Deliverable D3.1

Good Practice Guidelines on Telemedicine Services for Chronic Obstructive Pulmonary Disease

Component: C 3
Version & Date: V1.5 - July 15, 2010
Deliverable type: Report
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Executive Summary

Europe’s healthcare systems are facing a huge challenge, with limited financial resources, an elderly population predicted to rise by more than 50% by 2050 and the prevalence of chronic diseases also on the increase. This will place a tremendous economic burden on governments, care professionals, employers and consumers. Telemedicine services have the potential to improve the lives of many chronic diseases patients while relieving part of the actual burden from health institutions.

The present document describes good practice guidelines concerning telemedicine services for one of the main chronic diseases, Chronic Obstructive Pulmonary Disease (COPD). These guidelines are one of the outcomes of the Regional Telemedicine Forum, a collaboration of 9 European regions which aims to deliver Good Practices Guidelines and policy recommendations addressing the key challenges that hinder the wider use of telemedicine. The main contributors to the present document are Region of South Denmark, Veneto Region, the Ministry of Health of Catalonia and Northern Norway Regional Health Authority.

The main identified challenges to a wider deployment of telemedicine services for COPD are common with other telemedicine services. Namely, they are: market fragmentation, lack of interoperability among the large number of ICT systems, lack of financial certainty as to how these new services and models will be reimbursed, legal questions such as the shift in the roles and responsibilities of the professionals involved, patient’s privacy and security aspects and the resistance to the organizational changes that this type of services demands.

Regarding good practices for implementing telemedicine services for COPD, overall, the incremental approach of ever larger pilots is deemed the best strategy to win acceptance among patients and health care professionals. Gradually larger pilots based on positive results are the key to increase awareness among all relevant stakeholders, creating the necessary momentum to introduce legislation and administrative changes to expand telemedicine services for COPD.

At the clinical level, good practice guidelines include education of patients and professionals regarding past pilot projects in order to earn trust in the technology and overcome resistance. At the same time, though, telemedicine services need to be introduced gradually, respecting the preferences and idiosyncrasies of the existing relationships between patient and doctor.

At the organizational level, coordination between related health care institutions is the key to the establishment of unified processes and systems. Establishing a unified EPR is a good start point towards further integration, such as a unified system for appointments. Multidisciplinary meetings to improve understanding of the disease across levels of care and reduce variation in practice are another practice that will benefit the effectiveness of the continuous care system enabled by telemedicine. At the technological level, interoperability, reliability and usability have to be the highest priority. Open modular platforms and voluntary certifications of technical interoperability are the best solution before the complete standard specifications for eHealth currently being developed are ready.
At the economical level, regarding funding, each region needs to define a model based on public funding, insurers and the user. In any funding model, though, cost-efficiency studies that demonstrate the added value of telemedicine services and the creation and implementation of new business models are fundamental to a wider deployment of these types of services. The reimbursement scheme for a successful deployment should be aligned across different levels of care in order to provide collaboration and integrated care. While there is no single formula, mixed payment schemes seem to eliminate negative effects of models which pay exclusively per case or per service.

At the policy level, policy makers need to take an active role to start the necessary coordination between levels of care, since it does not evolve spontaneously. Beyond that, the integration of COPD care with other chronic diseases in an integrated management of chronic diseases is recommended. Finally, raising awareness of the benefits of telemedicine services through larger implementations and information campaigns is deemed the best way to foster acceptance and facilitation of further expansion of telemedicine services for COPD.

The practices from Region of Southern Denmark, Veneto Region, Catalonia and the region of Northern Norway provide an illustration on the telemedicine services for COPD in these four regions of Europe.
Change History

Version Changes

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<tr>
<td>June 15&lt;sup&gt;th&lt;/sup&gt; 2010</td>
<td>V1.0</td>
<td>Initial draft with annexes from partners</td>
</tr>
<tr>
<td>June 17&lt;sup&gt;th&lt;/sup&gt; 2010</td>
<td>V1.1</td>
<td>Roughly added ideas from discussion on June 17&lt;sup&gt;th&lt;/sup&gt; and indications for input</td>
</tr>
<tr>
<td>June 25&lt;sup&gt;th&lt;/sup&gt; 2010</td>
<td>V1.2</td>
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1. Introduction

1.1 Purpose

The purpose of this document is to describe good practice guidelines for telemedicine services for Chronic Obstructive Pulmonary Disease (COPD). These guidelines are defined based on the regions taking part on the Regional Telemedicine Forum: Region of South Denmark, Veneto Region, the Ministry of Health of Catalonia and Northern Norway Regional Health Authority. The development of good practice guidelines is a neccessary milestone towards the improvement of telemedine services for COPD in the participating regions and beyond.

This document may guide the Competence Centres (CC) and regional experts in setting up telemedicine services for COPD. The important task of these guidelines is to obtain substantial and sufficient knowledge from the work carried out in the participating regions in RTF in order to be able to understand all requirements involved in setting up a telemedicine service.

1.2 Structure of document

The document is divided in 3 chapters and the annex, with 4 sections. Chapter 1 refers to the introduction and structure of the document. Chapter 2 presents the context of COPD, including a brief description of the disease, and the present needs analysis regarding COPD. Then, it analyzes the role of telemedicine in COPD and the parameters of evaluation.

Chapter 3 summarizes the good practices that where identified through the interregional collaboration. After describing the methodology used to share and identify the good practices, strategies to facilitate telemedicine are described. A final section describes the main conclusions.

Annex A is divided in 4 sections, one for each of the participant partner, detailing their most relevant pilot service.

1.3 Acronym

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<tr>
<td>ADL</td>
<td>Activities of Daily Living</td>
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<td>COPD</td>
<td>Chronic Obstructive Pulmonary Disease</td>
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<td>EPR</td>
<td>Electronic Patient Record</td>
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<tr>
<td>Acronym</td>
<td>Description</td>
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<tr>
<td>HRQL</td>
<td>Health-Related Quality of Life</td>
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<td>GOLD</td>
<td>Global initiative for chronic Obstructive Lung Disease</td>
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2. Context of COPD

2.1 Description of disease

Chronic Obstructive Pulmonary Disease (COPD) is not one single disease but an umbrella term used to describe chronic lung diseases that cause limitations in lung airflow. The most common symptoms of COPD are breathlessness, or a ‘need for air’, excessive sputum production, and a chronic cough.

COPD leads to a serious deterioration in quality of life and it is estimated to affect 9% of those aged 40 to 70. Smoking is the main cause of COPD. It is believed that 50% of those aged over 50 who smoke or who have smoked and have chronic respiratory symptoms, such as coughing, expectoration and/or wheezing, may suffer from undiagnosed COPD.

There is evidence of the relationship between exposure to tobacco smoke and the deterioration of pulmonary function. Giving up smoking stops the advance of the disease and reduces the number and the seriousness of acute attacks. Other risk factors less often associated with the condition include exposure to smoke in the workplace, environmental pollution, antecedents of bronchial hyperreactivity and recurrent respiratory infections in childhood.

Diagnosis of COPD should be considered in any patient who has symptoms of cough, sputum production or dyspnoea or history of exposure to risk factors for the disease. The diagnosis requires spirometry; post-bronchodilator FEV1/forced vital capacity <0.7 confirms the presence of airflow limitation that is not fully reversible

 Oxygen therapy at home and stopping smoking are the only treatments that change the natural course of COPD.

2.2 Needs analysis of patients, clinicians, healthcare organisations, buyers, institutions

2.2.1 Patient level

COPD significantly reduces the quality of life. Shortness of breath, chronic coughing, wheezing, weight loss, heart failure in later stages and exacerbations that often require hospitalisation, contribute to the generally poorer quality of life of COPD patients. COPD is often accompanied by de-conditioning and a low level of social activity. To improve the quality of life of patients the following three needs were identified:

- Reducing the visits to emergency services

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1 Definition by the American Thoracic Society
Facilitating treatment and home

Responding to the psychosocial needs of the patients are the main challenges to overcome.

Routine visits to hospital for treatment and monitoring represent a significant burden on the life of COPD patients. The health-related quality of life (HRQL) of patients of COPD would improve if they could avoid part of their visits to the hospital and be treated or monitored without leaving their homes.

Home based treatments can benefit patients health related quality of life (HRQL), but depend to a large degree on the patient’s personal discipline when following the indications of the medical professional. Low adherence to the prescribed treatment or exercise protocol is one of the obstacles that limit the success and implementation of home-based treatment and rehabilitation. Health education and specific training are necessary to ensure correct following of the treatment, empowering the patient to contribute to the management of the disease.

Beyond alleviating the specific COPD symptoms, the psychosocial needs of patients with chronic respiratory disorders are significant. Managing even basic tasks such as bathing and dressing increases dyspnea and undermines confidence and self-esteem. The prevalence of depression is high in elderly patients with COPD, and is associated with lower self-rated HRQL and reduced ability to perform activities of daily living (ADL).

The three challenges at the patient level are interrelated. Solutions need to take the above three needs into account and provide an integrated response. Telemedicine services can provide a response to these challenges as detailed later in this document.

2.2.2. Clinical level

The following list outlines the main challenges identified at the clinical level, which will be described underneath:

- Tackling COPD, one of the illnesses with the highest morbidity and mortality
- Prevention and early detection of COPD
- Reducing the need to visit emergency services of diagnosed COPD patients
- Improve care, ensuring permanent monitoring
- Empower patients with the knowledge and skills to actively participate in the management of the disease
- Development of deeper understanding of the disease at primary health care level
- Reduction of variation of clinical practice for COPD
An estimated 210 million people have COPD worldwide. More than 3 million people died of COPD in 2005, which corresponds to 5% of all deaths globally. In 2002 COPD was the fifth leading cause of death. Total deaths from COPD are projected to increase by more than 30% in the next 10 years. Thus, urgent action needs to be taken in order to reduce the underlying risk factors and thereby the incidence of COPD. Estimates show that COPD will become by 2020 the fifth most important cause of lost years of life or years lived with disability and by 2030 the third leading cause of death worldwide.  

In Catalonia in 2005 there were 6,925 deaths from respiratory disease and the number of cases of respiratory disease requiring hospital treatment was 93,331 (10.2% of all hospital cases). 21% of these were for COPD, and of this number 8.7% were readmitted to hospital within 30 days of being discharged. The Norwegian National Strategy for COPD (for 2006 – 2011) estimates 200,000 people with COPD, 20,000 of them in the region of North Norway. Approximately 10% of all COPD patients are expected to have an annual need for rehabilitation due to their medical condition, giving approximately 2,000 candidates in Northern Norway, of which 600 are receiving rehabilitation annually in 2010. In Italy, the National Institute of Statistics estimates that respiratory system diseases represent the third most common cause of death in Italy (after cardiovascular diseases and neoplasms). In particular, COPD causes about 50% of deaths for respiratory diseases. In 2006, COPD mortality was 20,418 for male patients and 15,333 for female patients, but it is also increasing in females. In the Veneto Region, the mortality was 2,533 patients (53.3 patients per 100,000 citizens).

