# IS-ACTIVE

## Inertial Sensing System for Advanced Chronic Condition Monitoring and Risk Prevention

### D2.1 – Requirements analysis

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# Abbreviations

A list of abbreviations used in this document, with the exception of the abbreviations used in the systematic review (paragraph 2.3).

| | |
|---|---|
| 6MWD | 6-Minute Walk Distance |
| ADL | Activities of Daily Living |
| BAN | Body Area Network |
| BPOC | Bronhopneumopatiei Obstructive Cronice (COPD) |
| C | Could-have |
| COPD | Chronic Obstructive Pulmonary Disease |
| CRP | C-reactive protein |
| D | Deliverable |
| DALY | Daily Adjusted Life Year |
| ELS | Elias University Hospital |
| $FEV_1$ | Forced Expiratory Volume in 1 second |
| FVC | Forced Vital Capacity |
| GOLD | Global initiative for chronic Obstructive Lung Disease |
| GP | General Practitioner |
| GPS | Global Positioning System |
| HR | Heart Rate |
| ICT | Information and Communication Technology |
| INE | Inertia Technology |
| LHL | Norwegian Heart and Lung Organisation |
| LTOT | Long-Term Oxygen Therapy |
| M | Must-have |
| MEP | Maximum Expiratory Pressure |
| MIP | Maximum Inspiratory Pressure |
| MoSCoW | Must-have, Should-have, Could-have, Won't have |
| NOR | NORUT Northern Research Institute |
| NST | Norwegian Centre for Telemedicine / University Hospital of North Norway |
| PACT | People, Activities, Context of use, Technology |
| PEF | Peak Expiratory Flow |
| PRM | Physical and Rehabilitation Medicine |
| PRS | PROSYS |
| QoL | Quality of Life |
| RR | Respiratory Rate |
| RRD | Roessingh Research and Development |
| S | Should-have |
| $VO_2$ max | aerobic capacity / maximal oxygen uptake |
| W | Won't-have |
| WHO | World Health Organisation |
| WP | Work Package |

## Contents

# 1 Introduction

The goal of the IS-ACTIVE project is to devise a person-centric health care solution for patients with chronic conditions, based on miniaturised wireless inertial sensors, which provide distributed motion caption and intelligent recognition of activities and situations. The role of the home as a care environment is emphasised, by providing real-time support to patients in order to monitor, self-manage and improve their physical condition. This will be validated in patients with Chronic Obstructive Pulmonary Disease (COPD). In this deliverable (D2.1) the requirements analysis of the IS-ACTIVE project is presented.

In order to develop the user requirements a number of steps were taken. First of all, the most recent information concerning COPD and the activity of COPD patients, the role of ICT in COPD care, and how to encourage people to be more active, was gained and this state of the art is presented in chapter 2. Next, a user-centred approach is used for developing requirements, using scenarios. The corresponding method is described in chapter 3, followed by the developed scenarios in chapter 4.
The state of the art and scenarios were the starting points for a requirements analysis workshop, held September 30th 2009 in Vienna, Austria. The set-up, agenda and notes of this workshop are presented in chapter 5. The outcomes of the workshop served as initial concept in the development of functional requirements, which are stated in chapter 6. A final discussion is presented in chapter 7.

# 2 State of the art

This chapter provides an introduction into COPD and the importance of activity in COPD. Next, this chapter comprises two some examples about persuasive applications for the encouragement of physical activity and one systematic review about the role of ICT in COPD care.

## 2.1 Introduction into COPD

Roessingh Research and Development, October 2009

### *2.1.1 Chronic Obstructive Pulmonary Disease*

Global initiative for chronic Obstructive Lung Disease (GOLD) definition of COPD [1]: *"COPD is a preventable and treatable disease with some significant extrapulmonary effects that may contribute to the severity in individual patients. Its pulmonary component is characterised by airflow limitation that is not fully reversible. The airflow limitation is usually progressive and associated with an abnormal inflammatory response of the lung to noxious particles or gases".*

The cause of COPD is attributed to the total burden of toxic gases and particles that individuals inhale during their lifetime, mainly due to the smoking of tobacco products [2]; smoking is the primary cause of COPD, others risk factors include indoor and outdoor air pollution, dust and chemicals [3]. The inflammatory response seen in the lungs of patients with COPD is actually an exaggeration of inflammatory responses normally seen in people who smoke, but do not have COPD [4]. The mechanisms for this amplification are not yet understood but may be genetically determined [5]. Once COPD is established, airway inflammation persists, even after many years of smoking cessation [6]. The amplified inflammatory response is linked to an altered structure and function of central airways (bronchitis), small airways (bronchiolitis), lung parenchyma (emphysema) and pulmonary vasculature (pulmonary hypertension).
COPD has a progressive course especially in patients who continue to smoke [7] and it influences quality of life drastically, causing primarily shortness of breath (dyspnoea) and lacking physical exertion capabilities [8]. Other symptoms include fatigue, sputum, and coughing. COPD is associated with extrapulmonary effects, including systemic inflammation, skeletal muscle wasting, increased risk of cardiovascular disease, anaemia, osteoporosis, and depression. These systemic effects contribute to the limitation of exercise capacity of these patients and to worsen prognosis, independent of their pulmonary function [9]. GOLD developed the spirometric classification of COPD severity based on post-bronchodilator $FEV_1$ and $FEV_1/FVC$ ratio: the patient is classified GOLD I (mild COPD), GOLD II (moderate COPD), GOLD III (severe COPD) or GOLD IV (very severe COPD).

Exacerbations represent a further amplification of the inflammatory response in the airways of COPD patients, and are most commonly caused by infection of the tracheobronchial tree and air pollution [10]. It all has a serious negative impact on patients' quality of life and lung function, and it can take several weeks before symptoms and lung function to recover [9, 11]. Literature also showed that patients with frequent exacerbations recover their physical activity level to a lesser extent than patients without frequent exacerbations [12, 13] and in some patients exacerbations result in prolonged activity limitation [14].

### *2.1.2 Burden and costs of COPD*

Chronic Obstructive Pulmonary Disease was worldwide the fifth leading cause of death in 2002 and according to the World Health Organisation (WHO) 3 million people died of COPD in 2005, which is equal to 5% of all deaths globally that year [15]. Of the six leading causes of death in the United States, only COPD has been increasing steadily from 1970 to 2002 [16]. The prevalence and burden of COPD are projected to increase in the coming decades due to continued exposure to COPD risk factors and the changing age structure of the world's population. Worldwide, WHO predicts that COPD will become the third leading cause of death by 2030 [15].
In the European Union, the total direct cost of respiratory disease is estimated to be about 6% of the total health care budget, with COPD accounting for 56% of these costs [17]. An economic analysis of data from the "Confronting COPD International Survey" study, a large-scale survey conducted in North America and Europe, has shown that COPD has a high economic impact on society. The majority of disease costs in the survey were associated with inpatient hospitalisations. The results of the survey suggest that interventions that improve COPD outcomes by decreasing symptoms and preventing acute exacerbations could substantially decrease the costs associated with this disease [18, 19]. COPD is the fourth-largest cause of hospital admission as primary diagnosis, and a high proportion of patients are admitted through the emergency room as unplanned hospitalisations [20]. These costs are higher compared to many other chronic diseases [21], and in the United States COPD is the most expensive of the chronic diseases found in elderly patients [22].

### *2.1.3 Daily physical activity and physical condition*

The term daily physical activity is defined as the totality of voluntary movement, produced by skeletal muscles during everyday functioning and includes exercise (defined as the planned, structured, and repetitive bodily movement carried out to improve or maintain one or more aspects of physical fitness) [23]. The ability to perform exercise, even the activities of daily living, depends on the interaction between the muscles, the lungs and the heart. COPD patients, when they become symptomatic, become dyspnoeic and patients with severe COPD are dyspnoeic even when they perform daily activities and are impaired in their ability to exercise [1]. It takes less exercise to reach the point at which shortness of breath becomes uncomfortable.
This inactivity of COPD patients is part of a vicious circle (Figure 2.1b): dyspnoea leads to inactivity, which affects basic daily activities negatively, which leads to physical deconditioning [9, 24]. The situation is complicated further by the fear they experience by exercising to the point of severe shortness of breath.

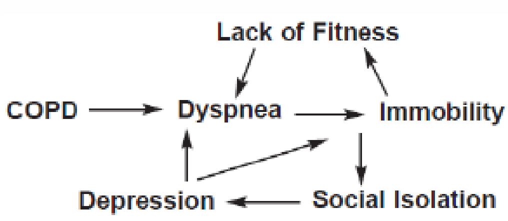


*Figure 2.1b: Vicious circle in COPD: improvement in one of the processes has effect on all aspects of the disease [9].*

To break this vicious circle COPD patients have to remain physically active, so physical deconditioning can be prevented. Furthermore, levels of physical activity in daily life are related to higher risk of hospital readmission [14, 20], activity reduces hospital admission in COPD patients [25], and lower activity levels are linked to shorter survival [26]. Prevention of decrease in activity level is important, and it is stated in the COPD guidelines that increasing physical participation in everyday activities is among the important goals of treatment in patients with COPD [1]. Regular exercise helps the COPD patient to let the muscles and the heart perform more efficiently: the physical condition will improve and with the same lung function they can do more. Physiotherapy can provide physical exertion training and breathing and strength exercises.

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## 2.2 Persuasive technologies – some examples

Norwegian Centre for Telemedicine, University Hospital of North Norway, NORUT Northern Research Institute – October 2009

This section presents some “persuasive” technologies that may act as a teaser for further reading, for reflection, and inspiration for the work with design requirements in IS-ACTIVE.

### *2.2.1 Introduction*

Motivating and encouraging ourselves, friends and family members to be more physically active, is a challenging task as we all know. Exploiting technology to support such encouragement and guidance will be even more challenging. Technology devices have no long-lasting personal relationship with its user: it may infer the situation wrongly, give bad advices and miss out on psychological vital accomplishments. However, technologies are now becoming pervasive and non intrusive, and with appropriate user interaction and sensing capabilities they may provide support for the user that no human could do.
A success factor for *persuasive* technologies is their ability to persuade the user to *change behaviour,* the *sustainability* of this change, their applicability in achieving increased physical activity in daily life, and provide guidance for correct physical exercising.

### *2.2.2 Houston*

Houston [1] is a mobile activity journal that encourages people to be more active in their daily life. The prototype system is based on a PDA, a step counter, and functions for sharing the step counts with friends. The main goal of Huston was to identify design requirements for future work in persuasive exercise technologies, and less on the actual prototype and its user interface. Houston focuses on how to encourage people to incorporate opportunistic physical activities in their daily life, which means increasing their level of physical activity by for instance walking instead of driving, taking the stairs instead of the elevator, etc. They base their work on studies that showed that health benefits can be achieved by a daily step increase, and that social support can motivate people to stay active.

They evaluated the prototype with 3 groups of women for 3 weeks. A baseline version of the software was used the first week to establish individual daily step count goals. The remaining two weeks, one group used the non-sharing version and two groups used the sharing version.

An interactive user interface on a mobile phone accepted both automatic and manual input. Users could for instance change step counts when the pedometer over- or underrepresented their physical activity and they could add comments describing for instance why the step count had been low a particular day.

Depending of the version, the interface included possibilities to:

- Edit step counts, and add comments
- View progress (including progress towards daily goal, step counts for the last 7 days, and progress of buddies)

- Interaction with buddies (such as sending step counts and comments, and requesting comments)
- A congratulation message and a star when goals are met

Results showed that sharing groups were significantly more likely to meet their goals. Feedback about Houston was also very positive and several participants had plans continuing with it and increasing their physical activity after the pilot study.

The main findings, which also are highly relevant for IS-ACTIVE, are:

- Give the users proper credit for (all) activities. I.e. the system should infer activities correctly, and should have functions for user editing in case it does not.
- Provide personal awareness (feedback) of activity level :both past behaviour and current status, and activity level performance.
- Support social influence: pressure, support, and communication.
- Take into account the practical constraints of users' lifestyles: appropriate device size, individual goal setting, etc.

### *2.2.3 UbiFit garden*

UbiFit [2-6] is a later work of the same group that was behind Houston. In UbiFit they continued their research on encouraging people to incorporate regular and varied physical activity into everyday life, but focussed on exploiting an "awareness display" as a mean of providing positive feedback on the user's achievements.

The prototype had three components, 1) a fitness device, 2) an interactive mobile phone application, with an editable journal and detailed information about the user's physical activities, and 3) a glanceable mobile phone display. The fitness device includes: 3-d accelerometer, barometer, humidity, visible and infrared light, temperature, microphone, and compass. UbiFit garden includes no community tools.

Relevant results for IS-ACTIVE are that users appreciated the glanceable display and found it an essential part of the system and the awareness of their physical activity. The field trial showed that users with the glanceable display performed better that those without.

To motivate behaviour change, physical activities and goal attainment are shown as a blooming garden on the screen background of the user's mobile phone. The user is not punished for inactivity; the garden is always green with a blue sky. Butterflies of varying sizes are used to illustrate goal attainment for the current week (large butterfly) and past three weeks (small butterflies). Different types of flowers represent cardio training, resistance training, flexibility training, and walking. Activities such as walking, running, and the use of an elliptical trainer and stair machine are automatically inferred by the fitness device, while activities like dancing, swimming etc. are not (these have to be put manually journaled). The users can view a list of daily physical activities performed, edit information, add comments, and view progress towards goals.

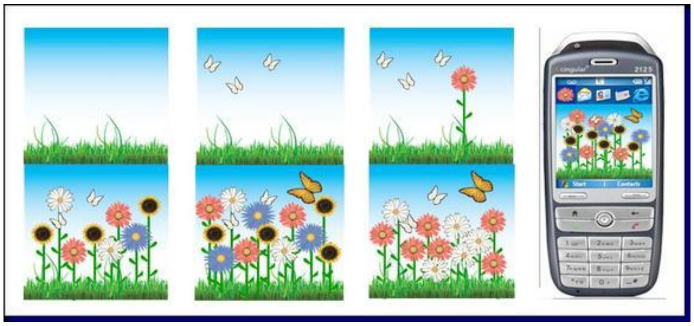

Figure 2.2a; the UbiFit garden, retrieved from dub.washington.edu/projects/ubifit

The UbiFit Garden system was validated first in a 3-week field trial, and later in a 3-month field trial.

Some of the overall lessons learned by the UbiFit team on persuasion that are highly relevant for IS-ACTIVE are:

- A persuasive technology must sustain the individual's interest and adapt to changes in goals and abilities.
- It is important to account for a wider range of activities than those who are predefined or can be automatically inferred, by letting the user edit the data.
- Do not punish short-term deviation or breaks in activities, but focus on getting them back on track as soon as possible.
- Understanding, appreciating, and adapting to the users wide range of social situations are critical for success.
- The size of the device is important, especially for females due to their clothing.
- Exploiting social support is a two-edged sword, leading to motivation or backslides into old habits.

### *2.2.4 Fish'n steps*

Fish'n steps [7] are an approach to promote physical activity using a social game that links users daily step counts to the well-being of their fish in a virtual fish-tank. The prototype technology used was a step counter, a public step-count loading kiosk, and a virtual fish tank visualised both on the private PC and on the public kiosk screen.

The experiment had both private and common team fish tanks, and the individual step counts affect the emotional state of the anonymous user fish - and subsequent the overall state of the team's fish tank. Users were to be motivated by comparison of the state of each team member's fish, and competition between different teams fish tanks.

Figure 2.2b; Fish'n steps, retrieved from (c) siemens.com

The small trial gave varying results and the outcome depended on the participant's current level of activity and their desire to change it. However, the study showed several effects of the design of intervention and these lessons should guide future designs of such systems.

- Emotional negative feedback through a not-growing fish is not encouraging.
- Cooperation and competition gained mixed results, some found that there was enough competition in life and incompatible with the spirit of the game, while others found it stimulating and challenging.
- Anonymity did not produce significant results, but led team members to spend time trying identifying the team participants as they found it awkward communicating with anonymous peers.
- Users found the device and the public uploading procedure intrusive.

However, a main lesson learned is the value of positive encouragement to foster long-term behavioural change, rather than negative feedback when users fail to meet their expectations.

### *2.2.5 Jinsei Game Puchi*

Adding motion sensors to toys has also led to mass-marked products where the user's activity level directly influences the game play.

The Jinsei Game Puchi is an example of a pedometer-based children toy game where you have to exercise in order to play the game. For every 300 steps the user makes he or she is able to move through the game. As long as you keep walking you can raise a family, have a job and grow up. Two players can play together on one device or have one each and play together having them communicating with each other.


Figure 2.2c; Jinsei Game Puchi, retrieved from http://www.takaratomy.co.jp/products/jinsei/product/jinsei-petit/index.html

Another example of persuasive toy games, however not addressing activity, is the digital pet-game Tamagotchi where the state of a digital pet is based on the attention and follow up it receives from its owner. A sad pet is to trigger an emotional reaction of its owner in order to gain sufficient attention, be fed, and getting exercise. Tamagotchi has been an enormous success and has sold more than 70 million worldwide since it was released in 1996.

### *2.2.6 Other related works*

Expresso.com makes commercial stationary bikes with interactive features. They are networked and let users take part in multiplayer on-line bike races with other participants. The gears and steer handlebars are like ordinary bikes and the pedal resistance changes with the terrain in the game. Prices are around $5000.

Figure 2.2d; Stationary bike, retrieved from http://www.expresso.com

Breakaway [8]: a small sculpture placed on the desk, encourages to take breaks more frequently. Ambient display, sensors on office chair.

“Sports over a Distance” [9]: people physically apart play soccer together by means of a life-size video conference screen, and a regular soccer ball as input device.

MOPET [10]: a wearable system for fitness training.

Fitness game with a bodily interface [11]: exercising while exploring surroundings or playing a fitness game in a virtual environment.

PlayMate [12]: physical activity captured by an accelerometer-based pedometer reinforces the game character in a virtual game environment.

Kukini [13]: a design for an everyday immersive fitness game for runners. It is modelled on role-playing games and has quests, cooperative and competitive social play, and collection of items upon completing tasks.

Neat-o-Games [14-16]: racing and Sudoko game on mobile terminals to encourage activity, data from a self-built triaxial wearable accelerometer controls the avatar. The avatar represent the user in a virtual race with others over a cellular network. Sudoko hints by activity points.

Virtual Specialist (VS) [17]: advises patient on diet and exercise programmes.

Online lifestyle diary with a persuasive computer assistant [18]: addresses overweight problem. Assistant in form of an animated iCat with different facial expressions which provides cooperative feedback.

Handheld Animated Advisor for Physical Activity Promotion [19] [20] [21]: PDA, animated exercise advisor, dialogue system, integrated accelerometer.

Mobile Lifestyle Coaching [22]: comparison of a Smartphone interface versus a traditional web application for personal computer. Included are a self-monitoring diary (food and physical activity), goal-setting, social facilitation and compliance factors.

The Wellness Diary[1] [23]: health journal on personal mobile device, daily journaling of various wellness parameters.

[1] http://betalabs.nokia.com/betas/view/wellness-diary

Chick-Clique [24] [25]: motivation to exercise, teenage girls, mobile phone application, social connection with peers, collecting, sharing and comparing personal fitness information.

"Jogging over a Distance" [26] [27]: allow distant joggers to socialise and motivate each other through mobile phones, spatial audio.

TripleBeat [28]: to help runners achieve their exercise goals. Mobile phone, musical feedback, glanceable interface, virtual competition.
MP-Train [29]: a mobile, music and physiology-based personal trainer. Mobile phone, walking/jogging/running, physiological sensors, and music to encourage speed up, slow down, and keep pace.

Automated activity programme by means of Internet and mobile phone [30]: action and motivation support system, schedule and reminders, message-board for sharing experiences, wrist-worn accelerometer, real-time activity feedback through Internet.

Other relevant framework and surveys:

- "Healthy living with persuasive technologies: framework, issues, and challenges" [31]
- "A theory-based framework for evaluating exergames as persuasive technology" [32]
- "Internet-based physical activity interventions: a systematic review of the literature" [33]
- Computer-tailored physical activity behaviour change interventions targeting adults: a systematic review [34]
- Healthcare via cell phones: a systematic review [35]

### 2.2.7 Examples of publicly available systems

Some examples that may be used for inspiration in the design process of IS-ACTIVE are:

- U-Mon[2] - Mobile Fitness and Health Advisor,
- GoWear[3] - Fitness system to help manage lifestyle
- SportsDo[4] - GPS tracking of sporting activities
- BiM Active[5] – GPS fitness tracking
- SportsTrackLiveMobile[6] - GPS live sports tracking
- WalkMe[7] - GPS walking assistant keeping track of your performance

Input/measurements include heart rate, pulse rate, calories, steps, time in physical activity, sleep duration, speed, distance travelled, gradient, pace, altitude, ascent, descent, performance, galvanic skin response, skin temperature and heat flux.

