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Expert Advice on Cystic Fibrosis

European Reference Networks & Centres of Expertise: ECORN-CF

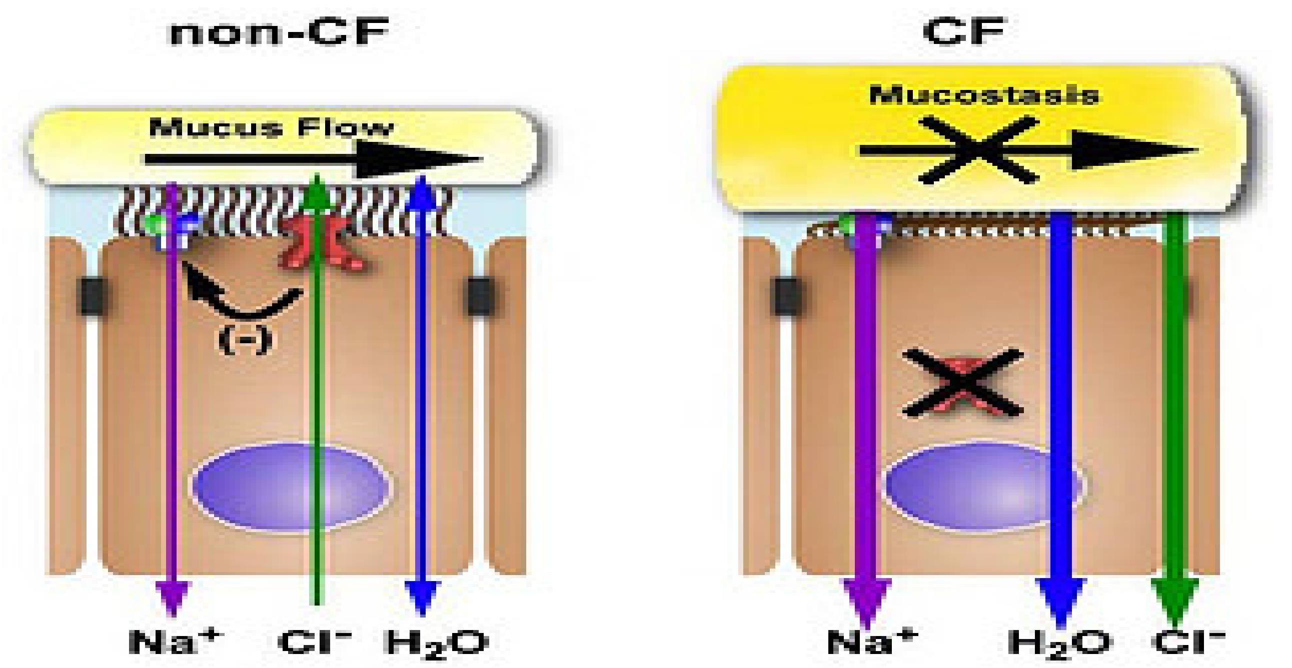
About Cystic Fibrosis (CF)

Epidemiology

- Most common autosomal-recessive lethal hereditary disorder in Caucasians
- In Europe:
  - Median CF birth prevalence 1/3500
  - Frequency of „healthy carriers“ of one CFTR-mutation 1/30

Aetiology

- Mutation in cystic fibrosis transmembrane conductance regulator gene (CFTR) → codes for a chloride channel in the cell membrane:



Source: microbiologybytes.com

Source: Mukoviszidose1.de/davidarling.info

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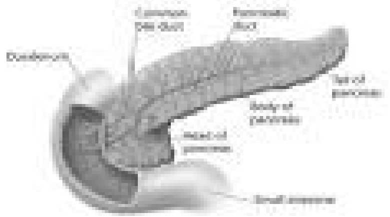
→ Sticky / viscous secretions in many organs, mainly



Chronic obstruction and infection

↓

Destruction of lung tissue

↓

Respiratory failure

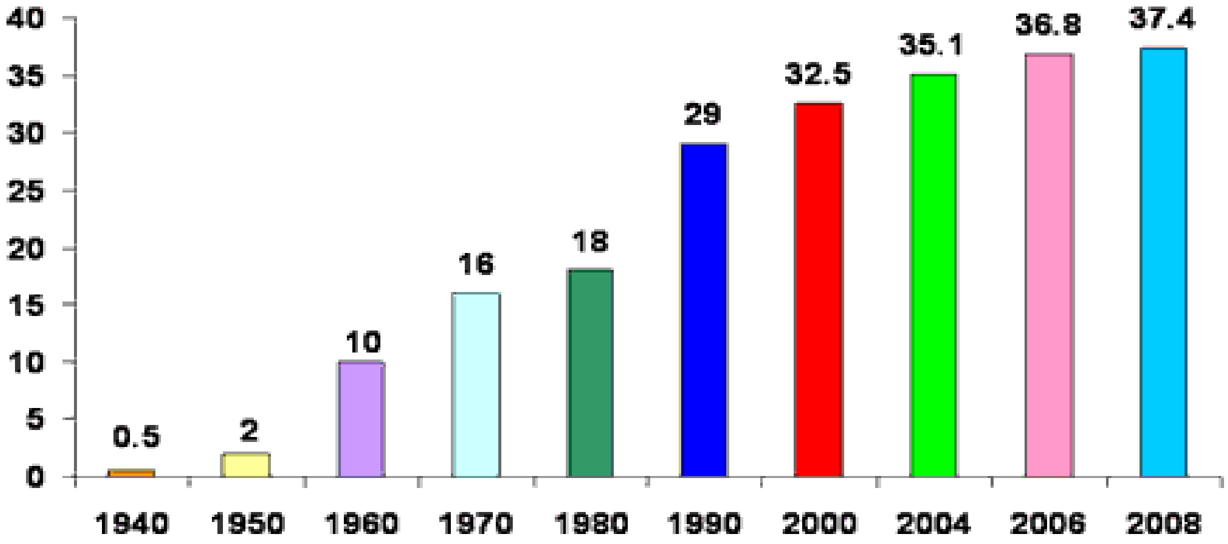
Chronic obstruction and damage of pancreatic tissue

↓

No pancreatic enzyme release

↓

Maldigestion / failure to thrive



Average Life Expectancy in Cystic Fibrosis
Better Treatment = Improved Survival

Source: Cystic Fibrosis Foundation

For patients born after 2000 estimated: median life expectancy will be around 50 years

→Better treatment: availability of enzymes, antibiotics and specialized care

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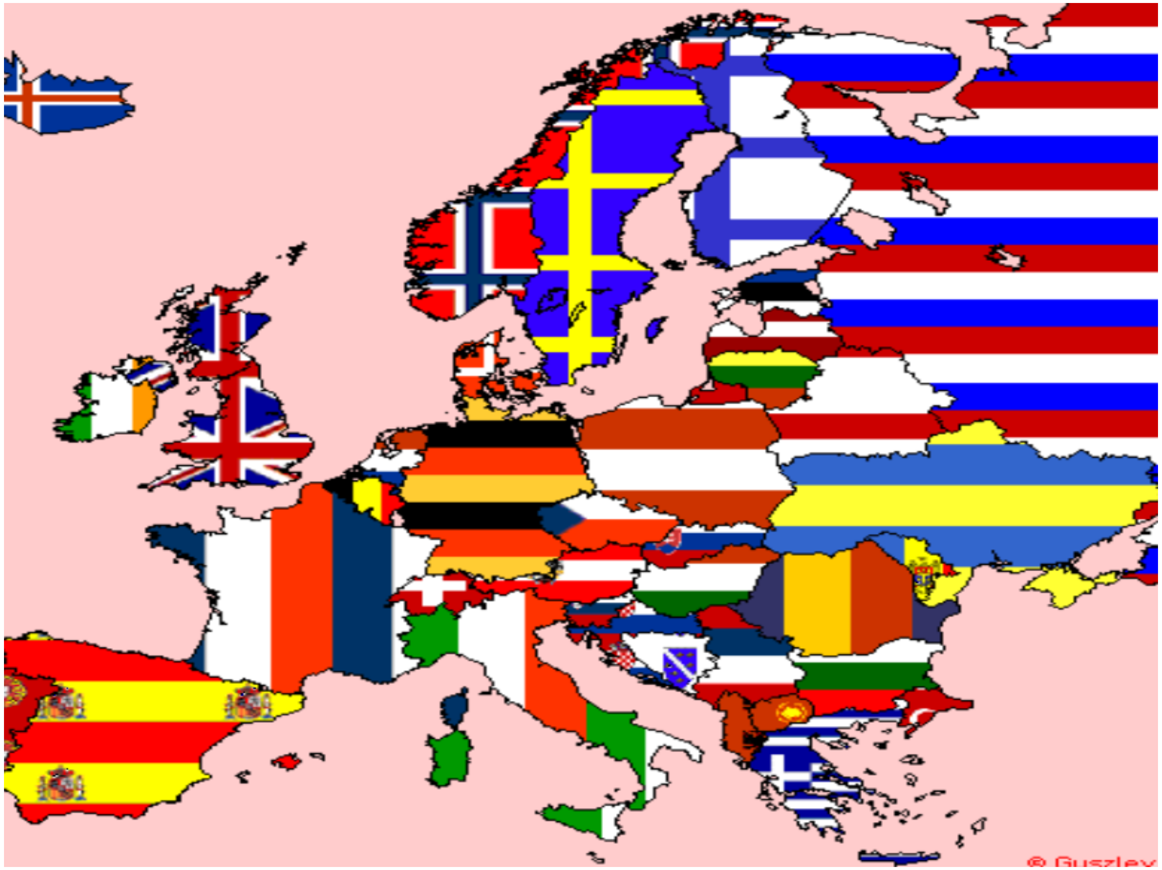

