ECORN-CF
(Grant agreement n° 2006105)

Final Technical Implementation Report M36
(May 1, 2007 – April 30, 2010)

Provided by the co-ordinator Johann Wolfgang Goethe-Universität, Frankfurt/M, Germany
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Final Technical Implementation Report
Provided by the Coordinator (GUFH-Frankfurt)

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ECORN-CF (Grant agreement n° 2006105)

Final Technical Implementation Report (M1-M36)

**Contract number:** 2006105  
**Proposal title:** European Centres of Reference Network for Cystic Fibrosis  
**Acronym:** ECORN-CF  
**Starting date:** 01/05/2007  
**Duration of the project:** 36 months / until 30/04/2010  
**Reporting period:** 01/05/2007 – 30/04/2010  
**Main partner:** Klinikum der Johann Wolfgang Goethe-Universität, Frankfurt/M., Germany  
**Number of associated partners:** 15 (excluding main partner)  
**Total amount of the project:** 800.245,00 € (after Amendment 2: 800.244,88 €)  
**EC Co-funding:** 460.000,00 €  
Pre-financing: 138.000,00 € (as specified in I.5.1)  
First further prefinancing payment: 92.000,00 € (as specified in I.5.2)  
Second prefinancing payment: 92.000,00 € (as specified in I.5.2)  
Payment of the balance requested: 51.542,94 €
1 Executive summary

Being part of DG SANCO’s Public Health Program (2003-2008), ECORN-CF’s mission has been to help protect and improve health by developing and co-ordinating a health information and knowledge system. Our approach has been to facilitate access to high quality information for patients with rare diseases or other interested lay persons and care team members by building a multi-lingual web-based model of a “European Centres of Reference Network for Cystic Fibrosis” (ECORN-CF).

1.1 Achievements

During the project’s three-year runtime nine local websites called “Expert Advice” were implemented in the respective languages and are being run by the local experts from Belgium/the Netherlands, the Czech Republic, Germany, Greece, Lithuania, Poland, Romania, Sweden and the United Kingdom in their mother tongues. Furthermore, an English “Central Archive” has been implemented which currently contains more than 700 quality checked questions and answers (QA pairs). Relevant QA pairs from all expert advices are translated into English and sent to a quality assurance team. Only if the answer is in accordance with European consensus statements, guidelines and – in the absence of these – consented local and foreign expert opinion, the QA pair is published in the English Central Archive. If the answer is only satisfactory or with flaws, the English answer is amended and a feedback loop ensures that the answer in the original language is also updated in the local expert advice. Thanks to this input experts have been able to expand their knowledge. We also developed an electronic questionnaire – one for patients and one for family members – in order to learn more about the health care situation in the different countries. All registered lay person users were asked by e-mail to fill in the questionnaire on the internet anonymously.

An in-depth quality assessment system was developed by the ECORN-CF project members which enables the scorers to evaluate not only the subcategories of content quality (e.g. correctness) but also of formal quality (e.g. comprehensiveness). A set of blinded questions coming from different language zones was scored by the same scorers at two points in time during the funding period of the project. The results of this in-depth assessment were presented during two of our four quality round tables which took place in Frankfurt and Prague. At these meetings we also discussed tricky questions and brainstormed measures to promote and improve the local expert advices. Looking at the questions asked it became obvious that “travelling with CF” is an area with a substantial need for guiding information. A first draft was discussed during the last quality round table and the paper about “travelling with CF” was submitted to the “Journal of Cystic Fibrosis” in May 2010.

The progress of the project has been disseminated regularly by sending the “ECORN-CF Newsletter” to several distribution lists (e.g. all European patient organizations, Eurordis, Orphanet). The “ECORN-CF Snippets” have complemented the dissemination from time to time.

In conclusion, the pilot project has been able to show:

- Feasibility of European Networks of Centres of Expertise (European Reference Networks) by making ECORN-CF the model implementation
- Feasibility of cross-border quality management of health care
• Patient involvement in designing, implementing and sustaining such European networks is crucial
• Participants evaluated the network as a significant contribution to the quality of care in their own countries and in all member states

1.2 Weak points

Shortly after having started the first local expert advices on the internet, we had to face that quality takes its time. The target response time of only two working days turned out to be unrealistic. Therefore, we abandoned the idea of assuring the questioners of a certain response time. Now, a pop-up on the website informs the user after having submitted the question that: "We try to answer your question as quickly as possible, but quality has the priority over speed. So, please, understand that it may take a couple of extra days if reassurance with other experts is necessary."

Another weak point implies a time aspect on the one hand and a language aspect on the other hand. In order to be able to assess the quality of all questions and answers (QA pairs) it is indispensable that they are translated into English. Sometimes, however, the time span between the date when the QA pair is published on the local site and the date when the English translation is sent to the quality assurance team is quite long and the quality of the translation varies from expert to expert.

While the quality assurance loop is certainly one of the most interesting and beneficial parts of the project it also means a lot of extra non-care effort for the experts who have to spend their scarce time to do translations. This might also be the reason why not as many new language teams could be recruited for joining the ECORN-CF expert advice as expected. It is one thing to write an answer about one’s own field of expertise in one’s mother tongue and another thing to translate the question and answer into English.

2 Specification of the project

The impetus for the project “European Centres of Reference Network for Cystic Fibrosis” was the following situation: The distribution of expertise for specific care of rare diseases does not follow a general rule across all EU member states. The Rare Disease Task Force has shown in its mapping experience that there is a wide variation of level of structures for the care of these patients. It ranges from national Centres of Reference with a clearly defined list of diseases covered to an arbitrary mixture of more or less developed local centres to no discernible structure at all. Although it might prove helpful to have patients travel to a specific centre of expertise in an extremely rare situation, the better solution to reach the ideal situation of all patients having equal access to the highest quality of care would be the dissemination of knowledge and competence. The Rare Disease Task Force has therefore proposed to let the information and the expertise travel instead of the patients.

The ECORN-CF pilot project can serve as a model for the implementation of a structure across many European member states that helps spread the highest level of knowledge and raise the competence of all participating members of the care team to the highest level available in the EU. Additionally, it helps empower the patients because the expertise is dissiminated in a combined effort with the patient
organizations and since ease of access is granted for the patients by offering services of information and expert advice in the native language of the patients.

2.1 Objectives

The general objective of ECORN-CF has been to facilitate access to specific health care aids for patients with rare diseases, exemplified by building a model of a “European Centres of Reference Network for Cystic Fibrosis” that comprises:

- Advice for patients, relatives and friends of patients and the professional health care team
- Implementation of accepted European guidelines and evaluation of the adherence to these
- Quality assurance measures to raise levels of expertise towards the highest levels in Europe
- Expertise provided irrespective of residence and mother tongue of patient and/or health care professional
- Referral to patient organizations and strengthening patient decision aids
- Information on medical and psychosocial aspects of the disease

Cystic fibrosis was chosen as a model rare disease for such networking in Europe because it fulfils several aspects that have been very important for risk reduction for the program, even though they cannot necessarily be expected in every other rare disease. Cystic fibrosis meets the following crucial prerequisites:

- The diagnostic criteria are simple and unequivocally accepted
- Cystic fibrosis is a deadly chronic disorder with a need for a high level of expertise
- Centre oriented care has been shown to improve prognosis
- Therapeutic intervention has dramatically increased prognosis over the last twenty years
- There is a high level of established and published consensus on diagnostic and therapeutic strategies
- Costly therapies call for evidence-based decision making, evidence is much better than in most other rare diseases

This special situation in the case of cystic fibrosis allows reaching the specific objectives:

- Demonstrate the feasibility of a networking structure to implement European highest-level expertise in the member states
- Support the implementation and the adherence to European consensus of care
- Establish a European quality assurance program with dissemination of the highest quality of knowledge throughout the member states
- Make use of E-health technologies to uncouple expertise and advice from other health system strengths or weaknesses
- Allow access to specific information for patients and care team members at the highest level of expertise in all member state languages at the same level of quality
2.2 Methodology

2.2.1 Methods

The web-based system is able to manage all incoming lay people and care team member questions that are coming from all participating language zones together with the respective answers. The system makes use of a native speaking contact between the questioner (often CF individual or parent) and the answering specialist. All kinds of care team specialists take part in ECORN-CF: physicians, nurses, dieticians, physiotherapists, psychologists, social workers, etc. All users from all member states have the same easy access to the ECORN-CF expert advice in their language of choice. Over the course of time the local archive of each language zone has become more and more valuable since the user can find answers already given by keywords or by using the free-text search function.

In a second loop, each relevant question answered locally has been translated into English and then sent to the coordinators of work package 4 and 5 for quality check. All this happens in the implemented internal system of ECORN-CF. The coordinators of the quality check assign the question-answer pair to a so called proof editor who checks if all aspects of the question are answered, whether the answer is according to evidence and existing guidelines, if formal and stylistic aspects are also considered, etc. There is a ranking: “good” – “with flaws” – “unacceptable”. If the question-answer pair is ranked “good” it is published in the English Central Archive. If there are flaws or if the answer is unacceptable, the answer will be amended and then published. The local expert advice team will also be informed, so that the answer in the original language can be improved as well. This single-question feedback guarantees the same level of quality in all expert language groups. Additionally, all experts are trained “on the job” so that they can reach the optimal level of how to give advice. Since quality is an iterative process all members of the network have been involved in this debate and were invited to join our quality round table meetings in order to reassure or redefine quality standards or to contribute to consensus finding. For further details regarding the quality control, please also refer to section 3.2.1.2. – II.a.

Fig. 2.2.1-1 The flowchart shows the way from question to answer and the two different loops of the ECORN-CF system. It starts with the incoming
question that is asked in one of the local expert advices in the center box.

The statistics page, which can be accessed by all local moderators, forms an integral part of the ECORN-CF expert advice. The following data is updated permanently and can be retrieved by simply clicking on the respective link in the system:

**Local Expert Advices**

- Answered questions per team
- Answered questions per team member
- Time spent per answer and per team
- Average time spent per answer
- Minimum time spent per answer
- Maximum time spent per answer

**ECORN-CF Archive**

- Proof read questions
- Proof read questions per team member
- Time spent per answer
- Average time spent per answer
- Minimum time spent per answer
- Maximum time spent per answer

**Referral**

- Referral to patient organization
- Referral to patient decision aid
- Referral to patient organization and decision aid

**Guideline**

- Answers with applicable guideline
- Answers WITHOUT applicable guideline
- Answers according to a guideline
- Answers NOT according to a guideline
- Answers with need for a guideline to be worked out

All editors (= experts) of the ECORN-CF expert advice can easily retrieve the following information:

- Questions considered for FAQ list
- Questions with guideline applied

All experts involved in the project have access to the “Reference Documents” section as well where all ECFS consensus reports and guidelines can be viewed or downloaded. An extensive list of additional literature concerning guidelines and consensus statements in CF or further information about the fine scoring are available.

In the “User Guides” section there are two documents: an ECORN-CF manual for moderators and editors and an explanation about how to answer questions (for new editors).
One of the most critical benchmarks was the time needed before an answer was published. The analysis showed that the original idea of having at least 80% of the answers online within two working days could not be achieved due to the complexity of the questions and the additional time needed for the quality control system. We therefore had to decide for quality over speed and made a change in the user information stating that: “We try to answer your question as quickly as possible, but quality has the priority over speed. So, please, understand that it may take a couple of extra days if reassurance with other experts is necessary.”

2.2.2 Project organization and management

All work packages were lead by a leader and one or more deputies. The coordinator, being the leader of WP1, WP3 and WP7, was the node of communication and his main task was to keep the wheels turning.

All associated partners were actively involved in the work packages. Collaborating partners did not receive any funding from the project but apart from that they had the same rights and the same duties.

While the tasks of the horizontal work packages (WP1 – WP3) were mainly fulfilled by the respective work package leaders and their deputies, there was a vivid and fruitful cooperation of the core work packages and all associated and collaborating partners.

According to the grant agreement, the steering committee consisted of:

- all WP leaders
- Stuart Elborn (UK, Belfast), the current President of the ECFS (European CF Society)
- Karleen de Rijcke (BE, Brussels), the President of CF Europe
- Birgit Dembski (DE, Bonn/Magdeburg), CF individual and working for the German patient organization Mukoviszidose e.V.
- Anna Arellanesová (CZ, Prague), mother of a CF child and working for the Czech patient organization Klub nemocných CF
- Ségolène Aymé (FR, Paris), director of Orphanet and leader of the RDTF (Rare Disease Task Force)
- Thomas O. F. Wagner (DE, Frankfurt), member of the RDTF and coordinator of ECORN-CF
- Yann le Cam (FR), chief executive officer of Eurodis
- Christel Nourissier (FR), general secretary of Eurodis
- Kris de Boeck (BE, Leuven), Milan Macek (CZ, Prague), Burkhard Tümmler (DE, Hannover) as WP leaders, deputies or associated partners of another EU project called EuroCareCF (DG Research) and David Sheppard (UK, Bristol / coordinator of EuroCareCF)

Many of them were also associated partners of ECORN-CF and were therefore permanently involved so that overlaps with other projects could be avoided and synergies could be fostered.

Furthermore, the steering committee helped reach a consensus on important documents like the “Template for crossing borders” or the “Medical Report”, which form part of the paper “Travelling with Cystic Fibrosis: Recommendations for Patients and Care Team Members.” This publication has been endorsed by the European
Cystic Fibrosis Society (ECFS) and was submitted to the Journal of Cystic Fibrosis in May 2010.

At the end of 2009, a strategic advice was requested from the whole steering committee about how the ECORN-CF service could be made sustainable when the EU funded project period is over. The resulting recommendation was to ask for funding by the patient organizations which has helped the project to be continued after the end of the funding period.

2.3 Results

The following achievements have been made during the funded period of the project:

- Expert advice for patients, relatives of patients and the professional health care team has been provided in different languages. [http://ecorn-cf.eu/index.php?id=60&L=8](http://ecorn-cf.eu/index.php?id=60&L=8)
  
  A total of 835 questions have been answered up to April 30, 2010.

- Questioners have had access to expertise irrespective of their place of residence and mother tongue.
  
  A total of 9 language zones have been covered.

- Questioners have been referred to patient organizations whenever necessary and patient decision aids have been provided. Approximately 6 % of all questioners have been referred to patient organizations.

- All relevant question and answer pairs have been translated into English and have been quality checked before publication in the English Central Archive. [http://ecorn-cf.eu/index.php?id=86&L=0](http://ecorn-cf.eu/index.php?id=86&L=0)
  
  A percentage of 80 % of all question and answer pairs were published in the Central Archive. The other 20 % were country-specific questions, e.g. about insurance issues, that were not relevant for the Central Archive.