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[2] http://u-mon.com
[3] http://www.gowearfit.com/Learn-More/GoWear-fit-armband-Specifications
[4] http://www.sportsdo.net
[5] http://bonesinmotion.com
[6] http://www.sportstracklive.com
[7] http://www.getjar.com/products/27281/WalkMe and http://www.healthvault.com/websites/ HVSandboxWalkMe-WalkMe.html?breadcrumb=6

Software is for diaries, activity managers, training programmes, target heart rate zone calculator, and walking test. Share, compare and compete. Uploads to PC and web community portals, blogs, RSS, Google Maps etc.

### *2.2.8 References*


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## 2.3 The role of ICT in non standard COPD measurements and therapy

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### *2.3.1 Introduction*

Chronic obstructive pulmonary disease (COPD), is a serious public health problem in many countries throughout the world [1]. COPD is a respiratory disease characterised by airflow limitation in the lungs which is usually partially reversible and generally progressive, mostly caused by long-term smoking. The chronic airflow limitation is caused by a mixture of bronchiolitis and emphysema [2]. COPD causes high levels of disability, primarily among the elderly, but it also affects many patients before they reach retirement age. COPD morbidity and mortality are increasing, especially in countries with an aging population, with cigarette smoking being an important risk factor [3]. According to the latest WHO estimates (2007), COPD counts for globally for 5% of all deaths and estimates show that COPD becomes in 2030 the third leading cause of death worldwide [4]. On the worldwide ranking list of disability adjusted life years (DALYs), COPD is predicted to rank seventh in 2030 [5]. From the patient’s perspective, COPD is a disease with a profound effect on physical, psychological and social function, with exacerbations leading to substantial reductions in quality of life [6, 7].

The economic burden of COPD is considerable and will continue to grow as the number of elderly people continues to increase [8]. In 1999, it was reported that the increase in COPD-related healthcare costs in the Netherlands between 1993 and 2010 might be as high as 60%, at constant prices [9]. Not only combining prevalence projections with age-specific information on the use of healthcare in physical units and the unit costs of care, but also including the effects of trends on the amount of care per patient and on the unit costs of the components of care, the maximum rise in total costs projected would be around 140% over the period 1994 to 2015 [10]. In the United States, COPD is the most expensive of the chronic diseases found in elderly patients [11]. Furthermore, COPD is the fourth-largest cause of hospital admission as primary diagnosis, and a high proportion of patients are admitted through the emergency room as unplanned hospitalisations [12]. The hospital admissions due to exacerbations constitute a major problem in the management of the disease due to their negative impact on prognosis and costs [13, 14].

As the burden of COPD on healthcare resources and costs increases, the need to find inventive ways to care for these patients has become of greater importance [15]. The unbalance in supply and demand in healthcare makes the challenge even more complex [16]. Many developed countries, including the Netherlands, deal with an acute nursing shortage, and there is no realistic prospect that this situation will change in the near future [17-19]. A substantial physician shortage is also suggested, which is expected to develop in the coming years in various countries [20]. A fundamental change is required in the process of care and we need to identify patient management approaches that would ensure appropriate monitoring and treatment of patients while reducing the cost involved in the process [15]. Provision of care directly to the patient’s home represents an alternative to conventional hospital outpatient treatment [21]. Information and communication technology (ICT) can play a crucial role, and telemedicine and home telecare technologies have been growing dramatically [15, 22]. Yet, the use of ICT applications explicitly targeted on chronic care for COPD patients has not been evaluated. In order to comprehensively assess and determine the benefits of these interventions for COPD patients, it is essential to perform a systematic review that can critically synthesise the results of various studies in this area.

Therefore, the work to date on ICT in COPD care at home is investigated. This article presents a systematic literature review conducted with the aims of a) evaluating the patients' and healthcare professionals' view on home-based ICT-enabled interventions; b) evaluating the impact on COPD patients' physical, functional and cognitive status and other health outcomes; c) identifying available evidence regarding impact of these interventions on healthcare costs; and d) exploring opportunities and challenges for implementation of the interventions.

Key ICT application domains in healthcare include telemedicine and home telecare. The first is defined as the direct provision of clinical care for patients at a distance, including diagnosis, treatment or consultation, via telecommunications [23, 24]. Its primary function is to provide specialist consultation to distant communities, rather than to provide a tool for self-management of chronic disease. Home telecare on the other hand refers to the use of ICT-enabled health services and virtual visits of healthcare professionals for effective delivery of care and management of patients with chronic diseases at home [25]. It aims to increase patients' independence and quality of life, and to produce cost savings for authorities [26]. For this study, ICT applications encompass:

a) Home telemonitoring: used for remote data capture and analysis [27-31]. It refers to a telecommunication device that enables automated transmission of a patient's health status and vital signs data from distance to the respective healthcare setting. It does not involve the electronic transmission of data by a healthcare professional at the patient's location. Only patients or their family members are responsible for transmitting their data without the help of a healthcare provider [15, 22, 32]. b) teleconsultation and videoconference (telemedicine); c) teleassistance and education and d) telehealth (home telecare). By way of teleassistance home-monitored patients are able to contact their case manager or other healthcare professionals (using different access media) to report problems and get solutions and advice [33]. Telehealth refers to the provision of patient education and other health-related services at a distance using telecommunication technologies [34, 35]. Furthermore, telephone-based care service can combine telemonitoring with health messages that engender patient understanding for adherence to care plans [36].

### *2.3.2 Methods*

Published literature between July 2004 and July 2009 was searched using the Medline (Pubmed.org). A query was designed using MeSH terms ('pulmonary disease, chronic obstructive' AND ('home care services' OR 'telemedicine' OR 'telemetry' OR 'tele-communication'). Additional queries consisted of the terms: 'pulmonary disease, chronic obstructive' AND 'applications, medical informatics' or 'pulmonary disease, chronic obstructive' AND 'applications, medical informatics' AND 'home care services'.

All abstracts were read and an article was included when it presented the implementation of ICT systems facilitating chronic care for COPD patients. Basic support only via the ordinary telephone was regarded a form of ICT as well. The methodology had to be developed explicitly for patients suffering from chronic disease. If the evaluation of the application comprised patients, the study population had to include a patient group suffering from COPD or other chronic respiratory failure. When several publications were derived from the same research project, but each focusing on other aspects, these were all included. Not only articles from peer-reviewed journals and reviewed international conference proceedings, but also reports and non-reviewed journal articles were included, for the purpose of gaining a broad perspective. Book chapters, newspapers and websites were not included. An article was excluded, if the systems were developed for chronically diseased patients but not targeted at COPD patients. The literature search was not language restricted. Furthermore, Google Scholar was used to extend the number of articles. Entered search terms were: ‘COPD + ICT’ and ‘COPD + information communication technology’. Additionally, the reference list of the included articles was searched.

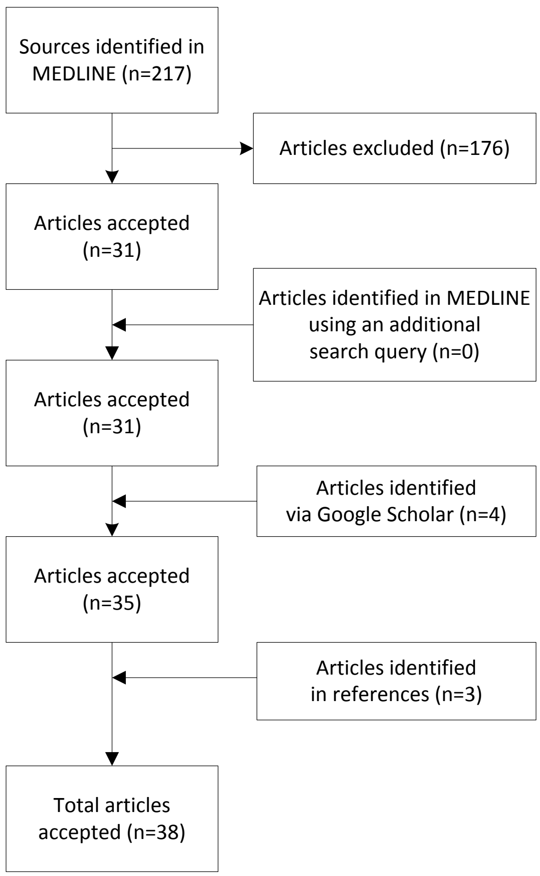


Figure 2.3a; ICT for COPD patients studies identified in Pubmed from 2004-2009

Table 2.3a; Journals with at least two relevant publications

| **Journal** | **Publications (n)** | **Impact Factor 2008** | **5-Year Impact Factor (2003-2008)** | **Period** |
|---|---|---|---|---|
| European Respiratory Journal | 3 | 5.545 | 5.746 | 2006, 2008, 2009 |
| International Journal of Medical Informatics | 2 | 2.754 | 2.425 | 2008, 2009 |
| IEEE Engineering in Medicine and Biology Magazine | 2 | 1.466 | 1.994 | 2006, 2007 |
| Journal of Telemedicine and Telecare | 5 | 0.890 | 1.009 | 2005-2008 |
| Telemedicine Journal and e-Health | 10 | 1.389 | 1.595 | 2004-2008 |
| Thorax | 3 | 7.069 | 6.978 | 2008-2009 |

### 2.3.3 Results

The first PubMed query provided 217 articles, of which 31 articles fit the inclusion/exclusion criteria after assessment of abstract and article. The additional query resulted in 212 articles but none fit the criteria. Google Scholar retrieved four articles, and three relevant articles were added by references (Figure 2.3a). The total 38 articles were published in 20 different journals or conference proceedings. Ten articles were published in Telemedicine Journal and e-Health, five in the Journal of Telemedicine and Telecare, three were published in the European Respiratory Journal and three in Thorax, and two other sources had each two papers published (Table 2.3a).
The articles were categorised by:

1. system description: any novel system that was developed for the facilitation of chronic care of COPD patients;
2. research studies: application of existing ICT applications for care of chronically ill patients;
3. comparative studies: comparison with traditional approaches, including clinical trials;
4. qualitative studies: focus on user's usability and acceptance, and potential role of systems;
5. reviews.

Furthermore, the various ICT systems could be categorised into (1) telemonitoring (2) teleconsultation and videoconferencing; (3) telecommunication for the provision of patient assistance and education; (4) telecommunication for patient support in exercise programmes; and (5) only telephone-based care service. The appendix presents an overview of the reviewed articles.
Furthermore, each paper presented findings that could be classified into four thematic categories: (1) patient and healthcare professional perspective; (2) effects on patient outcome and health status; (3) cost aspects; and (4) organisational impact. The results, conclusions and limitations of the included studies are summarised in the narration of this article.

### 2.3.4 Publication content

Part of the included studies were targeted explicitly on COPD patients (15 studies) or chronic respiratory failure patients (3 studies). However, most papers dealt with more than one disease. These were mainly heart failure, diabetes mellitus or chronic wound patients (see table appendix). Furthermore, most studies described a combination of several ICT applications (17 studies). Some study projects focused on one aspect of home-based healthcare services, either teleconsultation and videoconference (2 studies); telemonitoring (7 studies); teleassistance and education (1 study); support for home-based exercise programmes (2 studies), or telephone-based services (3 studies).

<u>Telemonitoring</u>
The majority of publications reported the use of ICT applications for monitoring a patient's status (24 studies). In most studies, data capture referred to physiologic parameters (e.g. blood pressure, arterial oxygen saturation, pulse and respiratory rate, forced spirometry, electrocardiogram, temperature) collected by sensors [33, 45, 49-51, 53, 54, 59, 63, 67-69, 71]. In other studies, both biological signals and information on health status (e.g. symptom data gathered through specifically designed questionnaires) were remotely measured [40-44, 47, 57, 65]. Additionally, telemonitoring included the recording of exercise data [52, 55, 56, 70]. One study used GPRS for uploading of

exercise data from a cell phone to a website [52]. Furthermore, in one study the patient's position was monitored using a GPS module [56].

Data were sent to a central repository via the Internet [40-44, 49-52, 56, 57, 59, 63, 69, 71], a conventional telephone line [45, 47, 53, 54, 65, 67, 68, 70], or data cables to a local laptop or mobile networks [33, 55]. Once the information was transferred, in most research projects, it was reviewed daily by the case manager (nurse or nurse practitioner) or a call centre operator. Some systems included automatic alerts in the case of abnormal monitoring results. Depending on circumstances, a telephone call was made or a nurse was sent to the patients' homes. In most systems, monitoring reports were available to all care providers involved, to support treatment decision-making.

Teleconsultation and videoconference

The second large category dealt with teleconsultation and videoconference (11 studies). Virtual visits were frequently described: via two-way audio and video interactions patients could communicate with their nurses, as an alternative or add-on for face-to-face home visits, or as a way to contact the case manager to report problems and to get solutions and advice [42-44, 53, 54, 71]. Only a few studies reported specialist consultations to distant communities one in the USA [49] and one in Japan [60]. Furthermore, one group designed a videoconferencing system for communication between healthcare personnel with medical specialists in a remote hospital, with an application for multimedia multi-collaborative conferences [33]. One study described a teleconsultation system connected with the patient's home and the hospital for nurse use only [69]. Finally, one study evaluated the feasibility of consultation with a respiratory specialist via telephone or e-mail, to reduce the pressure upon time available for face-to-face consultations [58].

Teleassistance and education

Another category consisted of studies relating to teleassistance and education (10 studies). Some of those dealt with the provision of educational material to patients and professionals via the Internet for better management of the disease [42]. Other studies incorporated educational tools in their monitoring devices to enhance disease knowledge and self-management, enabling patients and their caregivers to make better informed decisions about healthcare. An example is the Heath Buddy, part of Health Hero System [41, 65], and there are other systems [57, 64]. An ICT platform with a call centre coupled to a web-based application facilitating the management of patient records was also used [38, 40]. Other forms of teleassistance were the provision of feedback to patients, including medication reminders and measurement schedules [59]; and provision of support via telephone and e-mail [42, 67, 68].

Support for home-based exercise programmes

A few studies aimed at supporting patients in home-based exercise programmes (4 studies). By way of preinstalled music tempos on their cell phone, patients were supported in performing the prescribed walking exercises [46, 52]. Another study focused on the effect of motivational support via regular phone calls [70]; and one study aimed at increasing response rates of patients in providing exercise data [56].

Telephone-based care service

A few home-based ICT healthcare services only consisted of telephone calls initiated by nurses (3 studies), with different purposes (promotion of exercise compliance [70]; follow-up after hospital discharge [72]; or as add-on for regular care [64]).

<u>Review articles</u>
Six reviews evaluating the implementation of ICT applications in COPD care were found, including one systematic review [26]. However, no review specifically targeting telemedicine or home telecare for COPD patients was found.

### *2.3.5 Patient and healthcare professional perspective*

<u>Usability</u>
There are some differences in the reported patient usability of the various home-based ICT applications. While some studies reported equipment issues, most of the evaluations of the implemented ICT did not mention these. In the study of Mair *et al.* [53] it is reported that nurses experienced problems concerning the installation, the picture and sound quality of the communication device, and the reliability of physiological monitoring. Since the participating nursing team lacked confidence that it was a safe way to provide healthcare in this context and it was not perceived as improving efficiency, the implemented telecare service seemed unlikely to become normalised as part of routine healthcare delivery. The study of Horton [45] showed similar findings. Here, the care team was afraid that the patients might have trouble sending the briefings, and in case of severe illness, the patients would not be able to handle the equipment. In the study of Vitacca *et al.* [68], 24% of the pulse arterial saturation (pSat) trend transmissions failed for, among other reasons, initial inexperience of the nurses, poor comprehension of the device instructions by the caregivers, or the instrument complexity. The time required to train the users in the operation of the pSat instrument was high (mean time 30 min). Medvedev *et al.* [55] reported patients preferring data transmission by their physiotherapist during a home visit to automated daily data transmission via mobile networks. According to Medvedev *et al.* this was due to the patients' limited computer skills.
However, Finkelstein *et al.* [44] explicitly pointed out it is not correct to assume that older individuals, who are not previously exposed to current technology, cannot be trained to use such technology. They stated that the major problem with this target population is not their inability to use technology, but their initial reluctance to try it on their own. Indeed, their results showed that patients can use telehomecare with moderate levels of training. The technical quality of the virtual visits via videoconferencing was rated at 94.7%. Those were considered to be as useful as actual visits in 90.7% of the cases. Liddy *et al.* [51] reported that most patients and all care givers found the technology easy to use and useful. Furthermore, Botsis and Hartvigsen [26] suggested it is reasonable to believe that elderly patients will be familiar with technology in the near future.
Besides, some studies described improved systems, to increase the usability and effectiveness. For example, Shin *et al.* [63] developed a system which enables ubiquitous service in reporting the patients' data to their doctors at any time and any place using the code division multiple access (CDMA) based cellular phone network, as a substitute for a wireless network like Bluetooth or Zigbee, which has a limited connection area. Koizumi *et al.* [49] created and tested a multi-station telemedicine support system, with a real-time connection between three remote locations: the homes of two patients with chronic respiratory failure, the hospital of the attending physician, and the hospital of the pulmonary specialist. In this way, medical history and monitored biological variables could be exchanged.

Acceptance

In general, the studies reported telemedicine and home telecare being well accepted, although patients might not want to lose face-to-face contact [26]. Finkelstein *et al.* [44] conducted a perception questionnaire before and after the ICT intervention. These tests indicated that subjects developed a more positive perception of home telecare after experiencing it for several weeks. Initially, home telecare was not acceptable for every patient. Several eligible candidates refused to participate because of concern about the equipment. Those who actually experienced the system had more positive views than the control group. Partridge [58] conducted a questionnaire among patients attending a busy respiratory outpatient service. Thirty patients (18.3%) reported that they would not find other forms than face-to-face consultation acceptable. The findings of the study of Rahimpour *et al.* [59] suggested that self-efficacy and anxiety are likely to be important constructs in patients' acceptance of home telecare. Via tailored components in the training programmes for patients to use home telecare, the anxiety could be reduced and the self-efficacy could be improved. However, Rahimpour reported that participants acknowledged various benefits which promoted acceptance: cost and time savings; the promotion of active participation in their health management and empowering them to perform better self-care; improvement of their health management by their doctors by providing more accurate and up-to-date information, to help them make better decisions; and the system could have a preventative role in terms of providing early warning when their health conditions were deteriorating.

Perceived advantages and disadvantages

Most studies report a high patients' and caregivers' satisfaction with telemonitoring [44, 45, 50, 51, 60, 69, 71]. Liddy *et al.* [51] reported that patients were overwhelmingly positive towards home telemonitoring. Patients and caregivers felt a sense of security. The nurse practitioners thought the units were useful and might have reduced the need for office visits and home visits. Physicians found that data from the home telecare units helped them assess patients' stability and helped them with monitoring patients. However, the reliability of the peripheral equipment was sometimes a concern for nurse practitioners, physicians, and patients. In line with that, Lamothe *et al.* [50] stated professionals felt greatly helped in their clinical decision-making and timely interventions by the data available with the use of telehomecare. More rapid adjustments of treatments were made possible and new clinical conditions were identified, which resulted in higher quality of services.

The study of Whitten and Mickus [71] also reported overall patient satisfaction with the telehealth services they received. Patients believed that telehealth was a good way to receive care and felt comfortable with the equipment they were using. There was no strong belief that in-person visits were superior to telehealth visits. Ninety-six percent of the respondents reported having no concerns about taking part in the project. Concerning the advantages of receiving home telehealth services, 52% of respondents listed increased contact with providers as the primary benefit. Other common responses included general approval of the system's overall performance (24%) and improved efficiency for the nurses involved in providing the services (13%). Another common response was an improved feeling of security from having the system available (7%). The majority of participants responded that there were no disadvantages (60%). Several individuals cited a loss of personal contact with their nurses (10%) and hesitancy about using the technology or finding an appropriate place for the equipment in their home (17%).