Prevention and early detection of COPD is an area in which much more effort must be devoted in order to limit the growth of the number of COPD patients and maintain as much as possible their quality of life. Undiagnosed COPD patients are estimated to amount at about 50% of the total. Often COPD is diagnosed only when symptoms become apparent and quality of life has been substantially reduced.

For diagnosed COPD patients the most pressing need is to improve their quality of life by reducing their need to use emergency services and hospital stays. The high morbidity of COPD translates into frequent visits and stays at the hospital, but this provision of care limits the quality of life of patients and is not efficient for the doctors.

Simultaneously, there is the need to improve care, ensuring permanent monitoring of relevant vital parameters when needed. Depending on the patient this may involve a period at home to educate and encourage self-management. On later stages of the disease, a system of telecare alerts has been used as a safety net to monitor the advance of the disease and anticipate possible complications. In order to achieve this, there is the need to ensure patients follow the prescribed treatment and exercises. Physicians need this capability before routine visits to the hospital can be reduced substantially.

Then there is the need to provide patients with the knowledge and skills to participate more actively in the management of their own disease. Health Education and specific training are instrumental in order to develop patient’s empowerment and self-care capacity.

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2 World Health Organization on behalf of the European Observatory on Health Systems and Policies (2010): Tackling Chronic Disease in Europe :Strategies, interventions and challenges
Among health professionals, there is the need to develop, in the field of primary healthcare, deeper understanding of COPD in order to prevent possible complications of the disease. Vaccinations and cessation of smoke are two of the main areas in which could be tackled at primary health care, reducing the number of complications among COPD patients.

Finally, another aspect that needs further attention is reducing variations in clinical practice, especially in the handling of patients in acute phases of COPD. Given the life-threatening exacerbations it is crucial that all health care professionals dealing with COPD have clear guidelines on how to deal with COPD patients, especially those in acute phases.

2.2.3 Organizational level

COPD is a disease that puts a substantial organizational burden on the health care systems in most countries. COPD patients’ frequent and lengthy stays represent a growing part of the utilization of available health professionals and hospital beds. At the same time some of the care could be provided at Primary Health Centres, but a lack of coordination between Hospital and Primary Health centres prevent a more efficient utilization of resources. From the organisational point of view the main challenges are:

- Improving the sharing of information between hospitals and health care centres
- Identification and monitoring of patients receiving treatment at home
- Integrating prevention, care and rehabilitation
- Redefine workforce skill profile and establishing boundaries of responsibility
- Defining a Disease Management Program as part of an Integrated Care Model

At the organizational level there is the need to improve how information on the disease status for each patient is registered and shared between hospitals and health care centres. Different codification of diseases and conditions (semantics) is one of the issues preventing smoother collaboration between levels of care. Having complete information of the disease status for each case allows setting up the frequency and intensity of follow-up depending on the individual patient’s disease status and course of treatment. Beyond that, having aggregated information on the overall disease status allows spotting trends useful towards planning health service deployment and organization of resources.

Another organizational need is setting up quick, clear mechanisms to identify and monitor patients receiving treatment at home, for example those receiving oxygen therapy at their own homes. While hospitals and primary health centres do have common records, these are often fragmented and do not allow for integrated monitoring of the disease. A standardized and clear mechanism to quickly identify and monitor COPD patients receiving treatment at home is a necessary step towards seamless care for COPD patients.
Management of COPD should aim at providing a full response to patients’ needs, including monitoring, but also preventive measures and rehabilitation programmes. By taking a broader scope to manage COPD, health services are better prepared to respond to changing trends and prevent, as much as possible, severe cases of COPD.

At present there is still the need to clearly establish boundaries of responsibility among parties involved with COPD patients. The lack of clarity in defining the mechanisms of collaboration is a great obstacle towards providing seamless management of COPD patients. By establishing clear boundaries of responsibility smooth collaboration will be established without leaving gaps in the provision of care for COPD patients.

Overall, the organisational needs could be fulfilled by establishing a disease management program (DMP). When correctly implemented, a DMP for COPD would allow the seamless collaboration between primary care, hospitals, and other health care professionals and care givers. Beyond that, a DMP for COPD would facilitate an efficient allocation of resources at individual health care institutions and at the health care system overall. To be most efficient a DMP for COPD should be integrated into a larger Integrated Care Model, targeting chronic diseases.

### 2.2.4 Legal level

There are numerous legal challenges preventing a faster and smoother implementation of telemedicine. These tend to fall into two groups:

- Legal clarification regarding licensing, accreditation and registration of telemedicine services.
- Legal clarification regarding professionals’ liability, reimbursement and jurisdiction.

While special arrangements can be made for pilot projects, the lack of clarity for legislation on the above issues remains one of the big obstacles to the expansion of telemedicine.

Guaranteeing data privacy and security related aspects is essential in building confidence and trust in telemedicine systems. When collecting and processing personal data – particularly in the case of health data – the respect of the fundamental rights to personal privacy and to the protection of personal data must be guaranteed. Since such data could affect an individual’s personal and professional life, it is crucial that data privacy aspects are systematically assessed in telemedicine services in general and COPD services in particular.

There is the argument that electronic patient records (EPR) need to have access controls in order to show only the aspects relevant to the problem at hand and not the entire health record. How to determine which aspects are relevant and which are not for a given problem, though, is a difficult matter and subject to change over time.

The lack of legal clarity continues to be one of the main obstacles to wider use of telemedicine and the economic benefits it promises. Legislation that addresses current shortcomings and provides a strong backing for a large scale implementation of telemedicine is the most pressing need at the legal level.
2.2.5 Economic Level

The economic challenges of dealing with COPD can be divided into three main areas: cost, reimbursement and funding:

- Cost of COPD to health care services and to the economy in general
- Measuring the cost-effectiveness of overall strategies
- Systematic Analysis of cost-effectiveness of treatments at the patient level
- Reimbursement of telemedicine services
- Funding of telemedicine services

COPD is a costly disease. The direct costs of COPD are the value of healthcare resources devoted to diagnosis and medical management of the disease, whereas the indirect costs reflect the monetary consequences of disability, missed work, premature mortality and caregiver or family costs resulting from the illness. In the EU the direct costs of COPD amount to >3% of the entire EU health costs and the total cost burden is approximately 50 billion Euros a year. Approximately 41,300 lost work days per 100,000 people are due to COPD every year in Europe, with productivity losses due to COPD amounting to a total of €28.5 billion annually. COPD is a major drain on healthcare budgets, with 50% of costs accounted for by hospital admissions, much of which could be avoided through development of more responsive models of care that allow earlier recognition and treatment of exacerbation.

Cost is one of the key factors when designing an approach to tackle the growth of the burden of COPD in the overall health care systems. Since it is estimated that only 50% of people with COPD have been diagnosed, there is a strong argument towards spending more in early detection and prevention. For instance early detection of COPD using flow spirometry is important in terms of cost effectiveness. Improving early detection mechanisms and implementing them on a large scale is a powerful strategy towards reducing the overall cost of treatment. Yet, the actual costs to the health care system will continue to be on treatment and rehabilitation of COPD patients. Striking the right balance between prevention and treatment is thus one of the challenges at the economic level.

Further, there is the need to systematically evaluate the cost and improvement on the health condition of the patient. Oxygen therapy in particular has been identified as one of the expensive treatments often administered indefinitely even as its efficacy is not always properly evaluated.

Reimbursement is another major challenge at the economic level. Health services are generally reimbursed on a piece by piece basis. However, this approach has limitations in the case of COPD where integrated care from several health care professionals is required. If there is no incentive to share information, information about patients will often be incomplete and this will make decision making more difficult later. New models of reimbursement are needed to incentivise collaboration between different levels of health care and improve allocation of resources at the same time.
Finally, the most pressing economic need is funding to expand telemedicine services, because of the steep initial investment. Once the core of a telemedicine platform is in place it becomes easier to increasingly expand the number of patients receiving telemedicine service. However, even as telemedicine promises to reduce costs significantly, without appropriate funding it is not possible to set the main elements of a telemedicine platform.

2.3 Role of telemedicine within COPD

Telemedicine promises to make a major contribution in overcoming many of the pressing challenges of assisting the growing number COPD patients in an ageing population.

At the patient level, the role of telemedicine is most visible. By freeing patients from the burden of routine visits to hospital for monitoring, the contribution of telemedicine is already significant, especially for patients in rural areas. The role of telemedicine services for COPD, though, promises to go beyond mere monitoring. In the case of rehabilitation, telemedicine allows patients to continue in-hospital training effects after discharge through remote monitoring by the physiotherapist, thereby preserving safety for the patient.

At the clinical level, the use of telemedicine services for COPD has been reported to facilitate increased compliance by patients to the prescribed treatment. This phenomenon has been attributed to the convenience that telemedicine provides, allowing patients to transfer data or communicate with the health professionals without visiting health care institutions. It is not uncommon among participants in pilot projects to request telemedicine to be the default treatment.

The organisational benefits of telemedicine promise to reduce the burden of COPD patients on hospitals and emergency services. Telemedicine services allow monitoring of patients who receive treatment at home, reducing the need for routine visits. Beyond that, the closer collaboration between primary care and hospitals enabled by telemedicine, promises to further reduce the burden on hospitals and increase the quality of health care.

At the economical level, the role of telemedicine is to improve the allocation of resources, because the limited time and space available at health institutions is used more efficiently. This role in particular might be the one most effective in pushing for a large scale deployment of telemedicine to assist COPD patients. At the same time, though, initial investment to implement telemedicine services is a significant barrier delaying the adoption of telemedicine.

2.4 Parameters of Evaluation

Before adoption, any technology has to prove to be superior, or at least as good, to the approach that it intends to replace. Assessment on COPD telemedicine services should provide a broad description that covers clinical, technical, economic, legal, ethical and organizational issues.
The implicit complexity of healthcare organization is a major obstacle to carrying out the evaluations of the new care provision models. Below, are the main indicators that the evaluation of COPD telemedicine services should take into account, grouped on the following four areas: clinical, organizational, economic and technological level.

The evaluation at the patient and **clinical level** focuses on:
- Impact on health condition and health-related quality of life.
- Improved compliance with medications – correct dosage, time of administration etc.;
- Empowerment through education and self-management of the disease.
- Telemedicine service related indicators

At the **organisational level**, telemedicine systems are evaluated based on:
- Improvement to the allocation of resources through new work processes
- Increased collaboration with internal or external parties improving the course of treatment and a better continuity of care.