Quality of CF-care in Europe: are we on the same level?

Largest multinational study about health of CF-patients (data of about 29.000 patients from 35 European countries, Mc Cormick et al. 2010, Lancet):

→ CF-patients from EU-member states had better survival chances then patients from non-EU states (defined via membership in 2003, non-EU states mainly Eastern European countries)

→ Problem of availability of drugs, equipment, specialized care, especially for population of countryside as CF centers often located only in large cities

Equalization of quality of care for CF-patients all over Europe is of utmost importance

Initiation of the project "European Centres of Reference Network for Cystic Fibrosis“ ECORN-CF, funded by EU-commission as a pilot project

May 2007

Building up an internet platform on a European level

Team of experts answers questions of:

- CF-patients, relatives and all interested lay people
- Treating staff of CF-patients: physicians, physiotherapists etc.

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AIMS

- Simple and quick access to high-quality expert advice about CF for patients and professionals irrespective of origin, mother language and geographical distance to the next CF-center
- Exchange of expert knowledge between participating European countries
- Improvement of quality of expert answers via control- and feedback-systems
- Extraction of topics that need to be worked-up in order to find a common European consensus

How do we achieve those aims?

Implementation of the European internet-platform ECORN-CF with participating language zones

May 2007	Start of the project
October 2007	Czech, English, German
December 2007	Romanian
January 2008	Lithuanian
April 2008	Dutch, Polish
March 2009	Greek
October 2010	French

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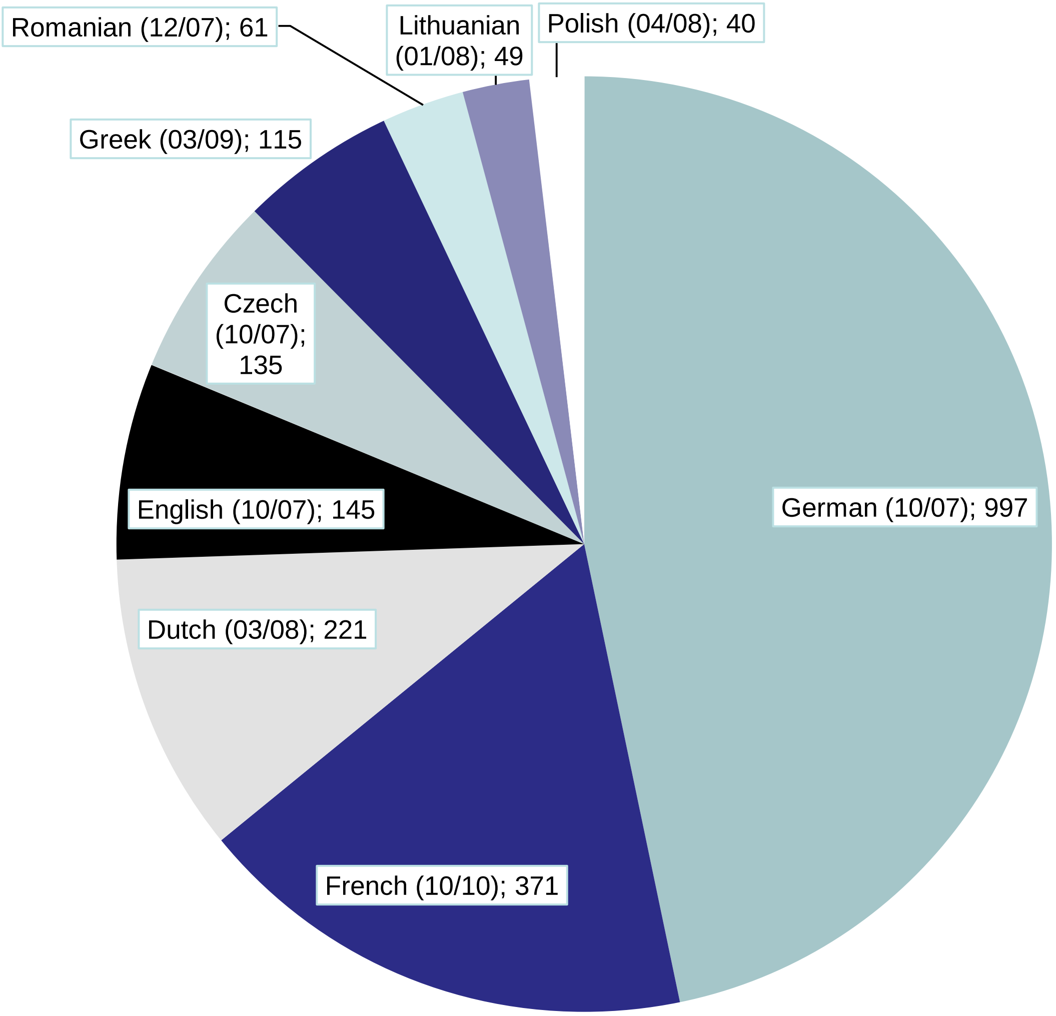
ECORN-CF:
Participaiting language zones and number of questions



∑ 2134 [02/13]

The way from question to answer

Home | ECORN-CF Archive | Contact | **English (Select Language)**

Expert Advice

Expert Advice | Central Archive | Team | About ECORN-CF | Local Partners | Cystic Fibrosis

Select Language

Please select your language.

- Česky (Czech)
- Deutsch (German)
- Ελληνική (Greek)
- English
- Française (French)
- Lietuviškai (Lithuanian)
- Nederlands (Dutch)
- Polski (Polish)
- Limba Română (Romanian)

Topics
Ask a Question
Travelling with CF
Edit Profile
Search
QA list for moderators
QA list for local editor
User Guides
Edit Keywords
Statistics
Reference documents

Login successful

You are now logged in as 'd'alguen'

Ask a Question

Before asking a new question: Please have a look at the topic list and use the search utility in order to find out if your question has already been answered.

Subject

TEST QUESTION: Cystic Fibrosis

Question

Dear expert team,

I have an important question regarding Cystic Fibrosis: ...

Best regards,
Testuser

Would you like to remain anonymous?

You can ask questions in this forum anonymously. In order to place an anonymous question, you have to make sure, you´re not logged in.

Please consider: With anonymous questions unfortunately we cannot send a notification E-Mail to you, if your question was answered.

If you register and login before you ask a question, we can inform you by E-Mail, as soon as your question is answered.

Your data, like name and email address, are only accessible to our experts. They are not visible for the public and are not made available to anybody else.