The study of Medvedev *et al.* [55] identified a lack of confidence by patients in the safety of exercising. Many patients became concerned that they were short of breath, although

they were actually in a completely safe state. When exercising under supervision of the physiotherapist, monitoring equipment could be connected to show that their heart rate was stable. The use of home monitoring during exercise was therefore identified as a desirable application.
Moreover, Finkelstein *et al.* [44] described an increase in satisfaction with an increasing level of telehomecare intervention. Subjects receiving physiological monitoring and video conferencing/ internet access in addition to standard care were most satisfied with their care. The greatest increase in satisfaction involved attention to concerns, feeling safe, ability to meet needs, and flexibility in scheduling.
It is remarkable that some studies demonstrated significant differences in perception between patients and their health-care providers with regard to telecare encounters [53, 54]. Participating patients consistently demonstrated more positive views of the telecare encounters than their healthcare providers. With regard to the accuracy of assessment of a patient's medical problems, patients believe that nurses can understand their problems quite well when using the telecare system, while in contrast the nurses are far less confident about this aspect of the telecare encounters [54]. According to nurses, clinical interactions using the system were less likely to achieve an accurate and full clinical assessment. The patients did not share this view [53]. However, the study of Raza *et al.* [60] concluded that patients understood quite well how telemedicine was different from in-person consultation and what role it could play in providing healthcare services. Hence, the different perceptions cannot be explained by a lack of understanding of the advantages and limitations of telecare among patients. The review of Botsis and Hartvigsen [26] also concluded that staff members are not always comfortable about using computer-based applications and some can easily be discouraged when new technological issues arise. This considered, people should be trained to use a system taking into account their level of expertise (if any) and the type of disease. The importance of training was also mentioned by de Toledo *et al.* [42].
The introduction of ICT has a great effect on the allocation of tasks, and it shifts responsibility for certain activities within the consultations. For example, not the nurse but the patient is responsible for providing data regarding physiological measures [53]. Mair *et al.* [53] found, for some nurses, this to have a negative impact on their professional identity and was even perceived as a potential threat to their work. There was anxiety that increasing utilisation of telecare systems might mean that fewer nurses would be required in the future. Furthermore, there were concerns that adoption of such systems would adversely affect, qualitatively, the nature of the work that nurses would be expected to undertake in the future and could have a detrimental effect on the holistic nature of nursing care [53].
Finally, adequate selection of patients appears to be crucial. In addition to their health status, their interest and motivation to self-manage their disease, and capacity to use the technology is central to success [50]. However, Horton [45] described a high level of concern among healthcare professionals about being able to decide which patients would be able to cope with the use of the equipment.

<u>Legal and ethical concerns</u>
A few studies mentioned the concern among healthcare professionals about issues regarding legality and data confidentiality [26, 39, 51, 53, 59], and only two of the reviewed studies described ethical concerns of ICT applications for chronic care [26, 53]. The review of Botsis and Hartvigsen [26] reported to not having identified major ethical or legal concerns in telecare for elderly people suffering from chronic diseases. According to this review, most studies stated that as long as data confidentiality and security were ensured there was no major legal problem. However, Botsis and

Hartvigsen argued that the characteristics, limitations and permissions in healthcare administered at a distance should be stated clearly. Mair *et al.* [53] reported that a repeated concern of the nurses was that of risk and whether, in a court of law, a telecare service would be deemed safe or not. Mair *et al.* argued that wider medico-legal issues of telecare systems need to be addressed centrally in order to increase professionals' confidence in using such a system. In the study of Liddy *et al.* [51] physicians were concerned about the medico-legal liability associated with receiving time-sensitive data (e.g. response time to critical values). Security was pointed out as a prime concern by de Toledo *et al.* [42]. Hence, different security levels were built into the system, according to the user, content of information exchanged, type of access, and location. Interviews conducted by Rahimpour *et al.* [59] revealed only a few participants being concerned about confidentiality of data and the transfer of information via the Internet. However, most of them had no concerns, as long as there was password protection and standard data security measures in place. Finally, Cooper [39] pointed out that the electronic medical record has the ability to improve the reliability and completeness of individual healthcare information and should therefore facilitate continuity of care between healthcare providers and minimise human errors. At the same time, legislation is a necessity to respect privacy in handling protected health information. Nurses interviewed by Mair *et al.* [53] raised questions about the legitimacy of telecare as a form of service provision. They thought it could be beneficial with reasonably well patients, whereas acute patients should still be in hospital. Botsis and Hartvigsen also considered there should be an active and open relationship with the possible ethical problems implied by ICT systems. Patients might not want to lose completely face-to-face contact with health-care professionals.

### *2.3.6 Patient outcome and health status*

Most studies use the number of emergency department visits and hospitalisations, quality of life scores, exercise capacity, and self-management as measures for patient outcome and health status. One study aimed at increasing patient access to healthcare by reducing the need to travel long distances. Below, studies are ordered by clinical outcome (as far as possible, since many studies include more than one outcome measure).

<u>Exacerbation rate (emergency department visits and hospitalisations)</u>
Several studies concerning teleconsultation and videoconferencing reported a reduction in emergency department visits and hospitalisations. Finkelstein *et al.* [43] found a difference in discharge rate to a higher level of care (hospital, nursing home) within six months of study participation between the group only receiving traditional home healthcare (42%), the group receiving add-on virtual visits via videoconferencing (15%), and the group also being monitored regarding physiological and symptom data (15%). There was no difference in mortality between the groups. Morbidity showed no differences between groups except for increased scores for activities of daily living at study discharge in the video and monitoring groups. In the study of Vontetsianos *et al.* [69] a visiting nurse was equipped with a case containing a laptop computer and a number of medical devices and a videoconference camera, for real-time audiovisual connection with the hospital. After nine months, there was a decrease in hospitalisations, emergency department visits and use of health services. The patient's disease knowledge and self-management also improved. There was a significant improvement in patient's quality of life of more than 28%.

In addition, several telemonitoring applications resulted in a lower exacerbation rate. Trappenburg *et al.* [65] studied the addition of a home-based telemonitoring device, the Health Buddy, to care as usual. The Health Buddy provided daily symptom-surveillance by a case manager and education to enhance disease knowledge and self-management. The intervention group showed a significant decrease in hospital admission rates and in the total number of exacerbations. There was a tendency towards decreased hospital days and outpatient visits. No significant changes in health-related quality of life were observed at follow-up between both intervention and control group. Monitoring of physiological parameters resulted in fewer home visits by nurses and fewer hospitalisations, in the study of Paré [57]. However, the monitored patients made more telephone calls than patients receiving regular homecare, although this difference was not statistically significant. For patients suffering from COPD, as from diabetes mellitus, the study of Dang *et al.* [41] showed no significant decreases in total emergency department visits, hospital admissions, and number of bed days of care, as a result from automated daily monitoring, this in contrast with chronic heart failure patients. In the Care Coordination programme set up by Joseph *et al.* [47] the patient (COPD, diabetes mellitus, congestive heart failure, hypertension, or mental illness) received a series of questions through the phone line on his messaging device each day, asking for clinical data and his perceived health status. This resulted in a decrease in emergency department visits and hospitalisations, as well as improving clinical outcomes with better glycemic control for patients with diabetes and improved lipid management for all patients.

The study of Vitacca *et al.* [67] showed that a programme, monitoring arterial oxygen saturation and providing assistance and education by nurses available via telephone, is effective in preventing hospitalisations, emergency room admissions and urgent general practitioner calls. COPD patients turned out to have a greater advantage of the teleintervention than other chronic respiratory failure patients.

As a result of a standardised integrated care intervention, based on shared-care arrangements among different levels of the system with support of ICT, Casas *et al.* [38] showed a lower hospitalisation rate for exacerbations and a higher percentage of patients without readmissions, without differences in mortality between intervention and control group. ICT-enabled integrated care was also studied by de Toledo *et al.* [42], described in section 7 and 8.3.

Finally, only one study, conducted by Sridhar *et al.* [64], reported no reduction in hospital admission rates, although a significant reduction in unscheduled need for primary healthcare and a reduction in mortality was proven. Sridhar *et al.* suggested that admission to hospital might be influenced by social factors such as isolation, depression and available support in the home.

<u>Quality of life</u>

Whitten and Mickus [71] evaluated the addition of telemedicine visits with a registered nurse to traditional face-to-face visits. It turned out to be not a significant predictor of health and wellbeing, either positively or negatively. Although those receiving telehealth had worse ratings on the SF-36 general health subscale after the intervention, this measure was only significant when controlling for a number of key variables in the model. The pilot results of Liddy *et al.* [51] demonstrate that telehomecare monitoring of physiological parameters can improve access to and quality of care. The overall effect of the programme on patient health and lifestyle was very positive.

Exercise capacity

The project of Hung *et al.* [46] reported to be successful in helping to treat the physical and mental problems often associated with COPD patients, by use of a platform which generates a text message to the patient's mobile phone telling him/her at what level of intensity (i.e. music tempo) he/she should be exercising. A comparable, but more extensive study was conducted by Liu *et al.* [52]. Patients were asked to perform daily endurance walking at 80% of their maximal capacity by following the tempo of the music from a programme installed on a cell phone, in the control group patients were verbally asked to take daily walking exercise at home. Patients in the cell phone group significantly improved their incremental shuttle walk test (ISWT) distance and duration of endurance walking after 8 weeks. The improvements in ISWT distance, inspiratory capacity and SF-12 quality-of-life questionnaire scoring at 12 weeks persisted until the end of the study, with less acute exacerbations and hospitalisations.

Wewel *et al.* [70] conducted a short-term intervention by regular phone calls to motivate former in-patients of the hospital for training (walking), without previous rehabilitation. Patients wore an actograph plus pedometer and kept a diary for determination of activity at home. After two weeks, there was an increase in 6-min walking distance (6MWD) and quality of life scores, whereby improvements in 6MWD correlated with changes in activity. This study seems to underline the effectiveness of continued motivational support in patients with severe COPD.

Medvedev *et al.* [55] developed a mobile Smartphone, linked via Bluetooth to a range of monitoring devices, with an application for entering daily exercise results (including times and durations of exercise, physiological data), which were integrated in patient records. The study of Nguyen *et al.* [56] combined monitoring of symptom data with the monitoring of exercise data. During a dyspnoea self-management programme, patients were equipped with a mobile device which delivers automated prompts to the patients to submit the data (push technology). The prompts were scheduled according to times specified by subjects. The study showed that push technology could increase response rates and help users provide more consistent, real-time symptom and exercise data.

Self-management

Between an intervention group receiving monthly phone calls from a respiratory nurse combined with a home visit every three months, and a control group receiving usual care from their primary care physician, or secondary care and/or the respiratory nursing service as appropriate, Sridhar *et al.* [64] found no differences in hospital admission rates or in exacerbation rates. Self-management of exacerbations was significantly different and the intervention group was more likely to be treated with oral steroids alone or oral steroids and antibiotics, and the initiators of treatment for exacerbations were statistically more likely to be the patients themselves. The intervention group showed lower mortality rates, an less unscheduled contacts with the general practitioner.

A nurse-initiated telephone follow-up programme after discharge form an acute-care hospital, conducted by Wong *et al.* [72], resulted in significantly improved self-efficacy in managing dyspnoea, it reduced the number of visits to accident and emergency departments, and it increased physical exertion.

Patient access to healthcare

Raza *et al.* (Veterans Affairs, USA) [60] showed that teleconsultation improved patient access to subspecialty care. Only 8% of the patients required an in-person clinic visit following a telemedicine visit. It was concluded that physicians were able to rely on medical history and radiology to manage patients across a broad spectrum of complex pulmonary conditions with the assistance of a non-physician healthcare provider at the remote site.

### *2.3.7 Costs*

In many studies there were cost reductions in terms of time saving [26, 43, 58], elimination of travelling expenses [26, 43, 59, 60], fewer hospitalisations or accident/emergency department visits [42, 43, 50, 52, 67-69, 72], and use of healthcare services [41, 64, 69]. This suggests that telemedicine and home telecare have the potential for cost saving when used as a substitute for in-person visits. Comparing the costs of implementing and sustaining home telehealth programmes against long-term institutional care surely makes it a more attractive and realistic short- and long-term solution to the societal ageing [48]. However, only five studies making a quantitative cost comparison in home-based ICT applications used by COPD patients were found. Two of those comprised a detailed cost analysis [43, 57].

Raza *et al.* [60] used videoconference for providing outpatient pulmonary consultation to a remote, underserved clinic site (over a distance of 346 or 215 kilometres). They demonstrated that within the Veterans Affairs (USA) telemedicine is cost-effective ($313/patient) as compared to patient travel ($585/patient) and provision of on-site subspecialty care ($1166/patient) [73]. In Italy, Vitacca *et al.* [67] demonstrated in a trial with severe chronic respiratory failure patients needing home oxygen therapy and/or home mechanic ventilation, after deduction of the teleassistance costs, an average overall cost for each patient of less than 33% than that for usual care. For COPD patients the cost per patient was more than 50% cheaper than for the control group.

De Toledo *et al.* [42] reported that the cost of the clinical experiment, performed in Spain, was €38,932 (€36,469 equipment, €1,656 communications). The telemedicine project concerned consisted of a care team, for patients assessable at any time through the call centre. Healthcare professionals shared a unique electronic chronic patient record (ECPR) assessable through the web-based patient management module or the home visit units. It is thought that the reduction of hospitalisation days will pay for the system before the end of the first year (mean duration of hospitalisation is 2.8 days, the number of patients considered is 157).

Finkelstein *et al.* [43] conducted a cost analysis as well. Here, the study comprised two intervention groups, which received either standard home healthcare (HHC) plus two supplemental virtual visits (VVs) each week and Internet access (video group), or standard HHC, the two weekly VVs, and Internet access, plus home-based physiologic monitoring and an electronic diary to report monitored measurements and symptom information (monitoring group). This project took place in the USA. The average visit costs were $48.27 for face-to-face home visits, $22.11 for average virtual visits (video group), and $38.62 for average monitoring group visits for COPD subjects. This cost difference was primarily associated with the amount of additional nursing time to conduct an actual visit and related travel costs.

Paré *et al.* [57] performed an extensive cost-minimisation analysis on a telehomecare programme, that comprised a web-phone with an integrated touch screen and modem programmed with a personalised protocol for monitoring several parameters of patient health. Once the information was transferred via the Internet, it was reviewed daily by the nurse responsible for remote monitoring of the patient’s health and compliance with prescribed treatment. This project was set up in Canada. The cost-minimisation analysis yielded positive results: the telehomecare programme cost $6,750 less than the traditional home care programme, representing a saving of $355 per patient. This

amounts to a net gain of 15% over traditional patient monitoring, a programme that cost $46,054. Here, the principal source of savings in the telemonitoring programme was lower hospitalisation costs – hospitalisations represented 64% of the cost of the traditional homecare programme ($29,686/$46,054). To a lesser extent, savings also came from the lower cost of care provided in the home. These savings represented 5% of the total cost of running the traditional homecare programme ($2,250/$46,054). However, these savings were largely eaten up by the increase in time spent by nurses on phone calls with patients. Finally, it was the technology that used up most of the programme's savings. The technology cost came to $24,216 or 53% of the total cost of the traditional home care programme. This also represented four times the cost of nursing services in the experimental group ($24,216/$5,816) and over 53% of the total cost of the telehomecare programme.
Concerning reimbursement for telemedicine and home telecare services, Botsis and Hartvigsen [26] reported that very few countries have consistent policies. According to them, this area should be further explored, otherwise it will not be possible to implement home-based ICT applications successfully. Kobb *et al.* [48] mentioned, given the current model of U.S. healthcare and the current Social Security Act in which home telehealth technologies do not fall under reimbursable home health services, many private-sector agencies are not driven to pay for home telehealth services, and this would explain why some of the largest successful programmes are in the public sector such as the VHA (Veterans Health Administration) [41, 47, 48, 60], U.S. Department of Defense [48] and CMS (Centers for Medicare and Medicaid Services, U.S. Department for Health and Human Services). Blanchet [37] agreed reimbursement issues are barriers, but he believed these are not insurmountable. With all the cost benefits, the convenience and satisfaction remote patient monitoring confers, more users will be won over. Ultimately, consumer demand and favourable cost-benefit ratios will continue to drive technological refinement, financial incentives, and large-scale adaptation.

### *2.3.8 Organisational impact*

Changing home care delivery models
Very few articles describe the impact of implementation of home-based ICT on the organisation of healthcare. Only Lamothe *et al.* [50] presented an extensive analysis of the changes in work processes. They pointed out that telehomecare and regular homecare services are not easy to bring together, because of their two underlying logics [50]. However, union of both models is essential. Kobb [48] stated that successful homecare delivery models are those integrated within the existing healthcare organisation's clinical infrastructure, or those with business models that support and sustain the use of these services within the care delivery system.
According to Lamothe *et al.* [50] managers and providers are facing two major challenges. First, the organisation of work, traditionally based upon pre-established intervention plans, must adapt to respond to ad hoc patients' needs and alerts. Second, constant linkages between the traditional and new models of services delivery become mandatory. Hence, an emergence of networks of services where primary care providers and organisations developed tighter and more efficient working links with nurses and doctors from the hospital and doctors working in private clinics, was observed.
As a result of the introduction of ICT applications, two new models of homecare delivery were identified by Lamothe *et al.* [50]: a specialised model and a planned polyvalent model. In the specialised model, the nurses were responsible for either central monitoring or response to alerts and home visits. The functional separation of the two

types of activities offered the advantage of insuring the presence of the required clinical competency. Also, it helped developing new personalised trust relationships between nurses and doctors. These are important conditions for success of implementation. However, this separation appeared to raise some difficulties. First, transfer of all needed information to "regular" homecare nurses may be hard to achieve. Second, with expansion of services, specialised clinical competencies required may raise problems with scheduling of personnel –primary care nurses may not have such competencies. Third, timely intervention in response to alerts may also raise problems of scheduling of personnel (planned work versus ad hoc responses). In the planned polyvalent model, a committee was responsible for the development of clinical guidelines, patients selection criteria, and planning of human resources. In this model other problems may arise. First, continuous education of nurses in various complex clinical conditions may become problematic. This would need to be considered with the addition of new clinical conditions. Second, this model forces nurses to rely on mutual adjustments. Efficiency issues may be raised. Third, distribution of telehomecare patients between many nurses may raise some discomfort or insecurity if they do not use the technology frequently. According to Lamothe *et al.* any attempt to expand the use of telehomecare throughout the organisation would require to evaluate the appropriateness of the chosen model and imagine ways to overcome negative impacts, since no model would fit all contexts [50].

Concerning the nurse management, Horton [45] concluded, likewise, that partnership working between health and social services has to be negotiated. Leadership roles should include addressing tensions and motivation within the team. Acquirement of skills and knowledge about various specifications of a different range of ICT devices might be challenging for the nurse management. Hence, an major obstacle in service redesign is the healthcare professionals' lack of knowledge and confidence. These difficulties may be overcome by training.

<u>Integrated care services supported by ICT</u>

Casas *et al.* [38] explicitly demonstrated the effectiveness of an integrated care service with support of ICT to prevent hospitalisations for exacerbations in COPD patients. Here, the preventive intervention relied on shared-care arrangements between primary care teams and hospital teams, which aimed to avoid duplicates and to generate synergies among different levels of the healthcare system. They stated that extensive ICT support is essential in integrated interventions including preventive strategies which promote behaviour changes in life style, combined with innovative home-based services.

According to de Toledo *et al.* [33] the expansion of e-Health solutions is hindered by the high costs and low flexibility of home and mobile telemonitoring systems. This situation may be improved by the use of standards to design open, plug-and-play and interoperable devices.

Roca *et al.* [61] stated that there is an increasing need for evolving from standalone sensors to systems that combine different types of sensors plus data analysis to facilitate decision making. Furthermore, these systems should not be used alone but as modules of ICT platforms designed to support patient management and collaborative tools for professionals working at different levels of the healthcare system. Finally, interoperability among systems should be achieved in order to facilitate clinical applicability and to ensure adoption. According to them, chronic care does not necessarily require sophisticated sensor technologies: instead, the flexibility of web-based applications supporting patient-oriented clinical guidelines may be a priority issue. They pointed out that it is time to set the organisational changes needed to deploy innovative services, and this could be achieved through the use of ICT platforms supporting integrated care services. Eventually, this will evolve into personalised health.

<u>Large-scale studies</u>
The current review included several large-scale projects, where ICT plays a fundamental supporting role in the integration of several care services and the facilitation of care coordination.
De Toledo *et al.* [33] set up a collaborative project consisting of three research groups in Spain, aiming at the interoperability of their individual telemonitoring solutions based on the ISO11073 / IEEE1073 (known as X73) family of standards. All three groups had worked before in mobile telemonitoring, but followed different approaches. In this joint project an integrated telemonitoring platform was created for the provision of interoperability with different sensors. The three telemonitoring systems included the CHRONIC system, used for disease management in chronic respiratory patients (call centre, applications for patient, case manager and specialist doctor as well as for professionals doing home visits; monitor devices for spirometry, ECG, pulse oximetry and blood pressure measurement). The other two experiences were HOLTIN (monitoring of chronic cardiovascular patients with data transmission through Bluetooth wireless technology and GPRS) and 3G-mHealth Doctor (facilitation of communication between healthcare personnel with medical specialists in a remote hospital, via 3G mobile networks, supported by UMTS; real-time transmission of medical data and videoconference, and non real-time services). In addition, de Toledo *et al.* [42] described the implementation of the integrated ICT applications for the facilitation of chronic care of COPD patients, as described before in section 7. A similar, but less advanced project, is that of Casas *et al.* [38], described in section 6.1.
Finally, the NEXUS project is an initiative to evaluate the wide implementation of an integrated model of care, using ICT to link stakeholders at all levels [61, 62]. This project runs in Spain, Norway and Greece from 2008 to 2011, in close relationship with a large European project (SOS) that includes 12 countries. Main objective is the validation of four services (wellness and rehabilitation; enhanced care for frail patients; home hospitalisation of chronic patients with severe exacerbations; support for diagnosis and/or therapeutic procedures). In this project ICT will play a fundamental supporting role (support for sharing information and decisions among healthcare levels and community services, and with patients and carers; remote monitoring of selected patients; tools for managing clinical knowledge, prediction and personalisation of the healthcare service). The project's results should help health technology assessment agencies and decision makers to facilitate the extensive deployment of the services and the sustainability of the care model.