The **economic evaluation** of telemedicine systems assess the overall cost-effectiveness based on:
- Reduction of costs for hospitalisation and readmissions
- Costs of medication
- Overall reduction of costs for personnel resources – even if the cost of one type of personnel increases this may be offset by savings on other types of personnel.
- Costs for ICT technology, equipment, devices, help desk and maintenance.

**Technology** is the fourth area included in the evaluation. It is divided in two areas:
- Reliability in terms of stability and security
- Ease of use and satisfaction for all categories of users (patients, caregivers and health professionals).

For each of these aspects the evaluation is composed of three components: Target achievement, qualitative feedback and success factors. Target achievement considers the quantifiable change in any of the aspects in relation to the improvement projected before the implementation of the telemedicine system. For instance, evaluating the change in perceived HRQL of a target group and a control group before and after implementing a telemedicine system and comparing this result with the initial predictions. Standard questionnaires such as SF-36 allow quantification of the perceived health gain for comparison. Other ways of measuring the impact in quality of life include the number of readmissions, or the hospitalization days per patient.

Qualitative feedback comprises the non-quantitative information, including patients and healthcare professionals’ opinions and experiences using the telemedicine system. While it is harder to systematically analyse qualitative data it is useful to complete the picture of quantitative data. Furthermore, it allows uncovering aspects that could not be anticipated. For example, interviewing patients about their experience of using the system can bring
new insights on why a telemedicine system increased (or decreased) compliance with medication.

Based on the quantitative data and qualitative feedback, it is important to identify the success factors associated with the telemedicine system being evaluated. Success factors are useful to prioritise user requirements regarding user interfaces and other aspects of telemedicine systems.
3. Good Practices Guidelines

3.1 Methodology used

The good practices described in the following sections are based on the contributions from the RTF partners and the result of the Thematic Workshop that took place in Barcelona in June 16th and 17th, 2010.

3.2 Strategies to implement telemedicine

Telemedicine promises to improve patient’s HRQL, health care institutions allocation of resources, and the overall cost to Health care systems. However, the large size of the population of patients affected by COPD and the wide range of health care professionals involved in assisting COPD patients creates a substantial inertia preventing change to happen. The expansion of telemedicine is further complicated by a legal and administrative framework still largely designed with only face to face medicine in mind.

An incremental approach is deemed the best strategy to win acceptance among patients and health care professionals. At the same time, though, where possible, integration of telemedicine in the regular practice should be done quickly enough so that duality of systems and the pilot effect does not become another source of complexity in the health services for patients of COPD.

The complexity of implementing telemedicine services for COPD (and telemedicine services in general) requires policy-makers to take an active role to create the necessary collaboration between levels of care and push for the necessary legislative changes.

3.2.1 Clinical aspects

At the clinical level four areas were identified to facilitate the implementation of telemedicine services for COPD (detailed below).

- Patient empowerment through education
- Teleconsultation to improve retention of information
- Decision support through evidence-based protocols
- Systematic evaluation of patient and professional outcomes through questionnaires

The success of telemedicine services depend to a substantial degree on the active participation of the patient in managing the disease. Patient educational sessions,
motivational counselling and distribution of education materials are the main interventions to motivate the patient to follow the prescribed treatment and exercises. These interventions have been reported to improve patient’s quality of life, health status and adherence to the treatment. Other benefits of such interventions are increased satisfaction with the service and a decrease in risky behaviour. After suitable training sessions it is relatively rare that patients opt-out of the program, even for patients over 70 years old. Facilitating treatment of the disease at home is particularly beneficial for patients in disadvantaged areas where mobility is an issue.

In countries where the broadband internet infrastructure is in place, teleconsultation through videoconference has proved to be one of the most cost effective tools for monitoring patients at home and empower them to actively manage their disease. Being able to prepare specific questions about the disease allowed them to better understand and retain the information provided by the nurse or physician. Videoconferencing has also been successfully deployed to provide language interpretation services in hospitals and for consultations between primary health centres and specialists at hospitals.

In order to expand the adoption of telemedicine services, it is important to convince health care professionals of the benefits and clarify possible doubts or fears they may have. In order to facilitate the adoption of telemedicine services among healthcare professionals, decision support is a main area to better support the health care professional. First of all, developing evidence-based protocols following established criteria such as the Global Initiative for Chronic Obstructive Lung Disease\(^4\) (GOLD) and clinical pathways has been reported to be an effective strategy of decision support. Educational meetings and the distribution of educational materials among health care professionals also help decision support of health care professionals.

Since telemedicine services for COPD are difficult to oversee by any single individual, it is crucial that patient and health care professional outcomes are evaluated systematically. Questionnaire-based evaluations can be easily distributed and allow comparison with previous evaluations and even with other telemedicine services that use the same questionnaire. For respiratory diseases such as COPD a broadly used questionnaire is St George’s Respiratory Questionnaire (SGRQ)\(^5\). This questionnaire has been translated to multiple languages and its validity and reliability amply reported in research papers.

### 3.2.2 Organisational aspects

At the organizational level, six different aspects were identified to facilitate the implementation of telemedicine services in general and for COPD (detailed below).

- Active involvement of policy-makers to orchestrate coordination between levels of health care
- Clear definition of separate and shared responsibilities between levels of care
- Shared EPR

\(^5\) [http://www.proqolid.org/instruments/st_george_s_respiratory_questionnaire_sgrq](http://www.proqolid.org/instruments/st_george_s_respiratory_questionnaire_sgrq)
- Scheduling system
- Multidisciplinary teams
- Training and redefinition of responsibility boundaries

The complexity and variety of people involved in COPD care means that better coordination will not emerge spontaneously. Decision-makers must make better cooperation a priority in order to overcome deeply rooted vested interests and professional scepticism. Better coordination will only become a realistic goal if it is adequately managed and politically supported. Regions where telemedicine services are most advanced have integrated the agreements required for telemedicine services with the rest of the agreements that are renewed each year between hospitals and municipalities (responsible for primary care centres).

Strong collaboration among health services that provide patient-centred shared care is the baseline for a successful implementation of telemedicine services for COPD patients. To that end, separate and shared responsibilities within and between levels of care should be clearly defined in order to prevent overlapping or gaps of responsibilities. There are three main areas identified for stronger collaboration:

1.- The first area for collaboration between health professionals is implementation of a shared EPR. Such an EPR should integrate the registration of symptoms, comorbidity signs (especially of anxiety and depression), health status, exercise tolerance, nutritional condition and lung function data. Health care systems need to converge to ensure that the same questionnaires and data systems are used. Fragmentation of information is one of the main factors preventing stronger collaboration between health professionals. By agreeing to a unified and complete EPR, Hospitals, primary care and other care levels do not have to repeat their work and can collaborate on a larger scale to assist COPD patients. In order to facilitate collaboration across borders, symptoms and diseases need to be described with an agreed interoperable set of definitions (ontologies), which are currently being developed by the EpSOS project.6

2.- Other organizational aspects such as a shared system to manage follow-ups, booking of services, and training should also be revised and coordinated. Good coordination between levels of health care is important not just for a better allocation of resources, but because patients’ perception of the quality of care and therapy compliance are largely determined by successful coordination. Key aspects are:

- “getting in” – getting access to appropriate care;
- “fitting in” – adapting the care to their requirements;
- “knowing what is going on” – receiving information;
- “continuity” – of staff and also coordination and communication among professionals;

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6 More information on Epsos project: www.epsos.eu
-difficulties in making progress through the system, mainly due to failures in the other four areas.

While there is no single solution for the implementation of telemedicine services, some regions have experienced organizational difficulties by having the telemedicine services spread across all the different departments. Thus, the solution of having a “telemedicine” department working in collaboration with other departments (e.g. department of respiratory diseases) could bring benefits, even as new difficulties are likely to arise.

3.- The third main area for stronger collaboration is a shared collaborative working environment for professionals dealing with COPD patients. Because so many professionals from different health care institutions are involved with COPD patients, it is imperative that they all share the knowledge as needed. For instance, regular multidisciplinary meetings have proven to be a useful tool to improve how difficult cases are dealt with.

From a human resource perspective, the implementation of a telemedicine service can bring substantial changes to the skill and staff requirements of the hospital and collaborating health institutions. Many of the approaches involve doctors being able to review more cases that are followed-up by a nurse. For such implementations of services there will be a greater need for nurses and these nurses will have to be trained on the new tasks that they have to undertake. Furthermore the boundaries of responsibility need to be clearly redefined for the collaboration to be smooth and the care level maintained. Together with the need of equipment, the needs of staff need to be taken into account and their training should be planned well in advance because otherwise can delay or even jeopardise the success of the service.

### 3.2.3 Technical aspects

At the technical level seven different aspects were identified to facilitate the implementation of telemedicine services for COPD (detailed below).

- Reliability over new features
- Multidisciplinary teams to improve usability
- Non-intrusiveness and modularity
- Interoperability & Use of standards
- Intelligent data management systems
- Data security and access tracing
- Speed of deployment
Reliability is a key success factor for the implementation of telemedicine services, because it is strongly connected with the trust that professionals and patients will have in the system. In order to provide the highest reliability it is often preferable to limit additional features and concentrate on key functionalities built with tested and trusted technologies.

Usability and simplicity are other key factors for acceptance and adoption among patients and health care professionals. In order to ensure usability of telemedicine services, multidisciplinary teams should participate in the design process of the system. Beyond usability, this intervention has been reported to bring additional benefits, both in terms of health care professionals’ adherence to guidelines and patient service use.

Non-intrusiveness and modularity are also important aspects when deploying solutions that will be at the patient’s home. Integrating solutions with technology already in the house, such as the TV, the telephone line, or mobile phone, not only reduces cost, but also facilitates acceptance and ongoing use. The modularity of the platform allows deployment of only the functionality required by the patient, without affecting the performance of the overall system.

The use of standards (IHE profile, HL7, LOINC, etc.) is essential to achieve functional interoperability within health systems. Policy-makers should promote open platforms (such as Elin and Linkcare) at every level of care and ensure that new applications and services use them. The recent initiative of the European Commission mandate M403 is a step in the right direction, but still far from providing a complete solution. In the meantime, however, industry consortia such as Continua Health Alliance or EHMI have also been working to develop voluntary labels which they award to equipment where interoperability meets the consortium’s standards. These are the best available guarantees for technical interoperability in the short term. Interoperability with clinical and administrative systems is a crucial aspect that needs to be considered early in the design.

