Project no.: 610658  
Project full title: eWALL for Active Long Living  
Project Acronym: eWALL  
Deliverable no.: D2.5  
Title of the deliverable: Clinical workflows and pathways

<table>
<thead>
<tr>
<th>Contractual Date of Delivery to the CEC:</th>
<th>31.07.2014</th>
</tr>
</thead>
<tbody>
<tr>
<td>Actual Date of Delivery to the CEC:</td>
<td>30.07.2014</td>
</tr>
<tr>
<td>Organisation name of lead contractor for this deliverable:</td>
<td>Aalborg University</td>
</tr>
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<td>Author(s):</td>
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<td>Participants(s):</td>
<td>P01, P04, P05, P06, P08</td>
</tr>
<tr>
<td>Work package contributing to the deliverable:</td>
<td>WP2</td>
</tr>
<tr>
<td>Nature:</td>
<td>R</td>
</tr>
<tr>
<td>Version:</td>
<td>1.0</td>
</tr>
<tr>
<td>Total number of pages:</td>
<td>59</td>
</tr>
<tr>
<td>Start date of project:</td>
<td>01.11.2013</td>
</tr>
<tr>
<td>Duration:</td>
<td>36 months – 31.10.2016</td>
</tr>
</tbody>
</table>

This project has received funding from the European Union’s Seventh Framework Programme for research, technological development and demonstration under grant agreement no 610658

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<tr>
<th>Dissemination Level</th>
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<tr>
<td>PU</td>
<td>Public</td>
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<tr>
<td>PP</td>
<td>Restricted to other programme participants (including the Commission Services)</td>
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<tr>
<td>RE</td>
<td>Restricted to a group specified by the consortium (including the Commission Services)</td>
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<tr>
<td>CO</td>
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Abstract:
This deliverable defines the relevant clinical workflows and patients pathways that ensure sustainable usage of all eWALL technologies and the platform in general. The identified workflows and pathways would be further refined to reflect on the defined eWALL usage scenarios and eWALL services during the real-user trials.

Keyword list: eWALL concept, eWALL services, patient pathways, clinical workflows, personalization of eHealth services, COPD, MCI
# Document History

<table>
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<tr>
<th>Version</th>
<th>Date</th>
<th>Author (Unit)</th>
<th>Description</th>
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<tbody>
<tr>
<td>0.1</td>
<td>May 2014</td>
<td>Stine Veje Hangaard, Albena Mihovska</td>
<td>First version</td>
</tr>
<tr>
<td>0.2</td>
<td>June 2014</td>
<td>Stine Veje Hangaard, Angeletou Angeliki</td>
<td>1st Revision</td>
</tr>
<tr>
<td>0.3</td>
<td>July 1, 2014</td>
<td>Stine Veje Hangaard</td>
<td>2nd Revision</td>
</tr>
<tr>
<td>0.4</td>
<td>July 3, 2014,</td>
<td>Stine Veje Hangaard, Francesco Infarinato, Monique Tabak</td>
<td>3rd revision</td>
</tr>
<tr>
<td>0.5</td>
<td>July 7, 2014</td>
<td>Stine Veje Hangaard, Monique Tabak, Albena Mihovska, Octavian Fratu, Catalina Pena</td>
<td>4th revision</td>
</tr>
<tr>
<td>0.6</td>
<td>July 28, 2014</td>
<td>Albena Mihovska</td>
<td>Final revision</td>
</tr>
<tr>
<td>1.0</td>
<td>July 29, 2014</td>
<td>Sofoklis Kyriazakos</td>
<td>Approved version</td>
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1 Executive Summary

This deliverable, D2.5: Clinical workflows and pathways, provides a description of the patient pathways and clinical workflows for COPD and dementia in all three demonstration countries – Denmark, Italy and the Netherlands. The patient pathways describe the pathways that the patients can follow from their diagnosis and throughout the course of their disease. Moreover, the patient pathways describe the rehabilitation program that the patient will perhaps follow at some point of his/her disease. The clinical workflows describe the different health care professionals’ roles and responsibilities in the patients’ care.