<u>Stakeholders</u>
Most projects aim at an integration of care services. Roca *et al.* [61, 62] described an new, integrated model used in the NEXUS project, to link stakeholders at all levels, and empower patients and care givers (Figure 2.3b). Blanchet [37] gave an overview of the commercial stakeholders in the field of remote patient monitoring. Company collaborations are now firmly in place with the creation of Continua Health Alliance, a group of technology, medical device, and health and fitness industry leaders devoted to establishing a market of connected personal health and fitness products and services. The Alliance was launched in June 2006 to address the lifestyle, health, and demographic trends contributing to the high costs of healthcare. Since its creation, the Alliance now has 133 member companies representing all remote patient monitoring fields, including IBM, iMetrikus, Intel, Medtronic, Philips, and Sprint. It has listed a set of technical guidelines, based on proven connectivity standards, to increase assurance of interoperability between devices. This will enable consumers to share information with caregivers and service providers more easily. The Alliance has also planned to catalog,

synthesise, and assess all telehealth studies and associated peer-reviewed cost-effectiveness literature, to determine strategies for increasing telehealth cost effectiveness, initiating quality improvement studies, and securing reimbursement for telehealth products and services.
As well as private coalitions, there are public initiatives too, including the NEXES project ("Supporting Healthier and Independent Living for Chronic Patients and Elderly", European Union Competiveness and Innovation Programme grant 225025) as described in section 8.3 [61, 62].Another project is Better Breathing (EU-funded market validation project under the eTEN programme [74]. Goal is the provision of a model for the continuous care of COPD patients by using ICT more effectively, thereby creating a more coherent and higher quality of healthcare. There were four pilot sites in Catalonia, Denmark, Norway and Wales that were used for market validation of the eServices. In the project, the COPD patient was monitored and cared for (eCare) as well as trained and rehabilitated (eRehabilitation) remotely. In addition, Better Breathing set up an online facility (ePatient Community) where COPD patients could communicate with other COPD patients by using the eCare device and an eProfessional Community, where professionals could meet and exchange experiences. An eLearning aspect was also added to the Better Breathing services as a way of creating an educational service for patients.

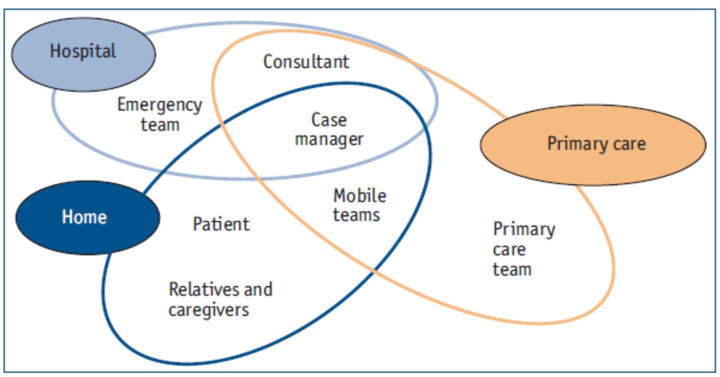


Figure 2.3b; Evolving trends of healthcare to support integrated care services, linking stakeholders at all levels. Shared-care arrangements among levels of care are required to apply patient-oriented clinical guidelines [62].

### *2.3.9 Discussion*

<u>Main findings regarding patient and healthcare provider perspective</u>
This study adopted an inclusive approach to encompass evidence to support implementation of ICT in non-standard measurements and therapies for improvement of chronic care of COPD patients. This was done with identifications of feasibility of several ICT applications, reliability, benefits to patients and providers, the impact on the health status of patients, cost benefits to healthcare systems and organisational impact. Articles which related to ICT-supported measurements and therapies, applied for COPD management, irrespective of study design, the type of ICT application, locations and setting, were included.
Home telecare systems should fulfil the following requirements for optimal performance: (1) be simple to use and operate without interruptions; (2) provide computer security and data confidentiality; (3) the ICT platforms must be modular and interoperable; (4) there

must be support for sharing information and decisions among healthcare levels and community services, and with patients and carers; and (5) support tools must be provided for managing clinical knowledge, prediction and personalisation of the healthcare service.

The included studies supported the usability and applicability, although some studies reported equipment issues [45, 53, 55, 68]. Differences in perceived user-friendliness might be explicable by variations in system quality, user-interface, and training and technical support. Particularly patient and provider training seemed an important aspect, and it was recommended that all people involved should be trained to use a system [26, 42]. In general, older individuals were believed to be well capable of using technology with suitable user interface and moderate levels of training [26, 44, 51]. With respect to related work, Hernandez *et al.* [75] showed that self-monitoring using mobile ICT is not limited by age or by patient lack of technological background in clinically stable COPD patients.

Furthermore, most ICT-based applications seemed well accepted by both patients and healthcare providers [44, 59], and patients' acceptance was influenced by having or not having used home telecare. It was reported that they developed a more positive perception after experiencing it for several weeks [44]. In addition, self-efficacy and anxiety were important constructs in patients' acceptance [59].

However, patients tended to demonstrate more positive views on ICT-enabled applications than providers [53, 54]. The discomfort experienced by healthcare professionals might be explicable by the alterations in the work that they undertake within chronic care, as the introduction of ICT has a great effect on the allocation of tasks and shifts responsibility for certain activities [53]. Moreover, adequate patient selection appeared to be crucial, considering the patient's health status, interest and motivation to self-management and capacity to use the technology [53]. However, healthcare professionals were not that confident being able to decide which patients would be suitable [45]. Whereas nurses expressed the view that older patients as a group were less suitable for home telecare, the patients themselves seemed to believe that it was particularly useful for older people, living on their own [54].

In general, benefits experienced by patients in home-based monitoring by way of ICT could be described as: an increased sense of safety and security; a perception of effectiveness and efficiency coming from regularly monitoring and the ease of access to healthcare professionals; better information on health status (measures and their monitoring through time); better self-monitoring of their condition as a result of better understanding of symptoms and ways to control them; and great satisfaction of teaching programmes [44, 45, 50, 51, 55, 60, 69, 71]. Physicians found that the data from the monitoring devices helped them assess patients' stability, and supported them in their clinical decision-making and timely interventions [38, 42, 50, 51], which resulted in higher quality of services. Televisits as an alternative to in-person visits were perceived as a good way to receive care [43, 44, 71]. Patients reported the increased contact with providers as the primary benefit [71]. Moreover, an increase in satisfaction with an increasing level of home telecare intervention was found [44].

Concerning ethical and legal issues, studies mentioned those just briefly. Main concerns were centered on data confidentially and security. If those were ensured, most studies stated there was no major legal problem. Ethical and legal issues could be better defined through a set of guidelines and standards. The Home Telehealth and Remote Monitoring special interest group of the American Telemedicine Association has focused on this but the target is home telehealth with no distinctions [76]. However, the development of specific guidelines for the delivery of these services to the elderly suffering from chronic diseases is necessary and should be a direction for future research. In the Netherlands, both face-to-face and virtual visits are regulated by the WGBO (Medical Treatment Contracts Act). A complementary guideline for online physician-patient contact has been provided by KNMG (Royal Dutch Medical Association) with directions regarding personal counseling by way of online communication, the provision of pharmacotherapy and the prescription of repeat medication, to ensure quality in the provision of consultation via the Internet [77]. Concerning the patient's privacy, standards are included in the WGBO and KNMG guideline, as well as in the WBP (Personal Data Protection Act) and the NEN 7510 standard (NNI, Dutch Normalisation Institute) [78]. At European level, telemedicine and telecare are now being harmonised and standardised by the European Commission, and scientific research is stimulated, in order to enhance ICT in healthcare [79]. However, specific guidelines are missing here as well.

A special legal framework for healthcare administered at a distance, clearly stating the characteristics, limitations and permissions in home telecare, will increase professionals' confidence in using ICT-supported systems. In the Netherlands, the RIVM (National Institute for Public Health and Environment) has recommended several precautions in the use of advanced medical technologies in homecare in order to reduce risks, e.g. further development of devices designed for home use; adaptation of user manuals; the placing of limitations on the assortment of devices that professionals use; employment of specialised nursing teams; instruction and supervision of patient and informal carers, and a clear demarcation of the tasks and responsibilities of all parties [80]. Furthermore, there should be an active and open relationship with the possible ethical problems, since patients might not want to lose completely face-to-face contact with healthcare professionals [26, 71].

<u>Main findings regarding patient outcome, costs and organisation</u>

The included studies reported a decrease in exacerbation rate, measured in the number of emergency department visits and hospitalisations, of COPD patients receiving ICT-based homecare (add-on virtual visits, telemonitoring, teleassistance and education), compared to a control group receiving conventional traditional homecare [42, 43, 50, 52, 67-69, 72]. Several studies showed the feasibility of stimulating COPD patients in home-based exercise programmes, resulting in an improved exercise capacity and quality of life [46, 52, 70]. Indeed, hospitalisation rates for exacerbations are assumed to be modulated by severity of the disease [1] in combination with concomitant factors, such as comorbities, patient's anxiety and depression [81], uncovered social needs and poor self-management of the disease. ICT-support in healthcare enables integrated care, which handles these multiple factors. By way of telemonitoring combined with educational programmes, home telecare enhances patient recognition of exacerbation symptoms. According to Wilkinson *et al.* [82] prompt treatment in COPD patients would improve exacerbation recovery and reduces risk of hospitalisation. It would also be associated with a better health-related quality of life.

The reported cost reductions were associated with time saving, eliminating of travelling expenses, fewer hospitalisations or accident/emergency department visits and use of health services. However, there were few extensive cost-effectiveness analyses and no studies concerning economic implications on the long term were found. Due to the limited data available, few countries have consistent reimbursement policies. In order to come to successful implementation of home telecare applications, this area should be further explored.

Concerning organisational impact, union of telehomecare and regular homecare services is essential [50]. However, it is still unclear which care models should be used. Extensively integrated care services with shared-care arrangements between primary teams and hospital teams will avoid duplicated and will generate synergies among different levels of the healthcare system [38]. The use of standards and open, plug-and-play interoperable devices will promote the expansion of ICT-supported healthcare solutions [33].

Limitations

The present review has inherent limitations with respect to the use of the limited search queries employed in PubMed and Google Scholar. Furthermore, this review only included articles focusing on chronic care for COPD patients, whereas most of the existing projects relate to other chronic respiratory diseases [27-31]. Therefore, many studies were excluded, although those might be quite similar to COPD projects and provide interesting results regarding large-scale application of advanced ICT platforms.

ICT-supported chronic care has been rapidly evolving. However, it is important to note that the whole field is still in an early phase of adoption, trying to consolidate extensive deployment of initiatives based on pilot experiences. At the time being, we are facing a transitional phase from existing pilot experiences to extensive deployment of health and social services targeting selected groups [61]. Large-scale studies have just been set up, with the results not being published yet. Therefore, these projects were not mentioned in the current review.

Basic limitations in many of the included studies were the small sample size, short follow-up period, and the lack of randomised assignment to the treatment and control groups. The way in which patients sort into treatment and control groups may cause problems in analysing the data. This could lead to some ambivalence in accepting the current data as proof of the positive impact of home telecare. This represents a significant problem, especially for those studies that produced interesting results. The diversity of outcome measures prohibits meaningful meta-analysis to build strong evidence for ICT-enabled homecare for COPD patients as well. Furthermore, Roca *et al.* [62] stated that there are significant gaps in the methodology of validating innovative healthcare services supported by ICT, which partly explain the lack of data formally validating the role of ICT in healthcare. The current approach is to use RCTs, although health technology assessment agencies acknowledge the need for new and more appropriate methodological approaches conceived specifically for validating healthcare services and their associated ICT tools. Another common problem pointed out by Roca *et al.* is that many pilot studies have shown high internal validity, but a questionable external validity because of high exclusion rates, mainly due to severe comorbid conditions and a lack of appropriate social support. Finally, the existing studies seem to indicate that more complex, multifaceted ICT applications integrating several levels of healthcare are the most effective, making the design of studies much more difficult.

Future perspectives

In recent years, there have been several innovative strategies aimed to decrease COPD admissions through patient empowerment and implementation of alternatives to conventional hospitalisation, like short-stay units, respiratory day hospitals and home-based programmes. However, to reduce the impact of disease on patients, healthcare systems and society as a whole, integrated care interventions with interplay between the roles of patients/carers, healthcare/ public health and community services, are needed. Several COPD-specific RCTs have consistently shown the potential of integrated care to enhance clinical outcomes while containing costs [62, 83-90]. The deployment of ICT platforms will be essential to come to such integration of healthcare services. For now, ongoing small-scale pilot experiences in Europe, such as the European Union-funded Better Breathing Project [74] are exploring the potential of integrated case services supported by ICT to address care pathways that cover the whole spectrum of COPD, from early diagnosis to end-stage disease, including end-of-life support. Recently, a new European project NEXES, where ICT plays a fundamental support role, has been set up to move towards a wider implementation of such a model [62]. In the Netherlands, several e-Health collaborations have just started: open platform e-Health (initiative of insurance company Menzis), the Koala project (Menzis, telecommunications and ICT service provider KPN and homecare provider Meavita), and Zorginnovatieplatform ZIP (collaboration of health and social service sectors, business and industry, and government) [91].

Moreover, the number of standalone sensors prepared for wireless connectivity has drastically increased in the last few years. The issue of security in systems operating with sensors combined with web applications has been reasonably solved. Current trends are focusing on the development of more advanced sensors (e.g. less intrusive, increased flexibility of function through software applications) and technologies (improved connectivity, e.g. ZigBee, and micro/nanotechnology for noninvasive diagnosis and monitoring). However, key issue appears to be the increasing need for evolving from standalone sensors to systems that combine different types of sensors plus data analysis. Finally, such systems should not be used alone but as modules of ICT platforms designed to support patient management and collaborative tools for professionals working at different levels of the healthcare system. Also, interoperability among systems should be achieved to facilitate clinical applicability and ensure adoption [61]. In this way, ICT will be able to facilitate integrated care.

### *2.3.10 Conclusions*

Organisational and societal changes, such as cost reduction policies, aging populations, a relatively small active workforce and an increase in the number of COPD patients, are the main driving forces for the development of ICT-enabled applications in chronic care for COPD patients. The findings of the present review indicate that there could be significant benefits for COPD patients and healthcare providers from such systems. Telemedicine and home telecare empower patients, motivate them for self-management, improve self-efficacy and health outcomes, and professionals are supported in clinical decision-making. However, the current organisation of healthcare and resistance to change in the relevant organisations hinder further implementation. The key to a wider implementation is providing stakeholders (i.e. insurance companies, industry, government agencies, healthcare professionals and patients) with robust data on the practical implications of initiatives, in order to assess whether high quality of care with lower costs and a lower human resources input could be combined. Hence, more research on telemedicine and home telecare should be conducted, regarding the cost-effectiveness of ICT systems in chronic care for COPD patients, in order to obtain the evidence required to utilise the techniques in routine COPD healthcare. Also, the interactive relationships between patients, professionals and organisational systems should be further explored to develop efficient homecare models, enabled by ICT platforms, with shared-care arrangements among different levels in the system. Research on interactions between public and private stakeholders is needed to establish optimal collaboration structures between all parties involved, and formulate consistent policies about implementation, coverage and reimbursement. Business models supporting and sustaining the use of telemedicine and home telecare services within the care delivery system, are essential and should be investigated.

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### *2.3.12 Appendix – table study details and main findings*

| ***Author; Year; Country*** | **Type of article[I]** | **Type of home-based ICT application** | **Sample[II, III]** | **Main findings** |
|---|---|---|---|---|
| *Blanchet [37]; 2008; USA* | R | Monitoring | NS (no systematic review) | Remote patient monitoring is no longer experimental, but fully mature technology is now available to host numerous patient care applications with major electronics and computer companies being involved. |
| *Botsis and Hartvigsen [26]; 2008; Norway* | R | Consultation and videoconferencing; Monitoring; Assistance and education | 54 studies | Patients preferred a combination of home telecare with conventional health-care delivery. Health-care professionals were positive. Organisational, ethical, legal, design, usability change required for widespread implementation. |
| *Casas et al. [38]; 2006; Spain* | CS | Assistance and education *(individually tailored care plan upon discharge shared with the primary care team with accessibility to a specialised nurse case manager through a ICT platform (the CHRONIC platform) with a web-based call centre)* | 155 COPD patients (65 IG, 90 CG); general practitioners, specialised nurses, primary care and hospital teams | A standardised integrated care intervention, based on shared-care arrangements among different levels of the system with support of information technologies, effectively prevents hospitalisations for exacerbations. |
| *Cooper [39]; 2009; USA* | R | Consultation and videoconferencing; Monitoring | NS (no systematic review) | Telemedicine is still relatively new and further exploration of methods and outcomes are needed, but has potential being introduced into multicentre clinical trials to facilitate quality control of pulmonary function testing. |
| *Cummings and Turner [40]; 2006; Slovenia* | SD | Monitoring *(self-management and self- efficacy with the use of electronic self-monitoring techniques)*; Assistance and education *(mentors supporting patients to acquire the skills for early identification, comprehension and response to their conditions)* | NS (COPD/CF) | A patient-centred model should guide the approach to the development and deployment of ICT. ICT should enhance patients' self-management and self-efficacy and rely on understanding users' needs and ensuring technology is both easy to use and useful. |
| *Dang, et al. [41]; 2006; USA* | RS | Monitoring *(computerised, Internet-based, in-home messaging/monitoring device: Health Buddy);* Assistance and education | 92 patients (19 CHF, 23 DM, 17 COPD); 2 care coordinators (nurse practitioner and social worker), secretary, geriatrician | Reduction of resource utilisation, especially in patients with CHF. |

| | | | | |
|---|---|---|---|---|
| | | *(provision of disease-specific education to patients and caregivers)* | | |
| *de Teledo et al. [42]; 2006; Spain* | SD, CS | Assistance and education *(system facilitating care coordination and access to the electronic chronic patient records (ECPR) for care givers; telephone support for patients via call centre; access for patients to educational material);* Consultation and videoconferencing *(consultation with case manager using videoconference);* Monitoring *(remote monitoring of biomedical parameters e.g. one lead ECG, spirometry, pulse-oximetry, blood pressure, heart rate and symptoms (questionnaire); results integrated in ECPR)* | 157 COPD patients (67 IG, 90 CG); care coordination by a hospital-based specialised nurse (case manager), a specialist and other hospital professionals (nurses, 43 respiratory lab technicians), 3 primary care professionals (not specialised in respiratory patients), and 2 nurses (care manager and assistant) doing home visits | Integrated services can support health professionals and improve the patients' health (less readmissions). The system is acceptable to professionals, and involves low installation and exploitation costs. |
| *de Toledo et al. [33]; 2006; Spain* | SD | Monitoring *(joint efforts of 3 research groups towards the interoperability of their telemonitoring solutions (CHRONIC system for COPD and HOLTIN system for CHF) based on the ISO11073 / IEEE1073 family of standards);* Consultation and videoconference *(3G-mHealth Doctor for communication between professionals)* | No patients involved. | The work towards interoperable telemonitoring devices based on standards is imperative to achieve mature e-health solutions that are not dependant on a single vendor. |
| *Finkelstein et al. [43]; 2006; USA* | CS | Consultation and videoconferencing *(virtual visits via two-way audio and video interactions with access to a web-based messaging system);* Monitoring *(physiologic monitoring with an electronic diary to report measurements and symptom information)* | 53 patients (24 CHF, 25 COPD and 4 CWC); (one control group and two intervention groups); nurses | Improved patient outcome at lower cost than traditional skilled face-to-face home healthcare visits. |
| *Finkelstein et al. [44]; 2004; USA* | CS, QS | Consultation and videoconferencing *(virtual visits with two-way audio and video interactions, with internet access);* Monitoring *(home-based physiologic* | 53 patients (CHF, COPD, CWC); (one control group and two intervention groups); nurses | All subjects were satisfied; satisfaction increased with an increasing level of intervention; subjects receiving physiological monitoring and video conferencing/Internet access in addition to standard care were most satisfied with their care. |

| | | | | |
|---|---|---|---|---|
| | | *monitoring and an electronic diary)* | | |
| *Horton [45]; 2008; UK* | QS | Monitoring *(local call centre with an integrated community response service, physiological parameters included oxygen saturation, pulse and respiratory rate)* | 6 case studies (COPD); 3 healthcare professionals, 1 call centre member | Rapid access to care, an increased sense of personal safety and security, and the continuity of care. However, the equipment was perceived as not user friendly. Concerning nursing management, partnership working has to be negotiated, and leadership roles include addressing tensions and motivation within the team. |
| *Hung et al. [46]; 2007; China* | SD, RS | Exercise programme *(exercise instructions via SMS)* | No patients involved. | Endurance training via mobile phone was successful in helping to treat the physical and mental problems. |
| *Joseph [47]; 2006; USA* | RS | Monitoring *(patient receives questions via telephone line asking for clinical data and perceived health status, data transmitted to care coordinator)* | NS (DM, CHF, hypertension, COPD and mental health patients); nurses, social workers, dieticians | Substantial gains in both decreasing the use of high cost care, such as emergency department visits and hospitalisations, as well as improving clinical outcomes with better glycemic control for patients with diabetes and improved lipid management for all patients. |
| *Kobb et al. [48]; 2008; USA* | R | Monitoring | NS (no systematic review) | Home telehealth is successful when integrated within the existing healthcare organisation's clinical infrastructure, at a lower cost than traditional healthcare. |
| *Koizumi et al. [49]; 2005; Japan* | SD, RS | Monitoring *(recording of medical history and biologic variables, including blood pressure, arterial oxygen saturation, three-lead electrocardiogram and end-tidal carbon dioxide);* Consultation and videoconferencing *(real-time connection of the homes of 2 patients, general physician and pulmonary specialist)* | 2 COPD patients; general physician, pulmonary specialist | Same information being exchanged remotely as in a face-to-face encounter. Improvement of patient's quality of life. |
| *Lamothe et al. [50]; 2006; Canada* | QS | Monitoring *(data e.g. oxygen saturation/pulse, daily sent via a wireless connection; if needed glucometer, spirometer, ECG, blood clotting)* | 82 patients (COPD, hypertension and/or cardiac insufficiency); nurses | Great potential to increase access to services and improve quality of care, but organisational change required. Patients were satisfied. |
| *Liddy et al. [51]; 2008; Canada* | QS | Monitoring *(1 or more peripheral devices e.g. blood-pressure monitor, weight scale, glucometer, information transferred to a secure server and uploaded to a secure web-based application,* | 22 patients (hypertension, cardiovascular disease, DM, COPD); 8 physicians, 5 nurses | Most of the patients and their informal caregivers found the technology user-friendly and useful. Healthcare providers were satisfied with the technology and found the equipment useful. |