Before you ask a question,

User login

Enter your username and password here in order to log in on the website:

Username:

Password:

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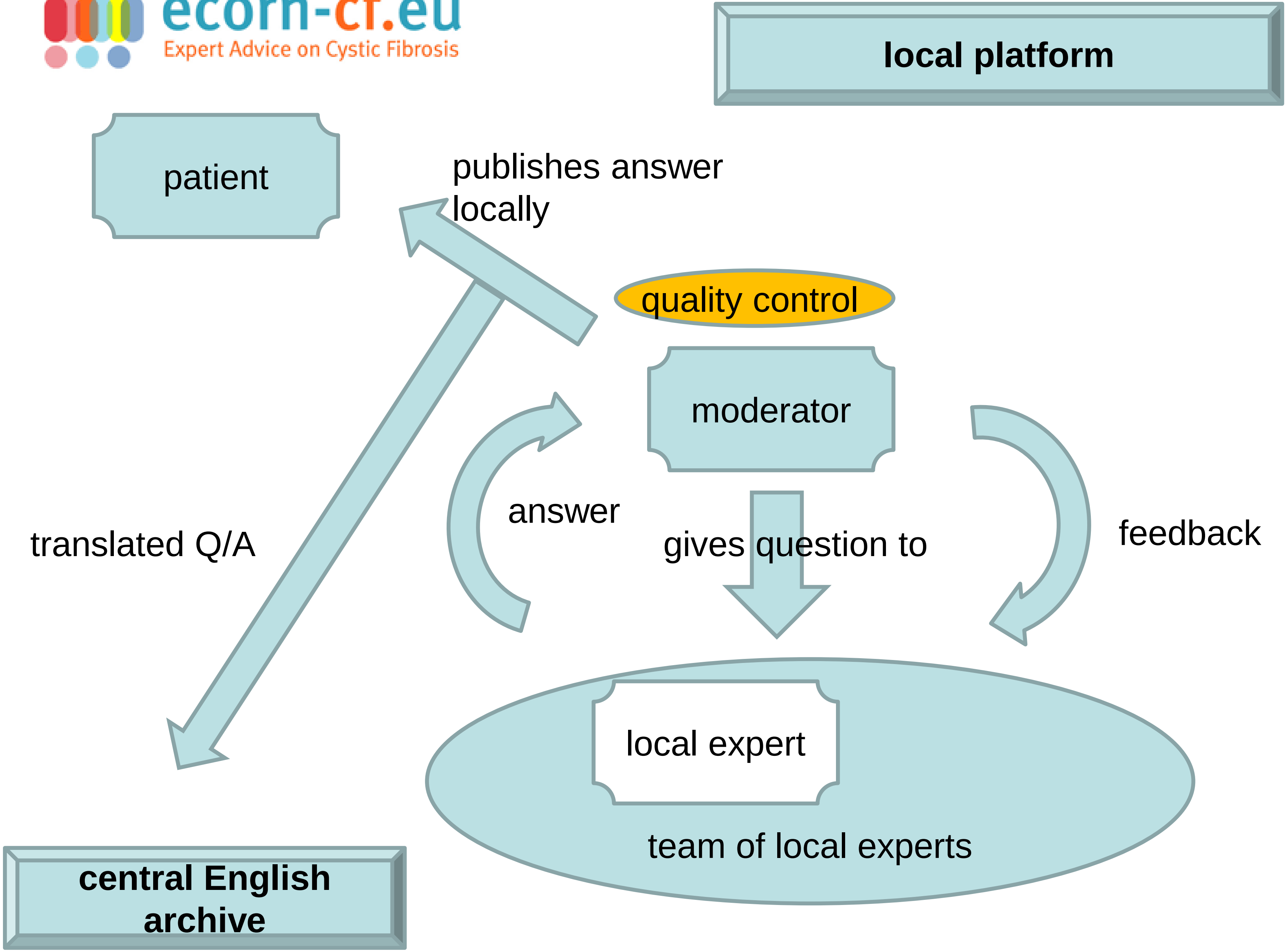

local platform

patient

publishes answer locally

quality control

moderator

answer

gives question to

feedback

translated Q/A

local expert

team of local experts

central English archive

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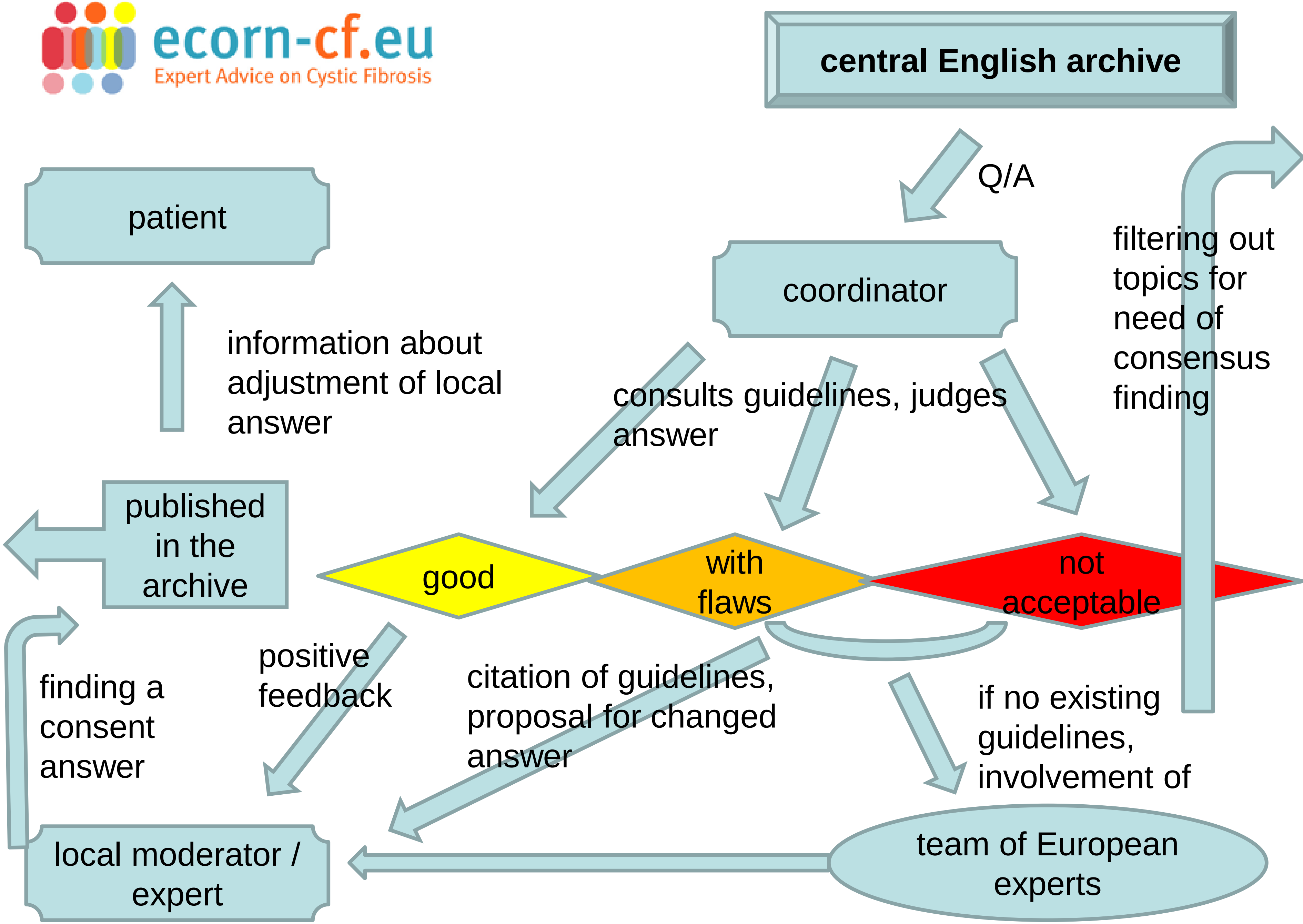