- The quality team of ECORN-CF has ensured that each answer (coming from the local expert advices and translated into English) was quality checked according to an evaluation system that was developed by ECORN-CF. These quality measures together with a single-question feedback make sure that all experts can "learn from the best" and are trained "on the job" so that the level of expertise can be increased towards the highest level in Europe. The detailed results of this quality process are given in section 3.2.1.2; II. of the report.

- Furthermore, an in-depth fine scoring was done twice during the project period. Please also refer to section 3.2.1.2; IId.

- An extensive list of accepted European guidelines in the field of cystic fibrosis was compiled which is the basis for the quality check of the answers within the system.

- The program has helped to extract data about lacking evidence-based guidelines. One area identified was “recommendations for travelling with CF.”

- The ECORN-CF study group drafted the paper “Travelling with Cystic Fibrosis: Recommendations for Patients and Care Team Members.” It is endorsed by the European Cystic Fibrosis Society (ECFS) and was submitted to the Journal of Cystic Fibrosis in May 2010. [ATTACHMENT 01_a-c](http://ecorn-cf.eu)
• Information on medical and psychological aspects of the disease as well as health care system utilization can be retrieved from the results of the patient questionnaire surveys.

• The expert advice serves as a model for the transfer of knowledge and expertise throughout European member states not only for rare diseases.

**European added value**

The application describes in detail a model for the European reference networks that have been addressed by the EU Commission to facilitate access to high level medical expertise to all patients with rare diseases in all member states. As shown in the listing above, the ECORN-CF model fulfils the objective of the work plan 2006 to disseminate the knowledge and expertise to all member states and reduce the necessity for patients affected from rare diseases to travel in search for adequate care and expert knowledge. Even though the expert care for CF is quite well established in some countries of the EU, this holds not true for all actual member states and certainly also not for all future member states. The advantage of transfer of expertise from high level countries to lower level countries is mediated by the European Union, thus the European added value is visible and can be traced back to the EU.

The model project has been able to show that people affected with rare diseases get easier access to high level expertise and the quality of life can be better maintained since the patient does not have to leave his native language surroundings. On the professional side of the project the networking yields increase in expertise for those not so close to actual developments, the co-operation has facilitated other knowledge transfer and research exchange as fringe benefits to the core activities of the project.

**3 Technical implementation of the project**

**3.1 Activities related to horizontal work packages**

**3.1.1 WP1: Management of the project**

Work package leader:
Thomas Wagner, Frankfurt

Deputy:
Tim Hirche, Frankfurt/Wiesbaden

**3.1.1.1 Objectives**

The coordinator was the node of communication whose main task was to keep the wheels turning.

We were the single point of contact for all project partners and the EAHC to monitor all activities, to coordinate that all planned activities are organised and reports are sent in due time as well as to provide administrative help.
The most important attributes of this Work Package (WP) were:

- being anticipatory and informing the partners in time about required actions
- being a motivator and keeping all partners in the loop
- being persistent and reminding the partners of deliverables, duties, etc.

3.1.1.2 Activities undertaken

- According to the agreement, we started with subcontracting to an IT business partner able to develop, implement and maintain an IT solution for the specific needs of the project.
- At the beginning of the project it was not possible to create a team spirit only by sending e-mails or by having telephone conferences. Thus, we decided to organize a 1st quality round table meeting that rather had the character of a kick-off meeting. The opportunity to get to know the project partners during the quality round table meetings was very helpful and proved a catalyst for the whole project. The quality round table meetings were organized together with our Czech partner, “Charles University Prague” (program, trip, hotel, catering, transfer, etc.). We also prepared extensive minutes after each meeting, which contained action items to be carried out, and we also followed up to make sure that the action items were completed by the set deadline. → ATTACHMENT 02_a-d
- We accompanied all language teams starting from zero to the launch of their local expert advice. We had to elaborate all website contents in German first and then had to translate everything into English. The English version served as a source text for the other languages. The language teams had to provide many documents, translations and input. Due to the fact that everybody was quite busy, often several reminders were necessary until the feedback was given/the input was provided. This was time consuming. After the launch we provided technical coaching and we also followed-up regarding publication of the banner on the respective websites. Furthermore, we monitored incoming questions (especially in the first weeks), reminding the local moderator/s to assign each question to an expert (editor) or to ask why a specific question was not answered or published so far, etc. We were also in close contact with the web designer constantly and improved the system continuously.
- We helped develop the questionnaire especially by checking the draft and giving comments for improvement.
- We made sure that all requested Technical Implementation Reports and Financial Reports were sent to the EAHC in due time. Previously, we put a lot of effort in explaining to the beneficiaries what we had learned from the project officer. We compiled extensive information for all beneficiaries explaining how to write the financial report. We also prepared helpful excel sheets for them to ease the monitoring of the budget for each beneficiary.
- Being responsible for budget allocation, we distributed the respective parts of the EC pre-payment to each beneficiary after having received each of the three pre-payments.
- In an ongoing effort, we had to maintain and update the websites for all languages on a daily basis. We were in close contact with the co-workers of WP4 and WP5, who are doing most of the quality control. If changes in the answers were necessary, the coordinator has always been involved. We have been in permanent contact with the web designer if there was need for improvement.
• We involved the Steering Committee to give their input about how the continuance of ECORN-CF can be secured after the end of the project period.

3.1.1.3 **Milestones and Deliverables**

<table>
<thead>
<tr>
<th>WP 1</th>
<th>Coordination of the project</th>
<th>Thomas O.F. Wagner</th>
</tr>
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<tbody>
<tr>
<td>D12</td>
<td>Interim reports at M6, M12+2, M18 and M24+2 and final reports at M36+2 plus contribution to all other work packages</td>
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<tr>
<th>D12</th>
<th>Final report</th>
<th>M36+2</th>
<th>Report</th>
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<td></td>
<td></td>
<td>Increase in spreading of expertise, quality of care and adherence to European guidelines</td>
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**Status of accomplishment of D12**
Delivered

3.1.1.4 **Problems encountered and solution of these problems**

Generally speaking we can say that managing the project required much more effort by the coordinator than expected, especially with regards to administrative matters. All activities mentioned above are the result of organizing and monitoring almost every step for the beneficiaries, providing everybody with necessary information and permanently following up or even “pushing”. For this reason, more person days were needed for this WP.

3.1.2 **WP2: Dissemination of the results**

Work package leader:
Jeannette Dankert-Roelse, Heerlen

Deputy:
Thomas O. F. Wagner, Frankfurt
3.1.2.1 **Overall Strategies and Methods**

The main aim of work package 2 was the communication within the project and to the public. The communication within the project was done mainly by electronic means and during the quality round table meetings. The communication with lay persons happened by means of patient organizations and their printed or electronic information systems.

Furthermore, the scientific and medical community was informed by electronic newsletters (“ECORN-CF Newsletter” and “ECORN-CF Snippets”) published during the project period. The Rare Disease Task Force (RDTF), the European High Level Group as well as the European organizations Eurordis and Orphanet were also informed about the progress of ECORN-CF and distributed the “ECORN-CF Newsletter” to their own distribution lists which increased the dissemination level considerably.

Scientific publications that are a product of the ECORN-CF project also raise the scientific community’s awareness of the project.

Other targeted measures were used as appropriate to get attention for the project.

3.1.2.2 **Objectives**

The communication of the special objectives and results of ECORN-CF was the main duty of work package 2. The project newsletter has been the main communication channel reporting about the project’s activities to organizations involved and interested in CF as well as to interested individuals. The integration of the project in the existing European and national structures (CF Europe, ECFS, etc.) as well as the cooperation with other European projects (EuroCareCF) has allowed a far reaching impact.

The other task of this work package was to make the expert advice teams and the quality round table meetings known to the public for which these initiatives are intended.

3.1.2.3 **Activities undertaken**

Twelve electronic newsletters were published during the whole project period that were distributed to all associated and collaborative partners. The “ECORN-CF Newsletter” was furthermore sent to the distribution lists of Cystic Fibrosis Europe, the Rare Disease Task Force (RDTF), the European High Level Group as well as to the European organizations Eurordis and Orphanet. This increased the dissemination level considerably. In the newsletters the activities undertaken by each work package were described or given special attention. After the distribution of the newsletter by e-mail, the newsletter remained available on the ECORN-CF website. Further information about the content of the newsletters can be found in section 3.1.2.4.

Other methods used were targeted measures to get attention for the ECORN-project such as a stand during the 2008 ECFS conference in Prague, the preparation of a flyer that was distributed to all participants of the ECFS conference of 2008 together with the regular conference pack, and a template in English containing information about the ECORN-project which could be used after translation in each participating
country to provide information to the patients, CF-care teams and the patient organizations. In 2009, oral presentations about the ECORN-project were given during the ECFS conference in Brest by Judy Bradley and Christoph Baltin.

Furthermore, a poster was presented by Jitka Brázová et al. about “ECORN-CF project in the Czech Republic: first experiences”. It was published in the Journal of Cystic Fibrosis (Volume 7, Supplement 2, June 2008). Further papers are in the pipeline. The paper “Travelling with Cystic Fibrosis: Recommendations for Patients and Care Team Members” is endorsed by the European Cystic Fibrosis Society (ECFS) and was submitted to the Journal of Cystic Fibrosis in May 2010. Apart from Tim Hirche et al. the whole ECORN-CF study group contributed to this paper. Daniela d’Alquen et al. is currently preparing a paper with the working title “Quality assessment of expert answers to lay questions about Cystic Fibrosis from various language zones in Europe (ECORN-CF) with a newly developed scoring system”.

In July 2008 we were contacted and asked to provide input for the DG SANCO funded project “Promoting Patients’ Involvement in EU supported health-related Projects - VALUE +”. Their questionnaire was filled in by three participants of ECORN-CF: Thomas Wagner (co-ordinator of ECORN-CF), Judy Bradley as a clinician and Birgit Dembski as a representative of a patient organization. The input given was integrated in the documents delivered by Value+. ECORN-CF is mentioned in the “Value+ Handbook”:

In the “Value+ Toolkit” ECORN-CF is mentioned in the section “Examples of good practice on patient involvement from European and national projects”:

Furthermore, ECORN-CF was presented at many occasions, here some examples:

- Prof. Thomas Wagner presented ECORN-CF at the “Wartburgkonferenz” (27th and 28th June 2008).
- The “orphaNews Europe” issued on September 17, 2008 contained an article about ECORN-CF: “ECORN-CF: An interactive information service for cystic fibrosis... where the information travels, not the patient”: http://www.orpha.net/actor/EuropaNews/2008/080917.html#Spotlight
- Prof. Thomas Wagner presented ECORN-CF at the “European Health Forum – Rare Diseases” in Gastein, Austria (10th October 2008).
- Karleen de Rijcke (CF Europe) presented ECORN-CF at the national general assembly (Belgium). The coordinator (Frankfurt) prepared an extended PowerPoint presentation.
- Ana Rath from Orphanet presented ECORN-CF in her presentation about “ICT tools for rare diseases: state of art and lessons to be learned” on February 19, 2009 at the Ministerial Conference of the Czech Presidency of the EU about “eHEALTH FOR INDIVIDUALS, SOCIETY AND ECONOMY” in Prague. The power point slides about ECORN-CF were prepared by the coordinator (Frankfurt).
- Prof. Thomas Wagner was invited by Antoni Montserrat to speak at the European Rare Disease Day in Brussels on March 3, 2009.
  http://www.youtube.com/watch?v=PIRtm9NFoOM
- The coordinator (Frankfurt) provided a poster for the Info Day 2009 of the EAHC in Luxembourg on March 18, 2009.
• Prof. Thomas Wagner presented ECORN-CF at the “5th Winter School” in Obergurgl, Austria (29th March – 2nd April 2009).
• Karleen de Rijcke (CF Europe) presented ECORN-CF at a national family meeting in Belgium.
• Follow-up information about ECORN-CF in the orphaNews Europe of October 28, 2009: http://www.orpha.net/actor/EuropaNews/2009/091028.html#16655
• Prof. Kris de Boeck presented ECORN-CF at the Miami CF Symposium on October 11, 2009.
• Prof. Kris de Boeck held a presentation at the “Société Française de la Mucoviscidose” in Paris on December 3-4, 2009.
• Prof. Thomas Wagner presented ECORN-CF (topic: physiotherapy) at the “6th Winter School” in Obergurgl, Austria (28th February – 4th March 2010).

3.1.2.4 Milestones and Deliverables

| WP 2          | Dissemination of the results | Jeannette Dankert-Roelse | D13  
|---------------|------------------------------|--------------------------|------
|               |                              |                          | D14  
|               |                              |                          | Newsletters, quarterly (at M3, M6 ... M36) plus publications when issued |

<table>
<thead>
<tr>
<th>D13</th>
<th>Newsletter</th>
<th>Quarterly</th>
<th>Report</th>
<th>Public</th>
<th>Dissemination of the project and its content to the general public</th>
</tr>
</thead>
<tbody>
<tr>
<td>D14</td>
<td>Scientific publications</td>
<td>M36</td>
<td>Publication</td>
<td>Public</td>
<td>Dissemination of the project and its results to the scientific community</td>
</tr>
</tbody>
</table>

Status of accomplishment of D13
Delivered

Altogether twelve of twelve required newsletters have been published during the 36 months of the project duration (“ECORN-CF Newsletter” and “ECORN-CF Snippets”). However, in some cases we did not meet the quarterly time interval.

At the start of the project in May 2007, a press release was issued to inform interested people, official bodies and departments how ECORN-CF started, about the goals of ECORN-CF, how we thought to achieve these goals and about the financial support of this project.
We decided not to issue a newsletter at the end of July 2007 because the project just started and there was no news to distribute.

In November 2007, the first newsletter of ECORN-CF was issued and distributed electronically. It contained background information on the project, information about the active partner countries in this project and the 13 collaborating organizations which are also interested in participating in the project, as well as a Who-is-Who of the several work package leaders and deputies and of the partners in this project. Moreover, it contained information on the quality assurance program, the minutes of the first round table meeting, and it described how the ECORN-website would work.

In March 2008, the second newsletter was issued; this newsletter contained a report about the implementation of ECORN-CF as far as this was achieved in the past year and how to go on to get all the participating partner countries involved; a description of the activities in the European Rare Diseases Task Force; an article about the development of the patient questionnaire to be used to assess current CF care as it is provided in Europe and an example of this patient questionnaire; and finally the program of the second quality round table meeting of ECORN-CF.

At the start of the project there was not much news. To get the websites started and to attract questions, we decided that it was more important to undertake activities that would inform lay people and CF-care teams about the possibilities of the ECORN website and what the local websites could offer. Therefore the available working days were used to develop a leaflet that was distributed among the participants of the 2008 ECFS conference and to write a template that, after translation to the respective local language, offered each ECORN-partner the possibility to inform the CF-centres, to publish information about ECORN-CF in the national CF-newsletters, or to put information about ECORN-CF in waiting rooms of CF-centres. For example, using this information in a short article about ECORN-CF in the Dutch CF-newsletter (which is published quarterly by the Dutch CF association) led to a considerable increase of questions for the website in the Dutch language. Finally, a short article was written to be published on the Orphanet website.