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| | | *accessible to care providers)* | | |
| *Liu et al. [52]; 2008; Taiwan* | CS | Exercise programme *(cell phone-based exercise programme, walking speed controlled by music tempo)* | 48 COPD patients (24 IG; 24 CG) | The cell phone-based system provided an efficient home endurance exercise training programme with good compliance and clinical outcomes in improving exercise capacity, breathlessness, quality of life, inspiratory capacity and air-trapping. |
| *Mair et al. [53]; 2008; UK* | QS | Consultation and videoconferencing *(videophone);* Monitoring *(medical sensors for blood pressure, pulse, temperature and pulse oximetry)* | 9 COPD patients; 11 nurses | The system did not provide an interactional advantage for the nurses and did not fit with the nurses' views of the most appropriate or preferred use of their skills. However, patients were mainly content. |
| *Mair et al. [54]; 2005; UK* | QS | Consultation and videoconferencing *(videophone link using standard analogue telephone lines);* Monitoring *(via the videophone with attachments for remote physiological monitoring of blood pressure, pulse, temperature and pulse oximetry)* | 22 COPD patients; 14 nurses | Significant differences in perception between patients and care providers, patients consistently demonstrated more positive views than care providers. |
| *Medvedev et al. [55]; 2008; Russia* | SD | Monitoring *(mobile Smartphone linked via Bluetooth to a range of monitoring devices (pulse oximeter, blood pressure monitor, ECG monitor);* Exercise programme *(exercise monitor)* | COPD patient; physiotherapist, health services | Objective of the pulmonary rehabilitation Smartphone application is to provide users with a tool to reduce dependence on the conventional, labour intensive services and to enable improved management of their rehabilitation programme. |
| *Nguyen et al. [56]; 2006; USA* | SD, RS | Monitoring *(mobile device with automated prompts asking patients to submit exercise and symptom data)* | 6 COPD patients | Acceptable response rates were found with subjects, preferring to have prompts delivered to coincide with their exercise activity. |
| *Paré et al. [57]; 2006; Canada* | CS | Monitoring *(web-phone with an integrated touch screen and modem programmed with a personalised protocol for monitoring peak flow rate, symptoms, medication; information transferred via the internet to the nurse);* Teleassistance and education *(tool for helping patients understand relationships between health state, environment, lifestyle, and* | 29 COPD patients (19 IG, 10 CG); nurses | Telemonitoring over a 6-month period generated $355 in savings per patient, or a net gain of 15% compared to traditional home care. Acceptance of technology by patients and significant clinical benefits. |

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| | | *management of medication)* | | |
| *Partridge et al. [58]; 2004; UK* | QS | Consultation and videoconferencing *(consultation via telephone or e-mail)* | 164 respiratory patients; respiratory physician | 30 patients (18.3%) were not agreeable to other forms of consultation; for patients with asthma and for those awaiting results of investigations especially, use of telephone consultation appears to be an acceptable and convenient way of reducing the pressure upon time available for face-to-face consultations. |
| *Rahimpour et al. [59]; 2008; Australia* | QS | Monitoring *(recording clinical indicators, using a wireless weight scale, single lead ECG, blood pressure cuff, spirometer, temperature probe, and pulse oximeter, with web-enabled tools for patient management by the care team);* Assistance and education *(providing feedback to patients including medication reminders and measurement scheduling)* | 10 focus groups including total 77 patients (COPD and/or CHF) | Most participants perceived the system as a useful and convenient mode of healthcare delivery, expressed positive attitudes and intent to use the system. However, there were concerns centered on the issues of cost, ease of use, clinical support, low self-efficacy and anxiety. |
| *Raza et al. [60]; 2009; USA* | RS | Consultation and videoconferencing *(two-way audio and videoconferencing system)* | 314 patients (COPD, benign pulmonary nodule, bronchial asthma, lung cancer); 6 pulmonary physicians, 2 nurses, 1 respiratory technician | Physicians are able to rely on medical history and radiology to manage patients across a broad spectrum of complex pulmonary conditions with the assistance of a non-physician healthcare provider at the remote site. |
| *Roca et al. [61]; 2008; Spain* | SD | Exercise programme *(stimulating physical activity and muscle training via mobile technology);* Assistance and education; *(support for diagnosis and/or therapeutic procedures with collaborative tools for professionals working at different healthcare levels; call centre);* Monitoring *(mobile phones including questionnaires and messaging services; wireless sensors for selected patients; laptop with wireless sensors for home-visiting professionals)* | > 5,000 patients (COPD, CHF, DM-II); (Spain, Norway and Greece); primary care team, community services, specialised team | The NEXES project is expected to develop strategies for the extensive deployment and sustainability of integrated care pathways for chronic patients. It is hypothesised that integrated care based on standardised pathways supported by ICT may enhance clinical outcomes and generate satisfaction for patients, carers and healthcare professionals. |
| *Roca et al. [62]; 2008; Spain* | R | Monitoring | NS (no systematic review) | Mobile monitoring technologies should be integrated into ICT platforms; the current trend toward integrated care will evolve |

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| | | | | into personalised health. |
| *Shin et al. [63]; 2007; Korea* | SD | Monitoring *(measuring SpO2 and ECG during patients' daily life at home via a wireless measurement device including a GPS module)* | NS (COPD and CHF) | Ubiquitous service in reporting the patients' data to their doctors at any time and any place. |
| *Sridhar et al. [64]; 2008; UK* | CS | Telephone *(monthly phone calls from the respiratory nurses and a home visit every 3 months, as addition to an intermediate care package, including pulmonary rehabilitation, self-management education and the receipt of a written COPD action plan)* | 122 COPD patients (61 IG, 61 CG); respiratory physician, nurses | Reduced need for unscheduled primary care consultations and a reduction in deaths due to COPD but no effect on the hospital readmission rate. |
| *Trappenburg et al. [65]; 2008; The Netherlands* | CS | Monitoring *(daily symptom-surveillance via Health Buddy, patients' responses are sent via telephone line to the browser-based care management tool);* Assistance and education *(education via Health Buddy to enhance disease knowledge and self-management)* | 115 COPD patients (59 IG, 56 CG); respiratory nurses | Adopting telemonitoring in everyday clinical practice is feasible and can substantially improve care and decrease healthcare utilisation. |
| *Vasquez [66]; 2008; USA* | R | Monitoring; Telephone | NS (no systematic review) | Basic forms, e.g. phonemonitoring, can be an important aspect in a patient's plan of care. |
| *Vitacca et al. [67]; 2009; Italy* | CS | Assistance and education *(nurse available for real-time teleconsultation; call centre/pulmonologist available for unscheduled phone calls);* Monitoring *(pulse oximeter)* | 240 patients (CRF, including 101 COPD), (120 IG, 120 CG); nurse tutors, pulmonologists | In CRF patients on oxygen or home mechanical ventilation, a nurse-centered teleassistance prevents hospitalisations while it is cost-effective. The COPD group seems to have a greater advantage. |
| *Vitacca et al. [68]; 2006; Italy* | RS | Monitoring *(pSat measurement sent by telephone modem);* Assistance and education *(telephone or e-mail)* | 45 CRF patients; 3 nurses, respiratory physician, general practitioner | Home monitoring was feasible, and useful for titration of oxygen, mechanical ventilation setting and stabilisation of relapses. |
| *Vontetsianos et al. [69]; 2005; Greece* | RS | Consultation and videoconferencing *(home-telecare software ISDN application including a videoconference camera for real-time audiovisual connection with the hospital using the patient's TV set; nurse use only);* Monitoring *(laptop computer with medical devices, including an electrocardiogram* | 18 COPD patients; multidisciplinary team (doctors, nurses, physiotherapists, social workers, clinical psychologists, dieticians and pharmacists) | Decrease in hospitalisations, emergency department visits and use of health services. The patient's disease knowledge and self-management also improved. |

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| | | *recorder, spirometer, oximeter and blood pressure monitor; nurse use only)* | | |
| *Wewel et al. [70]; 2008; Germany* | RS | Telephone *(regular phone calls to motivate patients for training)* | 21 COPD patients | The increased activity resulted in increased exercise capacity and quality of life, underlining the effectiveness of continued motivational support. |
| *Whitten and Mickus [71]; 2007; USA* | CS | Monitoring *(vital signs);* Consultation and videoconferencing *(videoconferencing, combined with face-to-face visits)* | 161 patients (COPD and/or CHF) (83 IG, 78 CG); nurses | The addition of telehealth to COPD/CHF patient care was not a significant predictor of health and wellbeing. Patients were satisfied with the technology and the way that care was delivered. |
| *Wong et al. [72]; 2005; China* | CS | Telephone *(nurse-initiated telephone follow-up)* | 60 COPD patients (30 IG, 30 CG); respiratory nurse | Increased self-efficacy in managing dyspnoea; reduced number of visits to accident/emergency departments; increased physical exertion. |

[I] *SD, system description; RS, research study; CS, comparative study; QS, qualitative study; R, review.*

[II] *Number of users (patients, nurses, physicians or other caregivers involved in the study); or number of studies included in the case of review.*

[III] *IG, intervention group; CG, control group; CRF, chronic respiratory failure; CHF, congestive heart failure; DM, diabetes mellitus; CWC, chronic wound care; CF, cystic fibrosis; NS, not specified.*

# 3 Methods: the development of scenarios & requirements

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In order to gain information to develop the functional requirements a state of the art was performed, presented in chapter 2. Next, a user-centred approach is used to develop scenarios and requirements, which is presented in this chapter. First, an introduction into user-centred design is given and the development of the scenarios and requirements is outlined next.

## 3.1 Introduction into user-centred design

Around 75% of the telemedicine initiatives fail during the operational phase after a pilot [1]. Furthermore, according to the review by Broens et al., determinants of success depends in 29% of the cases on technological reasons for failure, opposed to 37% of user acceptance as reason for failure [2]. This review also shows that technology acceptance is influenced by the users' attitude towards the technology. Thus by involving users in an early phase of development, technology can be fitted to their daily practice and environment of use [2, 3].
Nevertheless, most studies about activity monitoring systems reflect technological principles such as system architecture, sensor technology, measurement outcomes or data analysis techniques, and it is unknown if these activity monitoring systems actually comply with what users need. In developing a new system, one of the main difficulties is to identify and meet the user needs and consequently this is where systems can result in a failure, due to the often technology driven way of development, instead of user needs driven [4]. As technology should not be a mere focus in the design process, needs of users should first be clear and form the onset for design [5].
Health care work is seen as a multidisciplinary environment of "disciplines, tools, ICT and routines in an environment of unpredictable events and distributed decision making" [1]. Therefore Berg opts for a sociotechnical approach for system development, underlining the interrelationship of social features of the work with technical features of the system. The sociotechnical approach of Berg is merely a higher level perspective of how to design systems for health care, but does not give answers on how to involve users [6]. An approach that goes into more detail and puts users centre stage is the user-centred design. User-centred design takes the user as onset for design and involves them for evaluation of design choices [7]. It aims at improved communication between designers, engineers and users in order to enhance user acceptance and less failures in technological design [4]. The user-centred design is used to develop the requirements analysis, which is the objective of D2.1 of the IS-ACTIVE project.

## 3.2 Requirements development

User-centred requirements engineering is used to overcome the translational gap between what users need and to actually design the technology [8]. Two types of requirements can be distinguished: functional requirements and non-functional requirements. Functional requirements describe the functions of the system in terms of the input, behaviour and output. Non-functional requirements, or quality requirements, specify criteria to judge the system and are not descriptive for the behaviour of the system: they create boundaries set by the environment (e.g. users, context of use) for the concept to fulfil. Examples of non-functional requirements are security, reliability, privacy or usability [9]. Requirements elicitation can be achieved by different techniques such as document reading, questionnaires, interviews, protocol analysis, video and audio transcripts, use cases and scenarios or observations [10]. The challenge is *to proceed from individual, fuzzy statements of needs to a formal specification that is understood and agreed by all stakeholders* involved in the design process. However, these stakeholders such as technicians and users all have their own vocabulary, complicating communication throughout the design process [11].

In the IS-ACTIVE project an approach with scenarios was chosen for developing the requirements. Scenarios highlight goals suggested by the appearance and behaviour of the system, what people try do to with the system, what procedures are adopted, not adopted, carried out successfully or erroneously and what interpretations people make of what happens to them [12]. It is a good means of communication between the end-users and developers of the system. For developing the scenarios the PACT framework was used. Again, it puts the user at the centre of the design process. PACT stands for: People (the primary end-users of the system), Activities (the activities between the end-users and the system), Context of use (the environment of the system) and Technology (applications and components of the system) [13]. RRD developed a PACT table which incorporated a number of questions for each item of PACT, which served as a guideline in the development of the scenarios. This PACT table is included in the appendix. Two types of scenarios are developed: a user scenario for the current care of the COPD patient ("before" scenario) and a user scenario for how COPD care should be in the future using the IS-ACTIVE system ("after" scenario).

The IS-ACTIVE system can only be successful when it matches with the needs of professionals and patients in the routine clinical practice. Subsequently, it is our goal to bring the technical knowledge and clinical knowledge together in defining the functional requirements (see figure 3.2a). Therefore, a requirements workshop was organised where all partners of the IS-ACTIVE consortium were present, on September 30th in Vienna, Austria. Each clinical partner filled in a preparatory questionnaire (included in the appendix) in preparation to this workshop. Furthermore, the scenarios were finished prior to the workshop and served as a starting point for the requirements discussion during the workshop. The outcomes of the workshop served as initial concept in the development of functional requirements.

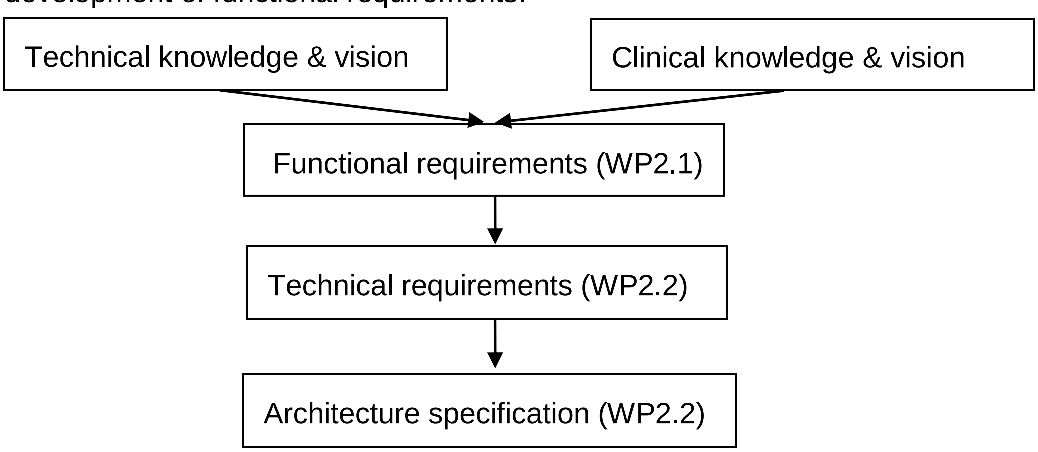


Figure 3.2a; development of requirements

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# 4 Scenarios

This chapter includes the scenarios written by the clinical partners – ELS, NST (& NOR), and RRD – of the IS-ACTIVE consortium. These scenarios were developed in order to serve as a basis for discussions within the project, to put ideas forward on what to do, and to provide information for partners with less knowledge about COPD and exercising. Each clinical partner developed one user scenario for the current care of the COPD patient ("before" scenario) and one user scenario for how COPD care should be in the future using the IS-ACTIVE system ("after" scenario). These scenarios were the starting points for the requirements workshop discussions. Hence, there are more ideas and functionalities described in these scenarios than will be developed in the future IS-ACTIVE system.

## 4.1 Scenarios University Hospital Elias

### *4.1.1 Before scenario - The rehabilitation programme in persons with COPD in PRM Department of Elias University Hospital*

Mr. Popescu, a 63-year old man has been diagnosed with COPD 15 years ago, and is now in stage GOLD II A. He worked many years as a town clerk, in a moist, dusty room. He had a sedentary lifestyle and used to smoke 20 cigarettes daily, and he became retired at the age of 58 years old. He is periodically assessed by the pulmonary specialist, who prescribes the medication and decides to send Mr. Popescu to the PRM physiatrist in order to be specifically evaluated. The physiatrist decided to admit him in the PRM Department where Mr. Popescu is evaluated in order to establish:

- Clinical global status (associated conditions which could interfere with the rehabilitation programme – i.e. cardiovascular, neurological, musculoskeletal diseases).
- Functional status – functional respiratory tests
- Endurance level ($VO_2$ max, lactate threshold, 6MWD)
- Strength and endurance of peripheral muscles
- Strength and endurance of respiratory muscles (MIP, MEP)
- Nutritional status
- Psychological assessment
- Health-related quality of life (Chronic Respiratory Disease Questionnaire in all dimensions – dyspnoea, fatigue, emotion and mastery)

The physiatrist and the physical therapist compose the rehabilitation plan based on specific and individualised goals. Mr. Popescu follows this programme daily, for 10 days, as an inpatient due to the lack of possibilities for home monitoring during the training programme. After these 10 days, Mr. Popescu is re-evaluated, in order to establish his new achieved baseline status and design for him a home training programme. The patient is educated to adjust the intensity level of the home training to avoid acute cardio and respiratory events. At this moment, the only possibility to avoid these events is to execute a "symptom-limited" level of training.

Mr. Popescu goes back home, where he continues daily the prescribed exercises as he has been trained by his physical therapist. After a 2weeks non-events period, Mr. Popescu, due to his high exercise tolerance, decides to enhance the intensity level of

training. Suddenly, Mr. Popescu feels bad, describing dyspnoea, breathlessness, and extreme fatigue. He is scared and decides to avoid any kind of physical activities and increases by himself, without medical advice, the medication doses. He contacts his pulmonary specialist and makes an appointment for next day. The pulmonologist re-evaluates the patient and readapts the drug prescriptions and Mr. Popescu is sent back home.
All these facts involve increased needs of medical resources, are time and human consuming, and Mr. Popescu developed symptoms of anxiety, depression and the feeling of insecurity and negative consequences of his illness.

### *4.1.2 Second Scenario*

Introduction

Mr. Popescu is a 63 years old man, who has been diagnosed with COPD in stage GOLD II A. He worked many years as a town-clerk in a moist, dusty room. He had a sedentary life style and used to smoke 20 cigars daily, and he retired at the age of 58 years old. Mr. Popescu discovered the IS–ACTIVE programme from the net and also from the BPOC Organisation, when he decided to contact us. His main reason was to improve his physical condition, because he wants to start working in his vegetables garden and wants to spend more time outside with his friends.

The team of IS-ACTIVE programme

In our team we have the rehabilitation physician, the pulmonologist, the physiotherapist and a certified nurse. The patient is seen first by the pneumonologist who evaluate the current stage of the disease and confirms the diagnoses. The next step is the functional evaluation made by the rehabilitation team. The nurse, Rodica, measures the anthropometry parameters (weight, height) and helps him to fill the ADL and Quality of life Questionnaires. Then, the patient takes the spirometry test and Peak $VO_2$ test. The physician and the physiotherapist establish the baseline of the physical condition and give him a home rehabilitation programme, which consists of walking 1km daily and breathing exercises. The total duration of the programme is 3 months.