central English archive

Q/A

coordinator

filtering out topics for need of consensus finding

patient

information about adjustment of local answer

consults guidelines, judges answer

published in the archive

good

with flaws

not acceptable

positive feedback

citation of guidelines, proposal for changed answer

finding a consent answer

if no existing guidelines, involvement of

team of European experts

local moderator / expert

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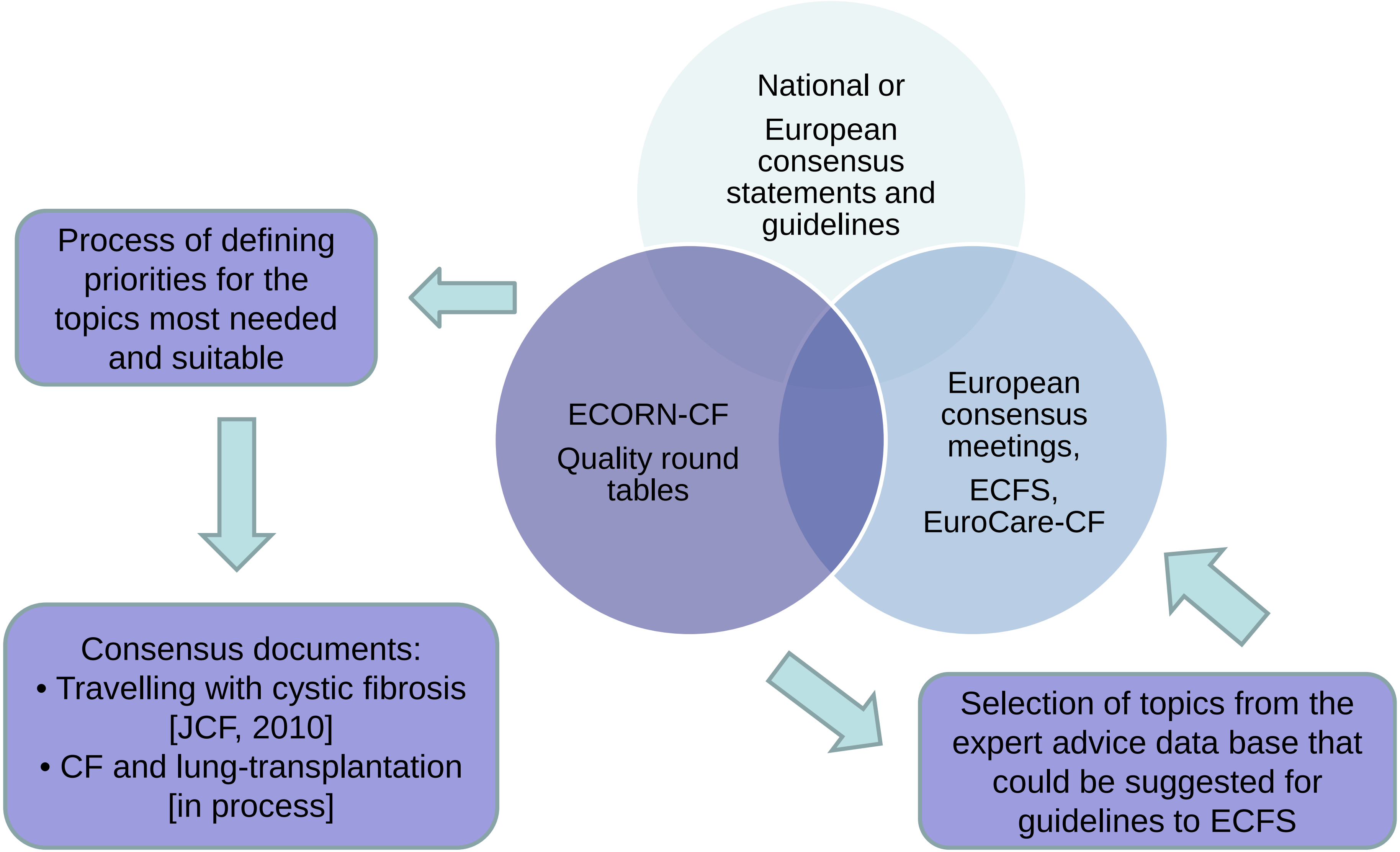
Process of consensus development for CF supported by ECORN-CF – networking with other CF networks



National or

European consensus statements and guidelines

ECORN-CF

Quality round tables

European consensus meetings,

ECFS, EuroCare-CF

Process of defining priorities for the topics most needed and suitable

Consensus documents:
- Travelling with cystic fibrosis [JCF, 2010]
- CF and lung-transplantation [in process]

Selection of topics from the expert advice data base that could be suggested for guidelines to ECFS

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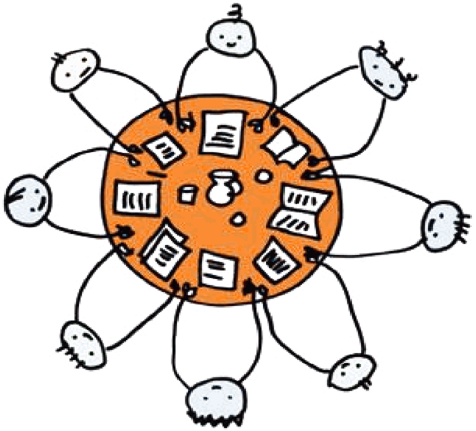


Extraction of consensus deficits from the expert advice data base

Discussion of the most interesting questions

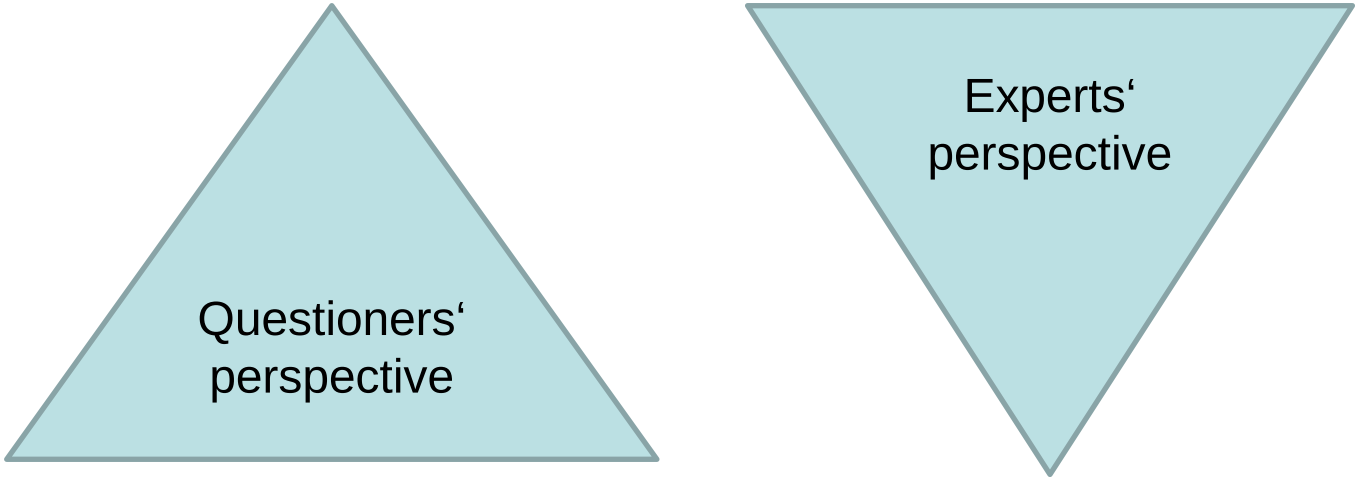
ECORN-CF quality round tables

Feedback about quality of answers in the course of time and in European comparison

Defining catalouge of important aspects for high quality answers
→examples and test questions
→ train the expert

Where do we stand?

Concerning quality of answers and satisfaction with them...