Due to these activities fewer newsletters than planned were edited in this period.

The third newsletter was issued in September 2008. It reported exhaustively about the discussions held during the second quality round table meeting, the problems that were encountered, e.g. the time needed to answer questions, the ways to ensure that the given answers are qualified and meet the set standards, and the actions that were undertaken to get ECORN-CF known better among the CF-communities in the countries of the associated partners.

The fourth newsletter was issued in March 2009. We reported about the quality round table meeting held on 4 and 5 November 2008 in Frankfurt. The main subject of the meeting on November 4 were the answers given in the course of 2008 by the various partners of ECORN-CF and how to give positive feedback in such a way that everyone can learn from it. Due to the sometimes divergent opinions about the quality of the answers, this clearly is not an easy task and the way how to do it was not solved.

In September 2009, the fifth newsletter was published, announcing the participation of a new partner in ECORN, namely Greece; moreover, it showed how the number of questions steadily increased, especially for new partners and that the number of questions stabilised in countries that were already online for a longer time.
In December 2009, the sixth newsletter was published, containing a report about the fourth quality round table meeting held in Prague, 5-6 October 2009, with a special focus on the fine scoring of the given answers and how to give feedback in order to improve the answers.

The seventh newsletter was published in February 2010. In this newsletter, a further report on the fine scoring of the answers was published. During the last quality round table meeting, most participants wondered if there were inter- and intra-individual differences between the 5 scorers who did the assessment on content and formal quality, and this was confirmed by comparing the scores of each scorer. Special attention was given to the “Question of the month” (example ➔ ATTACHMENT 03) which was introduced in October 2009.

The eighth and last “ECORN-CF Newsletter” was published at the end of April 2010. It contained a retrospective about the achievements of ECORN-CF and an editorial about the future of ECORN-CF, the present status of the number of questions and the main areas of interest for the people asking questions, possible new partners, and the results of the patient questionnaires.

➔ See ATTACHMENT 04_a-h

In order to inform the interested public more regularly about ECORN-CF we started to publish the one-page “mini” newsletter called “ECORN-CF Snippets” which was prepared by the co-ordinator in Frankfurt:

2nd Issue: November 2009: “How Swine Flu Helped Us Learn”
3rd Issue: January 2010: “ECORN-CF: Is the Glass Half Full or Half Empty?”
4th Issue: April 2010: “A Résumé from a Patient’s Perspective”

➔ See ATTACHMENT 05_a-d

Status of accomplishment of D14
Delivered

1. A poster written by Jitka Brázová et al. about “ECORN-CF project in the Czech Republic: first experiences” was published in the Journal of Cystic Fibrosis (Volume 7, Supplement 2, June 2008) and presented at the ECFS conference. ➔ See ATTACHMENT 06

2. The paper “Travelling with Cystic Fibrosis: Recommendations for Patients and Care Team Members” is endorsed by the European Cystic Fibrosis Society (ECFS) and was submitted to the Journal of Cystic Fibrosis in May 2010. Further to Tim Hirche et al. the whole ECORN-CF study group contributed to this paper. A tool box with travel relevant documents is provided online together with the paper (e.g. “Template for crossing borders”, “Medical Report”). ➔ See ATTACHMENT 01_a-c

3. Daniela d’Alquen et al. is currently preparing a paper with the working title “Quality assessment of expert answers to lay questions about Cystic Fibrosis from various language zones in Europe (ECORN-CF) with a newly developed scoring system”.

➔ See ATTACHMENT 05_a-d
3.1.2.5 Problems encountered and solution of these problems

Problems encountered

In the first year of ECORN-CF the main challenge encountered was to make ECORN-CF known to the CF-community in the ECORN-CF partner countries. Although most of the websites were launched in 2007 and 2008 it was difficult to get questions from CF patients and their families as well as from the CF care teams in some local expert advices. It seemed important to take action to make ECORN known to the CF-community.

Due to this necessary initiative, less time was available for all editions of the “ECORN-CF Newsletter” in 2008; in 2009 and 2010, however, the “ECORN-CF Newsletter” could be published as planned.

How were problems solved?

To increase publicity the following actions were undertaken:

- Patient organizations were asked to put a link to ECORN-CF on their websites and were encouraged to promote the service in their patient newsletters as well.
- An English template for an informative leaflet was given to all project partners for translation into their mother language so that they were able to provide the CF-centres. They could distribute it among the patients and their families.

3.1.3 WP3: Evaluation of the project

Work package leader:
Thomas O. F. Wagner, Frankfurt

Deputy:
Tim O. Hirche, Frankfurt

3.1.3.1 Objectives

The evaluation is divided in two parts: Part 1 (WP3) and part 2 (WP7). In WP3, the consistency of the plan and its realization has been evaluated by means of a target-performance comparison and project assessment tools. For part 2 of the evaluation aspects please refer to WP7 in section 3.2.4.

3.1.3.2 Activities undertaken

From the beginning of the project period, the concordance of the plan and its realization was monitored. This allowed early intervention in the rare case that tasks or objectives of a certain work package could not be accomplished within the set time frames. WP3 ensured constant communication with all WP leaders and followed-up the fulfilment of their project’s duties continuously. A quarterly interim report completed the evaluation process (ATTACHMENT 07_a-k). The document lists all work packages and the deliverables to be accomplished so that a target-performance
comparison could be done by giving comments. This evaluation helped us realise shortcomings and gave us the opportunity to do everything we could to catch up.

### 3.1.3.3 Deliverables

There are no specific deliverables to be accomplished in this work package. The target-performance comparison as described above was done quarterly at M6, M9, M12, M15, M18, M21, M24, M27, M30, M33 and M36. Measures were taken accordingly if needed.

### 3.1.3.4 Problems encountered and solution of these problems

**Swedish expert advice:** As an example of functioning target-performance comparison and project assessment, the problems in the Swedish group (beneficiary Ova Productions, Hans Kollberg) can be taken: In Sweden, as described in interim report M12, several competing patient organizations combined with an unfavourable change in the head of one of the leading CF centres and, on top of this, the vacancy in this position for half a year were all identified as contributing factors to the untoward delay in establishing the Swedish expert advice. Although the website was practically ready (all items were translated by Hans Kollberg, etc.), the Swedish beneficiary had problems in building an expert team that would be able to answer all incoming questions in the time period requested at that time. Therefore, action had to be taken. In October 2008, the Swedish expert advice was launched and the Swedish beneficiary took further necessary steps to tackle the problems by having an agreement with Annika Hollising of the Uppsala CF centre, University Children’s Hospital, Uppsala, Sweden. Please find detailed reports of the Swedish beneficiary attached (ATTACHMENT 08_a-c).

**Answering time:** We analysed in detail the average answering time in the expert advice taking all answers from the local platforms for the period of the respective starting time until the end of March 2008. When analysing the data it became obvious that the projected response time of two working days was not realistic. This issue was also discussed during our second quality round table meeting. As a result, we decided that the priority of the advice giving has to be on quality and not on speed and therefore we changed the “promise” given by a pop-up on the website to the person after having sent a question to the expert advice in this wording: “We try to answer your question as quickly as possible, but quality has the priority over speed. So, please, understand that it may take a few extra days if reassurance with other experts is necessary”. This seemed more adequate since we inform the questioner in the disclaimer that the system is not meant to be in any way helpful in emergency situations.

**Newsletters:** From the evaluation it became obvious that the leader of WP2 (Dissemination) sometimes needed more than 3 months to publish the next “ECORN-CF Newsletter” (please also refer to the explanations in section 3.1.2.4). Therefore, we decided to create a second type of newsletter that was called “ECORN-CF Snippets”. It was published by the project coordinator so that the deliverables of WP2 could be accomplished completely.

**New local partners (without funding):** The most obvious problem was the lack of new local teams from countries that would not have received any funding. According to the agreement, at least three new local partners (apart from the associated
partners) were supposed to be online and ready to provide expert advice by M12. We tried to recruit new partners by representing ECORN-CF at relevant meetings. At the ECFS conference in Prague in June 2008, for example, the president of the ECFS, Stuart Elborn, who is also beneficiary of ECORN-CF, publicized ECORN-CF at the plenary. Please also refer to section 3.1.2.3 for further activities undertaken to inform about ECORN-CF.

Several countries showed interest in joining ECORN-CF, e.g. Bulgaria, France, Greece, Hungary, Italy, Portugal and Spain. However, in the course of time it became clear that only the Greek and the French team were seriously interested in participating. In March 2009, we managed to expand the ECORN-CF list of partners and active languages by launching the Greek expert advice. This was a crucial step since the new partners in Greece did not receive any financial support and yet they considered the system so attractive that they joined the team. The collaborating partners have the same rights but they have to follow the same rules as well. The French platform is currently being implemented and supposed to be launched in the middle of 2010.

We think that the reason for this lack of new teams was not a lack of interest. The point was that the interested persons realized how much work it would have been until the expert advice could have started so that they seemed to be discouraged. Furthermore, the fact that the experts have to translate every question and answer into English might have been a reason for them to lose interest. An expert willing to spend some time on answering questions in his/her language for free, might not be willing to spend some extra time for free on translation work.

What the Italian cooperation with ECORN-CF was concerned we were in contact with Prof. Carla Colombo who is the President of the Italian CF association SIFC. She informed us that a local expert advice being quite similar to the local expert advice existing in Germany (before the ECORN-CF project came into existence) has been operational in Italy for some time. Therefore, we invited the stakeholders in Italy to join ECORN-CF. However, Carla Colombo did not see enough resources in Italy to translate all relevant questions and answers to include those in the Central Archive of ECORN-CF and have the answers quality checked.

Please find below parts of an e-mail that was sent to Prof. TOF Wagner by Prof. Carla Colombo on March 4, 2009: “As President of the SIFC I can ask the Board to forward to ECORN-CF all these questions [she means the questions asked in their own local Italian expert advice] so you can translate them into English and then put them in the English Archive. Of course if you are interested in this aspect it will be up to your project any expense for translation in English. In fact you have to consider that the service provided is quite expensive so it is very difficult for us to find extra funding to finance the participation in the Quality Round Tables. At this moment such a participation could be considered only if it is possible to use a conference call system.” [End of quotation from Prof. Carla Colombo’s e-mail] Such kind of financial support was not covered by our grant agreement and therefore cooperation was not possible.

Since the start of the Czech platform almost half the questions have been asked in Slovak (please see further information in section 3.2.3.5). Although the languages are similar, Czech Republic and Slovakia are different countries with different care situations and health care systems. Therefore, the Czech team tried to motivate Slovakian experts and patient organizations to start an ECORN-CF expert advice on their own (without funding for the experts though) and they also offered help to set up
the service. Unfortunately, there was no positive feedback from the Slovakian side. After all, one Slovak expert was willing to answer most of the Slovak questions asked in the Czech expert advice. This means that sort of a Slovak advice was “hosted” by the Czech platform. The questions answered by the Slovak expert were also quality checked and published in the Central Archive of ECORN-CF.

3.2 Activities related to project objectives (core work packages)

3.2.1 WP4: Expert advice to CF patients and other lay people

Work package leader:
Helge Hebestreit, Daniela d’Alquen, Würzburg

Deputy:
Thomas O. F. Wagner, Frankfurt

3.2.1.1 Objectives

The overarching objective of WP 4 was to allow ease of access to specific information for patients with CF at the highest level of expertise in all member state languages at the same level of quality. To achieve this aim, it was necessary to formulate a number of sub goals which could lead step by step to accomplishing the overall objective. Such sub goals are listed in the following:

I. Technical access to the internet platform in all participating countries for lay people / patients with CF
   a. Building up a network of experts
   b. Preparing the websites of the participating countries
   c. Implementing a web-based central English Archive
   d. Acquiring a substantial number of questions in the participating countries

II. Maintaining / achieving a high standard of provided information on the platform via quality control
   a. Establishing a control system of every Q/A pair reaching the English Archive via the coordinator with feedback to the experts
   b. Identifying important topics on which no European guidelines / evidence-based recommendations exist to include them in the ECFS consensus procedures
   c. Establishing and updating a literature list with a focus on European consensus papers
   d. Establishing a detailed scoring system to judge the quality of answers and to investigate different periods of the project
3.2.1.2 Activities undertaken

In the following section all activities undertaken are described in the order of the objectives listed above:

I. Technical access to the internet platform in all participating countries for lay people / patients with CF
   a. Building up a network of experts:
      In order to be able to provide the patients with the latest knowledge and the highest level of quality possible while answering their questions, it was mandatory to establish a network of experts on CF all over Europe. All participating countries recruited a panel of experts for their local questions and we ourselves (WP4), as the supervisors / coordinators of the central English Archive, recruited further national (German) and international experts to help with tricky questions. This panel of experts was not static, however, but - according to the need of special know-how - additional experts were recruited during the process of the project. All question/answer (Q/A) pairs with disputable and/or difficult content were always discussed with several experts in order to find the best consensus on the answer possible.

   b. Preparing the websites of the participating countries:
      In the first months of the project the main work consisted of preparing the websites of the different language zones: we started with the design of the German/English website and prepared texts about the introduction of the project and informational texts about cystic fibrosis. These texts as well as all relevant texts for the navigation within the system were sent to all participating countries in order to translate them into their local language. Thereafter, the texts were implemented on the respective national sites of the ECORN-CF homepage by a web designer. Introduction and information about all participating team members as well as the curricula of the experts were integrated in the ECORN-CF platform.

   c. Implementing a web-based central English Archive:
      In order to give patients from all countries access to all questions submitted from all other participating countries, a central English website was implemented. All relevant questions from all countries were translated into English after they had been published on the local website and were then sent to the English Archive. After quality check and possible changes/additions (see below), the Q/A pairs were published in the English Archive, so that every patient with English skills has access to all questions and their respective answers.

   d. Acquiring a substantial number of questions in the participating countries:
      The aim for the number of questions from patients and other lay people that was proposed by the ECORN-CF contract reads as follows: “a maximum number of 600 questions per year from patients and other lay people are expected.” An overview over the
number of questions in each of the 3 years of the project and the respective language zone is provided in Table 3.2.1.2-1:

<table>
<thead>
<tr>
<th>Country</th>
<th>Online since</th>
<th>No of questions May 1, 2007 - April 30, 2008</th>
<th>No of questions May 1, 2008 - April 30, 2009</th>
<th>No of questions May 1, 2009 - March 29, 2010</th>
</tr>
</thead>
<tbody>
<tr>
<td>Germany</td>
<td>October 1, 2007</td>
<td>106</td>
<td>169</td>
<td>188</td>
</tr>
<tr>
<td>Czech Republic</td>
<td>October 1, 2007</td>
<td>36</td>
<td>55</td>
<td>14</td>
</tr>
<tr>
<td>UK</td>
<td>October 1, 2007</td>
<td>4</td>
<td>31</td>
<td>19</td>
</tr>
<tr>
<td>Romania</td>
<td>December 19, 2007</td>
<td>3</td>
<td>16</td>
<td>21</td>
</tr>
<tr>
<td>Lithuania</td>
<td>January 31, 2008</td>
<td>4</td>
<td>17</td>
<td>12</td>
</tr>
<tr>
<td>Belgium/NL</td>
<td>March 5, 2008</td>
<td>0</td>
<td>57</td>
<td>44</td>
</tr>
<tr>
<td>Poland</td>
<td>April 10, 2008</td>
<td>0</td>
<td>14</td>
<td>9</td>
</tr>
<tr>
<td>Sweden</td>
<td>October 13, 2008</td>
<td>0</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Greece</td>
<td>March 25, 2009</td>
<td>0</td>
<td>1</td>
<td>13</td>
</tr>
<tr>
<td>TOTAL</td>
<td></td>
<td>153</td>
<td>360</td>
<td>322</td>
</tr>
<tr>
<td>Archive TOTAL</td>
<td>October 1, 2007</td>
<td>89</td>
<td>305</td>
<td>270</td>
</tr>
</tbody>
</table>

Table 3.2.1.2-1: The total number of questions in the English Archive is less than the sum of the questions from all the local platforms, as some internationally irrelevant questions were not published in the English Archive. Furthermore, it takes time to translate all questions into English before they can be published in the archive, so there is always a gap between the number of local Q/As and the number of Q/As in the archive at a certain time point.

