridge the funding gap.

## Expert Advice on Cystic Fibrosis – How Does it Work?

**1.**

**Interested people**  
- lay people or experts -  
**submit questions**  
in currently  
**10 languages**

online at

**ecorn-cf.eu**

**2.**

**Experts** from different  
fields **answer** the  
**questions in their**  
**mother tongue.**

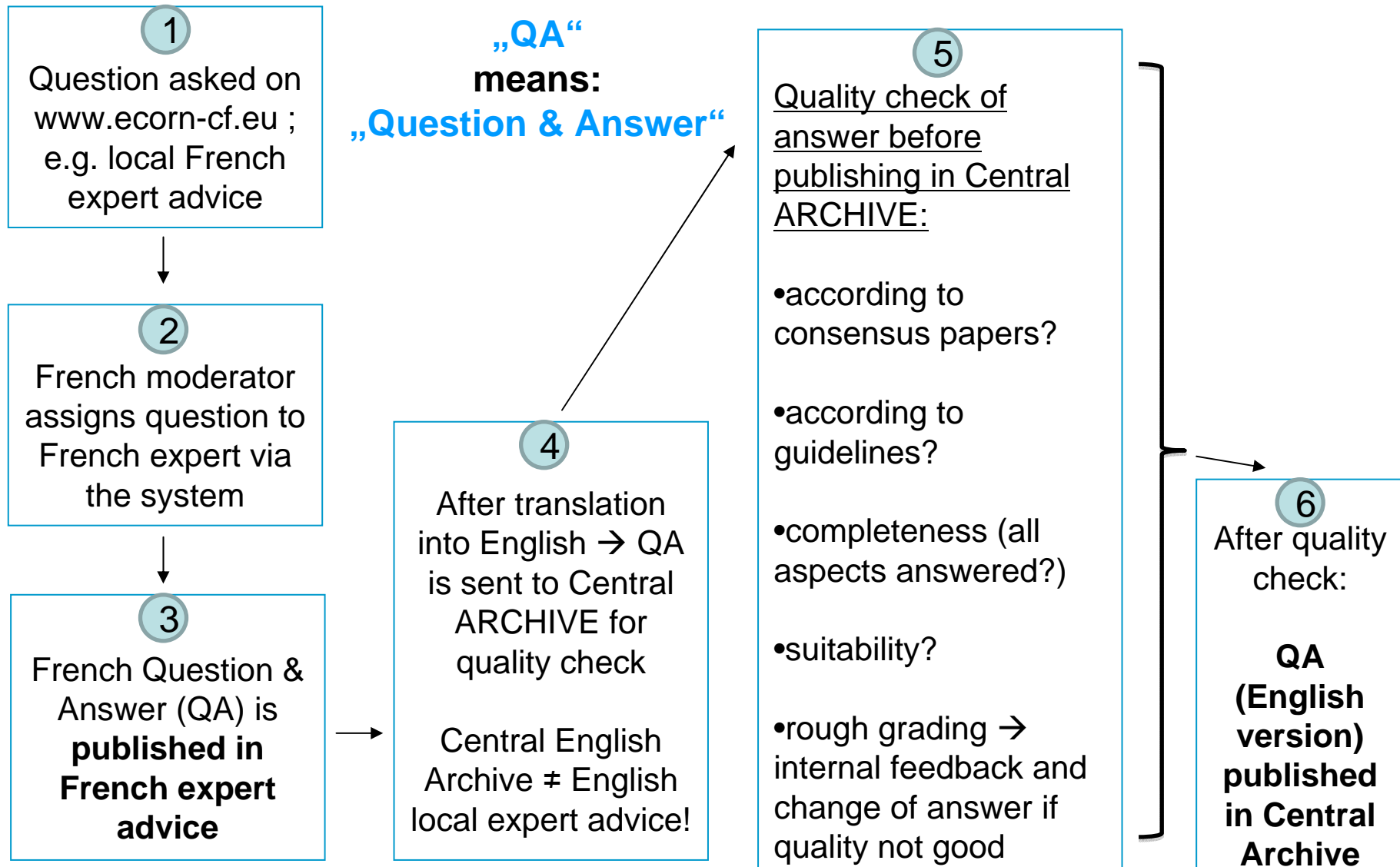
Question & answer (QA)  
pairs are **published**  
on the **local platform.**

**3.**

The **English translation**  
of a relevant answer  
is **quality checked**  
and amended if  
necessary.