As eWall should not only be targeted at the three demonstration countries this deliverable also provides a description of the organization of care in Romania within the user groups of COPD and dementia.

Finally, the deliverable provides a comparison of similarities and differences within the demonstration countries within selected areas.
2 Introduction

Independent living of seniors and citizens with chronically displayed illnesses has a huge impact on: (1) the life of the involved elderly or patients, (2) the national health systems, (3) the insurance companies, (4) the relatives and (5) the care-givers. The patients may suffer from a number of diseases, including a decline in cardiopulmonary conditions, weaker muscle functions and a declined neuromuscular control of the movements, which result in a higher risk of fall and a higher vulnerability for cardiovascular and pulmonary diseases. With respect to cognitive functions, patients may suffer from a decline of memory function, less ability to orientate and a declined ability to cope with complex situations.

The above create a complexity for the management of eHealth care environments because there is an assortment of patient conditions under various circumstances with a number of resource constraints that need to be handled. When chronic conditions do occur simultaneously in the same individual, the resulting phenotype, whose complexity is augmented and increased by and with ageing, becomes the most serious challenge not only for independent living but, as well, for the sustainability of health systems worldwide. According to Continua Health Alliance [1], lifestyle management can address 60-80% of all cases of unpredictable cases in the wellness and pre-illness conditions; thus minimizing the costs for the seniors and the National Health Systems (NHS). There is, indeed, a large number of initiatives [2], [3], products and services that aim to provide a robust strategy to face this challenge. Nevertheless, proposed solutions are often non-sustainable.

This deliverable is part of the activities of the European-funded under the Framework Program Seven (FP7) within Information Communication Technology (ICT) project eWALL [4] and deals with the issues related to the redesign of clinical workflows and patient pathways that are part of the primary care according to principles of the chronic care model, which is implemented in the patient-centred medical home. eWALL proposes an affordable, easy-to-install prefabricated wall that can be mounted on an existing wall and fade into the background all of the ICT technology needed to enable a number of services for the senior or chronically ill citizen. To this end a novel architecture design in support of the eWALL services delivered to the eWALL users has been proposed, which are further described in detail in Deliverables 2.1, 2.2, and 2.3, for references, please, check [4]. The goal of eWALL is to enable a proactive maintenance of patients suffering from chronic obstructive pulmonary disease (COPD) as well as patients suffering from mild dementia.

2.1 eWALL Concept, eWALL Services, and eWALL User Groups

2.1.1 eWALL Concept

The eWALL concept is a dynamic ‘caring home’ cognitive environment that “senses” and “learns” the needs of the corresponding primary eWALL user. It provides unobtrusive daily support, notifying informal and formal caregivers whenever necessary and serving as a bridge to supportive services offered by the outside world. The sensor devices and their intelligent interconnection in sensor networks together with novel user interfaces represent the crucial technical enablers of the eWALL assistive environment.

The eWALL concept is a holistic infrastructure model that uses an interactive wall-mounted device to provide a variety of context-aware closed-loop intelligent services by Service Oriented Architecture (SOA) approach. eWALL introduces the concept of “service bricks” as the minimum
functional service, resulting in personalization and adaptation to specific needs and preferences,
with efficient data and context sharing between different required services and artefacts, the
handling of multiuser identification, auto configuration and calibration systems by personalized
high usability user interactions and unobtrusive sensing to finally comply with patients’ needs. The
eWALL platform concept is shown in Fig. 2.1.

Fig. 2.1 eWALL platform concept for e-Health services.

2.1.2 Sustainable eWALL Services

The eWALL services are grouped into the following categories: (1) risk management and home
safety, (2) eHealth and (3) lifestyle management. eWALL combines advanced perception and
communication technologies with state-of-the-art presentation and interfacing mechanisms and end-
user friendly technology. The eWALL primary users (not limited to the categories adopted for
performing this research) are senior citizens with mild cognitive impairments and citizens with a
vulnerability for cardiovascular and pulmonary diseases.