How to start

The nurse gives to Mr. Popescu the electronic diary, the main wireless device with different sensors, the pulse oximeter looking as a bracelet, and the thoracic patch. She explains that the device must be worn whole day long, but only the thoracic patch should be kept on even at night, when the main device could be at a distance of maximum 3 meters. The main device receives and processes the information from the outside environment and the functions of the body. The information from the home and outside environment are: the quality of the air (temperature, humidity, dust, smoke, and pollen), noise, light, and GPS monitoring. The body information are: HR, RR, oxygen saturation (pulse oximetry), vegetative skin response, cough, sleep disorders (sleep apnoea), expiratory time and movement recorders, which detect the distance and the speed of walking, the climbing and descending of stairs, posture (standing, sitting, lying). This device will allow him to communicate with other patients having this unit, and give him and his doctor weekly rapports and alert signals. The nurse explains to Mr. Popescu how to fill the electronic diary and tell him that it must be completed daily with symptoms like cough, dyspnoea, fatigue, emotion and participation at social events, drugs consumption and others.

First two weeks at home

Mr. Popescu filled in the electronic diary daily and he managed to perform the therapeutic programme daily, except two days when he was more tired and his breathing was more difficult. He called his pulmonologist, who recommended him to increase the inhaler steroids dose. One day, he received an alert about the high humidity of the air, but the body parameters were within normal limits, so he continued the daily walking without any problems. Also, one night he received a sleep alert waking him up. At the end of the first week, he saw the rapport about the physical activity but he did not understand very well the graphic representation.
Generally, Mr. Popescu was very confident with his new device, especially because it helps him to manage the disease and enables him to collaborate with others. He was very delighted when he met two of his friends with COPD, who were in the same programme and they have had the opportunity to speak about the utility of the device.

Intermediate session at hospital

During the second session at the hospital, Mr. Popescu discussed with the nurse about the health events from the past two weeks. The nurse gave him more details about the information recorded by the device and the graph meanings. She told him that it would not be necessary to come at the hospital but at every two weeks he must read the patient rapport and if the medical parameters are good and he feels fine, he should increase the walking distance with 10%. She verified if he filled in the diary correctly. Rodica appreciated how Mr. Popescu managed the episode of dyspnoea calling the pulmonologist. About the night alarm, she advised him to keep the device open, not to close because it is important to correct the respiration, in order to avoid the complications arising from sleep disorders. The physical therapist, Alina reviewed the physical activity rapport and she observed that the patient does well with the therapeutic exercises. For the moment, he should continue the same rehabilitation programme.

## 4.2 Scenarios Norwegian Centre for Telemedicine / University Hospital of North Norway and NORUT

### *4.2.1 Before scenario Erik*

Erik is the non-talkative outdoor enthusiast living in a rural area in the Lyngen Alps. He is 58 year old, divorced, a full-time fisherman since age 16, now with his own boat. During the winter he has to work part-time due to his disease. His breathing problems are increased in the cold winter season and he cannot cope with physical activity in the same way as in summer. He is diagnosed with moderate COPD (GOLD stage II). He used to go hunting, hiking and sport fishing with friends; however this is becoming too difficult nowadays because of shortness of breath and fatigue. He is becoming inactive, spends more and more time at the kitchen table drinking coffee and watching TV. His shoulder aches more, his weight increases, he smokes heavily, and he feels really depressed. His grandchildren live in Tromsø, a 2 hour drive away. Unfortunately they do not visit him as often as before, since he is not able anymore to do outdoor activities with them, and grandpa is becoming a grumpy old man they think.

Erik is still able to do his own housekeeping and maintenance of the house and premises. The family gave him a stationary bike for his birthday, but he does not use it so much, because he is an outdoor kind of man and finds it boring. He feels more alone

and socially isolated – but keeps dreaming of taking up his previous activities and participate in hiking and fishing with his old friends.
Erik still smokes, and this causes regular exacerbations. When this occurs he makes an appointment with his GP. The GP handles this by medication, testing (CRP, PEF and spirometry), and if needed referral to a specialist at the hospital. His GP does not give any follow-up, except for when an appointment is made by Erik.
Erik was referred by his GP to Skibotn Rehabilitation Centre for a 4-weeks rehab programme[8]. He may return once a year, but it is difficult to be enrolled annually due to waiting lists. However, he does not yet need specialist treatment at the hospital due to his moderate COPD. Only those with severe COPD and those with oxygen treatment (LTOT) are referred to annual follow-up at the hospital. He receives physiotherapy for his work related shoulder problems, and not because of the COPD. His GP has referred him to the physiotherapist.
Erik does not want to participate at arrangements by the patient organisation (LHL)[9], often a combination of social and exercise activities. He regards this as to be for sicker people and with often too much talk about disease. Therefore, in addition to missing out on much needed exercising, he also looses the chance to meet peers with COPD. At the same time, his COPD limits him in his preferred kind of physical activity; joining his old friends for outdoor fishing, hiking and hunting activities.

### *4.2.2 After scenario Erik*

Overall goal for Erik**:** *To improve his physical condition within his capacity, so he can take part in his former outdoor activities again.*

Even though Erik does not want to participate in the indoor exercise sessions, he was persuaded by family to participate in an LHL outdoor walking group gathering. These gatherings are organised once a week. He is positively surprised and astonished to meet other former outdoor enthusiasts, now also being limited by their activity capacity. This positive experience stimulates him to reconsider his lack of interest in his old outdoor activities. He decides to participate in the next outdoor gathering by LHL, and there he also receives an activity registration and motivation sensors from the IS-ACTIVE system. The sensors measure duration of activity, length of walking, intensity and also uphill/downhill walking. His fellow “walking friends” at LHL also have such IS-ACTIVE sensors, and they are all networked providing both personal feedback (personal goals, competition against yourself) and the possibility to contribute in common group activity goals and coordination.
Motivating and positive feedback is tailored both to Erik and to the group. He receives his feedback tailored to his needs both on the sensors and his mobile IS-ACTIVE device. The feedback is both daily and during exercising and physical activities and includes personal goals, guidance, motivation, and progress information, and also progress and goal achievement for the group. During the year the group has to reach a total “predefined” activity goal (distance, up-hill, down-hill, etc.) together; all contributing to

[8] Referrals to a rehabilitation program are either done by a GP or a pulmonary specialist in Norway.
[9] The Norwegian Heart and Lung Patient Organisation is a nationwide interest organisation for people with heart and lung disease. LHL conducts rehabilitation, self-help support measures, information and introductory courses for patients, as well as study, fund-raising and information activities. They own and run two clinics, four rehabilitation centres, a technical college for the disabled, their own housing society, forty activity centres, and a patient ombudsman office.

their own activity results. The feedback is given in the form of something like the virtual garden.[10]

The IS-ACTIVE system can be used with varying supervision from healthcare personnel such as a rehabilitation physiotherapist or nurse. Erik has chosen to use the version without supervision of health care personnel, and he and his groups set the common goals themselves in cooperation with LHL.
Erik misses the frequent walks he did to the 400m high peak above his house. Therefore, based on what he learned at the rehabilitation programme in Skibotn, he makes a tailored exercise plan by help of the IS-ACTIVE system, hoping it will make it possible for him to reach the peak above his house within a month. He has a small daily exercise programme with a variety of exercises using weights, Pilates ball etc. Feedback on his performance and progress is based on sensors data fed into smart algorithms in his device.
His stationary bike is moved out on the terrace where he has a scenic view of the Lyngen Alps. The IS-ACTIVE motion sensors attached to the bike and himself may be used both on indoor and outdoor bikes. The bike is wirelessly connected to an online game where he regularly competes with his grandchildren in Tromsø, but of course grandpa is compensated for his COPD handicap. Sometimes he also measures vital signs (pulse, blood pressure) for his Personal Health Record to control his physical condition during heavy exercise and eventually to see how his condition improves. Improvement feedback is given by the IS-ACTIVE system (based on smart algorithms, configuration files and tailoring software).
He has also a motivational interactive application which can be used in house with a game controller and outside with sensors embedded in a fly fishing rod. This gives him tailored arm and upper-body exercising as a supplement to the biking.

He was sceptical about the use of electronic devices, but he finds the IS-ACTIVE sensors easy to use, with few buttons, and long lasting batteries. He did not even have to read the manual due to self-explanatory user interface of the system.
With help of the IS-ACTIVE tools he is brought to a level where he can take up many of the activities he liked to do, even though at a more moderate level than before. Most important is that he has learnt to cope with his disease, becoming socially active again, and exercises regularly now. All this contributes to his physical and psychological wellbeing.

### *4.2.3 Before scenario Sonja*

Sonja is a 70 years old talkative and social active urban lady. She is a widow and was diagnosed with COPD ten years ago, and is currently in COPD stage 3-4. She is a former teacher. Her children and grandchildren live near by, and she also enjoys a new relationship with a male friend. She moved into a flat on the third floor when her husband died. In the beginning she was capable of walking the stairs, but nowadays she prefers using the elevator due to the decreasing strength in her legs and it takes so much energy and time to walk the stairs. She enjoys dancing, shopping, and attending cultural activities in town, but nowadays she has problems doing this due to her increasing dyspnoea. Her cottage at Vannoya, a two hour drive away, is hardly ever used anymore because all the organisation, logistics and extra work involved is physically demanding

[10] http://www.seattle.intel-research.net/pubs/chi1111-consolvo.pdf

and exhausting (shopping, packing, travelling, unpacking etc.). Although she will not admit it, she still smokes a little.
Once a week she used to attend the patient organisations (LHL) dancing arrangements and this is where she also met her friend. Now participating is problematic for her, both due to her physical condition and to the air quality due to perfumes etc. Her friend still participates enthusiastically, not being limited by his heart disease.
Due to the severity of her illness she is annually referred by her GP to an 8 week pulmonary rehabilitation programme in the city. Twice per week they meet in a group to exercise, being educated about her COPD, and getting individual following-up – in a social supportive setting. She makes appointments when needed with her GP for various medical issues. On average she is admitted to hospital due to exacerbations about once to twice a year. She visits her pulmonary specialist at the hospital once a year, and is currently being considered for oxygen treatment. She sleeps badly, has lost weight and also has muscle atrophy. She should do more exercising daily tailored to her problems with balance, arm and leg strength, and breathing techniques during activity.
She receives home-care services from the municipality to help her overcome the burden of housekeeping, for instance bi-weekly cleaning of floors and making of the beds, since this is too heavy work for her and produces a lot of dust.

### *4.2.4 After scenario Sonja*

Overall goal for Sonja**:** *Improve her physical condition within her capacity, so she can get back into the social activity of LHL dancing*

Sonja was introduced to the IS-ACTIVE system by some fellow attendants at the LHL dancing arrangement, after she started to complain that it was becoming to exhausting for her to participate. Afterwards, she herself contacted a physiotherapist at the rehabilitation centre to get the professional supervision version of IS-ACTIVE she wanted.
Her IS-ACTIVE system provides tailored guidance for exercising her upper and lower extremities. The tailoring is based on data from several sensors, both wearable sensors and sensors embedded in fitness devices. When walking the outdoor stairs her wearable sensors provide audio guidance and play motivational music. Since people tend to overestimate their activity level, Sonja used the IS-ACTIVE tools to establish her baseline activity level. She also uses it to get feedback for motivation to a higher level of activity. Each week she has in addition a guidance session with her physiotherapist.
In order to strengthen her upper extremities her smart weight systems with embedded sensors provides feedback through music when she is doing correct movements and intensity. When she fails to do it properly she gets guidance through the IS-ACTIVE enabled TV device. She also has a wall attached IS-ACTIVE push-pillows/ boards with sensors to be used for strengthen both upper and lower extremities. Feedback is given in the form of sound and LED light.
When walking outdoor she uses the IS-ACTIVE sensor enhanced walking sticks detecting intensity and up and downhill walking. She also has a Pilates-ball with IS-ACTIVE sensors for monitoring movements, like up and down, duration, and intensity. The results are visualised on the TV where she can see if she has achieved her activity goals.
She just recently also started using the IS-ACTIVE virtual world dance party. It is a networked socially-enhanced virtual world dance game where users take part from their own living room, while doing exercises and activities in front of a large wall mounted

screen. The screen shows each user represented by an avatar of choice and sensors embedded in their environment (fitness devices, carpets) detect their movements and moves the dancing of the avatars in a similar way.

By means of the IS-ACTIVE tools Sonja has improved her physical condition, and has again started to participate and enjoy the LHL dancing sessions together with her friend, and they have even taken up using her remote cottage since Sonja feels stronger and less exhausted by her disease.

## 4.3 Scenarios Roessingh Research and Development

### *4.3.1 Current situation*

The history of COPD patient Bob

Bob is a 62 year old male and lives in the rural area of Enschede, the Netherlands. He was diagnosed with COPD almost ten years ago, and despite the fact he quit smoking, his disease is getting worse. Bob is a furniture maker, but due to his disease he stopped working. His dyspnoea became severe, he became more and more fatigued, was coughing a lot, and he felt increasingly limited in his physical capabilities – the intense scent and dusty work environment made him feel even worse. The consequence was that his self-confidence substantially decreased. Moreover, he felt uncomfortable around his colleagues, who did not really understand his problems. He decided to stop working, he is at home a lot, and Bob and his wife decided to buy a dog. Bob really enjoys the fresh air and walking with the dog in the forest.
During a visit to his general practitioner he was referred to the lung physician at the local hospital, since he was now in GOLD stage III, and from now on the lung physician would monitor him. He visits the hospital 2 times a year: once for an appointment with the lung physician and once with the nurse practitioner. They tell him that it is very important to stay active and strong: a lack of movement causes his physical condition to decrease rapidly, increasing his symptoms, and a vicious circle will ensue. When his body is in a better condition and shape, Bob is able to do more with the same lung function. Therefore, Bob has to participate in a COPD physiotherapy programme, but he rarely goes since he finds it too far from his house, and he finds it boring to do exercises there.

But Bob's situation is getting worse. This year Bob was even admitted to the hospital twice, due to exacerbations. He never overcame these exacerbations, and the recovery took longer the second time. At the moment he is at home. Last week, he paid his biannual visit to the hospital, this time to his lung physician. The doctor was worried, since Bob's symptoms are getting worse, and based on the spirometry results a large decline in lung function was found. Bob also lost 2 kilos of weight. The doctor again explains to Bob that exercise is really important to break the vicious circle and that nutrition provides his energy to breathe. If Bob's situation doesn't improve in the next 3 months, he should participate in a rehabilitation programme, where his activity behaviour and eating habits will be improved.
The dyspnoea remains very severe and he is afraid to experience extreme dyspnoea. He rarely walks the dog anymore. He likes to watch television, especially soccer and avoids physical activities and situations that might cause an attack of dyspnoea again. He rarely pays visits to his grandchildren anymore due to his disease, he feels physically limited and ashamed. His grandchildren say they sent him lots of e-mails, but he never reads them, because he doesn't know how this modern technology works. His lack of

movement causes that his physical condition decreases rapidly and he has trouble sleeping, caused by the low oxygen levels in his blood and the coughing. He also feels depressed, since he is less socially active. Therefore, Bob participated in the rehabilitation programme for 3 months. Within these 3 months Bob trained with other COPD patients which he enjoyed and he improved his physical condition. However, 2 months later, he reclined to his original low activity levels, since he was not motivated to be this active by himself.

#### *4.3.2 Future situation*

Introduction

In COPD care it is very important to stay active, so physical deconditioning can be prevented. Furthermore, levels of physical activity in daily life are related to higher risk of hospital admission and lower activity levels are linked to shorter survival. In the current COPD care, activity is promoted by the physiotherapist, but Bob has to travel to his physiotherapist. The rehabilitation programme went well, and Bob improved, but went back to his original activity level 2 months after the programme. Also, Bob is afraid to perform intense activities without the monitoring of the physiotherapist. Therefore he prevents movements without the supervision of a healthcare professional. Since Bob only receives feedback from his physiotherapist once a week (if he goes) it is difficult to stimulate him to be active. Furthermore, Bob feels limited in his physical capabilities, is depressed, afraid to perform activity, and is not socially active anymore, which together greatly reduces his quality of life.

The new IS-ACTIVE system could overcome these problems in COPD care, and the physiotherapist proposed the IS-ACTIVE system to Bob. The IS-ACTIVE system consists of a large set of sensors installed in his house and furniture, and a Body Area Network (BAN), which together enable the monitoring of his daily activities in and around the house, and guide him in improving his physical condition by providing personal context-aware feedback. The IS-ACTIVE system is connected to Bob's television screen, where a special channel now serves as the main screen for the system. He also received a PDA, which he can continuously take with him, inside or outside the house. The IS-ACTIVE treatment is focused on improving physical condition by monitoring activities, and guiding and promoting exercise. Social interaction is provided by group activity training, and outside-group sessions will improve social life and reduces depression. Monitoring during intense activities and exercises reduces anxiety, as well as including relaxation and breathing exercises. The IS-ACTIVE treatment can be used in everyday life of the COPD patient, or as a rehabilitation programme.

Scenario: a day in the life of Bob

*Monitoring*

At 8.00 o'clock in the morning, the IS-ACTIVE system detects by pressure sensors in his mattress that Bob has woken up and left his bed. He did not sleep very well last night, detected by the system's movement and sound sensors – there was a lot of activity and coughing recorded. He puts on his clothes and his BAN system which was recharged at night, and his amount of activity, activity pattern, and activity intensity measured by accelerometers; breathing frequency; and heart rate are continuously monitored automatically. Bob is only notified when something is wrong with the system when strictly necessary (like when the batteries are empty) and the system keeps track of the cause of a malfunction. Besides monitoring the on-body parameters, the IS-ACTIVE system automatically registers the time it takes Bob to perform certain standard activities, like walking stairs, or vacuum cleaning, during everyday life. When the system finds a deviating pattern, which could indicate that something is wrong with Bob, like a longer walk to the living room than normal, it will automatically be detected. The system also records the time spent in for example the bathroom and kitchen.

*Exercise, training and feedback*
Strength exercises are important in COPD care, and therefore the IS-ACTIVE treatment incorporates pre-programmed training exercises. At 10 o'clock Bob takes his small weights (with incorporated sensors) and executes the exercises as shown on the main screen. The BAN keeps recording activity, heart rate, and breathing frequency. His saturation is also measured during these exercises with a finger clip sensor, to warn him for low oxygen levels when necessary, on the main screen. An Embodied Conversational Agent in the form of a virtual physiotherapist provides feedback in natural language and Bob feels guided, motivated, and safe. The virtual physiotherapist is also learning how to present its feedback to Bob so as to not come across too strict or too lenient for Bob's likings. The system registers when Bob performs the strength training exercise and takes care that Bob distributes his activity over the day by providing feedback, suggesting to, for example, take a walk. After he finished his exercises Bob wants to go up the stairs but the system detects that his breathing frequency is high and gives him feedback that he should take a short rest half-way. Bob was glad with this advice, otherwise he would probably have to experience extreme dyspnoea. Besides the specific strength training exercises, Bob can always do relaxation or breathing exercises. He can use a button on the main screen to gain information about it anytime he wants. The system records all exercises Bob performed.
In the early afternoon, Bob does not feel very well, but the IS-ACTIVE system advices to take a walk (with the dog) since it senses that it is very nice weather outside, which can do him well. The system proposes a short route of 1 km with a description of the road to walk on his PDA, since it contains GPS. Bob puts on his finger clip sensor, so the system can warn him for low oxygen saturation levels on the PDA.

*Group training*
Besides the individual exercises, the IS-ACTIVE system also comprises group training, inside and outside. In the living room the main screen always shows the upcoming events like inside or outside group training sessions, for which Bob can apply on the main screen. Today, Bob participates in an online stationary cycling session, together with 4 other COPD patients. Bob has a stationary bicycle in his living room which is connected to the IS-ACTIVE system. The virtual physiotherapist guides him in the training. He can also see on the main screen how the other COPD patients are doing, relatively to their personal treatment goal, which was set automatically by the system and has been approved by his physiotherapist. Today, the system registers that Bob is not doing that well compared to normal, based on the measured parameters.

*Alarm*
Before he goes to bed, Bob fills in his diary that his complaints are worse than normal, just like yesterday. Together with the deviating daily life patterns, and the bad performance in his exercises today and yesterday, the IS-ACTIVE system sends an alarm message to the nurse practitioner and sends a notification to the physiotherapist. The alarm was treated by the nurse practitioner who adapted his medication use, and an acute exacerbation was prevented.