The number of Q/As in the last year of the project (the month of April 2010 is still missing in the statistics) stayed approximately on the same level as in the year before (322 Q/As vs. 360). Some countries increased their number of Q/As further in the last year of the project (like Germany, Romania, Sweden, Greece), others stayed on the same level or had even a decreasing number of Q/As (Lithuania, Czech Republic, UK, Netherlands/Belgium, Poland). This might be an indicator that after the great increase of Q/A pairs between the first and second year of the project, now a kind of plateau is reached. Probably many patients also profit from the access to all Q/As asked in the English Archive or in the archives of the respective local expert advice and find their questions already answered by reading Q/As about similar topics. Altogether, however, the total number of Q/As stays still below the
aim of 600 questions per year. But it can be stated, that the number of Q/As rose significantly from the beginning of the project to the second year before reaching a plateau; this successful increase has been achieved – at least in part – by the measures that were undertaken. Please see detailed measures for the solution of this problem under 3.2.1.4.

II. Maintaining / building up a high standard of information provided on the platform via quality control
   a. Establishing a control system of every Q/A pair reaching the English Archive via the coordinator with feedback to the experts

   This measure represented the main part of our daily work for ECORN-CF as all incoming Q/A pairs from patients and lay people to the English Archive were checked by us as the coordinators of the Archive. The coordinator reviewed the literature on that topic, especially if there were any existing consensus statements or guidelines. Then we checked if the question had been answered according to existing guidelines. Respective boxes on the website were marked if guidelines existed and if they had been taken into account. This procedure facilitated statistical analysis of guideline-conformance of the Q/A pairs later on. Furthermore, the coordinator (or proof editor) had to scale the Q/A pair on the website with a three-step system: “good”, “with flaws” and “unacceptable”. If the answer was scaled “good” and had been answered according to guidelines (in case guidelines existed on that topic), the answer was published in the Archive. In case the answer was judged as “with flaws” or “unacceptable” or was not according to existing guidelines, there was always feedback given to the original editor. In such a case (or if the Q/A pair dealt with a very specific and disputable topic), the coordinator sought further advice from other experts. He wrote an e-mail to one or more experts and tried to find a common answer which integrated all incoming proposals from the experts. In any case the coordinator wrote a detailed e-mail to the original author, discussing the topic with regard to other experts’ opinions or with regard to existing guidelines. A proposal for a revised answer was made and discussed with the original author. After a consensus with him and the other experts had been found, the new, revised answer was published in the English Archive.

   In addition, the revised answer was retranslated into its original, local language and the changes or additions were also published again on the local website in order to provide the local users with the extended information as well. A comment was made that the answer was extended or changed after consultation of some more European experts. If an e-mail address of the asking patient was available, he/she was informed via e-mail that the first answer had been changed. An overview over the quality of answers according to the 3-step scale and the existence and conformance with guidelines shows Table 3.2.1.2-2.
Table 3.2.1.2-2: (The total number of 108 Q/As in the first year in this table is higher than the number of 89 Q/As reaching the Archive mentioned in Table 3.2.1.2-1. This is due to the fact that in retrospect some Q/As finally reached the Archive after a long time and are counted afterwards to a former year at an actual date of doing the statistics)

Table -2 reveals that in the course of the project, the quality of answers according to the rough 3-step scoring scale improved from a already quite high percentage of "good" answers of 86,1% in the first year to 94,6% of "good" answers in the third year, while the number of answer with "with flaws" and "unacceptable" decreased in the course of the project. The same trend can be seen when looking at the guideline-conformance of the answers: if a guideline existed, the answers were in 80% according to them in the first year; this percentage increased to 88,9% and 92,5% in the second and third year. Thereby the percentage of Q/A pairs where guidelines were available ranged from 15,3-23,1% in the different years. The percentage of Q/A pairs where there was still a need to work out guidelines ranged from 4,6-9,6% in the different years. In conclusion, the reason to give a feedback from the expert team of Work Package 4 to the local moderator/editor and for changing an answer was mostly because the answer was extended and made more detailed, only in some rare cases the answer was sent back because it was not according to guidelines and had to be changed completely. The constant feedback and discussion about the quality or possibilities of improvement of the answer with the local editor seem to have led to a quality improvement of answers
and a higher guideline conformance of answers in the course of
time, which can be regarded as a great success of the project.

b. Identifying important topics on which no European guidelines /
evidence-based recommendations exist to include them in the
ECFS consensus procedures
For every single Q/A pair, the coordinator had to check if there
were existing guidelines on the topic, and if the answer was
according to them. If so, a respective button on the form had to be
activated. If there was no existing consensus statement / guideline
on the topic, but the need to work one out was acknowledged, the
coordinator marked the Q/A pair by activating another button. The
respective Q/A pairs could thus be identified easily and discussed
at the quality round tables. Furthermore, this procedure facilitated
the preparation of a list containing important topics requiring new
consensus statements. Thus, new European consensus
statements can and will be initiated from ECORN-CF, such as the
paper “Travelling with Cystic Fibrosis: Recommendations for
Patients and Care Team Members”, endorsed by the European
Cystic Fibrosis Society (ECFS) which has been submitted in May
2010.

c. Establishing and updating a literature list with a focus on European
consensus papers:
A list of European consensus papers was established (published
on the website of the European Cystic Fibrosis Society). A hard
copy of these papers were handed out at the first quality round
table in Frankfurt to the staff of the ECORN-CF project, the PDF
versions were sent to all experts via e-mail. An extended list of
additional literature concerning CF guidelines and consensus
statements was compiled during the process of the project and
sent to all experts by e-mail. Articles were provided via CD and as
PDF versions via e-mail. We were updating the current literature
lists in regular time intervals. All experts of ECORN-CF have
access to relevant documents in the download section of the
website.

d. Establishing a detailed scoring system to judge the quality of
answers and to investigate different periods of the project
One of the project’s cornerstones was to ensure that the answers
given by local experts fulfilled certain quality requirements, such as
to comply with existing European guidelines, in order to reach the
same high level of quality of care in all participating European
countries.
A scoring system was developed to assess the content and formal
quality of the given answers to patients’ questions. 5 experts from
4 different countries scored 108 answers from 6 participating
language zones. As some questions were scored at two different
points in time by the same scorers, not only the inter-individual but
also the intra-individual variability of the scoring system could be
evaluated.
The results of this detailed scoring process gave an insight into the
level of content and formal quality of the answers given in the
different countries: Czech Republic, Germany, Lithuania,
Netherlands/Belgium, Romania and the United Kingdom. Another important point was to investigate the development of quality of answers in the course of time when comparing answers from the beginning of the respective online period to those given 14-20 months later.

**METHODS:**

I. Selection of question/answer pairs

One aim of this study was to compare the quality of answers for patients and lay persons from the beginning of the online period of the respective language zone to a period which was confined by the date of the 3rd of July, 2009, about 2 years after the ECORN-project was initiated in May, 2007. This second period is referred to as “end period” in the following sections of this report in comparison to the “start period”. In other words, the expression “end period” does not reflect the end of the whole ECORN-CF project. Out of all 9 participating countries / language zones (Czech Republic, Germany, Greece, Lithuania, Netherlands/Belgium, Poland, Romania, Sweden and United Kingdom) only 6 could be included in this analysis. The remaining 3 countries (Greece, Poland and Sweden) had either not enough Q/A pairs available or the time interval between start period and end period was too short (due to a later start date of the national website).

For the start period, the first 10 Q/A pairs from the respective date of going online were chosen in chronological order, if available. For Lithuania and Romania only 5 Q/A pairs were available from the start period. For the end period, the last 10 Q/A pairs prior to the date of the 3rd of July, 2009 were chosen, if available. For Lithuania only 8 Q/A pairs were available from this period.

The total time span covering the start and end period varied between 15 and 20 months (median 17,8 months) according to the different start dates of the online website of the respective language zones. The time span between the start and end period varied from 4,25 – 18 months (median 8,5 months).

Another aim of this study was to investigate the reproducibility of the scoring system itself, therefore 5 Q/A pairs from the start period were selected for scoring which had already been scored by the same scorers for a quality round table one year before (September 2008). By scoring the same questions again after a time interval which does not allow remembering the previous score that was given by the individual scorer, the intra-individual variability of the single scorer could be investigated.

II. Scoring system

At the first quality round table of the ECORN-CF project on the 22nd of August, 2007, the expert round discussed and developed a scoring system in order to implement an instrument of judging the quality of answers given to lay people in the forum. An overview of the different aspects that are assessed by the tool and the respective marks that lead to a final grading of the answer is given in Table 3.2.1.2-3. The two main aspects of the quality of an answer were regarded as the content and the form. The content quality was subdivided
into 3 aspects. The most important aspect was the correctness of the content resp. if the content of the answer was according to existing guidelines (Table -3; I.1). To reflect the importance of this aspect for the whole content score of the answer, here 0 points were given for a poor answer, 3 for a satisfactory and 6 for a good one, whereas in contrast, the other 2 aspects of the content quality were scored only with 0, 1 and 2 points for a poor, satisfactory or good answer respectively. If the content of the answer was not correct and achieved only 0 points, the whole content score for the respective answer was regarded as poor. After being consented with all the experts of ECORN-CF, the scoring system was mailed to the entire staff of ECORN-CF with detailed explanations and examples for all aspects of the content and formal quality assessment. Training of the experts was initiated by sending example Q/A pairs to familiarize them with the new scoring system and – more importantly – to improve the quality of answers by highlighting the important aspects of an answer.
I. CONTENT QUALITY

<table>
<thead>
<tr>
<th>Grade</th>
<th>Points</th>
</tr>
</thead>
<tbody>
<tr>
<td>POOR</td>
<td>0</td>
</tr>
<tr>
<td>SATISFACTORY</td>
<td>3</td>
</tr>
<tr>
<td>GOOD</td>
<td>6</td>
</tr>
</tbody>
</table>

I.1 CONTENT CORRECT, ACCORDING TO GUIDELINES

I.2 COMPLETENESS OF THE ANSWER, SUITABILITY

<table>
<thead>
<tr>
<th>Grade</th>
<th>Points</th>
</tr>
</thead>
<tbody>
<tr>
<td>POOR</td>
<td>0</td>
</tr>
<tr>
<td>SATISFACTORY</td>
<td>1</td>
</tr>
<tr>
<td>GOOD</td>
<td>2</td>
</tr>
</tbody>
</table>

I.3 OPENNESS

<table>
<thead>
<tr>
<th>Grade</th>
<th>Points</th>
</tr>
</thead>
<tbody>
<tr>
<td>POOR</td>
<td>0</td>
</tr>
<tr>
<td>SATISFACTORY</td>
<td>1</td>
</tr>
<tr>
<td>GOOD</td>
<td>2</td>
</tr>
</tbody>
</table>

TOTAL SCORE FOR CONTENT QUALITY

<table>
<thead>
<tr>
<th>Grade</th>
<th>Points</th>
</tr>
</thead>
<tbody>
<tr>
<td>POOR</td>
<td>0-3</td>
</tr>
<tr>
<td>SATISFACTORY</td>
<td>4-7</td>
</tr>
<tr>
<td>GOOD</td>
<td>8-10</td>
</tr>
</tbody>
</table>

II. FORMAL QUALITY

<table>
<thead>
<tr>
<th>Grade</th>
<th>Points</th>
</tr>
</thead>
<tbody>
<tr>
<td>POOR</td>
<td>0</td>
</tr>
<tr>
<td>SATISFACTORY</td>
<td>1</td>
</tr>
<tr>
<td>GOOD</td>
<td>2</td>
</tr>
</tbody>
</table>

II.1 COMPREHENSIVE STYLE

II.2 PERSONAL STYLE

<table>
<thead>
<tr>
<th>Grade</th>
<th>Points</th>
</tr>
</thead>
<tbody>
<tr>
<td>POOR</td>
<td>0</td>
</tr>
<tr>
<td>SATISFACTORY</td>
<td>1</td>
</tr>
<tr>
<td>GOOD</td>
<td>2</td>
</tr>
</tbody>
</table>

II.3 EXTENT OF ANSWER

<table>
<thead>
<tr>
<th>Grade</th>
<th>Points</th>
</tr>
</thead>
<tbody>
<tr>
<td>POOR</td>
<td>0</td>
</tr>
<tr>
<td>SATISFACTORY</td>
<td>1</td>
</tr>
<tr>
<td>GOOD</td>
<td>2</td>
</tr>
</tbody>
</table>

TOTAL SCORE FOR FORMAL QUALITY

<table>
<thead>
<tr>
<th>Grade</th>
<th>Points</th>
</tr>
</thead>
<tbody>
<tr>
<td>POOR</td>
<td>0-2</td>
</tr>
<tr>
<td>SATISFACTORY</td>
<td>3-4</td>
</tr>
<tr>
<td>GOOD</td>
<td>5-6</td>
</tr>
</tbody>
</table>

Table 3.2.1.2-3: Scoring system judging content and formal quality of Q/As.