A successful e-Health system should be able to maximize the potential societal impact of its use,
and thus, should be able to support a broad range of target users. The general user groups
would normally involve a myriad of primary end users that can be categorized according to their human
health state, and a number of secondary end users and third parties (e.g., technology providers) [5].
Smart home systems enable constant monitoring and interpretation of health-related parameters
(e.g. ADL’s, medicine intake, physiological parameters) in the primary user’s everyday life, which
give the informal caregivers (i.e., a group of secondary users) the information necessary to feel
comfortable about the person they care for, and need to rely less on professional expertise, leading
to reduction in visits to doctors. For various chronic conditions, in which the use of professional
healthcare services is mandatory, everyday monitoring and interpretation of the patient’s relevant
data can provide professional caregivers (another secondary user group) with the information vital
to enable the focus of their efforts on those patients who need it most. The development of intelligent interaction and user interfaces enables healthcare professionals (i.e., another group of secondary users), to receive the relevant information when and where they need it in a simple and understandable way. Thus, the key requirements for enabling a sustainable e-Health system are the personalization and adaptation to specific needs and preferences, with efficient data and context sharing between the different required services and artefacts, and the handling of multiuser identification, auto configuration and calibration systems by personalized high usability user interactions and unobtrusive sensing.

2.1.3 eWALL User Groups

This deliverable relates to the patient pathways and clinical workflows relevant to the COPD and in support of the eWALL user groups.

In eWALL, for facilitating research and evaluation, the human health is seen in one of two possible states: (1) healthy (i.e., elderly users with age related impairments-ARI), and (2) sub-healthy (i.e., users diagnosed with Chronic Obstructive Pulmonary Disease-COPD or suffering from mild cognitive impairments, such as short term memory, language, execution of complex or parallel tasks). Both groups are considered as primary users. The first group of primary users may have a low level of cognitive and/or physical impairment but their condition does not require specific assistance or therapy; for the second group, more functional support and supervision would be necessary to maintain an independent and relatively normal daily functioning. Both primary user groups would need to interact to a certain extent with two different types of secondary user groups, namely:

1) Professional caregivers: including nurses, home care support professionals, medical doctors (general practitioners, lung physicians);

2) Informal caregivers: this user category contains the primary user’s family, neighbours, friends and anyone else not from the professional healthcare field that provides any type of support, including social support, housekeeping, or more disease specific support.

In order to define a set of functional requirements that align with the targeted end-user groups, typical human-centred design approaches for e-Health technology, such as ISO 9241-210 (British Standardization Organization, 2010) or user-centred design (Usability Professionals Association, 2013) were applied to enable that the prospective primary end user is the focal point during the design of the capability framework to help better define the context and required use and, thus promote, a high degree of user friendliness, usefulness and adoption.

2.1.4 eWALL Usage Scenarios

The eWALL usage scenarios are defined from the point of view of the primary and the secondary users with the purpose to create a common view on the services needed. The eWall system is described as a series of functionalities, for each persona. Each one of these functionalities could correspond to a module of the eWall system. Modules should be loosely coupled and as less co-dependent as possible. Communication between modules can be done via middleware and data and knowledge repositories. A module output will be transformed into knowledge that will form the user profile. The user profile describes in depth the profile of the person for which the eWall home installation is being used, from a therapeutic perspective.
Based on the scenarios a number of application categories were defined as shown in Table 2.1.

Each of the application categories in Table 2.1 contains several possible applications, which have to be prioritized and defined in further detail. Many applications may interact with other applications in various ways.

<table>
<thead>
<tr>
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<tr>
<td>1</td>
<td>physical exercise</td>
</tr>
<tr>
<td>2</td>
<td>daily activity monitoring</td>
</tr>
<tr>
<td>3</td>
<td>daily functioning monitoring</td>
</tr>
<tr>
<td>4</td>
<td>nutritional coach</td>
</tr>
<tr>
<td>5</td>
<td>safety</td>
</tr>
<tr>
<td>6</td>
<td>medication support</td>
</tr>
<tr>
<td>7</td>
<td>social integration</td>
</tr>
<tr>
<td>8</td>
<td>healthcare support</td>
</tr>
<tr>
<td>9</td>
<td>calendar</td>
</tr>
<tr>
<td>10</td>
<td>cognitive stimulation</td>
</tr>
<tr>
<td>11</td>
<td>domotics</td>
</tr>
<tr>
<td>12</td>
<td>outdoor guidance</td>
</tr>
<tr>
<td>13</td>
<td>health monitoring</td>
</tr>
</tbody>
</table>

eWALL has the purpose to support ADL for the described primary end user groups for an improved quality of life and overall cost-efficiency. ADL can be divided into basic ADLs and instrumental ADLs.