*Healthcare professionals*
Information about the physical condition and activity performed at home is important for the healthcare professionals. The right action can be taken at the right time, and enables the specialist to monitor his disease progress. The professional can monitor the progress of the patient by logging in on a web database. Both the physiotherapist and lung specialist/nurse practitioner are able to view patient's data and are warned when the condition deteriorates.
The physiotherapist can see the amount of activity, activity intensity, and activity pattern (distribution of activities over the day) per day, per week, per month and per year. He can also see the saturation, heart rate, breathing frequency and diary recordings for the same time periods. Furthermore he can see how often Bob performs exercises and how well they are going. He receives a notification when the exercises and/or activity patterns change. He can then send a personal message to the main screen to the patient or invite him for a personal appointment at the practice. The nurse practitioner can see the same data, but receives a notification when the diary recordings say that Bob feels worse than normal. The nurse practitioner can then send a personal message to the patient's main screen, adapt his medication, or invite Bob for a personal appointment at the hospital. The lung physician can see the same data but will just receive notifications; only the nurse practitioner will take action.

3 months later
Bob is enthusiastic about the system and motivated to be active since he can monitor his own progress. On the main screen he often looks for his progress per week, and compares it to the weeks before. He can also see the amount of exercises and training he did. He sees that his activity is improving and he feels safe, guided and motivated by the IS-ACTIVE system. He also likes that he met a lot of peers with the same problems in the group training sessions. They even started up a monthly soccer training group especially for COPD patients!

# 5 Requirements analysis workshop

A workshop took place at September 30, 2009, in Vienna to develop the requirements. This chapter describes the set-up and includes the notes of this workshop.

## 5.1 Workshop – Vienna, September 30, 2009

Prior to the workshop, every clinical partner filled in a short questionnaire about how COPD care is currently provided and how each clinical partner foresees it to be provided by means of the IS-ACTIVE system. Next, all clinical partners were asked to develop scenarios as input for the workshop: one user scenario about current COPD care ("before" scenario) and one user scenario on how COPD care should be in the future using the IS-ACTIVE system ("after" scenario). By using the questionnaire and the PACT table, it was analysed what users do and want, and the answers to the PACT table were incorporated as a storyline in the before and after scenario. The goal of these user scenarios was to get the first concrete needs and ideas of the different clinical partners of the consortium, and served as the starting point for the workshop. Furthermore, a state of the art was prepared by NST/NOR and RRD, in order to inform the other partners of the consortium.

The goals of the workshop itself were

- to inform about the state of the art & ideas of clinical partners,
- to determine the project scope and technological possibilities,
- to determine the (preliminary) user needs from the scenarios,
- and to formulate the first requirements.

During the workshop the state of the art and the scenarios were presented to all partners of the consortium. Based on the information and ideas presented, the technical partners discussed the technological feasibility and possibilities, and together with all partners a project scope was determined. This was the starting point for the development of the user (clinical) needs, which was organised by 4 plenary group sessions, according to the PACT approach. The common elements from these scenarios of the clinical parties were defined, and a start of defining requirements was made, by categorising these according to the MoSCow method (must-haves, should-haves, could-haves, won't haves).[11]
Based on the results of the workshop the functional requirements were further developed, and feedback was provided by e-mail from all partners of the consortium. The results of the requirements analysis are presented in chapter 6.

[11] Clegg, Dai; Barker, Richard (2004-11-09). *Case Method Fast-Track: A RAD Approach*. Addison-Wesley. ISBN 978-0201624328.

## 5.2 Workshop notes

All partners of the consortium were present: UT, RRD, INE, NST, NOR, ELS, PRS.

The following time table was the programme of the requirements workshop held September 30th 2009 in Vienna, Austria.

| | |
|---|---|
| 9.45 – 10.30 | State-of-the-art presentations<br>RRD & Norway |
| 10.30 – 10.45 | Coffee break |
| 10.45 – 11.15 | Scenario presentations<br>Norway, ESL, RRD |
| 11.15 – 11.35 | First impressions/technical feasibility |
| 11.35 – 13.00 | Development clinical needs |
| 13.00 – 14.00 | Lunch break |
| 14.00 – 14.45 | Finalise workshop |

*State-of-the-art presentations*

<u>State-of-the-art presentation RRD - Monique Tabak</u>

- Long-term effects are difficult to measure: how to solve?
- Treatment effects might result from the attention that is given to the patients.
- Sustainability not feasible to prove in the scope of this project.
- The article of de Toledo et al. should be included in the review with caution, the content is questionable.
- The focus of IS-ACTIVE should be on initial change in behaviour. Then a follow-up project could be used to prove sustainability. (Note**:** the project documentation should state that sustainability is out-of-scope).

<u>State-of-the-art presentation Norway - Lars Vognild</u>

- Should a system be used for ever or for a specific period of time?
- Fish'n steps: Encouraging Physical Activity with an Interactive Computer Game (2006), Siemens Corporate.
    - Mixed reaction to the negative feedback (perhaps due to association to living animal (fish). A recommendation was: "don't do the negative feedback".
    - Also: competition and anonymity can backfire.
- Consolvo et al, Design Requirements for Technologies that Encourage Physical Activity (CHI'06).
    - Give proper credit for <u>all</u> activities
    - Performance indicators
- UbiFit (flower field background on your cell phone)
    - Feedback continuously
- It should be possible to add an unrecognised activity to the system (Note: perhaps such a feature is too difficult for an elderly population).
- Networked exercise bikes, like Expresso.com. Existing products are too expensive, should be done in a cheaper, smarter, out-of-the-box way.

- PRS: Randomised positive feedback was found out to be better than feedback based on performance (in the context of World of Warcraft, online gaming).

*Scenario presentations*

Scenarios Norway – Tatjana Burkow

- Target group is Moderate COPD (Erik) and Severe COPD (Sonja) patients.
- In Norway it‘s more difficult to participate in health- and social activity programs due to the long winter season with snow and the long distances/ rural area.
- Many people move into flat apartments when they become older due to the winter climate.
- Goal for Eric in the scenario: reach a certain mountain peak.
- Erik scenario: Community tool with fellow ”walking friends”, tailored daily exercise plan (using weights, Pilates ball etc.), social biking tool with grandchildren, indoor and outdoor fly fishing exercise game.
- Due to non-severity of disease, Erik uses the IS-ACTIVE system without supervision of a healthcare professional.
- Goal for Sonja in the scenario: Be able to enjoy the social activity of dancing again
- Sonja scenario: Nordic walking stick with sensors, Pilates ball with sensor, push-pillow with sensors, stair motivating tool, virtual world dance party, regular guiding sessions on TV by a physiotherapist
- Issue: Should we consider monitoring during sleep?
- Issue: Design as a long-term system or an X-month treatment program?

Scenario's ELS – Mihai Berteanu

- Needed sensors: pulse oximeter, RR-thoracic brace/patch for sleep apnoea, expiratory time and cough.
- Movement sensors, posture sensors, vegetative skin response – emotion
- Outside information: temperature, humidity, light (day/night), air quality: pollen, smoke, dust.
- Respiratory movement sensor
- Mr Popescu has problems with understanding the graphical representations of physical activity (Note: understanding different types of graphical representations of activity data is something that can be researched separately with any kind of elderly population).

Scenarios RRD – Monique Tabak

- IS-ACTIVE system consists of on-body sensing, sensing in house (furniture) & exercise equipment, ambulant interaction device for feedback (PDA), main screen in living room.
- Goals IS-ACTIVE treatment: to improve QoL, improve/maintain “good“ physical condition, reducing social isolation.
- Monitoring activity, HR, RR continuously, monitoring daily life patterns (time spent vacuum cleaning, walking stairs), monitoring vital signs during exercise & intense activity.
- Priorities:
  - On body activity monitoring and personalised, context aware feedback
  - Guided exercise and feedback on performance and safety

  - Environment monitoring - continuously monitoring daily life patterns
  - Virtual Group training with social interaction
- Less priority:
  - Monitoring progress by healthcare professional
  - Alarm function (diary, performance exercise/training, daily life patterns)

*Project scoping*

Technological remarks - Mihai Marin-Perianu / Raluca Marin-Perianu

- The focus on Inertial (movement) sensors should be clear (as it is in the project title).
- More detailed body-information requires more sensors... prioritise.
- Heart rate / pulse oximeters should be used from third parties.
- Environmental sensing shouldn't be the core of the project, but can be used when available.
- Cough/breathing detection might not be feasible using inertial sensors alone, but might be a possibility to try them out.
- Battery lifetime and recharging needs to be kept in mind.
- Electronic Diary is desirable, but could be kept simple.
- Long distance link to care centre no priority.

*Clinical needs discussions (PACT)*

People

- GOLD II-III
- The goal for which the patients use the system is improving physical condition. Physical condition could be measured by means of endurance capacity tests (6-min-walk).
- Role of healthcare professionals: (ELS) healthcare professional should collaborate with patients to decide whether or not to use the IS-ACTIVE system. System should be distributed through the hospital route. Patients will be monitored (supervised) by the hospital staff.
- NOR: In Norway, the patient organisation or a physiotherapist at a rehabilitation centre can collaborate with patients to decide whether or not to use the IS-ACTIVE system. The more severe the patient is, the more guidance is needed.
- Different types/degrees of “supervision”: supervised by healthcare professional, unsupervised by professional, supervised by the system.
- ELS wants alarming to the patients in case of sleep apnoea.

Activities

- NOR: patients should have some knowledge of (rehabilitation) exercises before start using the IS-ACTIVE system; they will gain this knowledge from previously followed rehabilitation programs. In Norway rehabilitation is recommended for GOLD stage 2 – 4.
- ELS: Patients should get the IS-ACTIVE system after rehabilitation, because they need the knowledge about physical activity being important for COPD treatment.
- RRD: rehabilitation programmes are only used for COPD patients with severe COPD, so patients might be able to get the system from the physiotherapist, without having to go through rehabilitation programmes.

- RRD: The IS-ACTIVE system should preferably be set up in a modular way, so different COPD patients can get different set-ups of the system tailored to their disease progression and personal preferences.
- Motivation and acceptance of the patients is very important, otherwise the system will not be successful.
- We still need to define which activities we need to monitor exactly.

Context / communication

- Use the word "coaching" instead of "monitoring".
- Responsibility issues: who is responsible in case of an alarm? Who takes action? No immediate, “life threatening” alarm should be incorporated in the IS-ACTIVE system.
- Interaction depends on severity, and who you are (anxiety).

Technology

- See project scope.
- Sensor nodes: inertial sensing, no new sensors, interface to other sensors (Bluetooth)
- Feedback: D2.1 needs to include documentation on feedback (what are the different possibilities for generating and representing feedback) that will fit into the functional requirements. They should be detailed enough to derive the architecture requirements. Should be done in two weeks, together with Lars (NOR). The feedback functional requirements do not need to be very detailed.

*Finalisation*

| | |
|---|---|
| Must haves | Inertial sensor node system: activity, control, categories<br>Bluetooth interface sensors (oxygen saturation, HR, breathing)<br>Analysis tools: exercise and activity monitoring<br>Feedback using PDA, pc, television, other ambient devices |
| Should haves | Sleep apnoea detection (saturation, breathing)<br>Integration with other sensors (e.g. skin conductance)<br>Games for additional motivation |
| Could haves | Web portal<br>Electronic diary (predict exacerbations)<br>Integration with environmental data (e.g. weather)<br>Location (GPS) |
| Won’t haves | Emergency |

*Next steps*

Before **October 16,** 2009

Who: RRD, Norway, ELS

1. Create a list of detailed descriptions of physiotherapy exercises that we want to be able to recognise or incorporate into the 3D submarine game.
2. Create a list of activities of daily living that we need to be able to recognise. Be as specific as possible (e.g. walking: uphill and downhill, inside the house and outside).
3. Categorise the lists of exercises and daily activities according to the Must-Haves/Could-Haves/Should-Haves/Won't-Haves scale.
4. Updated version of scenarios, where point 1 and 2 (and 6) are incorporated

Who: RRD, Norway

5. Write a short state of the art for the deliverable about
    - User-interaction (Norway)
    - Role of ICT in COPD care (RRD)
    - Feedback (RRD & Norway)
6. Define functional requirements related to feedback. The level of detail should be enough to be able to derive the Architecture Specification (D2.2) from them.

Who: RRD

7. Finalise the Functional requirements for D2.1.
8. Introduction and methods for the deliverable.

Please send your documents to m.tabak@rrd.nl when something is finished, so it can be put in the deliverable.

Before October 19, 2009
Deliverable 2.1, draft version, including scenarios, state of the art, feedback, and functional requirements. Coordinator: RRD

Before October 23, 2009
Feedback from all partners concerning the deliverable 2.1, especially the functional requirements! Please send your feedback to m.tabak@rrd.nl

October 28, 2009
Final version deliverable 2.1

# 6 User requirements

This chapter describes the functional and non-functional requirements for the IS-ACTIVE system. It is a running document, and adaptations can be made during further development of the IS-ACTIVE project.

## 6.1 Introduction

The IS-ACTIVE requirements workshop was concluded with a table of characteristics of the IS-ACTIVE system divided into must haves, should haves, could haves and won't haves. It became clear that the main focus should be activity monitoring, exercise and feedback using inertial sensors with optional oxygen saturation, breathing and heart rate sensors via a Bluetooth interface – where user interaction is provided through various feedback devices. Besides, it would be nice to include sleep apnoea detection, to use games for additional motivation in exercising, and to integrate even more sensors like skin conductance. Additionally, it could be possible to include a web portal, an electronic diary to predict exacerbations, and integrate environmental data. Furthermore, it became clear that we will not include emergency notifications, sensors in furniture, or register the time spent in certain rooms in the house.
The system will be provided by the physiotherapist (all), the patient organisation (ELS & NST), or the nurse (preferably pulmonary) (NST). The system will be used as a regular training program of the physiotherapist (all) or after a rehabilitation program (NST).
In the following paragraphs a list of requirements is presented based on these workshop outcomes and the scenarios.

## 6.2 Functional requirements

Below the list of functional requirements is presented. The preference of each partner is indicated between brackets according to the MoSCoW method for a number of requirements. Where nothing is stated all partners agreed that (a part of) the requirement is a must-have, and these should be included in the IS-ACTIVE system. For requirements where there is some discrepancy between priorities, further intensification is needed. The technological possibilities of the requirements should be discussed in the next phase of the project (D2.2) and a choice for inclusion of the requirements in the IS-ACTIVE project will be made accordingly. Furthermore, the type of fitness devices included will depend on the exercises included, see the requirements supplement – exercises, §6.3, and the type(s) of feedback device(s) has/have to be defined later in the project (WP5).

**Abbreviations:**

| | |
|---|---|
| M | must have |
| S | should have |
| C | could have |
| W | won't have |
| ELS | Elias University Hospital |
| NST | Norwegian Centre for Telemedicine / University Hospital of North Norway |
| RRD | Roessingh Research and Development |

**1. On-body sensing requirements**

1.1 The system must continuously monitor activity, daily activities, and breathing (see 1.2, 1.3 and 1.5) by inertial sensors inside and outside the house, when the patient wears the IS-ACTIVE system.

1.2 The system must continuously monitor the amount of activity, the activity pattern (distribution of activities over the day), and activity intensity.

1.3 The system must continuously detect the type of daily activities walking, walking stairs, and in addition:
- cycling (outdoor) (**M**: ELS, RRD; **C**: NST)
- walking uphill/downhill (**M**: NST; **S**: ELS, RRD),
- walking stairs up/down (**M**: NST; **S**: ELS, RRD),

1.4 The system must continuously measure the duration of the activities stated in 1.3, and must in addition measure:
- distance and speed of cycling (outdoor) (**M**: ELS; **S**: RRD; **C**: NST).
- distance and speed of walking (**M**: ELS, NST; **S**: RRD).

1.5 The system must continuously monitor breathing by the respiratory rate and in addition
- expiratory time (**S**: ELS, RRD; **C**: NST)
- cough (**C**: ELS, NST, RRD).

1.6 The system must monitor the saturation and heart rate during exercise or intense activities by choice of the patient.

1.7 The sensors besides the inertial sensors must be equipped with a Bluetooth connection.

1.8 The system must monitor breathing and saturation at night to detect sleep apnoea (**S**: ELS; **C**: RRD; **W**: NST)

1.9 The system must monitor posture (standing, sitting, lying) (**S**: ELS, RRD; **W**: NST).

1.10 The system must monitor vegetative skin response and skin conductance. (both: **S**: ELS; **C**: RRD; **W**: NST)

1.11 It must be possible to enter information manually through a feedback device in case the sensors are not able to correctly detect activities (**M**: NST; **W**: ELS, RRD).

***2. Environmental sensing requirements***

2.1 The system must include fitness devices with incorporated inertial sensors, for monitoring treatment progress (see 3) and provide feedback during the exercises (see 6).

2.2 Inertial sensors must be attached to the bicycle (outdoor) of the patient.
(**M**: RRD; **S**: ELS; **C**: NST)

2.3 Inertial sensors must be attached to the bicycle (indoor) of the patient.
(**M**: NST; **S**: ELS, RRD)

2.4 The system must use information from the weather outside (**S**: ELS, NST, RRD) and the location of the patient (**C**: ELS, NST, RRD) for context-aware feedback (see 5.6).

2.5 The device must measure the quality of air (temperature, humidity, dust, smoke, and pollen).(**C**: ELS, NST, RRD)

2.6 The system must include an electronic diary to predict exacerbations. (**M**: ELS; **S**: RRD; **W**: NST)

### *3. General treatment requirements*

3.1 The system must be able to set a personal treatment goal of the patient in order to improve physical condition, quality of life and prevent exacerbations.

3.2 The physiotherapist (all) OR rehabilitation physician (ELS) must be able to adapt and approve the treatment goal set by the system.

### *4. Exercise & training requirements*

4.1 The system must provide exercises (see supplement) for the patient to train interactively using fitness devices with incorporated inertial sensors and the on-body sensors (see 1).

4.2 The executed movements of the patient during exercises must be shown on a feedback device when the patient is exercising OR exercises must be incorporated in virtual games on a feedback device.

4.3 The system must register when, how often, and for how long the patient performs exercises. (**M**: ELS, NST; **S**: RRD)

4.4 The patient must always be able to gain information about how to perform exercises in a visual and auditory manner on a feedback device. (**C**: ELS, NST, RRD)

4.5 The system must comprise group training and exercises, so the patient can perform the normally individual exercises (see supplement) in a group (**M**: NST; **C**: ELS; **W**: RRD)

- The system must be able to communicate with other patients.
- The patients belonging to one group must be networked.
- The individual treatment goals of the exercise performed as a group should be shown to the group as relative treatment goals on the feedback device.
- Besides the personal treatment goal of each individual patient, the group must have a predefined activity goal, set by the system.
- Besides the individual feedback, the group must receive feedback concerning the group activity goal, based on the data from the on-body sensors and the inertial sensors incorporated in the fitness devices.

### *5. General feedback requirements*

5.1 The system must keep track of the personal treatment goal based on the measured sensor data of the patient and should propose exercises AND/OR activity in order to accomplish the treatment goal.

5.2 The system must recognise the trends after feedback and learn from the feedback provided, and use the type of feedback that is the most effective for the patient.

5.3 The system must be able to give feedback both inside, and outside a patient’s home, as well when the patient is on the move.

5.4 The system must be able to detect personal preferences of the patient (like walking or cycling) and the patient must be able to fill in personal preferences as well into the system.

5.5 The feedback must be tailored and personal - the system automatically adapts the feedback to the patient’s personal preferences and health status.

5.6 The feedback must be context-aware, by making use of information regarding the patient’s surroundings. (**S**: ELS, NST, RRD)

***6. Feedback during exercise/training requirements***

6.1 The feedback during exercise must be focused on the right execution of the exercises (based on data from on-body sensors and sensors embedded in fitness devices), activity intensity, and safety (based on breathing, heart rate and saturation parameters).

6.2 Feedback must be provided during exercises on a feedback device, in a motivating manner, so the patient feels guided and motivated.

6.3 The patient must be noticed when saturation levels are too low (threshold determined by the system, and approved by the physiotherapist) and/or heart rate is too high (threshold determined by the system, and approved by the physiotherapist) and/or on-body parameters indicate severe dyspnoea (determined by the system). Otherwise, these parameters must not be shown to the patient during exercise. (**M**: ELS, RRD; **S**: NST)

***7. Feedback during activity requirements***

7.1 The feedback during activities in daily life must be focused on the amount of activity, based on the personal treatment goal (see 5.1) and in addition
   - must be focused on the right distribution of activities over the day based on the personal treatment goal (**M**: ELS, RRD; **S**: NST)
   - must provide feedback to the patient to prevent extreme dyspnoea (based on the data from the on-body sensors, determined by the system) (**S**: ELS, NST, RRD)

7.2 Feedback must be provided automatically by the system on a feedback device about the patient's daily activities in a motivating manner.

7.3 In case the patient wears the optional sensors during daily physical activities, the patient must only be noticed when measured saturation levels are too low (threshold determined by the system, approved by the physiotherapist) and/or heart rate is too high (threshold determined by the system, approved by the physiotherapist). (**S**: ELS, NST, RRD)

***8. Treatment progress requirements***

8.1 The patient needs to log in to gain access to the data.

8.2 The amount of activity and the activity pattern must be accessible for viewing on a feedback device with a graphical view by hour, daily period, day, week, month and year, depending on the type of feedback device together with the personal treatment goal and the progress (e.g. % of treatment goal achieved, or reference line).