III. Scoring procedure

5 scorers from 4 different countries were asked to score the 108 Q/A pairs. It was regarded as important that the scorers had different sub-specializations and perspectives on the patients. Prof. Věra Vávrová from the Czech Republic, Prof. Kris De Boeck from Belgium and Prof. Helge Hebestreit from Germany represented pediatric pulmonologists specialized in CF. Dr. Judy Bradley from the United Kingdom joined the team of scorers as a respiratory physiotherapist specialized in CF and Birgit Dembski from Germany as a representative of the German CF patient organization. As
scoring of the quality of answers always comprises a certain proportion of subjectivity, it was substantial to have a group of at least 5 experts to score the same Q/A pairs, in order to be able to define the inter-individual variability between the scorers and to have a balanced score for each Q/A pair. Q/A pairs with a dissent opinion of experts on the correctness of the content could thus be identified as well as trends of single scorers to always score lower or higher than the median. The 108 Q/A pairs to score were prepared in a way that the scorers were blinded to their country of origin as far as it was possible without loss of information. The Q/A pairs from different countries and points in time were mixed randomly and sent to the experts to score.

RESULTS

I. Methodical results

I.1. Intra-individual variability

To evaluate the intra-individual variability, 25 out of the 108 Q/A pairs were scored at 2 different points in time by the 5 scorers: in September 2008 for the quality round table in Frankfurt in November 2008 and in August 2009 for the quality round table in Prague in October 2009. With one year in between the two scoring times it was expected that the experts did not remember their former score and they were not allowed to look up their old records. If the scorer judged the same Q/A with the same grade twice (e.g. twice grade “good” or twice grade “satisfactory”) this was regarded as “complete congruence”. If the judgment of the scorer differed one grade in between the 2 points in time (e.g. one time grade “good”, next time grade “satisfactory”) this was termed “discrepancy over one stage”. Respectively, “discrepancy over 2 stages” implies that the scorer graded a Q/A one time as “good” and the next time as “poor”. Table 3.2.1.2-4 summarizes the number of Q/A pairs that showed complete congruence, as well as those with discrepancies over 1 or 2 stages separately for each of the 5 scorers. If the total number of Q/A pairs for a scorer is lower than 25, the respective scorer did not score the total number because he or she regarded some of the Q/A pairs as “unscorable”. Scorer 5 as a patient representative and non-medical staff scored only the formal aspect of the Q/A pairs.
<table>
<thead>
<tr>
<th>Scorer</th>
<th>CONTENT QUALITY</th>
<th>FORMAL QUALITY</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Complete congruence</td>
<td>Discrepancy over 1 stage</td>
</tr>
<tr>
<td>1</td>
<td>11/23 (48%)</td>
<td>11/23 (48%)</td>
</tr>
<tr>
<td>2</td>
<td>19/25 (76%)</td>
<td>6/25 (24%)</td>
</tr>
<tr>
<td>3</td>
<td>17/25 (68%)</td>
<td>8/25 (32%)</td>
</tr>
<tr>
<td>4</td>
<td>13/22 (59%)</td>
<td>8/22 (36%)</td>
</tr>
<tr>
<td>5</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 3.2.1.2-4: Intra-individual variability of different scorers. 25 Q/A pairs were scored at 2 different points in time. The numbers represent the number of Q/A pairs (percentage in brackets) that were scored 2 times with the same grade (complete congruence), that were scored the second time 1 grade lower or higher than the first time (discrepancy over 1 stage) and that were scored the second time 2 grades lower or higher than the first time (discrepancy over 2 stages).

Overall, intra-individual variability differed widely between the different scorers. Concerning the content quality, the percentage of Q/A pairs which were graded 2 times in complete congruence varied between a maximum of 76% and a minimum of 48% between scorers. The percentage of Q/A pairs which showed a difference over 2 grades when scored at 2 points in time by the same person ranged between a minimum of 0% and a maximum of 5%.

Concerning the formal quality, the percentage of Q/A pairs scored twice in complete congruence ranged between a maximum of 80% and a minimum of 40% between scorers. The Q/A pairs which were graded with 2 quality stages difference at the 2 points in time ranged from 4-14% between scorers.

In summary, 2 of the 5 scorers (scorer 2 and 5) were well consistent in their judgments; scorer 3 was quite consistent while scorer 1 and 4 showed a substantial incongruence of their scoring results over time. Most of the scorers showed a better consistency of their grading of the content quality compared to their grading of the formal quality of answers.
I.2. **Inter-individual variability**
The variability between the 5 scorers in their judgment about the quality of a certain answer is shown in Table 3.2.1.2-5.

<table>
<thead>
<tr>
<th></th>
<th>NO OF Q/A PAIRS (PERCENTAGE)</th>
<th>NO OF Q/A PAIRS (PERCENTAGE)</th>
<th>NO OF Q/A PAIRS (PERCENTAGE)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>ALL SCORERS GAVE THE SAME GRADE TO</td>
<td>WITH 1 STAGE BETWEEN MAX. AND MIN. GRADE</td>
<td>WITH 2 STAGES BETWEEN MAX. AND MIN. GRADE</td>
</tr>
<tr>
<td>CONTENT QUALITY</td>
<td>45/108 (42%)</td>
<td>54/108 (50%)</td>
<td>9/108 (8%)</td>
</tr>
<tr>
<td>FORMAL QUALITY</td>
<td>28/108 (26%)</td>
<td>41/108 (38%)</td>
<td>39/108 (36%)</td>
</tr>
</tbody>
</table>

Table 3.2.1.2-5: Inter-individual variability between the 5 scorers concerning content and formal quality judgment. The numbers represent the number of Q/A pairs (percentage in brackets) that were given the same grade from all scorers and that had a discrepancy of 1 or 2 stages between the highest and the lowest grade given from scorers.

In summary, the judgment of the 5 scorers differed widely concerning the formal quality of most of the questions. Concerning the content quality, the scorers were much more alike in their judgment, but surprisingly in only 42% of Q/A pairs the content was given the same grade from all scorers. In as much as 8% of Q/A pairs the content quality was scored with a wide difference ranging from “good” to “poor” between scorers.

Another interesting aspect of the inter-individual variability between scorers was the question if there was a trend when looking at the single scorers that some of them tend to always score higher or lower than the median of the group. To answer this question, the scores of the 108 Q/A pairs from every scorer were analyzed and the percentage of Q/A pairs that were scored more than 1 point resp. 2 points above or below the median score were determined. The results are shown in Table 3.2.1.2-6.

Scorer 1 scored clearly more often and markedly lower than the median concerning content and formal quality of Q/A pairs. Concerning the formal quality, this trend was even more distinct with almost no Q/A pairs scored above the median. Scorer 2 was relatively balanced in his scores: concerning the content quality, about 19% of Q/A pairs were scored below and 18% above the median. The score for the formal quality was very balanced and lay only rarely above or below the median score. The points given by scorer 3 were more often below than above the median score; concerning the content quality, the trend was more distinct and often the score was markedly below the median compared to the formal quality. Scorer 4 scored higher clearly more often than the median score (about 30% of his scores (formal and content quality) were above the median). Concerning the formal quality, the scores were more moderately increased than compared to the content quality, but almost no Q/A pairs were scored below the median.
Scorer 5, who judged only the formal quality of Q/A pairs, clearly scored more often above than below the median, but mostly moderately higher.

In summary, the tendency of a single scorer to score lower or higher than the median is consistent for content and formal quality. 2 scorers had a clear tendency to score below and 2 scorers a clear tendency to score above the median. One scorer was relatively balanced.

<table>
<thead>
<tr>
<th>CONTENT QUALITY</th>
<th>% OF Q/AS ≥ 2 PTS BELOW MEDIAN SCORE</th>
<th>% OF Q/AS &gt; 1 PT BELOW MEDIAN SCORE</th>
<th>% OF Q/AS &gt; 1 PT ABOVE MEDIAN SCORE</th>
<th>% OF Q/AS ≥ 2 PTS ABOVE MEDIAN SCORE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scorer 1</td>
<td>17,6</td>
<td>7,4</td>
<td>8,3</td>
<td>5,6</td>
</tr>
<tr>
<td>Scorer 2</td>
<td>12</td>
<td>7,4</td>
<td>10,2</td>
<td>7,4</td>
</tr>
<tr>
<td>Scorer 3</td>
<td>15,9</td>
<td>8,4</td>
<td>6,5</td>
<td>5,6</td>
</tr>
<tr>
<td>Scorer 4</td>
<td>4,6</td>
<td>2,8</td>
<td>10,2</td>
<td>21,3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>FORMAL QUALITY</th>
<th>% OF Q/AS ≥ 2 PTS BELOW MEDIAN SCORE</th>
<th>% OF Q/AS &gt; 1 PT BELOW MEDIAN SCORE</th>
<th>% OF Q/AS &gt; 1 PT ABOVE MEDIAN SCORE</th>
<th>% OF Q/AS ≥ 2 PTS ABOVE MEDIAN SCORE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scorer 1</td>
<td>24,1</td>
<td>17,6</td>
<td>0,9</td>
<td>0</td>
</tr>
<tr>
<td>Scorer 2</td>
<td>2,8</td>
<td>3,7</td>
<td>2,8</td>
<td>0,9</td>
</tr>
<tr>
<td>Scorer 3</td>
<td>9,3</td>
<td>9,3</td>
<td>4,7</td>
<td>0,9</td>
</tr>
<tr>
<td>Scorer 4</td>
<td>1,9</td>
<td>0</td>
<td>22,2</td>
<td>6,5</td>
</tr>
<tr>
<td>Scorer 5</td>
<td>2,8</td>
<td>2,8</td>
<td>19,4</td>
<td>6,5</td>
</tr>
</tbody>
</table>

Table 3.2.1.2-6: Tendency of the individual scorers to score above or below the median score. The numbers represent the percentage of Q/A pairs that were scored more than 1 resp. 2 points above/below the median score from all scorers.

II Project results

II.1. Each specific country

Apart from the methodical results of this investigation, it was of high interest to get some information about the quality of answers given in the ECORN-CF forum for lay people in the participating countries. Figures 3.2.1.2-1 through -12 show the content and formal quality of answers separated into the 6 language zones. Each figure shows the median score from the 5 scorers for every single Q/A pair as a column, which are assorted in the course of time. The squares flanking each column represent the highest and lowest score given. Dark grey columns signify answers of “good” quality, light grey columns those of “satisfactory” quality and white columns those of “poor” quality. The black columns at the end of the Q/A pairs from the starting and from the end period represent the median score of all Q/A pairs form the respective period.
The results for Q/A pairs from the Czech Republic are shown in Figures -1 (content quality) and -2 (formal quality). The mean score for all Q/A pairs from the start period compared to the one from the end period decreased only slightly (from 8.2 to 7.7), so that it can be stated that the quality remained on a barely “good” level during the time period covered by this investigation. Regarding the formal quality (Figure -2), the mean score for all Q/A pairs from the start period stayed the same compared to the one for all Q/A pairs from the end period on a barely “good” level.

For the content quality of the German Q/A pairs (Figure -3) the mean for the Q/A pairs from the start period decreased only slightly compared to the mean for the Q/A pairs from the end period (from 8.2 to 7.6). So it was in both periods still on a barely “good” level. The mean formal quality of the German Q/A pairs stayed the same for the start and the end period (Figure -4) on a “good” level.

For the content and formal quality of Q/A pairs from the Lithuanian platform the scores from the start and the end period were on a “satisfactory” level (Figures -5 and -6).

The overall content and formal quality of Q/A pairs from the Dutch platform (for questions from the Netherlands and Belgium) from the start and end period were on a clearly “good” level (Figures -7 and -8).

Regarding the content and formal quality of Romanian Q/A pairs, the mean score for all Q/A pairs were on a “satisfactory” level at the start and end period (Figures -9 and -10).

The content and formal quality of Q/A pairs from the United Kingdom on the English platform remained on the same clearly “good” level for the period studied (Figures -11 and -12).
**Fig. 3.2.1.2-1:** Content quality of the answers given to Czech questions on the ECORN-CF platform. 10 Q/A pairs from the start period and 10 Q/A pairs from the end period were assessed. The black columns represent the mean out of the scores from the 10 Q/A pairs of the start and end periods, respectively. Dark grey columns signify answers with a median score of good quality, light grey columns answers with a median score of satisfactory quality. The squares flanking each column mark the highest and lowest scores given to that Q/A pair.

**Fig. 3.2.1.2-2:** Formal quality of the answers given to Czech questions on the ECORN-CF platform. For details, see text and legend to Figure 3.2.1.2-1.
Fig. 3.2.1.2-3: Content quality of the answers given to German questions on the ECORN-CF platform. For details, see text and legend to Figure 3.2.1.2-1.

Fig. 3.2.1.2-4: Formal quality of the answers given to German questions on the ECORN-CF platform. For details, see text and legend to Figure 3.2.1.2-1.
Fig. 3.2.1.2-5: Content quality of the answers given to Lithuanian questions on the ECORN-CF platform. 5 Q/A pairs from the start period and 8 Q/A pairs from the end period were assessed. For further details, see text and legend to Figure 3.2.1.2-1.

Fig. 3.2.1.2-6: Formal quality of the answers given to Lithuanian questions on the ECORN-CF platform. For further details, see text and legends Figure 3.2.1.2-1 and -5.
Fig. 3.2.1.2-7: Content quality of the answers given to Dutch questions on the ECORN-CF platform. For further details, see text and legend to Figure 3.2.1.2-1.

Fig. 3.2.1.2-8: Formal quality of the answers given to Dutch questions on the ECORN-CF platform. For further details, see text and legend to Figure 3.2.1.2-1.
Fig. 3.2.1.2-9: Content quality of the answers given to Romanian questions on the ECORN-CF platform. 5 Q/A pairs from the start period and 10 Q/A pairs from the end period are assorted in the course of time. For further details, see text and legend to Figure 3.2.1.2-1.

Fig. 3.2.1.2-10: Formal quality of the answers given to Romanian questions on the ECORN-CF platform. For further details, see text and legends to Figures 3.2.1.2-1 and -9.
Fig. 3.2.1.2-11: Content quality of the answers given to English questions on the ECORN-CF platform. For further details, see text and legend to Figure 3.2.1.2-1.

Fig. 3.2.1.2-12: Formal quality of the answers given to English questions on the ECORN-CF platform. For further details, see text and legend to Figure 3.2.1.2-1.
II.2. All countries in comparison

A summary of the content / formal quality of answers from all participating countries from the start and the end period of this investigation is shown in Figures 3.2.1.2 -13 and -14. Each figure shows 2 columns for each language zone: the first represents the median of all scores for the Q/A pairs from the start period, the second one the median of all scores for the Q/A pairs from the end period. Thereby each Q/A pair was included by a single score, namely the median score from all 5 scorers. Then, the median for the Q/A pairs from the start period (e.g. 10 Q/A pairs) was calculated out of the 10 median scores that were given to the single Q/A pairs of the respective language zone. The squares flanking each column represent the highest and lowest median score given to a single question. Dark grey columns represent median scores of “good” quality, light grey columns those of “satisfactory” quality.