Questioners‘ perspective

Experts‘ perspective

Questioners‘ perspective

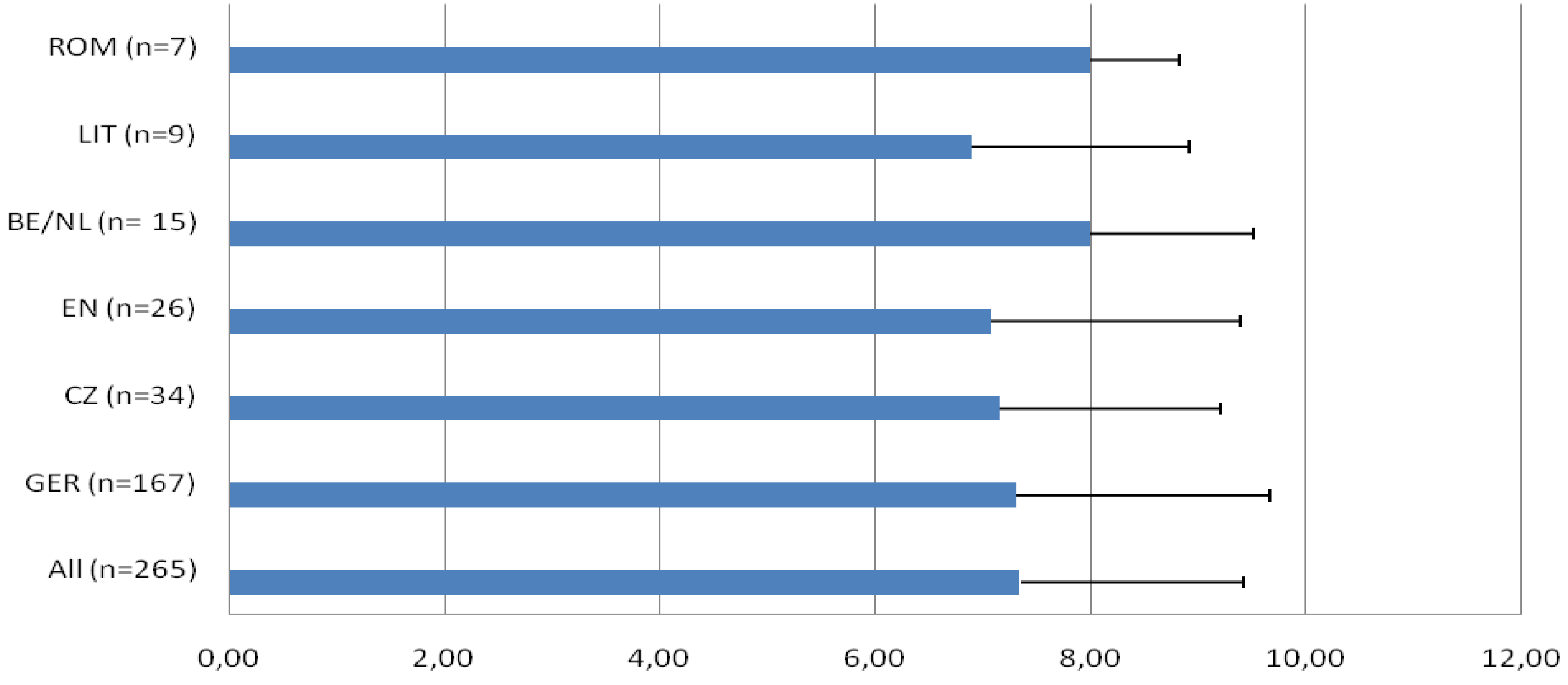
How satisfied were you with the answer(s)?

Questionnaires sent via e-mail to families and CF-patients

12/2008: 396
12/2009: 654

265 questionnaires returned
→ 25.2% return rate

How satisfied were you with the answer/the answers to your question/your questions?(10 = very satisfied)

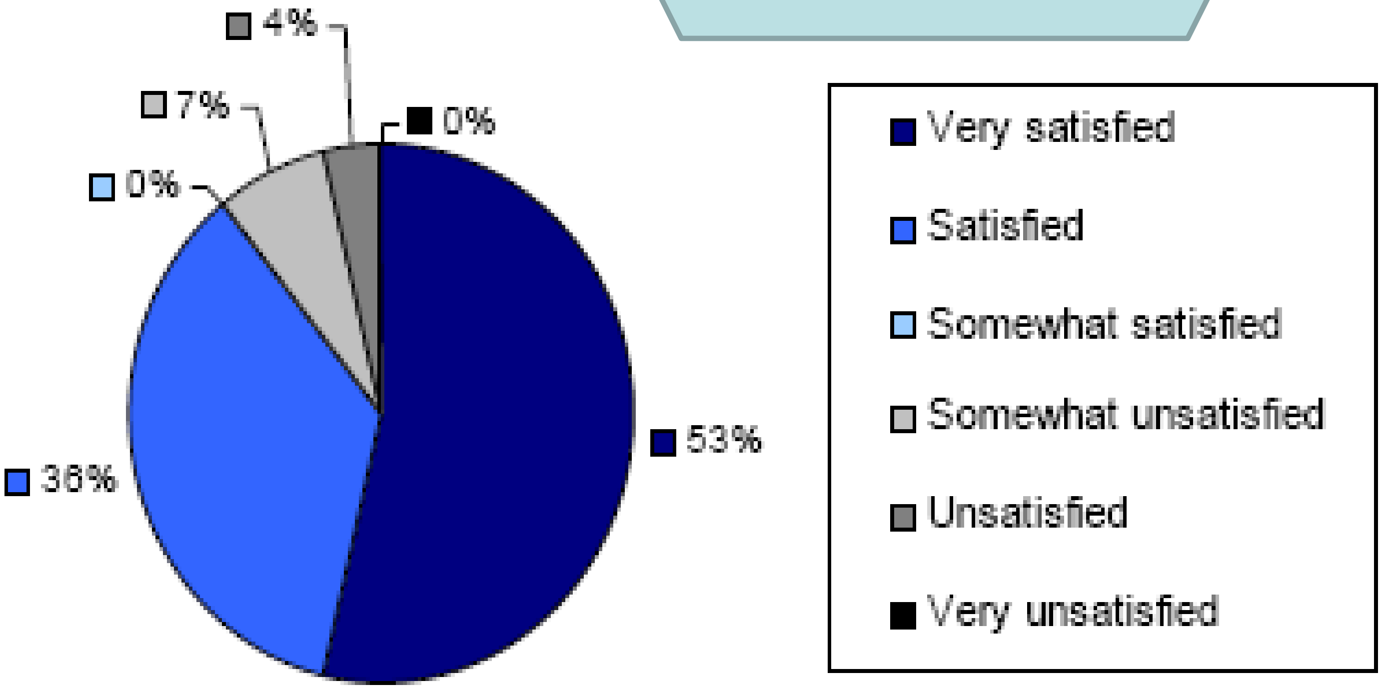


	All (n=265)	GER (n=167)	CZ (n=34)	EN (n=26)	BE/NL (n= 15)	LIT (n=9)	ROM (n=7)
SD	2,07	2,36	2,06	2,31	1,51	2,03	0,82
■ Mean	7,34	7,30	7,15	7,08	8,00	6,89	8,00

Survey among German speaking ECORN-CF users on their satisfaction with the expert advice

(n=28); Survey was sent to 60 registered users in September 2011

89% were satisfied
or very satisfied

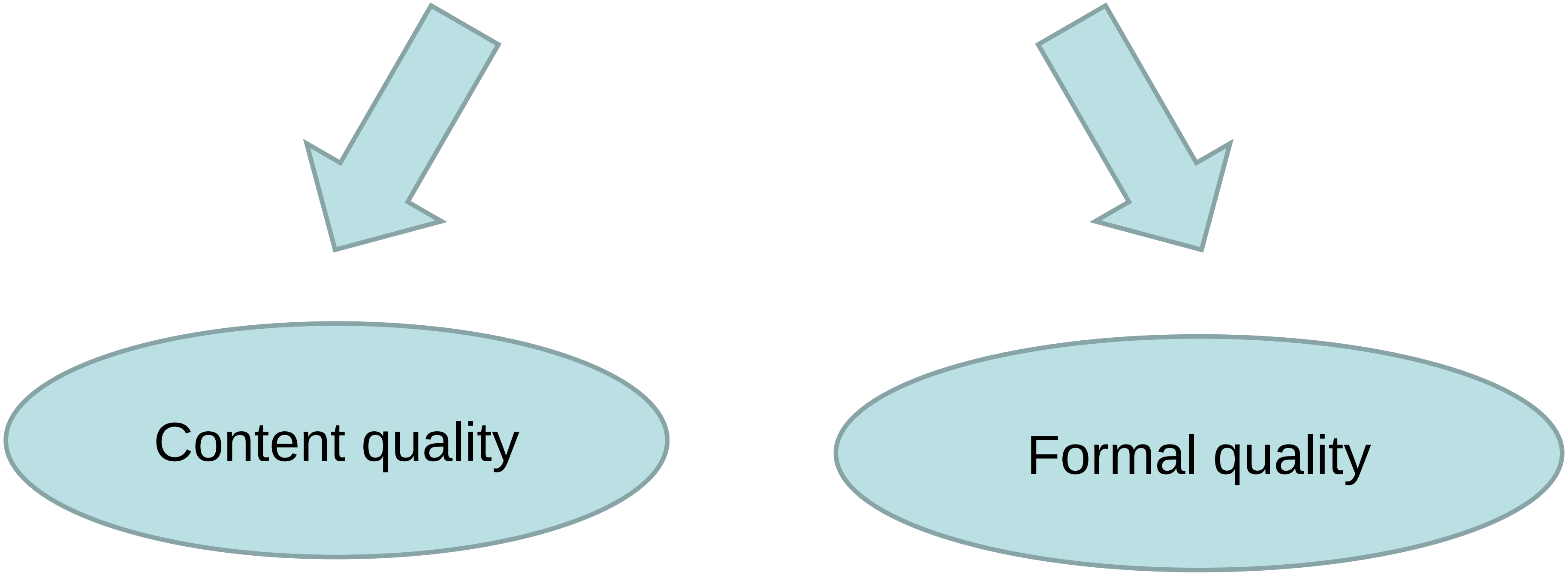


Aspects: "Overall evaluation", "Language Comprehensibility", "Information Content of the Answer" and "Waiting Time until Receipt of Answer"

Experts‘
perspective

Quality of answers in the different language zones in the course of time?