Intelligent data management systems will increasingly become another key factor in the overall environment of telemedicine services. The ability to merge vast amounts of data generated by medical treatments into meaningful information will be essential. Modern information technology can store vast amounts of data, but health professionals usually need carefully selected pieces of information combined in a specific way. Since time is critical, both in terms of costs and medical treatment, intelligent ways of condensing, aggregating and interpreting information must be found. ICT providers often ignore this, but high-level policy-makers should ensure these requirements are met when purchasing new systems.

Data security and data privacy need to be assured to earn the trust of patients and health care professionals alike. Robust encryption and data access tracing are the recommended strategies to ensure these aspects.

Speed of deployment of the necessary equipment to the patient’s home is another aspect to consider. Once a patient is found eligible for a telemedicine service, it should be set up within hours. Such a deployment has organizational obstacles to overcome as well, such as the set up of a dedicated internet connection. In order to handle the deployment

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7 The Lisbon Council (2010) “Government of the Future Centre” www.lisboncouncil.net/publication/
efficiently, creating a spin-off company to handle the platform is a formula that has been implemented successfully.

### 3.2.4 Economic aspects

At the economic level, five different aspects were identified to facilitate the implementation of telemedicine services in general and for COPD (detailed below).

- Funding model: balance between public sector, insurers and users
- Economic savings vs. improvement of care level
- Reimbursement schemes to support integrated care
- Integrated goals to maintain overall quality
- Mixed payment schemes (per service and per case)
- Adaptation of schemes to local environment

The lack of funding is one of the issues that can prevent a quick and wider deployment of telemedicine services.

There are four basic models for funding of telemedicine services for COPD and telemedicine services in general. The most common one is “public social care services” (sometimes with co-payments), then there are the “insurers or other third parties”, or finally there is the possibility to fund telemedicine services through the actual “users”. A number of countries implement a combination of these funding sources. Each region needs to find the suitable model and adapt it to their particular context and particularities.

Telemedicine services provide a better allocation of resources, but this can be used to reduce the costs of the system or to improve the level of care. Pilots to test the feasibility of telemedicine service for COPD can be scaled to fit a certain budget, and are eligible for a number of support funds. However, pilots need to prove that if the service is deployed at the large scale, the service is sustainable. Furthermore, even as some sort of cost savings are possible through the deployment of telemedicine services for COPD, there is a substantial initial investment, and therefore an increase in expenditure, before any economic benefits can be seen. Depending on the telemedicine service, however, there may not be any cost saving, but rather an increase in the level of care. Either way, deployment will follow pilot programs, and it is through these pilot programs that enough evidence must be gathered to make the economic case for full scale deployment. In order to do so, peer evaluation and comparison methods should be used. The costs of telemedicine should include the following items if present:

- the technology investment
- personnel training
- the time used by professionals to access and reporting
- the cost of connection

The comparison should be made against traditional methods with the same clinical efficacy, considering various aspects. The standardization of items to be considered for cost-effectiveness analysis is highly desirable.

Reimbursement is fundamental for deploying telemedicine services. If there is no clear, stable, and long term certainty about how the new models and services will be financed, it is highly unlikely that they will receive enough support. Reimbursement schemes should be aligned across different sectors for health professionals working together in COPD. Different incentives for different members of the same team may frustrate common efforts, where economic interests motivate different treatments. Effective care often depends on the cooperation of multidisciplinary teams, but yet in most European countries, different professional groups are paid according to separate schemes.

In order to provide integrated care for COPD, it is necessary that the goals set for health care professionals reflect this integration of services. Financial incentives encouraging a few narrow goals can lead to excessive focus on these goals, together with “gaming” or better reporting without any improvements in quality. Policy-makers as well as health care managers should set out quality indicators that reflect different aspects of quality (structure, process and, where possible, outcome).

At the same time, financial incentives are likely to impact differently across different groups of providers. Aspects to incentivize should be decided and then designed accordingly. Mixed payment approaches should be considered (such as fee for service and case fees), since this can mitigate negative effects of individual approaches.

For all the impact attributed to financial incentives, theory and empirical evidence suggest that a substantial amount of income has to be variable before providers can be expected to change their behaviour. Incentives should not therefore be too large, given the sensitivity of quality in health care and lack of clarity about the impact of different payment schemes. Where possible, pilot studies should be conducted before programmes are rolled out.

3.2.5 Legal aspect

At the legal level, four different aspects were identified to facilitate the implementation of telemedicine services for COPD and telemedicine in general.

- Acceptance
- Legal clarification
At the policy level, six different areas were identified to facilitate the implementation of telemedicine services for COPD and telemedicine in general (detailed below):

- Data protection
- Informed consent agreement

From the legal point of view, the paramount objective is to guarantee that telemedicine develops in such a manner that it benefits patient care while ensuring privacy and the highest standards of patient safety. Policy-makers and health care professionals at all levels should ensure that patients accept the new model of care based telemedicine.

Regarding telemedicine services themselves, there is a need to clarify licensing, accreditation and registration processes. For professionals working with telemedicine services, clarification is needed regarding liability, reimbursement and jurisdiction.

Data protection is a key part of new designs, but patients often demand full access to their own data. Where necessary, laws must be passed to ensure strict standards on data protection, and to affirm patients’ rights to access their records.

Until telemedicine services become commonplace and are fully regulated, it is necessary to sign agreements between involved parties (patients, health institutions etc). According to regulations a Medical Ethics Committee or equivalent relevant to the institutions providing the telemedicine service need to approve it. This can be a lengthy process and thus should be planned well in advance with all involved bodies.

### 3.2.6 Policy aspects

At the policy level, six different areas were identified to facilitate the implementation of telemedicine services for COPD and telemedicine in general (detailed below):

- Active role to facilitate coordination
- Balance between central and local administration
- Integration of chronic care programs
- Standardized evaluation of telemedicine services
- Raising awareness
- Enabling change

Policy-makers in European countries need to take a more active role in the expansion of telemedicine in general and applied to COPD in particular. Coordination between levels of care is a crucial aspect for the success of telemedicine and the necessary coordination does not happen spontaneously among the stakeholders involved. The range of issues associated with telemedicine requires policy makers to take action together with relevant representatives of the different stakeholders and to create the necessary regulations, protocols and campaigns. In some countries, new laws stipulate the information to be exchanged among health care levels and make electronic health care record an opt-out system rather than opt-in to facilitate the deployment of telemedicine services.
Governments should decide what mix of centrally controlled parameters and local autonomy they wish to implement in order to improve coordination. Policy-makers must take into account the likelihood of acceptance of the changes proposed. They should also consider whether their approach will integrate with established mechanisms of accountability and responsiveness. Similarly, policy-makers should choose between parallel policy initiatives or one integrated national strategy.

Integrated Management of chronic diseases has been implemented in a number of European countries, but these programmes rarely incentivise integrated approaches targeting several chronic diseases. Research shows that chronic illnesses and chronic conditions are increasingly interrelated. Policy-makers as well as decision-makers within public and private institutions should therefore consider integrating or linking chronic care programmes.

In order to promote telemedicine service, it is important to provide a detailed study based on Health Technology Assessment (for example MAST methodology9). Such an evaluation typically includes clinical, economical, organisational, socio-cultural, ethical and legal aspects. This kind of assessment, provides policy makers with all the necessary information to decide whether to invest in telemedicine services.

Raising awareness, confidence and acceptance of telemedicine is the most effective strategy in order to gather the necessary momentum to deploy large scale telemedicine services. There is a need for initiatives to enhance trust and acceptance of telemedicine among patients and health professionals in the best interests of safety and care. New ethical concerns arise from the wider deployment of telemedicine, including COPD services, because of the way in which the patient-doctor relationship is affected.

Overall, policy makers have the role of enablers, and should make it possible for health professionals to fulfil their new responsibilities. This involves setting up an appropriate legal framework, providing training, and helping to build trust between professional groups that are not used to working together.

### 3.3 Conclusions

Telemedicine services for COPD have the potential to improve the lives of many and to relieve part of the actual burden from health institutions. A number of obstacles remain before the impact becomes truly significant. Both for society and European industry, overcoming these obstacles will bring numerous benefits.

At the clinical level, education and training for patient empowerment in the disease self-management is identified as a key area to increase adherence to treatment and satisfaction of telemedicine services among patients. For health care professionals evidence-based protocols and informational materials on telemedicine are instrumental in increasing adoption of telemedicine services.

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9 More information on MAST available at www.telemed.no/methotelemed
At the organisational level, strong collaboration among different levels of health care provides better care for COPD patients. Areas in which collaboration is crucial are the shared use of a unified EPR, a common system to generate appointments, and finally multidisciplinary meetings aimed at dealing with difficult cases. Gathering the commitment by all sides involved to reach agreements is identified as a remaining obstacle, harder to overcome than technical issues. Some countries require by law the exchange of information or collaboration to hospitals and primary health care centres.

At the technical level, continuous quality improvement of the system is required. Reliability in particular is a sensitive area both for patients and health care professionals. Multidisciplinary teams in the design of the delivery system have been provided benefits both for patients and professional use. The use of common and secure standards and the effective management of ever larger sets of data are imperative to be considered in the development of telemedicine platforms.

At the economic level, no one-size–fits all approach has been yet identified. Each region needs to find a balance between funding from the public sector, insurers and the users. Regarding the reimbursement scheme, there is agreement that collaboration between health care levels needs to be incentivised. At the same time, though, each region needs to fine-tune its own system to increase collaboration while preventing negative behavioural changes.

At the legal level clarifying the legal framework with regard of licensing, accreditation and registration, liability, reimbursement and jurisdiction is necessary. Until such clarification exists, specific agreements are to be signed by all parties involved. Authorization to start a new telemedicine service can be a long process and needs to be planned in advance.

At the policy level, decision makers need to outline the balance between centralization and local autonomy to achieve the necessary coordination, standards and protocols. Integration of policies for other chronic diseases in order to develop integrated care models has produced some good results and is the recommended approach of the WHO.

Overall the conclusion is that collaborations like the present one will bring long term benefits as good practices are shared among Member States. The progressive adoption of telemedicine services will bring tougher scrutiny from society. Continuous improvement and sharing of good practices are the best strategy to overcome barriers to the large-scale implementation of telemedicine services.
4. ANNEX A - Good Practices of Telemedicine services

4.1 Identified practices in Region of Southern Denmark

4.1.1 Title of the practice
The COPD Briefcase.
The effect of telemedical nursing consultations for patients with Chronic Obstructive Pulmonary Disease (COPD).

4.1.2 Theme tackled by the practice
The COPD Briefcase aims at providing home-based care to chronic COPD patients. The COPD Briefcase has been designed to make it possible for the chronic patient to connect to the hospital via the Internet at home. This is supported by the following technologies: EDGE, 3G, WIFI (hotspots etc.), Ethernet (broad band) and/or satellite.