2.1.4.1 Basic ADLs
The basic activities of daily living consist of various self-care tasks: bathing, dressing and undressing, eating, transferring from bed to chair, and back; voluntarily control of toilet use; walking (not bedridden).

2.1.4.2 Instrumental ADLs
Instrumental activities of daily living are not necessary for fundamental functioning, but enable the individual to live independently within a community, e.g., light housework, preparing meals; taking medications; shopping for groceries or clothes; using the telephone; managing money.
2.2 COPD and MCI

COPD is a progressive yet preventable and treatable disease characterized by incompletely reversible airway obstruction, cough, dyspnoea, and phlegm. COPD is often associated with tobacco smoking and/or airborne particulate exposures (e.g., workplace contaminants, biomass smoke, or urban air pollution) but may also reflect inherited α-antitrypsin deficiency and/or idiopathic causes [6], [7]. Proactive diagnosis and ongoing multifactorial COPD management, comprising smoking cessation, influenza and pneumonia vaccinations, pulmonary rehabilitation, and symptomatic and maintenance pharmacotherapy according to severity, can significantly improve a patient’s health-related quality of life, reduce exacerbations and their consequences, and alleviate the functional, utilization, and financial burden of COPD [8].

Mild cognitive impairment (MCI) causes a slight but noticeable and measurable decline in cognitive abilities, including memory and thinking skills. The mild cognitive impairment causes cognitive changes that are serious enough to be noticed by the individuals experiencing them or to other people, but the changes are not severe enough to interfere with daily life or independent function. Because the changes caused by MCI are not severe enough to affect daily life, a person with MCI does not meet diagnostic guidelines for dementia.

This deliverable describes primary care practices from Denmark, The Netherlands, Italy, and some aspects to care in Romania. The deliverable guides how current COPD and MCI clinical care workflows can be adapted to the eWALL system and user requirements, highlighting the contributions of multidisciplinary collaborative team care, care coordination, and patient engagement to improve the patient outcomes.

The deliverable seeks to describe both the patient pathways and the clinical workflow at present time – without the eWall system. The description includes all countries where the eWall large scale demonstration is to take place (i.e., Denmark, The Netherlands, and Italy). The descriptions cover both primary user groups – COPD and MCI. The patient pathways and clinical workflow vary depending on both, the diagnosis and the nationality, and it is, therefore, considered rather important to describe both patient pathways and clinical workflows for each user group per country, in which the large scale demonstration is to take place. It must be mentioned that Austria also will be included as a demonstration country in the eWall project. However, the Austrian part of the demonstration will only include a few patients and will not happen in a clinical context. Therefore, the patient pathways and clinical workflows in Austria are not described in this document.

As a supplement, the document also contains a description of the patient pathways in COPD and MCI in Romania. In the long run eWall should be adapted to all European countries and it is, thus, considered relevant to take the patient pathways and clinical workflow in “non-demonstration” countries into account.

The descriptions also include information about rehabilitation. eWall should contribute to the rehabilitation of both user groups and a description of the existing rehabilitation offer for each country is therefore a key element in the development of eWall.

2.2.1 Clinical Workflows

The clinical workflows refer to the process by which tasks are done, by whom and in what order in a clinical context. A clinical workflow may also include a temporal aspect if relevant.
2.2.2 Patient Pathways

The patient pathways refer to the path, which the patient will follow throughout the healthcare system. The path typically starts when the patient contacts his/her doctor and addresses a health related problem. After that, the patient will perhaps meet a variety of healthcare professionals and sectors, which will define the patient pathway.
3 Denmark

3.1 The Danish Healthcare System

In order to understand the patient pathways and clinical workflows in the Danish context a basic understanding of the Danish health care system is important.