Development of a tool for assessing quality of expert answers (2007)



Content quality

Formal quality

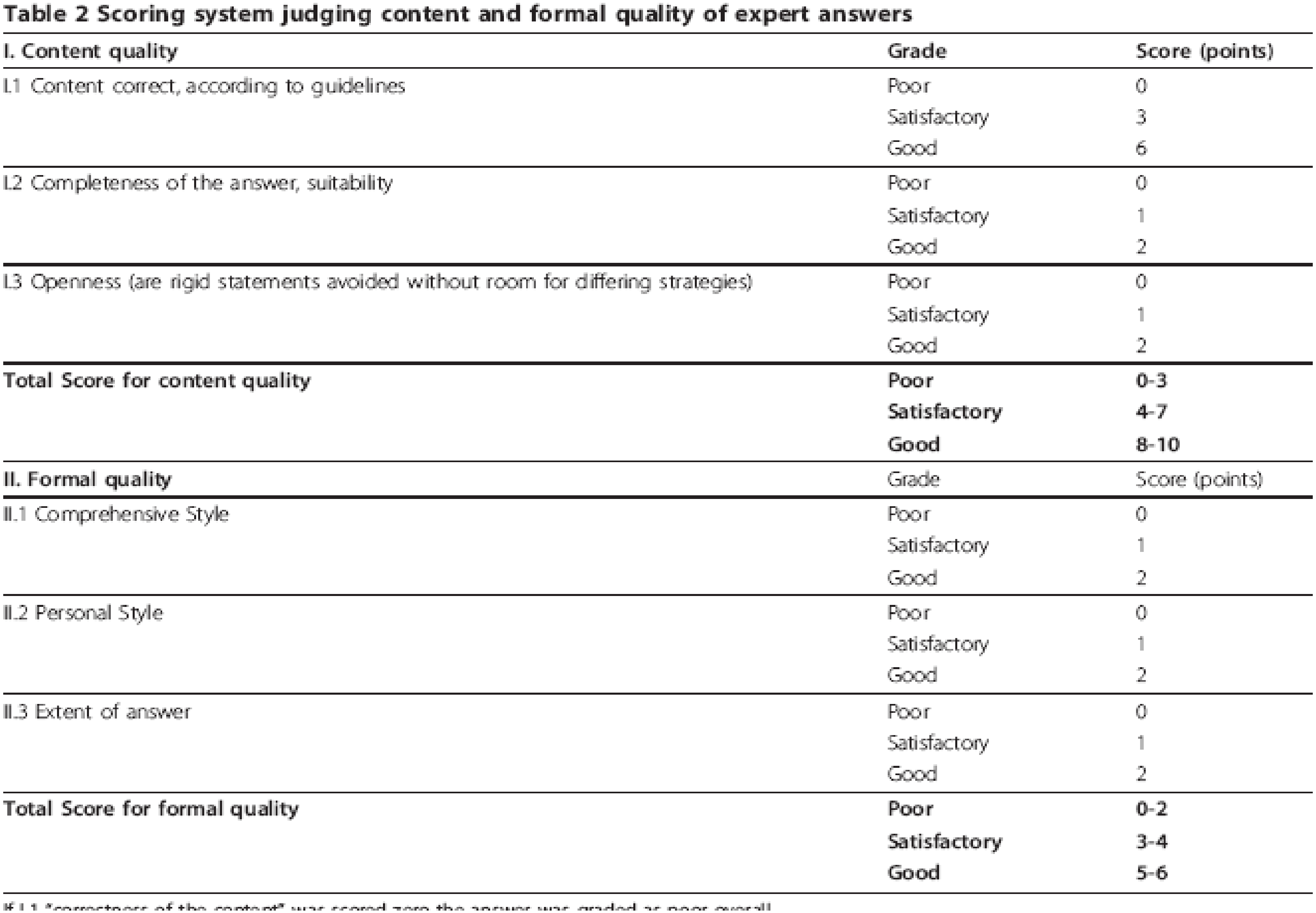
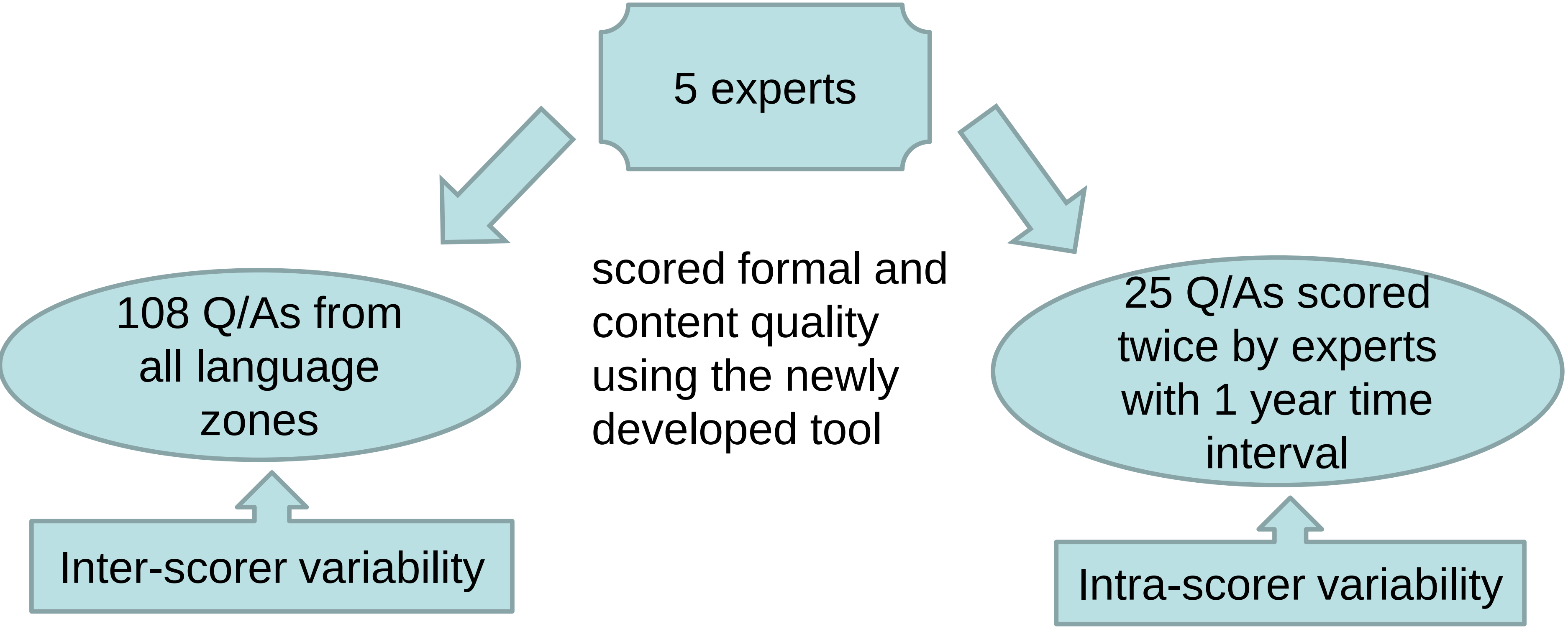