4.1.3 Objectives of the practice
The COPD Briefcase is expected to improve patients’ quality of life significantly either due to less hospitalisation or due to better treatment, less isolation and better management of the disease. In addition, it is expected that there will be a substantial financial gain in the healthcare sector due to either shortening of stay at the hospital or due to less hospitalisation.

4.1.4 Location and Background
Region of Southern Denmark - Denmark
In recent years, the Region of Southern Denmark (RSD) has paid special attention to telemedicine and welfare technology services. During the course of the last 3-4 years, RSD has successfully validated and deployed various services on a smaller scale which have demonstrated a major potential for scalability. RSD’s recent strategy for the care of chronic patients is, to a high degree, centred on ICT solutions and services to ensure continuity of treatment and care.

Home-monitoring is a service that can strongly support the strategy and have extensive impact on chronic care in RSD.
4.1.5 Detailed description of the practice

4.1.5.1 Origin

The COPD Briefcase pilot was developed as part of a European eTEN project Better Breathing. The primary endpoints of the COPD Briefcase were to reduce the numbers of readmission for patients with acute exacerbation in COPD by using telemedicine video consultation with the sub acute COPD patient at home and the respiratory nurse at the hospital, with high user satisfaction, patient as well as staff.

The patients got the telemedicine equipment with the purpose of giving the sub acute patient care immediately after discharge from the hospital by using nurse led videoconference and measurements with the patient staying at home.

4.1.5.2 Timescale

During a week the patients receive daily telemedicine nurse consultation which takes ½ hour. The patients are followed for 6 months. It takes about an hour to inform and include a patient in the consultation.

4.1.5.3 Bodies involved/implementation

The COPD Briefcase has been developed in collaboration between the Region of Southern Denmark, Funen Hospital and GITS (a regional SME). Funen Hospital is now part of Odense University Hospital, which is 1 of 4 hospital units of the Region of Southern Denmark.

4.1.5.4 Process and detailed content of the practice

The COPD Briefcase pilot was a service targeting COPD patient, during acute exacerbation and facilitating an early discharge and management of the process at home till its resolution. The equipment provided to the patient allowed nurse led videoconference and measurements with the patient staying at home. The goals of the study were to demonstrate a decrease in the number of readmissions during a follow-up period of 4 weeks. Up to 100 patients participated in the study (50 in the intervention group and 50 in the control group).

4.1.5.5 Timetable of the practices

The planning of developing the pilot service was carried out in the period 2006 - June 2007. The pilot began in June 2007 and ended in January 2009. Following, a randomized control trial was initiated in May 2010.

4.1.5.6 Architecture

In Denmark, the telemedicine services apply existing infrastructure. Nationally, the electronic health infrastructure is based on the Danish Health Data Network (DHDN). Today, all hospitals (60), all pharmacies (250), all local authorities (98),
99% of all General Practitioner clinics, 80% of specialized doctors and most vendors, laboratories etc., are connected to the DHDN.

4.1.5.7 Standard used

The electronic communication among the various parties is based on common standards that are developed, tested and certified by MedCom, which is a co-operative venture between authorities, organisations and private firms linked to the Danish healthcare sector. The organisation’s main task and purpose is to contribute to the development, testing, dissemination and quality assurance of electronic communication and information in the healthcare sector.

4.1.5.8 Legal framework

At hospital level, the legal framework of the telemedicine service was provided by the Medical Ethics Committee which approved the programme prior to launch. At patient level, an explicit consent had to be signed. In this consent, liability and privacy issues were clarified in order to provide a clear legal environment in which to operate.

4.1.5.9 Financial framework

The crucial aspect of the COPD Briefcase is a Business Case which demonstrates that savings are higher compared to costs. The Business Case of the COPD Briefcase will in particular depend on a considerable amount of hospital beds closings.

4.1.5.10 Policies level

Within the Region of Southern Denmark several initiatives are relevant to the deployment of the COPD Briefcase. One of the initiatives addresses procurement barriers for telemedicine applications. E.g. If a SME has taken part in the development of a telemedicine device in conjunction with the regional authority, the respective authority is prevented from procuring the telemedicine device from the respective SME.

4.1.6 Evaluation

4.1.6.1 Target achievement

Patients randomised to the intervention group receive, besides conventional treatment, daily nursing consultations via the telemedical equipment for 7 (± 2) days. Furthermore, the patients are given the telephone number to the Hotline and informed that it can be used every day between 8 am and 3 pm until the patient comes to outpatient review 4 (+2) weeks after discharge.

Eight telenurses are connected to the project and undertake screening, inclusion, teleconsultations, telephone and outpatient follow-up, data collection, and entry of data in databases.
4.1.6.2 Qualitative feedback

The qualitative feedback of professionals and patients was generally very positive throughout the practice implementation.

Patient's evaluation of the service:
- Technology is easy to use
- Make the patient feel secure after discharge
- Can stay at home – No transportation to the hospital
- Monitoring at home
- Uninterrupted consultation
- Intimacy
- The patients can decide the amount of time for consultation

4.1.6.3 Success factors

- The possibility to stay at home and avoid forth and back transportation to the hospital is of great advantage to a patient with de-ambulatory difficulties.
- Ambulances are not needed to transport patients.
- The physician reduces his/her acts in the final report: significant time savings allow them to visit a larger number of patients.
- The collaboration increases both between nurses and physician specialists, and between physician specialists and the patients who are more involved in the management of their disease.
- The readmissions were reduced by 14%.

4.1.7 Primary result indicators:

- The primary result indicators are the total number of readmissions 26 weeks after discharge (it was surveyed over four weeks).

4.1.8 Secondary result indicators:

- Time before first readmission
- Mortality
- Total number of readmission days 4, 8, 12 and 26 weeks after discharge
- The number of readmissions with COPD exacerbation calculated 4, 8, 12 and 26 weeks after discharge.
4.1.8.1 Issues and barriers encountered

4.1.8.2 Clinical level

- It is important for nurses to have access to physician specialists.
- The staff must be informed of the telemedicine service.
- Nurses must receive special educational courses in how to apply telemedicine applications and act in front of the telemedicine equipment.

4.1.8.3 Organizational level

- It is crucial for an organisation to consider at management and decision-making level whether the telemedicine service should be implemented.
- Staff must be taught and have specialist knowledge in order to carry out tele-monitoring (clinical and technical).
- Staff must be familiar with and feel secure in how to use telemedicine monitoring.

4.1.8.4 Technical level

Challenges include:

- Setting up a connection to the patient unit
- How to apply equipment
- Are images satisfactory, in order to see patients’ gestures and colours?
- Is the sound satisfactory, in order to hear the patients?
- Data collection
- Individual professional confidence of observations via telemedicine services

4.1.8.5 Economic/Financial level

- Due to high initial costs as a rule of thumb the COPD Briefcase should be targeted hospital units which serve large areas, such as 700,000 – 1,000,000 inhabitants. This amount of inhabitants will provide the best opportunities for positive Business Cases.
- For the moment randomised control trials of the COPD Briefcase are being carried out. As long as the randomised control trials have not been finalised and hereby the Business Case has not been finalised, it is not possible to carry out the necessary hospital bed closings. But once it has been finalised the savings can be carried out in practice.

4.1.8.6 Legal level

The telemedicine project was approved by the Ethics committee. Patients have given their informed consent.
4.1.8.7 Administrative level

- This telemedicine service is not recognized by the national health system, and it is not considered in the reimbursement system.

4.1.8.8 Strategies take to overcome barriers

4.1.8.9 Clinical level

The lack of acceptance of the telemedicine services by professionals and patients must be considered.

Security and reliability of the telemedicine application are the main areas of concern. Health professionals may often oppose telemedicine services because of lack of clarity in clinical liability issues.

4.1.8.10 Organizational level

It is important to provide information of the telemedicine service to the rest of the organization.

4.1.8.11 Technical level

The telemedicine applications provided must be well accepted both by professionals and patients. Some challenges with the network have been identified and selected to be addressed in future versions of the programme.

4.1.8.12 Economic/Financial level

4.1.8.13 Legal level

In order to clarify the aspects of privacy, liability and related issues, all the patients who have accepted to participate in the study were requested to sign an informed consent. The consent and the protocol of the study have been submitted to- and approved by the Ethical Committee.

4.1.8.14 Administrative level

Different coordination issues at administrative level have been overcome partly due to the positive environment towards telemedicine services

4.1.9 Lessons learnt from the practice

It is possible to reduce the number of readmissions after discharge with an exacerbation of COPD. The telemedicine nurse consultations provided a safe mechanism to control patients’ conditions and unexpected events after discharge.

Besides the resulting patient empowerment, which makes it possible for the patient to improve his/her own health, seems to become a core aspect of this service.
After discharge it is possible:

- to teach the patient, the relatives (and the homecare system) while they are at home
- to give the information needed to the patient and the relatives at any time
- to follow patients, give patients’ care, control how patients use the treatment
- to save time
- to give a better service to a lower cost

### 4.1.10 Contact information

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### 4.1.11 Other possible interesting information

[www.gits.dk](http://www.gits.dk) (supplier of the COPD Briefcases)

### 4.2 Identified practices in Veneto Region

#### 4.2.1 Title of the practice

The poly-specialistic teleconsultation in Home Care

#### 4.2.2 Theme tackled by the practice

The telemedicine service offers new ways to care patients with COPD and deambulatory difficulties and domiciled in disadvantaged areas.

#### 4.2.3 Objectives of the practice

Some features of a city like Venice (bridges, high water events, slow public transport, limited roads) include a series of hardships for the elderly and chronic patients, and severely limitation for their autonomy. For this reason, Venetian Local Healthcare Authority realized a project that helps these people, it improves the quality of life and offers a range of services directly to their homes, resulting in cost savings by avoiding the use of the maritime transport system, obviously more expensive.

This service allows to the hospital physician to visit patients in teleconsultation, under the Home Care. The following visits in teleconsultation are:
• Tele-pneumology and tele-surgery: for chronic patients with COPD in ventilation-oxygen therapy.
• Tele-cardiology: to monitor a pacemaker or heart failure
• Teledermatology: aimed at patients with arterial or venous ulcers, and to monitor follow-up of small events surgical

In this way, it would be possible:
• Improving quality of life for immobile patients
• Greater collaboration between nurses and medical specialists with virtuous effect on pathways of care
• Creation of a network of expertise between hospital and territory
• Reduction of distances

4.2.4 Location and Background

The Veneto Region has 21 Local Healthcare Authority and 2 Hospital Trust. The telemedicine service for patients with COPD has been designed and implemented in a Local Healthcare Authority which provides services in the province of Venice. The territory includes the islands of Venice, where health services have a high inconvenience to travel for both patients and healthcare professionals. The citizens of Venice are 270,000, of which 90,000 inhabitants live in islands and estuary.