Everybody who lives permanently in Denmark is free to use the Danish healthcare system where most examinations and treatments are free of charge [9]. The Danish healthcare system is divided into regional healthcare and municipal healthcare. Denmark is divided into five regions (The North Denmark Region, Central Denmark Region, Region of Southern Denmark, Region Zealand and The Capital Region of Denmark). The eWall demonstration will take place in The North Denmark Region. The Regions are responsible for both somatic and psychiatric hospital service, general practitioners, specialist and health insurance [10]. The general practitioners (GP) are private doctors but they operate within the public healthcare system. All Danes choose their GP which is typically the one that patients contact in case of illness. The GP will often do the diagnosis or treatment or refer the patient to the hospital or a specialist doctor if necessary [9].

Each region is divided into municipalities – 98 in all. The municipal healthcare covers preventive treatment, homecare, nursing homes, off hospital rehabilitation, social psychiatry, dental care and treatment of alcohol and drug abuse [10].

3.2 Patient Pathways (Denmark)

3.2.1 Patient pathways in COPD (Denmark)

In Denmark, the treatment of COPD patients differs depending on the severity of the disease. The severity can and should be assessed on the basis of both examination of lung function, symptoms and exacerbations, as shown in Table 3.1:

<table>
<thead>
<tr>
<th>Patient</th>
<th>FEV1 1</th>
<th>MRC2</th>
<th>CAT3</th>
<th>Exacerbations4</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>&gt; 50%</td>
<td>1-2</td>
<td>&lt; 10</td>
<td>0-1</td>
</tr>
<tr>
<td>B</td>
<td>&gt; 50%</td>
<td>≥ 3</td>
<td>≥ 10</td>
<td>≥ 0-1</td>
</tr>
<tr>
<td>C</td>
<td>&lt; 50%</td>
<td>1-2</td>
<td>&lt; 10</td>
<td>≥ 2</td>
</tr>
<tr>
<td>D</td>
<td>&lt; 50%</td>
<td>≥ 3</td>
<td>≥ 10</td>
<td>≥ 2</td>
</tr>
</tbody>
</table>

It is recommended that COPD patients are treated in a collaboration framework including the hospital, the patient’s general practitioner and the municipality. Therefore, each patient is likely to meet a variety of health care professionals who all contribute to the continuity of the patient’s care.

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1 FEV1: A spirometric test measuring the forced expiratory volume in 1 second
2 MRC: Medical Research Council breathlessness scale
3 CAT: COPD assessment test
4 Exacerbation: A worsening of COPD
All COPD patients will be stratified into groups depending on the severity of their disease. On this basis their pathway in the health care system will be determined. However, their pathway can change as their COPD can improve or worsen [11], [12].

Fig. 3.1 shows the patient pathways for COPD in a Danish context.

Fig. 3.1 Patient pathways for COPD in Denmark [11].
3.2.1.1 Stratification
Table 3.2 shows the stratification of COPD patients based on the severity of the disease.

<table>
<thead>
<tr>
<th></th>
<th>A</th>
<th>B+C</th>
<th>D</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treatment/control:</td>
<td>General practice</td>
<td>1. Newly diagnosed patients: Consider evaluation by specialist doctor</td>
<td>Lung specialized outpatient clinic/case manager</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2. After this, general practice (In some cases affiliation with lung specialized outpatient clinic)</td>
<td></td>
</tr>
<tr>
<td>Rehabilitation:</td>
<td>Individual counseling/rehabilitation at municipal level</td>
<td>Rehabilitation at hospital or municipal level</td>
<td>Rehabilitation at hospital level. After that, maintenance training at municipal level is recommended</td>
</tr>
<tr>
<td>(is offered to patients with MRC ≥ 3 and/or CAT &gt; 10 or CCQ &gt; 1)</td>
<td></td>
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</tr>
</tbody>
</table>

3.2.1.2 COPD Rehabilitation
The eWall system should especially focus on the rehabilitation pathway, as the system could provide assistance within this area in particular.