Table 2 Scoring system judging content and formal quality of expert answers

I. Content quality	**Grade**	**Score (points)**
I.1 Content correct, according to guidelines	Poor	0
	Satisfactory	3
	Good	6
I.2 Completeness of the answer, suitability	Poor	0
	Satisfactory	1
	Good	2
I.3 Openness (are rigid statements avoided without room for differing strategies)	Poor	0
	Satisfactory	1
	Good	2
Total Score for content quality	**Poor**	**0-3**
	Satisfactory	**4-7**
	Good	**8-10**
II. Formal quality	Grade	Score (points)
II.1 Comprehensive Style	Poor	0
	Satisfactory	1
	Good	2
II.2 Personal Style	Poor	0
	Satisfactory	1
	Good	2
II.3 Extent of answer	Poor	0
	Satisfactory	1
	Good	2
Total Score for formal quality	**Poor**	**0-2**
	Satisfactory	**3-4**
	Good	**5-6**

If I.1 "correctness of the content" was scored zero the answer was graded as poor overall

First scoring project, 2009



5 experts

scored formal and content quality using the newly developed tool

108 Q/As from all language zones

Inter-scorer variability

25 Q/As scored twice by experts with 1 year time interval

Intra-scorer variability

Tool suitable for assessment of content quality of answers ↔ formal quality high intra- and inter-scorer variability

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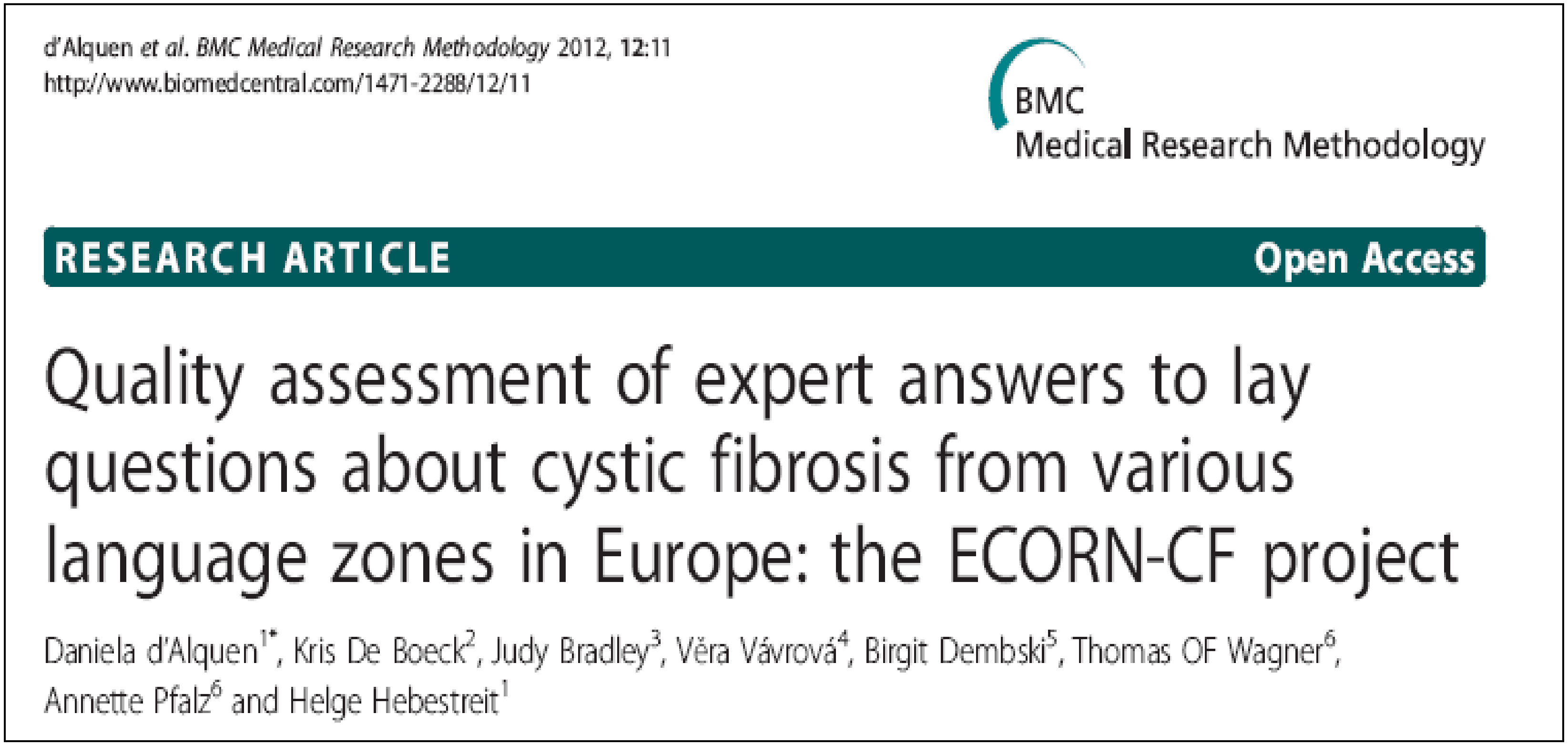

d'Alquen *et al. BMC Medical Research Methodology* 2012, 12:11
http://www.biomedcentral.com/1471-2288/12/11

BMC
Medical Research Methodology

RESEARCH ARTICLE **Open Access**

Quality assessment of expert answers to lay questions about cystic fibrosis from various language zones in Europe: the ECORN-CF project

Daniela d'Alquen[1*], Kris De Boeck[2], Judy Bradley[3], Věra Vávrová[4], Birgit Dembski[5], Thomas OF Wagner[6], Annette Pfalz[6] and Helge Hebestreit[1]

Latest scoring project, 2011/2012

What is the content quality of expert answers like in different language zones and in the course of time?

6 experts

scored content qualtiy

160 Q/As:
8 language zones,
10 Q/As from previous and 10 Q/As from actual period,
1-2 years time interval between periods

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Results

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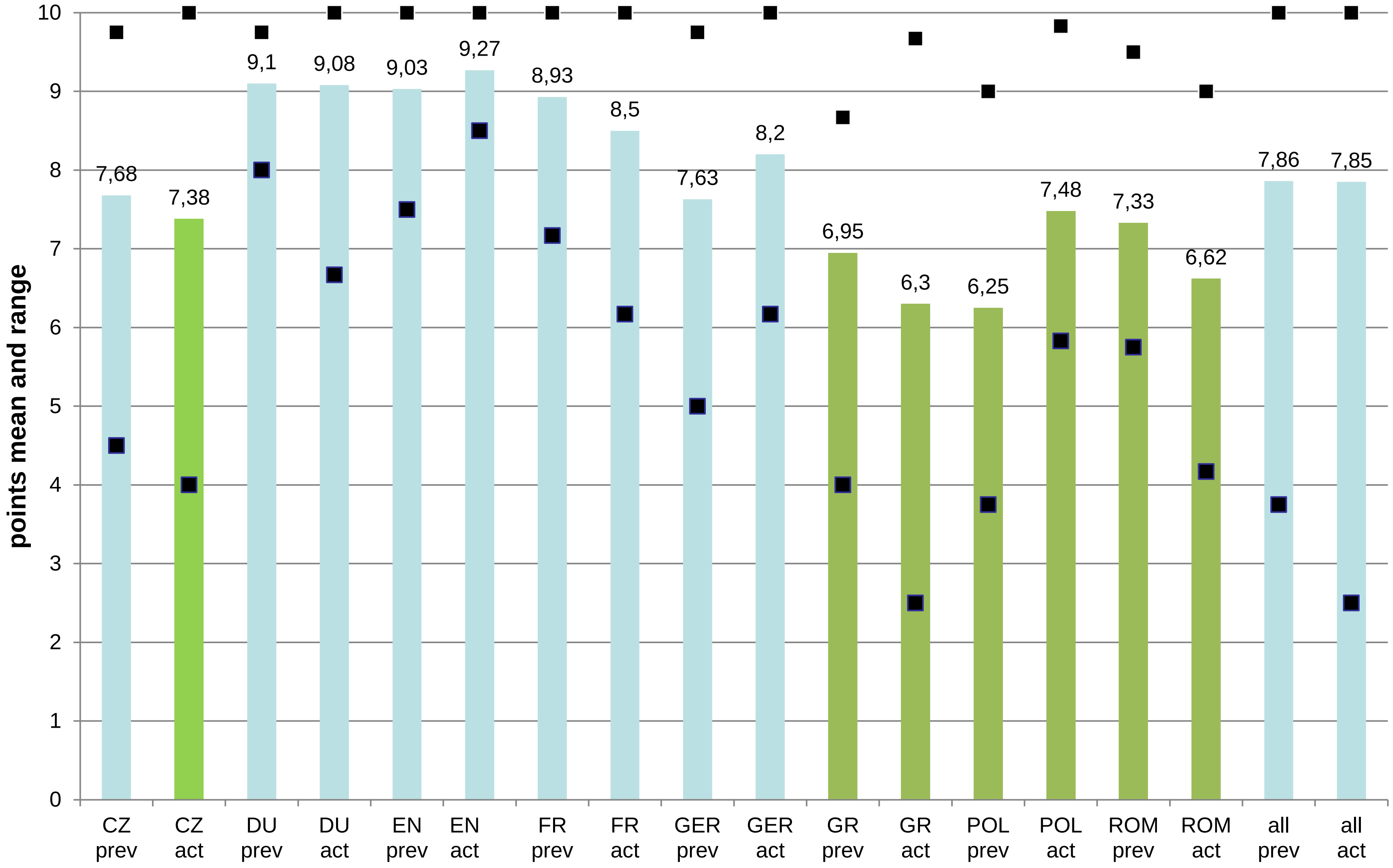
All countries, content quality