In 2007, the territory of the Venetian Local Healthcare Authority consist of 3440 patient with COPD, of which 978 afferent in two insular districts (districts 1 and 2).

4.2.5 Detailed description of the practice

4.2.5.1 Origin

Chronic diseases require frequent monitoring to assess the health state of the patient, assess drug compliance and maybe adjust the therapy. The high cost of transport in the territory of Venice limit the possibility of outpatient visits. Besides, visiting at the home allows a better control of adhesion therapy.

For this reason, Venetian Local Healthcare Authority decided to implement a telemedicine service aimed primarily at chronic patients living in the islands and estuary of the city of Venice.

4.2.5.2 Timescale

The telemedicine service was planned in the period March 2006 - September 2006, and implemented planning in the period October 2006 - January 2007.

In February 2007 stared experimentation. From September 2009, the service became active.
4.2.5.3 Bodies involved/implementation

The project involved 2 out of 4 districts of the Venetian Local Health care Authority, which has the general responsibility of the service. Venetian Local Health care Authority established a group of telemedicine and a Scientific and Technical Committee that managed the project.

The Technical and Scientific Committee is composed by the head physician of cardiology, of pulmonology and of dermatology, a reference nurse, the Quality and Accreditation section of the Venetian Local Health Authority, under the responsibility of Dr. Massimo Fusello.

The inter-district group for the telemedicine, established subsequently, is composed by an inter-district nursing coordinator for telemedicine, which serves as reference for the service.

The resource involved are:

- 18 home care nurses;
- 2 administrators: supplier of the software and a nurse as coordinator of the home care nursing in the Venice area;
- A computer technician
- 15 Medical specialists

4.2.5.4 Process and detailed content of the practice

4.2.5.5 Workflow of the practice

In service, the nurse in charge of the home visit is equipped with:

- a laptop and a device Spirometry Mir III e POCT I-stat Abot;
- a modem card;

The service is operated through two software applications. The first application is an outpatient program that allows to enter the registry and clinical data of patients, monitor the instrumental tests collected at home and end the visit (by the specialist). The second application is however a manager program installed in the laptop that allows the nurse to collect data equipment (cardiac, pulmonary and dermatological) and run a tele-synchronous, i.e. the teleconference with the physician. Everything is carried out through five main steps:

- implementation of booking through the ambulatory application (can be made in advance directly from the service station);
- Synchronizing with laptop (to be precise, the morning before leaving for the planned home access)
- Completion of the home visit on the laptop (while making the useful information gathered during the session, using the manager application)
- Synchronization (data are will transmit to physician, so that the two systems are catching up);
• Termination of the visit with the ambulatory application (closure of the visit by the specialist).

4.2.5.6 Timetable of the practices

Content: About timetable of the project, i.e. time of planning, time of implementation, time of used of the service,

Text length: max 10 lines each partner

In March 2006 the contract was concluded on Health Research to achieve their aims above described.

In October 2006 the project was presented to a National expo forum on telemedicine and e-Health and analyzed the strengths / weaknesses (SWOT analysis).

Between November 2006 and January 2007, were made:

• meetings with operators
• planning the introduction of the method
• Optimization of the software

On 15 February 2007 began the testing phase. Within a few months, the telemedicine visits were extended to six deprived places of the Venetian Local Health Authority.

There was not a clear passage from experimental phase to the actual activation phase.

The resources used include instrumentation, software and technical personnel who are familiar with the new methodology. All sectors were immediately involved:

• specialists who have voluntarily given their availability,
• nurses, who were convened according to the peculiarities of each (cardiology, pneumology, etc.) and submitted regular training,
• supplier of the software, included in the Technical / Scientific committee and where there was already extensive collaboration,
• administrative staff who are employed in general organization of work for the service, whose performance is regularly monitored.

Since the service is active (i.e. since 2007), the program has submitted frequent changes, hand in hand the normal technological progress, which allowed to implement additional functionality, such as tele-surgery.

4.2.5.7 Architecture

The general architecture of the telemedicine system consists of two workspace:

• workstation in the patient's home, where there are:
  • medical devices (spirometry and i-stat POCT) used by the nurse
  • a laptop computer, used by the nurse and connected to medical devices via interface to detect the clinical data
workstation in the hospital where the specialist is present and where there is a computer that receives data from the computer at home of the patient.

Transmission between two workstations is bidirectional: in fact, the system allows the sending data and medical history, inserted at the time of booking, to the computer of the nurse, and the transmission of clinical data obtained during a visit to the central server of the hospital that is linked to the specialist.

The telemedicine service adopts a client-server architecture, where the communication occurs between the personal computer that downloads data from the medical device and server of the hospital. The laptop act as gateway, and it is connects to the network through an Internet Key (MT505UP Wave Modem) for UMTS.

In terms of software, in order to visit the patient in teleconsultant, the system makes use of a specific application manager, residing on the network of Local Health Authority, in a central server that stores data, and a client application installed on the laptop where the nurses notes data in the patient's home.

4.2.5.8 Standard used

The telemedicine system does not use any interoperability solution among workstations or between laptop and medical devices. In addition, for the time being, the system is not integrated with hospital systems, for example document repository, ADT, etc. Since the Physician is in hospital, he is enable doctor to access to hospital systems, but the nurse has no access because he is in remote workstation.

In terms of standards, the system use HTML standard for sharing of documents, JPEG for images and MPEG for multimedia content. In order to communicate, the system HTTP standard and secure HTTPS version.

4.2.5.9 Legal framework

The Scientific and Technical Committee of Telemedicine provides for the participation of a forensic scientist that protects that the used protocols respects the ethical values of patients and are compliant with regulatory requirements.

4.2.5.10 Financial framework

The project was funded by Veneto Region through a funds finalized to health research. The funding was 60.000 €.

It is developed an analysis of the costs that was incurred and the cost that will be incurred in the implementation of technological and organizational model. This analysis has provided the necessity to implement teleconsultant or not. Drug-Economic analysis becomes a benchmarking tool for defining the choice between parallel but different procedures by procedure and tools designed to make a choice.

The project was also evaluated in terms of the costs of telemedicine visit, compared with the cost of traditional visit. Factors that were considered are: physician hourly cost, nurse hourly cost, time of execution of individual activities, the cost of transport of nurse and patient, the cost of software / hardware, and the need for reinvestment of telemedicine.

This drug-economic analysis highlights that telemedicine can prevail economically than the traditional visit if the local health authority achieves a sufficient number of visits per year and if in vestments are available.
4.2.6.1 Target achievement

Activities data:
- 714 visits in telemedicine 2007-2009
- 38 human resource involved
  - 18 home care nurses;
  - 2 administrators: supplier of the software and a nurse as coordinator of the home care nursing in the Venice area;
  - A computer technician
  - 17 Medical specialists

4.2.6.2 Qualitative feedback

Nurses are interviewed through a questionnaire concerning assessing the impact that the new organization has contributed to the perception of professionalism. The results are:
- 54% of nurses surveyed found that regardless of the clinical result, telemedicine is able to increase their professionalism,
- 22% of nurses increase the sense of security.
4.2.6.3 Success factors

The success factors list of practices:

- The ability to stay at home and to avoid moving to and from the hospital, is a sure advantage for a patient with deambulatory difficulties.
- Ambulances are not need to travel patient to visit: this, in a city like Venice, where the means transport in water are characterized by high costs, involves a significant cost savings.
- The medical practitioner reduces its acts in the final report: significant savings in time that allows him to visit a larger number of patients.
- The collaboration Increases both between nurses and medical specialists, and between medical specialists and the patient who is more involved in the management of their disease.

4.2.6.4 Issues and barriers encountered

4.2.6.5 Clinical level

The telemedicine service has some limitations from the clinical point of view:

1. Limitation of some cases of chronic diseases
2. Limitations in emergency cases,
3. Complex assessment of effectiveness to compare of outpatient visit and the visit to telemedicine, due to clinical instability of chronic patients

4.2.6.6 Organizational level

1. In telemedicine visit, a nurse spends more time in comparison to the traditional hospital procedure, because increases his or her tasks. Therefore, the involvement of more staff and a higher level of technological expertise are needed, in addition to normal nursing skills, in order to use the equipment properly.
2. The involvement of general practitioners is a crucial factor for the extension of service because cooperation is needed to ensure continuity of care. A major issue is the lack of knowledge on telemedicine that would impede its deployment: incentive programs should be needed arrange to involve more personal.
3. It is necessary create a reference permanent group concerning telemedicine

4.2.6.7 Technical level

1. There is no integration between the two software applications used in the service and information systems of hospital and districts: this one implies a slowdown of procedures for managing the profiles of patients. There isn’t a telematics platform from which accessing in web-based to see the patient’s electronic medical record. The nurse is forced to take the medical record paper with him at each home visit, if it is needed examine data of patient.
2. There is not integration between medical devices and hospital server. The captured data are not communicated to any information system.
3. The service follows the patient-cantered approach, seeking to give responsibility to the patient in self-management of their disease: in this sense the access to their clinical information would be useful to allow the patient. The software integration with the EHR becomes a real necessity.

4. The software that nurse uses for the acquisition does not allow the automatic data processing. If there are errors or anomalies in the acquisition of data, there are set alerts.

5. The digital signature for the reporting of specialists is not used, but it would be considered useful.

6. Internet is used in order to transmit clinical data. Internet is a common infrastructure and economic, but it involve some problems. For example, an insufficient band can be a critical factor in emergency, where the nurse should send real-time data to the specialist.

4.2.6.8 Economic/Financial level

1. Doubts about how to proceed in organization and technical terms

2. The initial investment is high: the technology equipment is often customized to the organizational needs; it suggests the need for an appropriate amortization schedule, which must considers the rapid obsolescence of the equipment.

3. It is needed to consider the costs of staff training and inefficiency due to the initial introduction of the new method during the start-up costs of “training” of staff phase.

4.2.6.9 Legal level

1. The software have to be conform the regulations in terms of privacy.

4.2.6.10 Administrative level

1. This telemedicine service, as in many other cases, is not recognized by the national health system, and it is not considered in the reimbursement system.

4.2.6.11 Strategies take to overcome barriers

4.2.6.12 Clinical level

1. During patient selection choose only chronic diseases

2. No utilization in emergency cases,

3. Not overcome

4.2.6.13 Organizational level

1. “nurse spends more time”: new service organization.

2. The involvement of general practitioners is included in “business agreement” in 2010

3. In order to implement a telemedicine service, it is important to provide a telemedicine group and a Scientific and Technical Committee. In this way, some issue can solve more easily.
4.2.6.14 Technical level

4.2.6.15 Economic/Financial level

1. It is important to develop an analysis of the costs that was incurred and the cost that will be incurred in the implementation of technological and organizational model. This analysis has provided the necessity to implement teleconsultant or not.