Figure -13 shows that Netherlands/Belgium and the United Kingdom are leading with respect to the content quality of answers, with a clear “good” quality of the content of their answers both during the start and the end period. These language zones are followed by the Czech Republic and Germany, which show an almost “good” quality of the content of their answers in both periods. Romania and Lithuania reflect only a “satisfactory” content quality of their answers at both points in time. The formal quality of answers, which is shown in Figure -14 follows a similar pattern with a clear “good” quality for the Dutch and English answers, a “good” resp. almost “good” quality for the German resp. Czech answers, and a “satisfactory” quality for the Lithuanian and Romanian answers.

Fig. 3.2.1.2-13: Content quality of the answers from all six language zones during the start and end periods. Each column represents the median of all scores for the Q/A pairs from the respective period. The squares flanking each column represent the highest and lowest median score given to a single question. Dark grey columns show answers of “good” quality, light grey columns those of “satisfactory” quality.
II.3. All countries together

Figures 3.2.1-15 and -16 show the content resp. the formal quality of answers from the start versus the end period when combining all Q/A pairs from all participating countries. The first column represents the median of the 50 Q/A pairs from the start period, the second column the median of the 58 Q/A pairs from the end period. First, the median score from all 5 scorers was determined for each question, then the median score for all Q/A pairs in one period was calculated. The squares flanking each column represent the highest and lowest median score given to a single question. The dark grey color of the columns signifies "good" quality.

The overall content quality of the answers from the start period and the end period remained on a good quality level (Figure -15). The formal quality of answers followed a similar pattern (Figure -16): it remained on an almost good level for the start and the end period when taking all countries together.
Fig. 3.2.1.2-15: Content quality of all answers given during the start vs. the end period from all participating countries. The first column represents the median of the 50 Q/A pairs from the start period, the second column the median of the 58 Q/A pairs from the end period. For each Q/A pair, the median score from all 5 scorers was calculated. Thereafter, a median score for each time period was determined. The squares flanking each column represent the highest and lowest median score given to a single question. The dark grey color of the columns reflects “good” quality.

Fig. 3.2.1.2-16: Formal quality of all answers given during the start vs. the end period from all participating countries. For details, see legend of Figure 3.2.1.2-15.
Summary, conclusions of the “scoring project” and impact on the ECORN-CF project:

- The scoring system described above was developed as an instrument for an effective quality control of the content and formal quality of answers, with the aim to improve quality in the course of time.

- The analysis of the intra-individual variability of each of the 5 scorers showed the limitations and weak points of this system: 2 scorers were well consistent in their judgments, 1 was quite consistent but 2 scorers showed a substantial incongruence of their judgments over time. As expected, most scorers showed a better consistency of their grading of the content quality compared to their grading of the formal quality. On the one hand, this reflects the subjectivity when scoring an answer. This problem is inherent in every system that involves human beings passing a judgment. On the other hand, our findings might indicate that there is quite a substantial number of Q/A pairs on topics without clear standards available that help to provide or judge an answer. This lack of standards can lead to more than one possible answer or to an incongruence of the judgment of a single scorer.

- The investigation of the inter-individual variability showed that in general the opinions about the grading of the formal quality of answers often differed widely between the 5 scorers. Concerning the content quality, scorers in 42% of Q/A pairs gave the same grade, but in 8% the same Q/A pair was scored as “good” and as “poor” by different scorers. Those Q/A pairs have been discussed at the quality round tables with the experts. It became evident that those Q/A pairs often dealt with topics lack standards or consensus guidelines. Thus, different opinions about the correctness or quality of an answer were possible. The discussion helped to determine topics on which a consensus document should urgently be worked out. Again, the variability between scorers depicted the problem of subjectivity: if one judges an answer as “good” or “poor” always depends – in addition to “hard facts” - on the subjective impression of the scorer. Furthermore, some scorers had a clear tendency to score either above or below the median score. 2 scorers showed a clear trend to score higher and 2 showed a clear trend to score always lower than the median. Only 1 scorer was relatively balanced. To overcome this subjectivity of the system, it is mandatory to have a group of scorers judging the answers independently in order to get a representative picture.

- Regarding the project results, we wanted to know the quality of answers in the different countries and the development of the quality in the course of time (was there any improvement?). The Netherlands/Belgium and the United Kingdom presented the best answers with a content and formal quality that stayed on a good to clearly good level in both periods. Germany and the Czech Republic followed with a good to almost good level of content and formal quality in the start and end periods. On average, Lithuania and Romania showed a satisfactory content and formal quality which did not change from the start to the
end period. Thus, there was no improvement in the course of time, but in 4 out of 6 countries/language zones, the quality of answers was on a very high level, so that there was not much room for improvement. In 2 of 6 countries, however, the quality stayed only on a “satisfactory” level. In consequence, there clearly is the need to work on the quality of answers in those countries. Probably more time and effort is required to achieve this aim. Possible measures were discussed at the last quality round table in Prague, such as a training according to the “Pendleton Rules”, which could be supported by short-term visits, or training in collaboration with the patient organizations, recruiting the adequate experts in the local expert team with the help of patient organizations, sending around examples of what is a good answer from time to time to all experts or organizing workshops to train the experts in giving good answers.

3.2.1.3 Deliverables

<table>
<thead>
<tr>
<th>WP 4</th>
<th>Expert advice for Cystic Fibrosis patients</th>
<th>Helge Hebestreit</th>
<th>D1</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>All associated partners (at M6) plus 3 new partners (at M12) online and ready to give expert advice to the patients + contribution to all other work packages</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>D1</th>
<th>Expert advice for Cystic Fibrosis patients</th>
<th>M6</th>
<th>Other</th>
<th>Public</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Status of accomplishment of D1**
Delivered

To fulfill D1, all associated partners (Czech Republic, Germany, Lithuania, Netherlands/Belgium, Poland, Romania, Sweden, United Kingdom) should have been online and ready to give expert advice to the patients at M6 (November 2007). Actually, only Czech Republic, Germany and the United Kingdom were online at the notified date (date of going online October 1, 2007). At M12 (May 2008), with Romania (December 19, 2007), Lithuania (January 31, 2008), Netherlands/Belgium (March 5, 2008), and Poland (April 10, 2008) almost all partners were online, except Sweden, which followed on October 13, 2008. The projected recruitment of 3 new partners at M12, could not be fulfilled; one new partner was Greece, which went online on March 25, 2009.
Since the start of the Czech platform almost half the questions have been asked in Slovak (please see further information in section 3.2.3.5). Although the languages are similar, Czech Republic and Slovakia are different countries with different care situations and health care systems. Therefore, the Czech team tried to motivate Slovakian experts and patient organizations to start an ECORN-CF expert advice on their own (without funding for the experts though) and they also offered help to set up the service. Unfortunately, there was no positive feedback from the Slovakian side. After all, one Slovak expert was willing to answer most of the Slovak questions asked in the Czech expert advice. This means that sort of a Slovak advice was “hosted” by the Czech platform. The questions answered by the Slovak expert were also quality checked and published in the Central Archive of ECORN-CF.

Other potential partners, such as Italy, Spain and especially France, showed great interest. The coordinator of the French CF Centre of Reference in Nantes participated in several quality round tables of ECORN-CF. The local French expert advice is currently being implemented and is supposed to be online by the middle of 2010.

In summary, D1 could not be fulfilled in the expected time frame, but all partners were online by October 2008 and Greece could be recruited as a new partner. Reasons for not fulfilling D1 in time were problems in recruiting local expert teams willing to provide the necessary translation work for the implementation of the local website and later to answer the questions and do the translation into English of all relevant Q/A pairs free of charge.

3.2.1.4 Problems encountered and solution of these problems

Acquisition of a substantial number of questions in the participating countries

From the data provided above, it is obvious that especially in the first year we were far away from the goal of 600 questions per year. One of the reasons is for sure that the project just started at that time.
Secondly, the number of questions asked strongly depends on the availability of internet access for the patients, and on the awareness of such a website providing the possibility to ask questions for patients with CF. In Germany, for example, the link to the expert advice on the homepage of the German patient organization had already existed for several years before the ECORN-CF expert advice started. This means that the CF patient forum had already been frequented very much in the past. Therefore, it is not surprising that the most questions were asked in the German system.

Here are some examples of measures that were taken to enhance the level of awareness and the number of questions asked in other countries, where the system was implemented for the first time.

**Dutch website:** ECORN-CF was announced to the patients via a press release in the newsletter for patients and families, and an article in a national journal for general practitioners before the Dutch site was online. Furthermore, the Belgian and Dutch representatives of ECORN-CF announced the launch of the Dutch ECORN-CF site in a newsletter which was sent to 1000 Dutch speaking CF families and health care professionals. An announcement was sent to “mucofamilies”; an e-group of CF families, “mucoJOVO”, an e-group of CF adults; and the health care professionals of the Belgian CF centres (physicians, physiotherapists, dieticians, psychologists, social
workers and nurses). Furthermore a message was posted on the www.muco.be website and a banner and a link to ECORN-CF were placed on the website of the Dutch CF organization. All these measures were very successful, as is evident from the clear increase in Q/As on the Dutch platform.

**Czech website:** The Czech representatives advertised ECORN-CF on the website of the Czech patient organization (a banner), the university (Charles Prague University) and hospital (University Hospital Motol) and to CF specialists in the Czech Republic during their regular meetings. Furthermore this information was added to CF teaching presentations to pulmonologists, allergologists and clinical immunologists and also GPs. A poster on ECORN-CF activities in the Czech Republic was presented at the European CF conference (ECFS) in June 2008 in Prague.

**Romanian website:** To increase the number of questions the Romanian ECORN-CF team put the ECORN-CF link on the UMFVBT website. The Romanian CF patient organization was contacted. Unfortunately there is no website of the Romanian association. Therefore, a link to ECORN-CF was established on the website of the Romanian organization for rare diseases including Prader-Willi Syndrome (www.apwromania.ro). In addition, the ECORN-CF banner and a short presentation of the project were posted on the web page of the county hospital.

**English website:** The ECORN-CF banner was placed on the website of Belfast City Hospital as well as on different websites of the university (Queens University) and the CF Trust. See for example: http://www.cftrust.org.uk/aboutcf/links/

Furthermore, ECORN-CF was promoted to patients and families, e.g. a letter was sent to every patient advertising ECORN-CF. ECORN-CF was also advertised at a recent information day for families and parents of CF.

**Lithuanian website:** Information was sent to specialists providing counseling and care to CF patients in Lithuania. There was a press conference related to the Rare Disease Day (February 29, 2008). Among other questions, information about the ECORN-CF project, its website and the possibilities to get information and ask questions related to CF was presented. One of the presentations at the Lithuanian "Genetics in Modern Medicine" conference, held on March 28, 2008 in Vilnius, included information about the ECORN-CF project, its website and invited to look and ask for information on CF. There were several interviews in national / regional mass media (TV, radio, newspapers) containing information about the Lithuanian part of the ECORN-CF website and possibilities to ask questions.

**In general,** there is a number of possible reasons why in some countries the number of questions asked via internet is still low despite all the measures taken to increase the knowledge about ECORN-CF:

- Internet facilities are not available for all families, especially in rural regions of certain countries. Therefore, CF patients / families in such countries are more used to address their local general practitioner or a physician with specialization in CF diagnosis and treatment than to ask questions online.
- Some CF societies (e.g. the Lithuanian and Romanian society) still do not have a website.
- In Lithuania, there is some information from Lithuanian CF families who have access to internet resources that the ECORN-CF website is informative enough for them without the need to submit questions online. They still prefer to contact their physicians directly when they have some special questions.
Response time to answer questions

The initial goal of 2 working days between the time a question is asked and the delivery of the answer in the local language to the patient turned out to be unrealistic. We discussed this topic on the various quality round tables and came to the conclusion, that a high quality of the answer has priority over the response time. As most questions are not trivial and require an extended exchange of information and views between different experts, this is a time-consuming process which, however, eventually leads to the best answer possible.

The problem has been solved by informing all users of the internet platform that this forum is not suitable to clarify acute and urgent medical cases but will provide the questioner with extended information and an answer with the highest quality possible; this means that if the topic needs further discussion with other experts, the time for awaiting an answer could be extended. Principle: quality is a superior objective over answering time.

3.2.2 WP5: Expert advice to members of the CF Care Team

Work package leader:
Stuart Elborn, Judy Bradley, Belfast

Deputy:
Thomas O. F. Wagner, Frankfurt

3.2.2.1 Objectives

The overall objective of this WP was to allow ease of access to specific information for care team members at the highest level of expertise in all member state languages

Our specific objectives within this work package were to accept questions/answers translated from all language zones into English and then coordinate the quality of the English translated answer.

3.2.2.2 Activities undertaken

The quality assessment in WP5 was conducted by reviewing the content in accordance with European consensus statements, guidelines, high quality primary research and in the absence of these, local expert opinion. We were responsible for quality checking questions and answers specifically from members of the CF care team, other work package (WP4) focused on quality checking expert advise for CF patients and other lay persons like family members.

The coordinator or co-workers (as appropriate) quality checked the English translation expert advice from CF care team questions. During the project period there were 27 questions from the CF care team around Europe in total which were translated into English in other packages and then quality checked within work package 5. There were 5 questions from the local English CF care teams and the
other 22 questions were from other European countries. Questions are considered being CF care team questions if the questioner registered as care team member and then asked a question in the registered mode. In rare cases also anonymous questions were considered being CF care team questions if it clearly appears from the question itself. The topics from CF care team members included questions about cross infection/hygiene or treatment interventions such as antibiotic therapy of physiotherapy. Where appropriate these questions were either quality checked by one of the ECORN-CF staff members (Stuart Elborn, Judy Bradley or Valerie Hall) or where it was deemed appropriate, another expert was consulted.

Other activities
- A representative of this work package attended and participated in the quality round tables.
- A representative of this work package participated in an in-depth quality assessment of patient questions within WP 4.
- Judy Bradley and Stuart Elborn have contributed to 2 papers (one in draft, one submitted) led by members of other work packages.
- Judy Bradley and Stuart Elborn also co-ordinated the local ECORN-CF English site. On the local English site there were a total of 18 questions asked (13 patient questions and 5 health professional questions).
- Judy Bradley has done a platform presentation on ECORN-CF at ECFS Conference 2009.
- Contributed to all interim reports requested.

3.2.2.3 Deliverables

<table>
<thead>
<tr>
<th>WP 5</th>
<th>Expert advice to members of the CF care team</th>
<th>Stuart Elborn</th>
<th>D2</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Expert advice for Cystic Fibrosis care team</td>
<td>M6</td>
<td>Other</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Limited to scientific community</td>
<td></td>
</tr>
</tbody>
</table>

Status of accomplishment of D2
Delivered

To fulfill D2, all associated partners (Czech Republic, Germany, Lithuania, Netherlands/Belgium, Poland, Romania, Sweden, United Kingdom) should have been online and ready to give expert advice to the patients at M6 (November 2007). Actually, only Czech Republic, Germany and the United Kingdom were online at the
notified date (date of going online October 1, 2007). At M12 (May 2008), with Romania (December 19, 2007), Lithuania (January 31, 2008), Netherlands/Belgium (March 5, 2008) and Poland (April 10, 2008) almost all partners were online, except Sweden, which followed on October 13, 2008. The projected recruitment of 3 new partners at M12, could not be fulfilled; one new partner was Greece, which went online on March 25, 2009.