Summary of Results

Some language zones show an increase and some a decrease in their content quality level of answers in the course of time
→ unchanged overall good content quality level taking all answers from all countries together

Only 1 of 3 countries starting with a satisfactory content quality level showed the desired increase in content quality in the course of time

Measures and efforts to achieve the aim of increasing quality of expert answers should be continued and further developed

Future perspectives:

Problems to solve

Impact of ECORN-CF

Problems to solve

Do the answers really reflect the same „European quality standard“?

Users expect „European advice“ but

- First reply from local expert
- Depends on local organization of expert panel

Quality control structures, training of „experts“ are of utmost importance to equalize quality of answers and establish a European standard

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Is this kind of care really independent of patient origin and local distance to CF-center?

Only true if all patients had access to the internet

→ **limiting factor**

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Money?

May 1st, 2007 – April 30th, 2010 (36 months)

Total budget: **800.245,00 Euro**

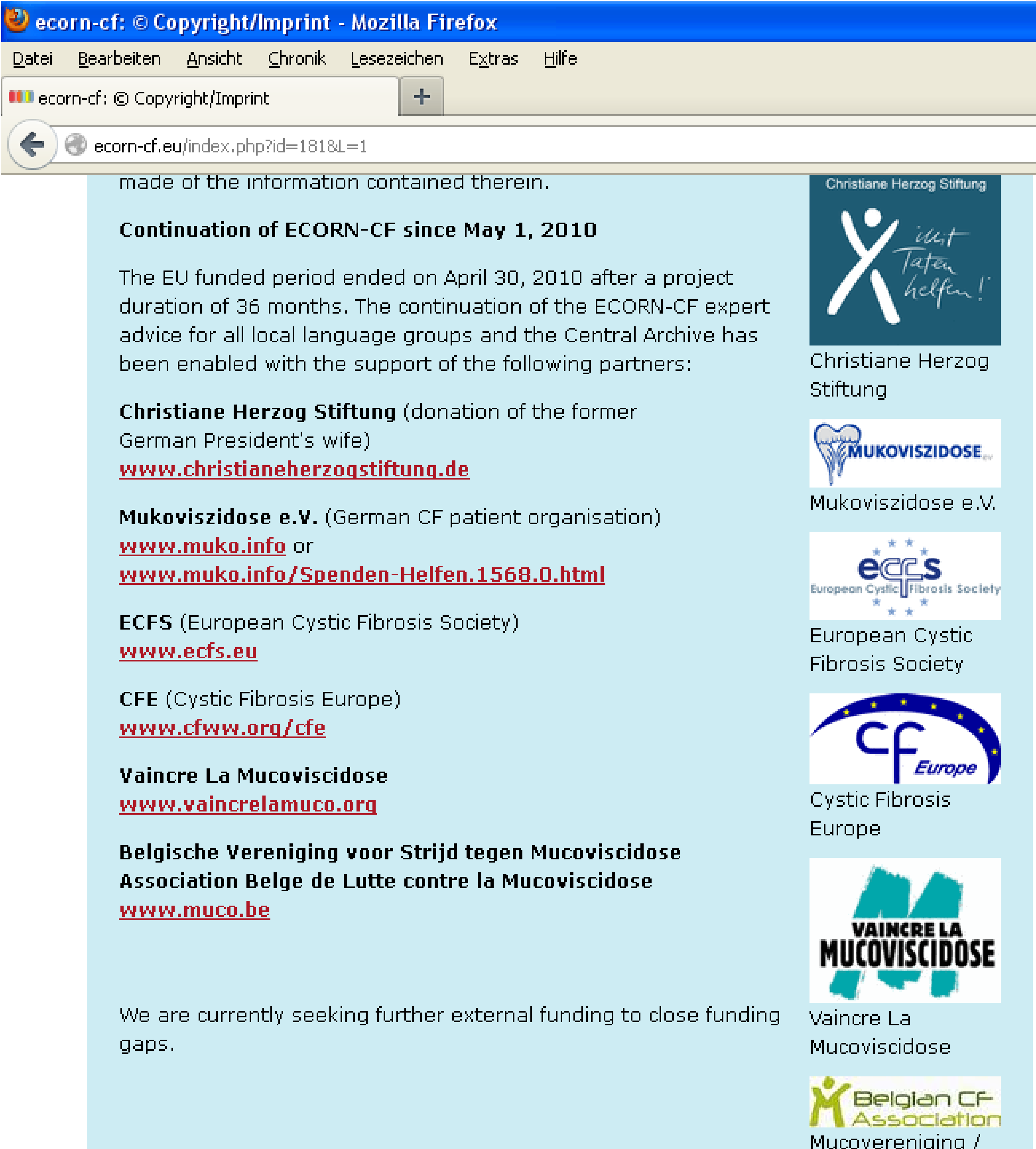
Co- funding by EU-commission
(Directions générales de la santé et des consommateurs DG SANCO public health program, Executive Agency for Health and Consumers EAHC): **460.000,00 Euro**

External funds of the German Christiane-Herzog foundation: **150.000,00 Euro**

Remaining **190.245,00 Euro** had to be covered by the participating partners

All language zones received money for administration and for time of experts

Motivation / pressure to fulfill ECORN-CF aims:
e.g. answer questions within 3 days



made of the information contained therein.

Continuation of ECORN-CF since May 1, 2010

The EU funded period ended on April 30, 2010 after a project duration of 36 months. The continuation of the ECORN-CF expert advice for all local language groups and the Central Archive has been enabled with the support of the following partners:

Christiane Herzog Stiftung (donation of the former German President's wife)
www.christianeherzogstiftung.de

Mukoviszidose e.V. (German CF patient organisation)
www.muko.info or
www.muko.info/Spenden-Helfen.1568.0.html

ECFS (European Cystic Fibrosis Society)
www.ecfs.eu

CFE (Cystic Fibrosis Europe)
www.cfww.org/cfe

Vaincre La Mucoviscidose
www.vaincrelamuco.org

Belgische Vereniging voor Strijd tegen Mucoviscidose
Association Belge de Lutte contre la Mucoviscidose
www.muco.be

We are currently seeking further external funding to close funding gaps.

Christiane Herzog Stiftung

Mukoviszidose e.V.

European Cystic Fibrosis Society

Cystic Fibrosis Europe

Vaincre La Mucoviscidose

Mucovereniging /

Since May, 2010

⇩

Money from associations, organisations and foundations:

→ However, costs incurred can not fully be covered

Money only for basic central administration

No money for language zones

In addition to over burdening daily work, experts spend their time to answer questions for ECORN-CF without receiving any money

Paralysis of local work in some language zones

Quitting ECORN-CF (Czech, Polish language zone)

Urgent and highly important issue to put ECORN-CF on a solid monetary basis for the future: ideally with the help of European organizations (ECFS / CF Europe)

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Impact of ECORN-CF

● Access to quality information for patients and professionals:

- Standardized quality information and advice
- No language and country barriers
- Growing archive of patient-oriented information

- **Collaboration of all parties involved in CF care:**

− # Disciplines (medical, paramedical, psychosocial)
− # Countries
− Clinicians, researchers and patients

● Improved CF care all over Europe:

− Quality control and exchange improves expertise and care
− Local experts are stimulated to implement European consensus guidelines
−Database and creation of consensus guidelines

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Thank you for your attention!!