2. The initial investment is high: not overcome.

3. The tasks of nurses have been modified in organizational level.

4.2.6.16 Legal level

1. The software have to be conform the regulations in terms of privacy.

4.2.6.17 Administrative level

1. The telemedicine service has to be formalized as health service.

4.2.7 Lessons learnt from the practice

Telemedicine is a way to provide health services using information technology. Information technology represents an increase of expenditure that is converted into a good investment only with a suitable organizational change services. The contribution of all actors is essential to speed up the implementation and to bring out the criticality.

4.2.8 Contact information

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4.2.9 Other possible interesting information

4.3 Identified practices in Ministry of Health of the Catalan Government

4.3.1 Title of the practice

The ‘Pulmonary rehabilitation program,’ was included in the initiative of the Ministry of Health of the Catalan Government “Viure en Salut a Casa” (Living Healthier at Home). The program undertook a gradual deployment and validation of well standardized patient-centred services addressed to citizens with highly prevalent chronic disorders.

4.3.2 Theme tackled by the practice

There were two main themes tackled by the pulmonary rehabilitation program. The first is providing continuous care between hospital and home care. The second was educating to promote healthy life-styles of clinically stable chronic patients, enhancing self-management and improving compliance with prescribed treatments.

4.3.3 Objectives of the practice

The rehabilitation program practice aimed to maintain the training effects achieved at the hospital when the patient goes home with the support of a monitoring device and the remote supervision of the physiotherapist.

Overall the goal was to keep COPD patients out of the hospital as much as possible. At the patient level, the practices aimed to enhance self-management directly or through carers, using e-learning tools. Beyond that, pulmonary rehabilitation program had the objective of increasing the quality of life and scores of satisfaction. At the organizational level, the aim was to improve coordination between levels of care, for instance primary care and specialized care, and coordination with social support. At the economic level the practice aimed to reduce the use of other health services, basically visits to primary care and specialized care. In connection with the reduced used of health services, the practice aimed to contain costs for the overall health care system.

4.3.4 Location and Background

The pulmonary rehabilitation program took place in Barcelona, the capital of the autonomous region of Catalonia and a city of approximately 1,6 million people. Hospital Clinic i Provincial de Barcelona (from now on Hospital Clinic) is the hospital of reference for an urban population of about 540.000 inhabitants (roughly one third of the population of Barcelona). This appeared as a natural surrounding for the initial deployment of the service.
4.3.5 Detailed description of the practice

4.3.5.1 Origin

The practice of pulmonary rehabilitation started from the wish to improve the rehabilitation process of COPD patients with a smarter allocation of care personnel. Since the early 1990s, Hospital Clinic Barcelona has been conducting a long string of pilot projects that have ensured continuous improvement of the system and the acceptance of health care professionals and patients alike.

4.3.5.2 Timescale

The program consisted of two phases. The first phase had duration of 8 weeks, during which patients received training for pulmonary rehabilitation at the hospital. The second phase had duration of 18 months, during which patients continued training at home. All patients performed complete controls 6, 12, 18 months after leaving the hospital, followed by the conclusion of the program.

4.3.5.3 Bodies involved/implementation

The healthcare authorities supporting the program at the highest level were the Ministry of Health of the Catalan Government and TicSalut, a public foundation that promote the use of information technologies in healthcare and the advance of telemedicine in Catalonia.

At the organizational level, Hospital Clinic was the leading institution, working in collaboration with three primary health care centres affiliated with the hospital. At the clinical level 75 COPD patients participated in the program.

4.3.5.4 Process and detailed content of the practice

The program started with a two month phase in the hospital during which they were trained with a set of exercises to improve their pulmonary capacity. During the following 18 months, all patients had to follow the exercise program at their homes, on periodic sessions (typically 3 per week).

The intervention group was monitored remotely by the physiotherapist, who would provide advice on healthy lifestyle, and how to improve self-management skills of the disease. The control group, followed the same exercise instructions, but without supervision. After leaving the hospital, all patients were controlled three times in six month intervals based on several parameters described in section 4.3.6.

4.3.5.5 Timetable of the practices

The pulmonary rehabilitation program was implemented from June 2007 to January 2009. The in-hospital phase had duration of eight weeks, followed by the out-of-hospital phase, which had duration of 18 months.
4.3.5.6 Architecture

The architecture of the application deployed for the pulmonary rehabilitation program was set by a platform called Linkcare. The Linkcare platform was developed by Hospital Clinic and has modularity, flexibility and scalability based on Service Oriented Architectures (SOA).

The Linkcare platform is based on an application server and database at the hospital which can be accessed from a PC browser over the secure intranet of the hospital. The application server communicates with a mobile phone in which the platform application has been installed. The mobile phone, in turn, communicates securely with the medical sensors required and sends the information encrypted to the server central server. The Linkcare services portfolio includes: health portal, call centre service, professional mobile access, patient wireless monitoring service, collaborative work service, security modules, and Interoperability module with hospital information systems and shared electronic patient records at corporate level.

For the pulmonary rehabilitation program, the mobile phone was paired with a pulse-oximeter to detect heart rate and oxygen saturation. The application on the phone allowed as well the administration of questionnaires and keeping track of sessions. After each session the system automatically transferred the recorded data to the central server, or, in case the network was not available, sent it when the network became available again.

4.3.5.7 Standard used

The Linkcare platform runs on different operative systems (Windows, Linux and Unix). During the program, the installation at Hospital Clinic ran on Windows Server 2003 and used Oracle 10g data base. It was built following a typical three layers’ structure: Data Access layer, Business logic layer and Presentation layer.

The platform uses standard communications and protocols. For the implementation of the program, at the server application side, TCP/IP v4 was used, but the platform supports as well TCP/IP v6. In the case of the mobile applications, Wi-Fi and existing mobile phone networks (GPRS and 3G) protocols are supported.

Regarding interoperability, the platform uses XML files and WebServices. This allowed the implementation with an HIS solution provided by SAP used during the pulmonary rehabilitation program, but other implementations are possible. Connection between sensors and mobile phones was done via Bluetooth. Finally, the application for data transfer on the mobile phone was built on J2ME technology.

4.3.5.8 Legal framework

The legal framework of the telemedicine service was provided, from the hospital side, by the Medical Ethics Committee, who approved the program before its launch. From the patient side, an explicit consent had to be signed to take part on the program. In this consent, liability and privacy issues were clarified in order to provide a clear legal environment in which to operate.
4.3.5.9 Financial framework

Since 1990 Catalonia has full autonomy to administer the funding that the central government in Madrid dedicates to the region. The Ministry of Health of the Catalan government provides public universal healthcare coverage, and plan, purchase and evaluate health services based on the health care needs of the Catalan population.

The current reimbursement scheme, however, is still designed considering only the provision of presentational health care. Telemedicine reimbursement schemes are still under negotiation. At present, public funding for the advance of telemedicine services allow conducting substantial pilot projects, but fall short of large scale implementation.

4.3.5.10 Policies level

At present there is a major policy framework that supports the development of telemedicine services for COPD in Catalonia. The “Strategic plan for telemedicine and teleassistance” was launched in December 2007, will last until 2012 and aims to develop in a telemedicine services in Catalonia.

Furthermore, the Health Care Plan of the Ministry of Health sets specific targets for 2010 focusing specifically in chronic respiratory diseases, setting the target to reduce mortality of these diseases by 10%. This Plan will set out measures aimed at promoting health, prevention, early diagnosis, treatment, rehabilitation and the reorganisation of resources, applying criteria of sustainability and equality for all areas. Particularly relevant for telemedicine services are the following topics of the plan:

- Early detection and treatment of COPD and asthma at all levels of healthcare.
- Establishing coordination between hospitals and primary healthcare to monitor and track COPD so as to provide a full response to patients’ needs, including preventive measures and rehabilitation programmes.
- Reducing variations in clinical practice, especially in the handling of patients in acute phases of COPD, through clinical protocols that improve the overall quality of service.
- Promoting programmes of home hospitalization and early discharge for patients who have suffered acute episodes of COPD.

Together with these objectives, the need to contain health care costs is also a powerful aspect motivating the expansion of telemedicine services for COPD in Catalonia.

4.3.6 Evaluation

4.3.6.1 Target achievement

The primary outcome of the service was that exercise tolerance was better maintained in the intervention group. The secondary outcomes were treatment compliance, behavioural (lifestyle) changes and cost and return of investment. The expected results cover efficacy
(enhanced daily physical activity, improvement of exercise tolerance, and better self monitoring) and cost containment.

Several areas were evaluated in all patients to evaluate the impact of pulmonary rehabilitation program. The key indicator to compare between the intervention and control group was exercise tolerance, together with the daily physical activity and pulmonary function. Beyond these aspects, patient’s perceived quality of life, satisfaction and program adherence were important to understand the perspective of the patient. From an economic point of view, use of health care resources, associated costs of the intervention and an estimation of the return of investment were also performed.

The level of adherence of both groups to the exercise regime was comparatively better in the intervention group after six months of follow-up. In this way, most of the parameters of exercise, quality of life and also the daily physical activity questionnaires showed better results in the intervention group than in the control group. These results could be explained because of the increased adherence to regular training. Additionally, it is very likely that these patients changed in a significant way their concept of healthy life thus successfully integrating physical activity as a part of their daily routine. From an economic point of view the rehabilitation program savings per patient and year were estimated to range from €937 to €6,232 according to the different rehabilitation modalities.

4.3.6.2 Qualitative feedback

The qualitative feedback of professionals and patients was generally very positive throughout the practice implementation. Patients’ concerns about the system were clarified through the training they received to learn how to use the system. The satisfaction while using the system and their perception of usability seems to have translated into increased adherence to the rehabilitation program.

On the professional side as well, the initial training seems to have significantly contributed to high satisfaction among the physiotherapists who participated in the study. A certain degree of organizational impact was reported but was not considered disruptive with their daily work. The professionals suggested a number of improvements in the application back-end (the one they used to access patients’ data). Most of the suggestions were related to incorporating new functionalities (notably connection with the hospital EHR) that were already planned as future improvements of the application.

4.3.6.3 Success factors

Several success factors could be identified in the program. The most relevant was the patient involvement throughout the process, from the education to the actual training and use of equipment. The empowerment of the patients allowed them to live more independently following an adequate lifestyle, but at the same time being properly monitored resulted in increased satisfaction.

From the professional side as well, the key success factors identified by professionals were having the possibility to objectively determine the level of performance during the
training session (via oxygen saturation data and heart rate) and maximizing the chances of maintaining the level of training achieved during the initial phase at the gym.