In Denmark all COPD patients who feel limited in performing their ADL because of their COPD should be offered a COPD rehabilitation. The aim of the COPD rehabilitation is to enable the COPD patients to achieve the best functional level and quality of life possible.

The minimum requirements for what a COPD rehabilitation program should contain are:

- Smoking Cessation
- Physical exercise
- Medical treatment
- Nutritional education and treatment
- COPD education

5 A case manager is assigned to secure a coordinated, intensified and personalized support for patients with complex needs

6 CCQ: http://www.ccq.nl/
- Psychosocial support

In Table 3.3 a description of each of these requirements is given.

**Table 3.3**

**MINIMUM REQUIREMENTS FOR COPD REHABILITATION IN DENMARK [11], [12]**

<table>
<thead>
<tr>
<th>Requirement</th>
<th>Description</th>
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<tbody>
<tr>
<td><strong>Smoking Cessation</strong></td>
<td>If the COPD patient smokes, he/she must:</td>
</tr>
<tr>
<td></td>
<td>• Be offered help to quit smoking</td>
</tr>
<tr>
<td></td>
<td>• Be informed about the harm caused by continuing smoking</td>
</tr>
<tr>
<td></td>
<td>• Be offered motivational talks</td>
</tr>
<tr>
<td></td>
<td>• Receive information about the option of pharmacological treatment</td>
</tr>
<tr>
<td></td>
<td>The smoking cessation can be conducted at either individual or at group level.</td>
</tr>
<tr>
<td><strong>Physical exercise</strong></td>
<td>Patients with mild or moderate COPD is encouraged to walking or cycling.</td>
</tr>
<tr>
<td></td>
<td>Patients with moderate COPD should have the option of being referred to physical exercise supervised by a physiotherapist.</td>
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<tr>
<td></td>
<td>Physical exercise in a profound rehabilitation program should be offered to COPD patients in a stable phase that is limited in performing their ADL because of dyspnoea in spite of optimal medical treatment. This will mostly concern patients with severe or very severe COPD. The exercise should be individualized based on functional level, dyspnoea score and saturation. Aerob exercise should be mandatory in COPD rehabilitation.</td>
</tr>
<tr>
<td></td>
<td>The exercise can be implemented as either walking or cycling supplemented with strength, balance and/or circuit training focusing on specific functions such as climbing stairs or using arms. The patient should exercise at least 3-4 times pr. week for at least 20-30 minutes, whereas two exercise sessions should be supervised. The exercise program should last for at least 7 weeks. It is recommended that the exercise sessions are organized in groups of 8-10 patients.</td>
</tr>
<tr>
<td></td>
<td>The functional training should focus on energy-saving behavior and the use of assistive devices if relevant.</td>
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</table>
After participating in a rehabilitation program the patient should continue to do the exercise at home.

**Medical treatment**
The health care professional must follow up on the proper use of the medicine, for example, correct inhalation of preparations.

**Nutritional education and treatment**
Patients with COPD have their weight and height registered and their body mass Index (BMI) calculated. The weight is checked regularly.

Patients with COPD who have an unintentional weight loss will be informed about special dietary guidelines for COPD patients. They are also given the opportunity for referral to individual nutrition therapy, and both weight and assessment of dietary intake are monitored at regular basis.

Obese COPD patients are recommended to reduce weight and they are referred to individual nutritional treatment and weight control.

**COPD education**
The COPD patient must be taught at:
- Understanding of COPD, reasons for COPD and consequences thereof
- Treatment, the effects and side effect of medical treatment
- Inhalation technique, cleaning of equipment and inhaler
- Breathing exercises
- Signs of worsening of COPD
- Conditions improving cohabitation
- Coping anxiety by shortness of breath
- Nutritional diet
- Exercise
- The psycho-social element, how to handle physical and social activities

**Psychosocial support**
Patients with COPD have their social situation and the psychological response pattern on the disease evaluated, as it may be relevant to offer support.

It is considered important to clarify the possible presence of psychosocial factors of social isolation, anxiety and depression. Thus, COPD patients should be monitored and assessed in relation to their psychosocial situation. Depending on the severity of psychiatric symptoms, the need for specialist referral or psychological treatment should be assessed.