8.3 Results of the exercises (see 4.3) must be visualised on a feedback device together with the personal treatment goal.

8.4 The system must generate weekly reports about the patient's status, including the amount of activity, activity pattern, results of the exercises, personal goals and progress information. This could be incorporated in a Personal Health Record so the patient can monitor his/her progress. (**M**: ELS; **S**: NST, RRD)

***9. Healthcare professional requirements***

9.1 The physiotherapist OR a nurse (preferably pulmonary) (NST) must have access to the patients data in order to monitor progress by the Personal Health Record (**C**: ELS, NST, RRD) by a personal log in.

9.2 The device must generate weekly reports about the patient's status, with all the measured data. This could be incorporated in a Personal Health Record so the healthcare professional (see 9.1) can monitor the patient's progress. (**S**: ELS, NST, RRD)

9.3 The healthcare professional (see 9.1) must be able to send a personal message to the feedback device of the IS-ACTIVE system of the patient. (**C**: ELS, NST, RRD)

9.4 The patient must be able to choose the amount of supervision (no supervision option: patient sets own goals, or professional supervision option: physiotherapist sets goals, and extra guidance sessions with physiotherapist). (**M**: NST; **W**: ELS, RRD)

## 6.3 Non-functional requirements

Non-functional requirements include constraints and qualities. *Qualities* are properties or characteristics of the system that its stakeholders care about and hence will affect their degree of satisfaction with the system. *Constraints* are not subject to negotiation and, unlike qualities, are (theoretically at any rate) off-limits during design trade-offs.

*Usability*

- The system must be easy to use for patients with limited computer skills
- The system must be easy to use for patients with reading disabilities
- The system must be easy to learn by the patients
- The system must be fun and motivating to use for the patients
- The system must provide support to the patient when necessary (help function)

*Operational requirements*

- It must be possible to use the system in rural areas (with limited network capabilities)
- It must be possible to use the system in cold winter climate
- The system must have a modular set-up so it is able to adapt to the needs of the patient.

*Security*

- Confidentiality: Information stored in the system must only be available for authorised users.
- Integrity / availability: Unauthorised persons must not be able to change the information in the system.
- Law: The system must fulfil national legislations on procession of personal data based on the European directive on the protection of personal data.

*Maintainability*

- The system must be easy to maintain by the user.

## 6.4 Requirements supplement – exercises

The exercises described below are part of the exercises COPD patients usually have to perform in order to improve strength, balance, breathing, mobility, flexibility and endurance or a combination of these. Some of these exercises were part of a previous study with the focus on self-management of COPD patients, developed by the physiotherapists of that investigation.[12] Other exercises were developed by NST.

Each clinical partner has its preferences in which exercises should be included in the IS-ACTIVE programme. The common must-have exercises are indicated by bold numbers.

| | |
|---|---|
| NST | Must have: 1, **4, 5**, 11, 12, 13, **14,** 16, 17, **18**, 19, 20. Nice to have: 3 |
| ELS | Must have: 1, 2, 3, **4, 5,** 6, 7, **14,** 15, **18**. Should have: 8, 9, 10, 11, 16, 17, 19, 20. Could have: 12, 13. |
| RRD | Must have: **4, 5**, 8, 9, 10, 12, **14**, 15, 16, **18**. Rest is nice to have. |

A short, preliminary, description of each exercise is presented below. The choice of which exercises will eventually be included in the IS-ACTIVE programme will be made based on the technological possibilities, and these will be described in more detail after the final choice for the included exercises is made.

### *6.4.1 Breathing exercises*

Exercise 1: Pursed-lips breathing

- Breathe in through nose.
- Breathe out through mouth with pursed lips.

This breathing technique is mainly used with/after shortness of breath after exertion, to promote recovery.

Exercise 2: Chest/side/diaphragmatic breathing

- Put one hand on the belly, and the other hand on the thin flank.
- Breathe in through nose.
- Breathe out through mouth.

The chest breathing is often limited in COPD patients, and it is important to sustain / improve this breathing.

Exercise 3: Optimise diaphragm function

- Breathe in quietly through nose (fill lungs completely so that belly is expanded).
- Breathe out quietly through mouth.

[12] Effing T, Kerstjens H, van der Valk P, Zielhuis G, van der Palen J. (Cost)-effectiveness of self-treatment of exacerbations on the severity of exacerbations in patients with COPD: the COPE II study. Thorax. 2009 Nov;64(11):956-62.
Weltevreden, P., COPD physiotherapy home exercises, COPE-actief, 2008

#### *6.4.2 Endurance exercises (also during daily life)*

<u>Exercise 4: Cycling</u>

- Upright position.
- Saddle on “hip height” (so that knees can be stretched).
- Self evaluation of start and stop condition (dyspnoea, Borg scale).
- During and after cycling: pursed-lips breathing in case of dyspnoea.
- Stabilise breathing after cycling with breathing exercise.

<u>Exercise 5: Walking</u>

- Relax the shoulders.
- Walk in upright position.
- Self evaluation of start and stop condition (dyspnoea, Borg scale).
- During and after walking: pursed-lips breathing in case of dyspnoea.
- Stabilise breathing after walking with breathing exercise.
- If possible use Nordic walking sticks during walking.

#### *6.4.3 Sputum mobilisation exercises*

Excess of sputum is a potential danger to get an airway infection, which could cause an exacerbation.

<u>Exercise 6: Huffing</u>

- Sit and lean with arms on the table.
- Breathe deeply a couple of times.
- Breathe out strongly with open mouth and tight the abdominal muscles.
- A forceful arm movement backwards (of both arms) can ease the huffing technique.

<u>Exercise 7: Coughing</u>

- Sit and lean with arms on the table.
- Breathe deeply a couple of times.
- Breathe out maximally till a coughing stimulus.

#### *6.4.4 Mobility exercises*

In COPD, the thorax tightens, and a “barrel chest” can develop. It is important to remain thorax mobility and flexibility.

<u>Exercise 8: Rotation</u>

- Sit, straight, on a stool, in front of the mirror, with the hands in the neck.
- Turn the shoulders left to right.
- Sit up straight.
- Keep pelvis straight.
- Breathe out during rotation of the shoulders.
- If it is too difficult: put your hands, crossed, on your shoulders.

<u>Exercise 9: Lateral flexion</u>

- Sit, straight, on a stool, in front of the mirror, with the hands in the neck.
- Move with the elbow towards the floor.

- Move the back only left/right, sit up straight.
- Breathe out during movement left/right.
- If it is too difficult: put your hands in the side.

Exercise 10: Extension
- Sit in front of mirror.
- Straight up back by stretching the arms upwards.
- Breathe in during stretching the arms upwards.
- Shoulders should stay above the hips.
- If it is too difficult: put your hands on your back.

Exercise 11: Rotation
- Sit straight on a stool, or stand upright.
- Lift one elbow up slowly (to the side) as high as possible, move slowly downwards, lift then the other elbow, repeat.
- Breathe in during exertion, breathe out during relaxation.
- Lift both elbows (to the side) as high as possible, keep hands together.
- Turn body slowly to one side and then to the other (let arms follow body movement), keep back stretched.

#### *6.4.5 Strength exercises*

The muscle strength is often greatly reduced in patients with COPD. Muscles in the shoulders and chest are involved in breathing.

Exercise 12: M.biceps brachii
- Stand up right or eventually sit straight on a stool.
- Have a weight in the hand, flex the arm, and stretch the arm.
- Move the forearm, the upper arm and elbow stay in the side:
  - One arm at the time
  - Left and right arm in turns
  - Both arms simultaneously
- Breathe in during exertion, breathe out during relaxation.

Exercise 13: M. serratus anterior
- Lie on your back.
- Stretch out arms with a weight:
  - One arm at the time
  - Left and right arm in turns
  - Both arms simultaneously
- Breathe in during exertion, breathe out during relaxation.

Exercise 14: Mm. quadriceps
- Step with one leg on the lowest tread of the stairs, also step with the other leg on the same tread, and step back.
- Stand up straight.
- Stretch your legs.
- Put both feet on tread.
- Use the rail when necessary.

Exercise 15: Mm. quadriceps
- Stand in front of chair.
- Bend the knees with the bottom backwards.
- Just before you touch the chair, you stop and move upwards.
- Breathe out when you bend the knees.
- Keep back straight.
- Feet below hips.

### *6.4.6 Combination exercises*

Exercise 16: Weight circles (strength, thorax flexibility**,** and balance)
- Standing or eventually sit straight on a stool. One weight in each hand.
  - Hold hands together and make circles. Start with small circles and gradually increase the size of the circle.
  - Start with hands together, arm cycling. Start with small circles and gradually increase the size of the circle.

Exercise 17: Rubber band exercise (strength, thorax flexibility)
- Stand up straight or sit on a stool with a rubber band in the hands and under the feet.
- Pull the rubber band upwards, move arms down and backwards:
  - Left and right arm in turns
  - Both arms simultaneously

Exercise 18: M. quadriceps (strength and balance)
- Stand up straight.
- Lift one foot with bended knee to hip height level, repeat several times, preferable without touching the floor with the foot.

Exercise 19: Pilates I (strength and balance)
- Sit on the ball, move up and down, keep feet on the floor.

Exercise 20: Pilates II (strength and balance)
- Sit on your knees with the ball (on an exercise mat) in front of you, arms on top of the ball.
- Move body forward while standing on toes until knees are fully stretched.
- Same as above, and continue to roll the body on top of the ball until hands touch the floor.
- Walk on hands, while the ball stays under the thighs.

# 7 Discussion

The development of the user requirements of the IS-ACTIVE project was the central aim of this deliverable (2.1). In order to devise these, a state of the art was performed and a user-centred approach was chosen, using scenarios, for the development of the requirements. Furthermore, a requirements analysis workshop was held September 30th 2009, in Vienna, Austria. The use of a set of scenarios is useful in supporting users' needs elicitation and communicating a concept of technology understandably. The scenarios were developed in order to serve as a basis for discussions within the project, and to provide information for partners with less knowledge about COPD and exercising. Hence, there are more ideas and functionalities described in these scenarios than will be developed in the future IS-ACTIVE system.

During the workshop the IS-ACTIVE consortium decided that the main focus will be activity monitoring, exercise and feedback using inertial sensors with optional additional sensors via a Bluetooth interface, using various feedback devices, in order to improve the physical condition and quality of life of COPD patients. The corresponding requirements are categorised into requirements we must have, and requirements where there is some discrepancy between priorities of the three clinical partners. Since this is an international project we believe that these differences are important and should be possible: different countries have different needs. The choice for the inclusion of the requirements in the IS-ACTIVE system will be based on technical feasibility, and they will be addressed in order of priority.
In particular, possible exercises were included in the requirements supplement, but each clinical partner had its preferences in which exercises should be incorporated in the IS-ACTIVE programme. The choice of which exercises will eventually be included will be made based on the technological feasibility of each exercise, taking the clinical importance into account, involving user assessment of the technology. The included exercises must be described in more detail after this choice is made, in line with the development of the system architecture (D2.2), e.g. what movement should the system exactly detect, what sensors should be used, etc. Furthermore, the choice for the type of fitness devices with incorporated sensors that will be used in the IS-ACTIVE system is related to the choice of the exercises. The feedback requirements should be further specified as well, including the type of feedback device. WP5, task 5.1, focuses on enhanced user interaction and real-time feedback – design and implementation of user interfaces; usability analysis of user interaction; and feedback methods.

In this deliverable, a user-centred, general set of user requirements is defined, and with this list of requirements we all agree with the direction of the IS-ACTIVE project. It is important to note that this list of requirements is under development, and adaptations can be made, and are needed, during further development of the IS-ACTIVE project. It still needs a more in-depth (quantitative) definition, taking user's assessment of technology into account, and in line with adaptations made for the final system architecture, technical specifications have to be developed next (in D2.2).

# 8 Appendices

## 8.1 Questionnaire

The ISACTIVE system can only be successful when it matches with the needs of professionals and patients in the routine clinical practice. Only then can advantages, compared with existing products and services, be obtained and will it be used in COPD care. That is why we start with some questions focusing on how the COPD care is currently provided and how you foresee it to be provided by means of the ISACTIVE system.

We would like you to answer the questions as good as you can (deadline: Tuesday 22 September 2009). For extra clarification you might be interviewed by Monique Tabak (telephonic interview), between September 22- September 25 2009. We therefore ask you to fill in your contact information below.

Your name:……………………..

Your organisation:………………………..

Your role in the organisation: ………………………..

Your e-mail address: …………………

Your phone number: ……………………

Will you attend the project meeting (Sept 30)? Yes/No

When will you be available for a telephonic interview? Please fill in the table below:

| | Tuesday 22 Sept | Wednesday 23 Sept | Friday 25 Sept |
|---|---|---|---|
| 9.00 – 12.00 hr | | | |
| 13.00 – 17.00 hr | | | |

**QUESTIONS:**

**COPD patients**

1. What are the problems COPD patients are facing in your country? Please specify (e.g. social isolation, limitation in movement, ….)

2. Which problems of the COPD patients could be treated by the ISACTIVE system?

**Current COPD care in your country**

3. What type of treatment do COPD patients receive in your country?
    a. Psychological cognitive treatment

       Please specify (memory, language, coping, …..)

    b. Physical functional treatment

       Please specify (strength training, cardio, …..)

    c. Other treatment

       Please specify (e.g. specific rehabilitation programme, nutrition counseling, …..)

4. Which health care professionals are involved in current COPD care?
    a. Please specify (lung physicians, nurse, physiotherapist, psychologist, ……)

    b. What is the main task of each healthcare professional? Please specify.

*E.g. lung physician: exacerbation treatment, monitoring overall health condition*

5. What is the role of organisations in COPD care in your country?
   a. Which organisations are involved? Please specify.

   b. What is the main task of each organisation? Please specify.

**Future COPD care with the ISACTIVE system**

6. For what type of care/treatment do you want to use the ISACTIVE system? Please specify (e.g. physiotherapy, nutrition counselling, …)

7. Which tasks would you like to transfer from current COPD care to the home-environment? Please specify (e.g. strength training, exercise training, providing nutrition information, …)

8. Could you please describe the strong aspects with respect to the usefulness and ease of use of the ISACTIVE system?

## 8.2 PACT table

The goal of the IS-ACTIVE project is to devise a person-centric health care solution for patients with chronic conditions, especially COPD patients, based on miniaturised wireless inertial sensors, which provide distributed motion capturing and intelligent recognition of activities and situations. The home should become the main care environment where patients can receive real-time feedback in order to monitor, self manage and improve their ***physical condition*** according to their specific situation. The aim is also to improve ***quality of life*** for COPD patients by improving condition, resting, and sleeping; and reducing anxiety, depression, and social isolation. By real-time personalised feedback and an attractive user-interface self-managing skills and motivation will improve.
The PACT table below can be used as a guideline to develop scenarios, especially the "after scenario". Please try to answer all the questions, and incorporate them in the scenarios as a story.

| **People** | |
|---|---|
| **Subject** | **Information for scenario *(examples are given in italic)*** |
| COPD patients | 1. Define the main symptoms and characteristics of the COPD patients that will use the IS-ACTIVE system. Like: dyspnoea, age, mood state, education, etc. |
| | 2. Describe why the COPD patients will use the IS-ACTIVE system: with what goal will they use the system. |
| | *3.* Describe the inclusion and exclusion criteria in order to use the IS-ACTIVE system (e.g. education, age, information).<br>*For example: COPD patients should follow an educational course about the system before they can use it.* |
| | 4. Describe (pathology related) difficulties when COPD patients need to interact with the IS-ACTIVE system. Define certain needs the technology has to fulfill due to the COPD population?<br>*For example: older persons have difficulty reading small letters, this would mean that text size should be large enough in the IS-ACTIVE system. Also, manuals should be adapted to the educational background of the group of persons* |
| Health care providers | 5. Describe with what goal each health care professional involved in COPD care will use the IS-ACTIVE system.<br>*For example: the physiotherapist would like to monitor and improve the physical condition of the COPD patients with less involvement, since the physiotherapist is overloaded with patients.* |
| | 6. Describe the inclusion and exclusion criteria for each health care professional in order to use the IS-ACTIVE system (e.g. education, age, information).<br>*For example: health care professionals should follow an educational course about the system before they can use it.* |
| **Activities** | |
| Treatment | 1. Describe in which phase of the COPD treatment the IS-ACTIVE system is used.<br>*For example: after an exacerbation, continuously, from GOLD III, during a rehabilitation programme, after a rehabilitation programme.* |
| | 2. Describe what aspects of treatment are on an individual basis, and what |

| | |
|---|---|
| | aspects are on a group basis.<br>*For example: a COPD patient has two physical therapy group-sessions per week, and one individual appointment with a dietician.* |
| | *3.* You described the type of treatment COPD patients receive in the questionnaire. Now describe the average frequency and duration of treatment patients usually receive.<br>*(…. times per week, ….minutes per session).* |
| | 4. Describe how often the IS-ACTIVE system will be used by the COPD patients.<br>*For example: the COPD patient is continuously monitored, but executes strength training exercises twice a week.* |
| | 5. Describe the role of the healthcare professionals involved.<br>*For example: the physiotherapist determines a personal goal for the patient, which he fills in the IS-ACTIVE system.* |
| | 6. Describe how the COPD patient and health care professionals interact by means of the IS-ACTIVE system during treatment. And with what frequency.<br>*For example: by video, television, phone, text messages, email, chat, visits at clinic.* |
| | 7. Describe any risks involved for the COPD patients with the execution of activities in the IS-ACTIVE system.<br>*For example: the IS-ACTIVE system told a COPD patient to perform certain exercises for his physiotherapy. A health risk during this exercise could be desaturation or a very high heart rate. To avoid dangerous situations, saturation and heart rate could be monitored during the exercise.* |
| | 8. Should the IS-ACTIVE system have additional functions besides monitoring and improving physical condition and quality of life?<br>*For example: providing information about medication use.* |
| **Context** | |
| Environment | *1.* Describe where the IS-ACTIVE system is used by the COPD patient.<br>*For example: the COPD patient uses the system for physiotherapy exercises at home but uses it everywhere to monitor his physical condition, whether he is at home or outside.* |
| | 2. Describe where the IS-ACTIVE system is used by the healthcare professionals. |
| | 3. Describe any environmental factors that should be monitored.<br>*For example: when you monitor the current weather conditions, the patient would not receive the feedback “take a walk outside” when it is raining. You could also monitor particles in the air, to detect smog.* |
| **Technology** | |
| Sensing | 1. Describe what information is needed from the IS-ACTIVE system to monitor and improve physical condition and quality of life of COPD patients at home?<br>a. Describe what on-body information is monitored.<br>b. Describe what information is monitored in the environment.<br><br>*For example: activity parameters, monitoring parameters, safety parameters, patient characteristics, physiotherapy exercises like 6 minute walk test, assessment of symptom severity, sleep parameters, eating parameters, training* |

| | |
|---|---|
| | *sessions, educational information, the amount of activity per day, the time in which a certain exercise was finished, etc…* |
| | 2. Describe the type of sensors used to address this information.<br>*e.g. accelerometers, pulse oximeters, etc.* |
| Data transmission | 3. Describe how the data is presented to the health care professionals. What data is presented to what professional? And with what frequency?<br>*For example: only the physiotherapist can see the data of the patient, but in more detail compared to the COPD patient. He could also see the activity patterns of the patient, per week & month. He would like to access the system once a day.* |
| | 4. Describe how health care professionals have access to the IS-ACTIVE system.<br>*For example: personal log-in.* |
| | 5. Describe what data is presented to the COPD patients, how it is presented, and with what frequency.<br>*For example: the COPD patient can see his activity data presented on a television screen in his living room, per day and per week. He sees the amount of activity he performed compared to his personal goal, which was set by the physiotherapist. He can access his data continuously, whenever he likes to.* |
| | 6. Should there be an alarm function in the IS-ACTIVE system?<br>*What type of alarm function? How is this organised?* |
| Feedback | 7. Describe the goal of feedback provided to the patient in the IS-ACTIVE system.<br>*For example: to achieve progress on the long term, to give feedback about specific exercises, for safety.* |
| | 8. Describe what type of feedback is presented to the COPD patients.<br>*For example: face-to-face feedback, artificial feedback, personalised feedback, context-aware, feedback from activity parameters, feedback from condition parameters, feedback from safety parameters.* |
| | 9. Describe how feedback is presented to the COPD patient in the user-interface.<br>*For example: graphical representation, text, sound.* |
| | 10. To what type(s) of device(s) is the feedback presented?<br>*For example: on a PDA that the COPD patient continuously wears, which is in connection with the IS-ACTIVE system.* |
| | 11. Describe with what frequency feedback is provided, for each type of feedback you want to include in the ISACTIVE system.<br>*For example: saturation data will be presented to the patient every 10 seconds during exercise, but activity data will give feedback messages maximum 4 times per day.* |