Finally, the pulmonary rehabilitation program represented clear innovation in allocation of resources since more patients can be monitored by the same number of professionals. In the presentational approach, the availability of space at the gyms and/or their distance from patients' homes are often limiting factors. In the adopted approach this limitation was significantly reduced.

4.3.6.4 Issues and barriers encountered

4.3.6.5 Clinical level

As with most telemedicine services, at the clinical level one challenge is to keep the quality of care and decrease the stays at the hospital. However, lack of acceptance of the telemedicine services by professionals and patients had to be considered. Acceptance of a technology depends mainly on the degree of trust in the technology. In the case of telemedicine security and reliability of the technology are the main areas of concern. Health professionals often may oppose resistance to telemedicine services because of lack of clarity in clinical liability issues. Beyond these aspects, appropriate selection of target patients that takes into account the advance of the disease and predisposition towards trying telemedicine services needs to be in place.

4.3.6.6 Organizational level

At the organizational level one of the barriers encountered was basically the fear of health professionals that the telemedicine practices would interfere with the on-site provision of health care. The work pressure in health institutions often leads to the impression that attending patients through telemedicine is not possible without substantially impacting the work responsibilities for presentational care. Furthermore, the lack of reimbursement scheme for telemedicine in line with those of presentational care limits the motivation to collaborate with other health care levels.

Difficulty of coordination between different levels of care was another organizational barrier on the implementation of telemedicine services like the pulmonary rehabilitation program, which involves hospital and primary health centres. Furthermore, pulmonary rehabilitation programmes are rather new to primary care centres. Introducing the service among the professionals and ensuring continuous deployment is not easy.

4.3.6.7 Technical level

At the technical level, providing high enough reliability of measurements and information to earn the trust of health professionals and patients was the most challenging barrier. Because of the sensitive aspects of health, even with reliability rates equal or higher than in other sectors, failure cases attract intense bad publicity that can jeopardize the implementation of the program and even other telemedicine services.

In the case of pulmonary rehabilitation, the challenge was to deploy technology that was acceptable for the patient and provided all the information required by the health professionals in order to monitor progression.
4.3.6.8 Economic/Financial level

The barriers at the economic and financial level were to find the resources to fund the deployment of new equipment for the pulmonary rehabilitation program. Beyond the equipment, resources for training materials and the time devoted to training need added to the total cost of the program. Even when the savings foreseen are larger than the costs, finding enough economical support is often a barrier to overcome to implant telemedicine services.

4.3.6.9 Legal level

At the legal level it was necessary to seek pertinent approvals of the hospital organization and patients participating in the pulmonary rehabilitation program. Even for programs with substantial experience, getting all approvals is a lengthy process for which is necessary to plan in advance.

4.3.6.10 Administrative level

At the administrative level lack of coordination between different levels of health care was the largest barrier to overcome.

4.3.6.11 Strategies take to overcome barriers

4.3.6.12 Clinical level

In order to overcome the possible lack of acceptance, substantial effort was dedicated to explain both to patients and professionals how the program works, and the results of extensive pilot programs in the past. The substantial experience of Catalonia in telemedicine provided the most valuable argument towards assuring both patients and health care professionals that telemedicine was a safe strategy to deal with COPD.

To assure the suitability of patients for the program, a set of criteria was defined. Patients included are COPD patients (GOLD II, GOLD III and GOLD IV), that accepted to participate in the study. However, patients with a cardiovascular disease; musculoskeletal disorders; neurologic disease and other comorbidities that could compromise the normal development of the protocol were excluded. All patients completed the study with the exception of 8 cases that suffered an exacerbation in the course of the follow-up, prompting the team to drop them from the study.

4.3.6.13 Organizational level

At the organizational level the most effective strategy to overcome barriers was to facilitate coordination through streamlined workflow and consistent integration of information. Health care professionals reported that the practices did not significantly interfere with the rest of the work processes in which they were involved. Such a positive evaluation of the program was seen as a result of the clarity of tasks and processes involved.
The favourable climate in terms of overall health policy to the expansion of telemedicine was instrumental in facilitating the collaboration of the different parts involved in the project.

4.3.6.14 Technical level

The interoperability challenges involved in the program were overcome by using a platform that has been successively improved through numerous iterations of this and other programs.

The applications provided were well accepted both by professionals and patients, and provided good reliability and ergonomy. Some minor issues with the network were identified to be addressed in future versions of the program.

4.3.6.15 Economic/Financial level

Even as the savings derived from telemedicine promise to outweigh the investment, overstretched health services often lack the resources to implement ambitious telemedicine programs. Clear and detailed cost-benefit analysis of past pilots and small-scale implementations was the best strategy towards gathering the necessary support. It is foreseen that as the public sector invests more money in telemedicine services, the private sector will produce more competitive solutions further reducing the cost of telemedicine.

4.3.6.16 Legal level

In order to clarify the aspects of privacy, liability and related issues, all the patients that accepted to participate in the study were requested to sign an informed consent. The consent and the protocol of the study had been submitted and approved by the Hospital Clinic Ethical Committee.

4.3.6.17 Administrative level

Coordination issues at the administrative level were overcome thanks to the positive climate to expand telemedicine services in Catalonia.

4.3.7 Lessons learnt from the practice

The results reaffirm the notion that the telemedicine service used in the pulmonary rehabilitation program significantly contributed to the maintenance of the training effects. Additionally, it provided a safe mechanism to control patients’ conditions and unexpected events during the exercise session.

Another aspect contributing to the increased adherence to the prescribed exercises is the integration of education on the effect of a healthy lifestyle on the advance of the disease. The resulting empowerment of the patient to improve his or her own health seems to be one of the key aspects of the program.
4.3.8 Contact information

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4.4 Identified practices in Northern Norway Regional Health Authority

4.4.1 Title of the practice

The home-based rehabilitation programme

4.4.2 Theme tackled by the practice

The programme was providing home-based rehabilitation as a supplement to outpatient rehabilitation provided by the hospital.

The patients’ ordinary TV and a remote control were used as an interface to the services offered at home, while the healthcare personnel were using their ordinary systems (PCs etc). The basic set-up at the patients’ home consisted of their TV, a remote control, a dedicated computer, and a broadband connection between the home and the hospital.

4.4.3 Objectives of the practice

The home-based rehabilitation programme offered in the EU-financed project; Better Breathing should make it possible to reach patients who were not able to participate in outpatient rehabilitation today, either due to the distance, or because they were too ill to participate whatever the distance.

4.4.4 Location and Background

Northern Norway Regional Health Authority

Northern Norway regional Health Authority (RHA) has since 2002 hosted Norwegian centre for Integrated care and Telemedicine (NST). During these years a lot of pilot projects have been running within different fields of clinical aspects. NST has successfully validated and deployed various services on a smaller scale which have demonstrated a major potential for scalability. RHA recent strategy for the care of chronic patients is, to a high degree, centred on ICT solutions and services to ensure continuity of treatment and care.
4.4.5 Detailed description of the practice

4.4.5.1 Origin

The home-based rehabilitation pilot was developed as part of a European eTEN project; Better Breathing. The Norwegian partners were The Norwegian Centre for Integrated Care and Telemedicine (NST) and The Northern Research Institute (NORUT). The primary endpoints were to reach patients who were not able to participate in out-patient rehabilitation today, either due to the distance, or because they were too ill to participate whatever the distance.

The Norwegian Better Breathing services were long term, and could be offered as a rehabilitation programme (eCare, eRehabilitation, eCommunity and eLearning) for a specific period of time, or as separate services for long term follow up.

4.4.5.2 Process and detailed content of the practice

The home-based rehabilitation pilot was a service targeting COPD patients who were not able to participate in out-patient rehabilitation, either due to distance, or because they were too ill.

The core service building blocks were:
1. COPD educational videos.
2. An instructional and follow-along exercise video.
3. A Patient Health Diary with questionnaires, vital signs measurements, and activity step counter.
4. Individual follow up by healthcare personnel.
5. Group-based training by physiotherapist
6. Group-based education by doctor, nurse, physiotherapist, dietician etc

4.4.5.3 Architecture

The patients’ ordinary TV and a remote control were used as an interface to the services offered at home, while the healthcare personnel were using their ordinary systems (PCs etc). The basic set-up at the patients’ home consisted of their TV, a remote control, a dedicated computer, and a broadband connection between the home and the hospital.

At the hospital there was a need for a computer to be used for the TV meetings and the individual consultations. At home each patient needed a Residential Patient Device (a small dedicated computer), a remote control, a web camera, a step counter, and microphone / headset.

4.4.6 Evaluation

4.4.6.1 Target achievement

The evaluation covered the following areas; user acceptance of technology and services, usability of the solution, and medical effects.
Data collection included:

- Interviews with the patients, before and after the intervention
- St George’s Respiratory Questionnaire (SGRQ)
- The System Usability Scale (SUS)
- Medical measurements; Spirometry, oxygen saturation and heart rate, and
- 6 Minutes Walk test and dyspnea score rated by Borg’s scale

Other recognised effects of COPD rehabilitation, such as reduced hospital admissions, were not directly addressed in our study, but other studies report that rehabilitation decreases the number of admissions of COPD patients by up to 50%.

4.4.6.2 Qualitative feedback

The concept was appreciated and fully accepted by the patients, and it inspired and effected changes in behaviour. The medical results were similar to those achieved in outpatient rehabilitation at UNN. The technology was user-friendly and easy to use. Even though the number of participants was limited, the results indicate that home based rehabilitation can be a useful contribution and supplement to more traditional means of rehabilitation.

4.6.3 Success factors

Immediate rehabilitation programme. The impact of rehabilitation on quality of life and exercise capacity for COPD patients resulted in statistically significant improvements in four domains; dyspnea, fatigue, emotions and patients' control over disease. 31 randomised controlled studies were included in the review. Rehabilitation was defined as “exercise training for at least four weeks with or without education and/or psychological support”.

Our main goal was to reach groups of patients that would otherwise not receive help and care, either because of long travel distances or because of bad health conditions and we calculated the price of our solution. Our estimate showed that the cost per patient in home-based rehabilitation is 40% lower than the cost of outpatient rehabilitation. In addition, travel costs of €375 are avoided per patient who participates in home-based rehabilitation compared to outpatient rehabilitation.

The current technology is built out of web software components, according to open standards, and embedded in a dedicated PC platform running Linux. Thus, it will be possible technologically to migrate and support similar services, or service components, on a personal computer without too much effort. We selected a dedicated computer and TV interface in order to reach people not to familiar with personal computers. Our data also shows that even the participants with personal computer skills are very positive to access Better Breathing services through the means of a big TV screen and a dedicated remote control.

4.4.7 Other possible interesting information
More information about the Better Breathing Project can be found on the project website at www.betterbreathing.org.