Since the start of the Czech platform almost half the questions have been asked in Slovak (please see further information in section 3.2.3.5). Although the languages are similar, Czech Republic and Slovakia are different countries with different care situations and health care systems. Therefore, the Czech team tried to motivate Slovakian experts and patient organizations to start an ECORN-CF expert advice on their own (without funding for the experts though) and they also offered help to set up the service. Unfortunately, there was no positive feedback from the Slovakian side. After all, one Slovak expert was willing to answer most of the Slovak questions asked in the Czech expert advice. This means that sort of a Slovak advice was “hosted” by the Czech platform. The questions answered by the Slovak expert were also quality checked and published in the Central Archive of ECORN-CF.

Other potential partners, such as Italy, Spain and especially France, showed great interest. The coordinator of the French CF Centre of Reference in Nantes participated in several quality round tables of ECORN-CF. The local French expert advice is currently being implemented and is supposed to be online by the middle of 2010.

In summary, D2 could not be fulfilled in the expected time frame, but all partners were online by October 2008 and Greece could be recruited as a new partner. Reasons for not fulfilling D2 in time were problems in recruiting local expert teams willing to provide the necessary translation work for the implementation of the local website and later to answer the questions and do the translation into English of all relevant Q/A pairs free of charge.

3.2.2.4 Problems encountered and solution of these problems

It was anticipated that there would be a maximum of 300 questions of care team members per year. There were relatively few questions to be quality checked within WP 5 despite trying a number of strategies to increase questions from clinicians. We tried to address the lack of questions from the target group, i.e. local CF care teams and European CF teams, in a number of ways in this reporting period.

- Local CF Teams
  - We held another information session at our joint adult and paediatric research meeting.
  - We had links to the ECORN CF site on local University web pages
  - We included information on ECORN CF in information provided to patients
  - We reviewed questions from a local Ask the expert site and found out that there were very few clinician questions asked on this site and the majority of questions not from patients were from students asking for information on CF disease.
• European CF Teams
  o There was a flyer at the European CF conference in Prague to advertise this service to the wider European CF care team and there was an ECORN stand at the conference which our team was involved in manning.
  o Judy Bradley was invited to do a presentation on the ECORN-CF at a European nursing session at ECFS Conference 2009.

3.2.3 WP6: Quality assurance program

Work package leader:
Jitka Brázová, Prague

Deputy:
Thomas O. F. Wagner, Frankfurt

3.2.3.1 Objectives

The two main goals of WP6 were: establishment of a European cross border quality assurance program and the implementation of European consensus.

3.2.3.2 Activities undertaken

The quality assurance program was one of the core activities of the project; all associated partners had to contribute and had to stick to the rules determined by the group as a whole. Quality assurance can only be obtained if every participant at every local site stands to the rules.
The main tools of quality assurance in this project were single-question feedback and quality round tables where all faults and weaknesses were discussed openly.

During the three years of the project period, local websites in nine language zones went online (Belgium/the Netherlands, Czech Republic, Germany, Greece, Lithuania, Poland, Romania, Sweden and the United Kingdom). We worked as coordinators with regard to the implementation of a European cross border quality assurance program and European consensus. In close cooperation with WP4, we helped control the quality of a part of the incoming question/answer pairs from all countries by scoring them after they had been translated into English.

The most difficult and unclear cases were discussed during the regular annual meetings (Quality Round Tables) that we organised in cooperation with the Frankfurt head office. We cooperated with experts for Cystic Fibrosis in the Czech Republic, Germany, Romania, United Kingdom, Lithuania, Poland, Sweden, Belgium and the Netherlands. We closely cooperated with CF relevant organizations (ECFS, CF Europe, EuroCareCF, etc.) and all participants interested in the quality of care of CF patients (open access) to reach consensus on diagnostic and therapeutic measures.

At the beginning of the project two sets of test questions (two questions in each set) were sent to all experts including us. The answers were blinded beforehand and we participated in the scoring of experts’ answers according to the newly developed scoring system. The results of the scorers were then presented and discussed at the first quality round table meeting in Frankfurt.
In close cooperation with WP4, we helped with the scoring of the sets of question/answer pairs from different countries (Germany 10 Q/A pairs, United Kingdom 10 Q/A pairs, Czech Republic 10 Q/A pairs, Lithuania 10 Q/A pairs, Romania 5 Q/A pairs).

A total of 55 Q/A pairs from the countries mentioned were mixed and blinded, and comments in the Q/A pairs giving a hint at the origin country were deleted as completely as possible. Together with four other experts, we participated in the detailed scoring of the experts’ answers according to a modified scoring system (developed in accordance with the ECORN-CF participants at the first QRT in Frankfurt in August 2007; it meant to give us more information on the quality of answers in the different countries).

The results of the 5 scorers were then presented and discussed at the third quality round table in Frankfurt in November 2008. In preparation of the last QRT in Prague in 2009, the same 5 scorers rescored 25 of the “old” Q/A pairs and 33 new Q/A pairs. The results were presented and discussed. Please refer to section 3.2.1.2; II.d. for further information.

A patient questionnaire was prepared, translated in all needed languages and sent to registered lay person users twice in the course of the project (in December 2008 and 2009). Please refer to section 3.2.4 for further information about the results of the questionnaire’s evaluation.

One of the items in the questionnaire was a question about the answer the family member or the patient got from ECORN-CF. To improve the website and its usefulness for the users (and as a result to strengthen its popularity) we wanted to know whether the questioners were satisfied or not with the answer(s) they got. We therefore asked them to give a score from 1 (not at all) to 10 (very satisfied) on the question “Were you satisfied with the answer to your question?” (Table 3.2.3.2-1).

The first e-mail requesting to fill in the questionnaire was sent on December 12, 2008 to 396 e-mail addresses. We received back 88 family questionnaires and 45 patient questionnaires; this equals a return rate of 33.6 %.

The second e-mail requesting to fill in the questionnaire was sent on December 2, 2009 to 654 e-mail addresses. We received back: 73 family questionnaires and 42 patient questionnaires. Return rate: 17.6 %.
Family Questionnaire: How satisfied were you with the answer?

<table>
<thead>
<tr>
<th>Country, n</th>
<th>Mean (10 = very satisfied)</th>
<th>Standard deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>CZ, 21</td>
<td>7,9</td>
<td>2,7</td>
</tr>
<tr>
<td>DE, 82</td>
<td>7,0</td>
<td>2,9</td>
</tr>
<tr>
<td>EN, 17</td>
<td>7,2</td>
<td>2,6</td>
</tr>
<tr>
<td>LT, 6</td>
<td>6,8</td>
<td>1,3</td>
</tr>
<tr>
<td>NL/BE, 9</td>
<td>7,9</td>
<td>1,1</td>
</tr>
<tr>
<td>PL, 4</td>
<td>7,8</td>
<td>1,9</td>
</tr>
<tr>
<td>RO, 5</td>
<td>8,0</td>
<td>2,1</td>
</tr>
<tr>
<td><strong>Total, 144</strong></td>
<td><strong>7,3</strong></td>
<td><strong>2,6</strong></td>
</tr>
</tbody>
</table>

Table 3.2.3.2-1

One of the main goals of this WP was the implementation of a European consensus. Since the second QRT in Prague in 2008, we started drafting a consensus paper on a very important topic which is travelling with CF. Written recommendations on this very broad topic have been submitted for publication to the Journal of Cystic Fibrosis, an impact journal of the European Cystic Fibrosis Society (see also section 3.2.3.3).

We helped advertise the project not only on a national but also international basis.

In 2008, a banner of ECORN-CF was placed on the European Cystic Fibrosis Society website.

We managed an ECORN-CF booth with online access to the project website during the European CF conference in Prague in June 2008.

We helped organise that ECORN-CF flyers were provided with every conference bag during the European CF conference in Prague in June 2008.

We had a poster about ECORN-CF in the Czech Republic during the European CF conference in June 2008 in Prague (ATTACHMENT 06).

3.2.3.3 Deliverables

<table>
<thead>
<tr>
<th>WP 6</th>
<th>Quality assurance measures</th>
<th>Jitka Brázová</th>
</tr>
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<tbody>
<tr>
<td></td>
<td></td>
<td>D5</td>
</tr>
<tr>
<td></td>
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</tr>
<tr>
<td></td>
<td></td>
<td>D7</td>
</tr>
<tr>
<td></td>
<td></td>
<td>D8</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Quality Round Tables at M12, M18, M24, M30</td>
</tr>
</tbody>
</table>
**Status of accomplishment of D5 – D8**

Delivered

D5 – accomplished (22nd – 23rd August 2007, Frankfurt)
D6 – accomplished (23rd – 24th April, Prague)
D8 – accomplished (6th – 7th October 2009, Prague)

All planned Quality Round Table meetings (QRT) were successfully organised, two in Frankfurt, two in Prague during the whole project period.

These meetings allowed all experts involved in the process to meet. We also very closely cooperated with CF relevant organizations (ECFS; CF-Europe, EuroCareCF etc.) and all participants interested in the quality of care of CF patients (open access) to reach consensus on diagnostic and therapeutic measures.

The most important topic of the meeting and one of the main goals of this work package was evidence-based medical discussion of difficult questions and extraction of topics for new guidelines that could be suggested to the ECFS. During the meeting in Prague in April 2008, we decided to prepare a consensus statement on a very important issue - Travelling with CF. Therefore, an important part of the third and fourth QRT was a Consensus Meeting on “Travelling with CF” and the preparation and then finalizing of a paper on Travelling with CF (endorsed by the ECFS) which was submitted to the Journal of Cystic Fibrosis in May 2010 (ATTACHMENT 01_a-c).

During the last QRT we decided to start a project called “ECORN-CF: Question of the Month”. Every month, starting in December 2009, an expert from one of the countries involved in the project selected a question which originally came to their local ECORN-CF website and was later published in the Central English Archive after the internal ECORN-CF quality check. The answer was completed with related expert literature and then sent via e-mail to all experts in all collaborating countries (ATTACHMENT 03).

After each quality round table meeting, the participants and other colleagues involved in the project received all information discussed during the meeting by e-mail. The minutes of the meetings also included action items to be accomplished, outcomes of the meeting and copies of the presentations (ATTACHMENT 02_a-d).

The summary and the highlights of every meeting were published in eight ECORN-CF Newsletters (ATTACHMENT 04_a-h).
3.2.3.4 Problems encountered and solution of these problems

There were no great problems during the duration of the project at all. The project was well prepared and we complied with all planned requirements.

At the beginning and during the project, relevant guidelines were published on the ECORN-CF website and sent to all co-working partners as a rule for correctness of the answers. One problem at the very beginning was how to answer a question with regard to addressing the questioner, the way of answering, the kind of language to be used (lay person friendly language versus professional language for care team member questions) and terminology, etc. During the first quality round table, a guide to answering the questions was prepared and then published on the ECORN-CF website. All upcoming problems were discussed and usually solved during our regular quality round table meetings.

3.2.3.5 Further tasks of WP leader: Management of the Czech Expert Advice

We started with the Czech Republic ECORN-CF website in October 2007. After corrections at very beginning, our website is now working successfully. We have answered 113 questions so far. It is still true that almost half of the incoming questions are in the Slovak language (see Table 3.2.3.5-1). There are 10 Czech CF experts ready to answer any question covering all topics related with CF.

<table>
<thead>
<tr>
<th>Description</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Czech CF experts involved in the project</td>
<td>10</td>
</tr>
<tr>
<td>Already answering experts</td>
<td>10</td>
</tr>
<tr>
<td>Average time / answer (days:hours)</td>
<td>8:05</td>
</tr>
<tr>
<td>Number (%) of questions asked in Czech / Slovak language</td>
<td>69/54 (56/44)</td>
</tr>
<tr>
<td>Number (%) of questions from Health care professionals</td>
<td>3 (2)</td>
</tr>
<tr>
<td>Number (%) of questions from Students</td>
<td>3 (2)</td>
</tr>
</tbody>
</table>

Table 3.2.3.5-1: General information on the Czech ECORN-CF website since October 2007

The spectrum of questions has permanently been very broad. Patients, parents and other care team members were still asking about CF basics – like sweat chloride test, making the diagnosis, severity of specific mutations etc. Others asked about ABPA, Pseudomonas, atypical CF, adverse effects of pancreatic substitution, antibiotics like macrolides, inhalors, airway clearance techniques, possibility of having a baby, lung transplantation, social contributions, etc. There were a few questions from students writing their thesis on CF related topics (see Figure 3.2.3.5-1).
Fig. 3.2.3.5-1: Czech ECORN-CF asked questions regarding topics

Sometimes it is not easy to answer a question and it is very useful to have the possibility to recheck the correctness of the answer by involving other CF experts and also to discuss these tricky questions on regular project meetings.

It is somewhat problematic that the answers are corrected by the internal quality check team only after we already published it on the local website. The reason for this is the time gap between the publication of the original question and answer pair in the local expert advice and the English translation of the Q/A pair being sent to the quality team for the check. On the one hand the questioner receives the answer quite quickly this way, but on the other hand the answer sometimes had to be changed later according to the corrections from the quality team. Since many questioners asked anonymously, we were not able to inform them about changes in the answer. A poster on ECORN-CF in the Czech Republic was presented during the European CF conference in June 2008 in Prague (ATTACHMENT 06).

We also prepared one “Question of the Month” in April 2010. The topic was dental plaque in CF (ATTACHMENT 03).

Since the beginning of the project the Czech team (mostly the moderator) had to deal with Slovak questions despite the language differences and health care system differences regarding these two separate countries. Since December 2008 we had a Slovak collaborative CF expert who is dealing with most of the Slovak questions coming to the system.

We also advertised the project especially at the beginning.
We translated a flyer on ECORN-CF into Czech in a public user friendly way so that everyone who wanted to know was able to receive basic information about the project.
We gave an oral presentation about ECORN-CF in the Czech Ministry of Health. We closely cooperated with the CF patient organization and they advertised ECORN-CF with every project they did.
We advertised the ECORN-CF project on the University Hospital Motol website (a banner).

We informed our colleagues (CF specialists) about the project during our regular meetings; we added this information to CF teaching presentations to pneumologists, allergologists and clinical immunologists and also general practitioners.
3.2.4 WP7: Evaluation of the impact of the program on quality of care and on the implementation of guidelines

Work package leader:
Thomas O. F. Wagner, Frankfurt

Deputy:
Ernst Rietschel, Cologne

3.2.4.1 Objectives

Evaluate the following objectives:

The main goals of the whole project were to be reflected by the results of this WP.