All checked QA pairs  
are published in the  
**Central Archive.**

# The web-based system of ECORN-CF

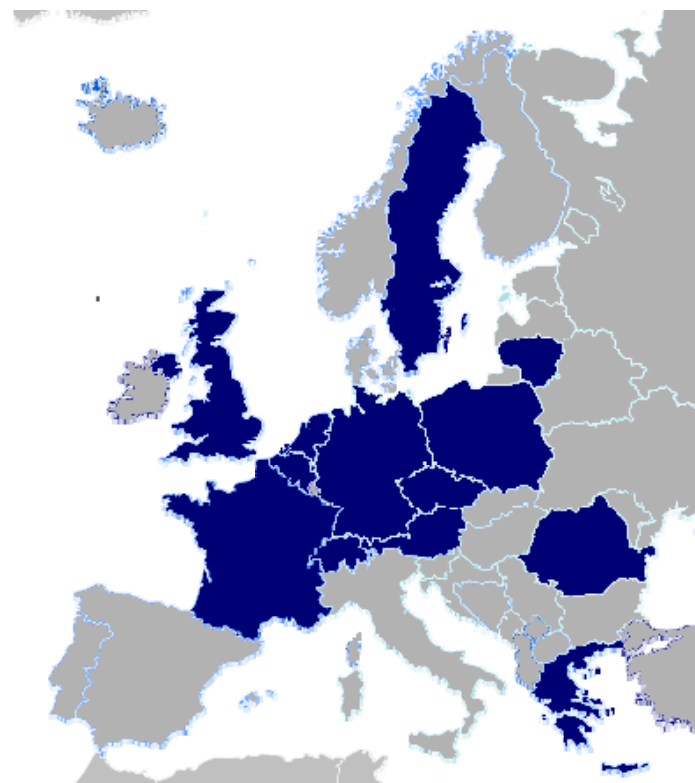




## Expert Advice on Cystic Fibrosis – Who is Part of it so far?

### Languages currently represented by ECORN-CF participants:

- Czech – Czech Republic
- Dutch – Belgium, Netherlands
- German – Germany, Austria, Switzerland
- Greek – Greece
- English – United Kingdom
- French – France
- Lithuanian – Lithuania
- Polish – Poland
- Romanian – Romania
- Swedish – Sweden





## Further Activities of ECORN-CF

- **Papers of ECORN-CF Study Group**
  - “Travelling with cystic fibrosis: Recommendations for patients and care team members”; Journal of Cystic Fibrosis Volume 9 (2010) 385 – 399
  - A paper called “Quality assessment of expert answers to lay questions about cystic fibrosis from various language zones in the ECORN-CF project” has been submitted in May 2011.
- **Quality Round Table Meetings** (four so far; two in Frankfurt, two in Prague)  
The next meeting is planned for the annual meeting of the ECFS in June 2012 in Dublin.
- **Fine Scoring (cross-border)**: A team of a least five experts from different countries scores a certain set of question & answer pairs from all participating countries according to a system that was developed by ECORN-CF (see article mentioned above).  
The next fine scoring is planned for Spring 2012.



## Expert Advice on Cystic Fibrosis – Do You Need More Information?

**For further information  
on how to join the ECORN-CF expert advice,  
please contact:**

Prof. Dr. Thomas O. F. Wagner  
Goethe University Hospital Frankfurt  
**info@ecorn-cf.eu**