- Allow ease of access to specific information for patients at the highest level of expertise in all member state languages at the same level of quality

- Implementation and feasibility of networking between experts and patient organizations

- High level expertise in all member states


- Implementation of a European cross border quality assurance program

3.2.4.2 Activities undertaken

Quality of the expert advice to patients and care team members (expert advice, networking and quality assurance program) has been evaluated by a work package team with strong emphasis on patient involvement.

The first nine months were needed to develop a patient questionnaire. This questionnaire could then be used continuously and was automatically sent out to registered questioners. Since the fraction of returned questionnaires was considered too low, the questionnaire was circulated on two separate occasions: at M20 (month 20), and close to the end of the whole project funding phase (month 32), to see whether there were any changes in the perception of quality of care (rating by patients) or changes in the offerings or utilization of the specific health care system. Quality of advice for patients, relatives of patients and the professional health care team were evaluated, and the results of the content quality and the formal quality have been summarized in WP 6 and WP 4 (especially in section 3.2.1.2; II). We will, therefore, not address again the quality assessment tools and results in this WP report but concentrate on the patient questionnaire results.

The whole set of questions asked and analyzed is given in Table 3.2.4.2-1.
The questionnaire was sent out automatically with a request to be completed to all those registered users who had asked at least one question in logged-in mode at the time the first answer to one of their questions was published.

The response was poor. Therefore, we sent out a personalized request from Frankfurt beginning from month 20 (Dec 4, 2008) and month 32 (Dec 2, 2009) again via email to all "lay persons." During the second call, people were encouraged to fill out the questionnaire a second time.

- The first call was sent out to 396 people.
- During the second call, 654 messages were sent.
- From the first mailing on Dec 4, 2008, until the last day before the second mailing, i.e. until Dec 1, 2009, a total of 88 questionnaires (FAMILY) and 45 questionnaires (PATIENT) were received.
- From the second mailing on Dec 2, 2009 until Apr 30, 2010, a total of 77 questionnaires (FAMILY) and 43 questionnaires (PATIENT) were received.
- This adds up to a total of 173 questionnaires (FAMILY) and 92 questionnaires (PATIENT).

Table 3.2.4.2-1: List of questions asked

(the questions' results specifically addressed in this report are highlighted in bold characters)

1. **How satisfied were you with the answer/the answers to your question/your questions? (10 = very satisfied)**
2. Please indicate from which country you are
3. Are you male or female?
4. What is your age?
5. How old were you when you were diagnosed?
6. What is your weight? (kilogram)
7. What is your height? (meter, centimetre for example 1,68)
8. Do you take enzymes (for example Kreone, Panzytrate)?
9. Do you have diabetes?
10. When did diabetes start? (give year, for example: 2002)
11. Was your diabetes diagnosed by oral glucose tolerance test?
12. How do you treat diabetes?
13. **What is your FEV1? (My FEV1 is) (percentage, e.g. 50%)**
14. What is your FEV1? (My FEV1 is) (litre, e.g. 1,5 l)
15. Do you need supplemental oxygen?
16. Do you have pseudomonas?
17. If you have pseudomonas, for how many years?
18. Did you have cepacia during the last three months?
19. Is lung transplantation available in your country?
20. Did you undergo lung transplantation?
21. CF doctor for children available?
22. CF doctor for adults available?
23. Are there specialized multidisciplinary CF centres for children available?
24. Number of specialized multidisciplinary CF centres for children
25. **Are there any specialized multidisciplinary CF centres for adults available?**
26. Number of specialized multidisciplinary CF centres for adults
27. What kind of CF care do you make use of? (CF specialist for children (pediatric care))
28. What kind of CF care do you make use of? (CF specialist for adults)
29. What kind of CF care do you make use of? (specialized multidisciplinary CF centre for children)
30. What kind of CF care do you make use of? (specialized multidisciplinary CF centre for adults)
31. What kind of CF care do you make use of? (additional)
32. **Please give the distance to the care you make use of (kilometre)**
33. How often do you see your CF doctor per year?
34. What is the regular content of your planned visit? (whole body examination)
35. What is the regular content of your planned visit? (lung auscultation)
36. What is the regular content of your planned visit? (discussion of health status and medical problems having occurred since last visit)
37. What is the regular content of your planned visit? (weight asked)
38. **What is the regular content of your planned visit? (weight measured)**
39. What is the regular content of your planned visit? (height asked)
40. What is the regular content of your planned visit? (height measured)
41. What is the regular content of your planned visit? (pulmonary function test performed)
42. Microbiology: How many samples (1) per year?
43. Is an oral glucose tolerance test performed once a year?
44. When you are hospitalized: Which kind of hospital care do you make use of?
45. How is intravenous antibiotic treatment performed?
46. Is there segregation according to bacteriological status in your clinic?
47. Do you have access to specialized CF physiotherapy?
48. Do you travel to another country in order to receive certain treatments? (for which treatment?)
49. Do you travel to another country in order to receive certain treatments? (which country?)
50. **How would you score your quality of life? (10 = very high quality of life)**
51. Which education did you undergo? Please give highest level
52. Which education did you undergo? Please give highest level(additional)
53. **Please give your monthly family income (EUR)**
54. Please give your monthly family income (Other currency)
55. **Please give the monthly sum you additionally spend on CF care (EUR)**
56. Please give the monthly sum you additionally spend on CF care (other currency)
57. Do you want to make any comments or give additional explanations?

The questions’ results specifically addressed in this report are highlighted in bold characters. The language zone abbreviations are:

- **BE/NL**: Dutch language zone (including questions from Belgium and the Netherlands
- **EN**: English language zone
- **CZ**: Czech language zone
- **GER**: German language zone
- **All**: all language zones compiled together
Question 1: How satisfied were you with the answer/the answers to your question/your questions? (10 = very satisfied)

One domain of interest was the patients’ satisfaction with the answers of the experts: Missing values were treated as such and were excluded from the calculation.

Fig. 3.2.4.2-1:

The graph shows that the patients were quite satisfied with the answers they received from the experts, since 10 on the scale of satisfaction was equal to “very satisfied.” The numbers analysed were very different in the respective language zones, though. In Romania and Poland, the number of answers given to this question in the questionnaires returned did not allow any calculation.

If one wants to compare patient satisfaction or health care system utilization, it might be important to take into account the respective health status of the patients in the different language zones.

Question 13: What is your FEV1?

We therefore asked question 13: “What is your FEV1?” explicitly wishing to get the fraction of the reference value (percentage of the expected FEV1).
The graph shows that there is a wide variation in FEV1 in all participating patients and satisfaction does not correlate with FEV1 impairment (data not shown). The FEV1 ranged from as little as 20 percent of predicted to more than 100 percent in questioners of all language zones. With respect to the quality of the services offered with such an expert advice system, this means that the service is available to and sought after by all groups of patients, those very happy with normal lung function as well as those in a very limited health status.

**Question 25: Are there any specialized multidisciplinary CF centres for adults available?**

Although we know quite exactly the situation of care for CF patients in the different member states of the European Union, it was quite useful to address this question (Figure 3.2.4.2-3). While there was a 100-percent awareness of specialized care centres for adult patients in Belgium and the Netherlands, there was much confusion in the other language zones. While Germany, as a matter of fact, like in many European states, has a quite sophisticated system of care for adult patients, of course, there are nevertheless quite a few respondents who are not aware of this and indicate there were no such centres available. This is very important information, since less than half of the adult patients in Germany are regularly seen in such specialized centres, and one reason could be that the patients do not even know they exist.

**Fig. 3.2.4.2-2:**

<table>
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<th>CZ</th>
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<td>25,68</td>
<td>22,28</td>
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<tr>
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<td>84,15</td>
<td>72,70</td>
<td>66,80</td>
<td>81,14</td>
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In Figure -3 we have included the data coming from Romania (ROM) and Lithuania (LIT), since the situation seems to be quite different there, which explains the overall percentage of awareness of availability or of availability as such of just below 50.

Question 32: Please give the distance to the care you make use of (kilometers)

Figure 3.2.4.2-4 shows the average distance a patient has to travel in his respective language zone to reach his or her CF centre. The maximum distance in Germany and in the English language zone was 300 km (single patients reporting this distance in each of these countries), while in Romania two patients indicated they had to travel 800 km and one patient 900 km. In Belgium/the Netherlands, the longest distance to cover was 125 km, in Poland more than half of the respondents traveled more than 150 km.
Question 38: What is the regular content of your planned visit? (weight measured)

Looking into quality of care that can be judged reliably by the patients themselves, we picked for this analysis the adherence of the CF care teams to the accepted recommendation to check the body weight of the CF patient on every occasion.
It is obvious that none of the participating language zones reach the benchmark of 100 percent\(^1\) even with such an easy to perform quality indicator as measuring the patient’s body weight. It has to be stressed that this indicator is very important for the assessment of the health condition of the CF patient since there is a strong correlation between body weight (body mass index derived from weight and height) and there should be hardly any excuse for not taking that crucial measure. While 93 percent of all patients in the Dutch language zone report regular assessment of their body weight, the value is below 80 percent in all other regions. The information that some 6 percent of the respondents indicate that the body weight is never measured seems very dramatic.

**Question 50: How would you score your quality of life? (10 = very high quality of life)**

We have included the small numbers of questionnaires of some of the language zones in Figure 3.2.4.2-6 to show that there is no large difference in the quality of life between the respondents. The variability is substantial but certainly does not seem to correlate with such dramatic differences in the burden on the patient from e.g. travelling (compare to Figure -4).

---

Question 53: Please give your monthly family income (EUR)
Question 55: Please give the monthly sum you additionally spend on CF care (EUR)

In this instance, we calculated the fraction of the monthly family income spent on CF care. Unfortunately only 30 percent of all respondents were willing to provide information on family income. We therefore cannot make any correlations between medical indicators or quality of life scores and family income. Overall, the respondents (n=143) said they are spending 7.32 percent ± 0.12 of their family income on CF care.

Summary of the results that can be taken from the questionnaires: The low number of respondents was a limiting factor, since due to the low number of questionnaires received from some of the language zones there were no significant differences detectable when compared to the well-established language zones.

It became evident, though, that the quality of care as indicated by the benchmark of measuring body weight on every patient-doctor contact is not sufficient in most participating countries, although the best results were achieved in the Dutch language zone. This is a good opportunity to look for differences in the health care systems and the training of the care teams in order to learn from the best. This, as
well as the fact that the pilot project has been able to show feasibility of cross border quality management and assessment with patient participation, is among the most important results of the whole project.
Due to small sample size and short duration of the pilot project, however, it was not possible to show whether there were any changes in the perception and/or utilization of the health care system in any of the participating countries.
Further analysis with the aim of publication in a peer review journal is ongoing.

### 3.2.4.3 Deliverables

| WP 7 | Evaluation of quality of care and of the implementation of European Consensus | TOF Wagner | D9  
|      |                                                                                      |            | D10  
|      |                                                                                      |            | D11  
|      |                                                                                      |            | Patient questionnaire (M6), first patient survey completed (M12), second patient survey ready (M24), second patient survey completed (M30) |

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<tr>
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<tr>
<td>D11</td>
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</table>

**Status of accomplishment of D9 – D11**
Delivered

The questionnaire was delayed due to extensive rewriting by the patients and patient organizations involved. D9 thus was only accomplished after nine (instead of six) months. From month 9 the questionnaire was automatically sent to all registered users. D10 and D11 were delivered in time.

### 3.2.4.4 Problems encountered and solution of these problems

The only problem encountered was the low response rate to the questionnaires. We decided, therefore, to add a batch-wise procedure to the automatic process. Thus, we sent the questionnaires in December 2008 (Month 20) and December 2009 (Month 32), which yielded a much better response rate.
The delayed response due to the contingency action taken did not have an impact on the results of this WP or the project as a whole.
4 Attachments

Please find the attachments mentioned above on the following pages.

Attm 01_a-c: Paper Travelling with CF_DO NOT PUBLISH!
Attm 02_a-d: Minutes of the quality round table meetings
Attm 03: Example_Question of the month
Attm 04_a-h: ECORN-CF Newsletters
Attm 05_a-d: ECORN-CF Snippets
Attm 06: Abstract of poster of Jitka Brázová
Attm 07_a-k: Evaluation
Attm 08_a-c: Report of Ova Prod., Sweden
ATTACHMENT 1

Attm 01_a: Paper Travelling with CF_DO NOT PUBLISH!
Attm 01_b: Paper Travelling with CF_Tool Box Doc 1
Attm 01_c: Paper Travelling with CF_Tool Box Doc 2
ATTACHMENT 2

Attm 02_a: Minutes of the 1st QRT
Attm 02_b: Minutes of the 2nd QRT
Attm 02_c: Minutes of the 3rd QRT & consensus meeting
Attm 02_d: Minutes of the 4th QRT & consensus meeting
ATTACHMENT 3

Attn 03: Example Question of the month
ATTACHMENT 4

Attm 04_a: ECORN-CF Newsletter Issue 1
Attm 04_b: ECORN-CF Newsletter Issue 2
Attm 04_c: ECORN-CF Newsletter Issue 3
Attm 04_d: ECORN-CF Newsletter Issue 4
Attm 04_e: ECORN-CF Newsletter Issue 5
Attm 04_f: ECORN-CF Newsletter Issue 6
Attm 04_g: ECORN-CF Newsletter Issue 7
Attm 04_h: ECORN-CF Newsletter Issue 8
ATTACHMENT 5

Attm 05_a:  ECORN-CF Snippets Issue 1
Attm 05_b:  ECORN-CF Snippets Issue 2
Attm 05_c:  ECORN-CF Snippets Issue 3
Attm 05_d:  ECORN-CF Snippets Issue 4
ATTACHMENT 6

Atm 06: Abstract of poster of Jitka Brázová
ATTACHMENT 7

Attm 07_a: Evaluation M6
Attm 07_b: Evaluation M9
Attm 07_c: Evaluation M12
Attm 07_d: Evaluation M15
Attm 07_e: Evaluation M18
Attm 07_f: Evaluation M21
Attm 07_g: Evaluation M24
Attm 07_h: Evaluation M27
Attm 07_i: Evaluation M30
Attm 07_j: Evaluation M33
Attm 07_k: Evaluation M36
ATTACHMENT 8

Attm 08_a: Report 1\textsuperscript{st} year of Ova Prod., Sweden
Attm 08_a: Report 2\textsuperscript{nd} year of Ova Prod., Sweden
Attm 08_a: Report 3\textsuperscript{rd} year of Ova Prod., Sweden
5 Approvals

Report compiled by Annette Pfalz

Approved on June 30, 2010 by: Project Leader (Prof. Thomas O. F. Wagner)