In cases of development of moderate to severe depression, reference to a psychiatrist and treatment with conventional
Each individual patient’s needs should be assessed on the basis of the patient’s physical and mental state and then noted in the patient’s journal. Also, the goals for each partial element of the rehabilitation should be set. The eWall system should be able to contribute to all of these partial elements of rehabilitation. Both, patients and health care professionals should be able to set goals and keep track of the progress towards these using the eWall system.

The rehabilitation takes place at a hospital or at municipal level depending on the severity of the patient’s disease. A COPD rehabilitation program continues for 7-12 weeks. The eWall system should therefore match this time period. It may be useful if the eWall system should even be available to the patient a little longer than this, as it must be expected that some level of introduction training in using the eWall system will be necessary [11], [12].

3.2.2 Patient Pathways in MCI (Denmark)

In Denmark, MCI patients are not stratified into groups as this is done for COPD patients. Also, there are no suggestions for health promoting activities, as MCI is a progressive chronic disease that is mostly irreversible [13].

3.2.2.1 Patient pathways in dementia in the North Denmark Region

The patient pathways in dementia within the context of the North Denmark Region are shown in Fig. 3.2.
MMSE: Mini-Mental State Examination
GDS: Global Deterioration Scale

Fig. 3.2 Patient pathways for COPD in Denmark [14].

After the diagnosis, an interview follows, where both the patient and relatives participate. In that connection, a plan of action is completed with the purpose of planning the ongoing social medical effort. This interview is repeated annually [14].
3.3 **Clinical Workflows (Denmark)**

3.3.1 **Clinical Workflows in COPD**

The organizational context of the COPD treatment in Denmark is shown in Fig. 3.3.

![Clinical workflow for COPD in Denmark](image)

**Fig. 3.3 Clinical workflow for COPD in Denmark [12]**

The general practitioner is recommended as the main actor of the COPD patient care. However, the patient care effort should be coordinated in collaboration between the health professionals of the different sectors. The role of the GP is therefore essential in the COPD patient care as he/she coordinates the treatment throughout the course of the disease. Please note that in severe cases a case manager can be assigned who will then have the main responsibility for coordinating the patient care [12].

The COPD rehabilitation takes place at either hospital (regional) or municipal level depending on the severity of the disease. The responsibility for rehabilitation of the more severe COPD patients lies at hospital level [12].

3.3.1.1 **Agreements in the North Denmark Region**

In the North Denmark Region the following recommendations have been agreed upon:
**Level 1**: Mild and moderate COPD. GP coordinates and sees the patient for 1 annual control.

**Level 2**: Severe COPD. GP coordinates, but occasionally patients are followed at the outpatient clinic by specialist doctor or nurse.

**Level 3**: Very severe COPD. The patient is followed at hospital level by specialist doctor and/or nurse [15].

### 3.3.1.2 Clinical workflow in the North Denmark Region

The clinical workflow within the COPD patient care in the North Denmark Region is shown in Tables 3.4a-3.4c.

<table>
<thead>
<tr>
<th>TABLE 3.4A</th>
<th>CLINICAL WORKFLOW IN COPD LEVEL 1[15]</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Activities</strong></td>
<td><strong>Capabilities needed</strong></td>
</tr>
<tr>
<td>Smoking cessation</td>
<td>Smoking cessation instructor</td>
</tr>
<tr>
<td>Dietary advice</td>
<td>Nutritionist</td>
</tr>
<tr>
<td>Exercise</td>
<td>Trained instructor</td>
</tr>
<tr>
<td>Medical treatment/supervision</td>
<td>Doctor or nurse with special expertise within COPD</td>
</tr>
<tr>
<td>Patient education</td>
<td>Health professional with special expertise within COPD</td>
</tr>
</tbody>
</table>
| Psychosocial support | Health professional with special expertise within COPD | Region (GP)
| Municipality (network groups) |

<table>
<thead>
<tr>
<th>TABLE 3.4B</th>
<th>CLINICAL WORKFLOW IN COPD LEVEL 2A (STABLE PHASE) [15]</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Activities</strong></td>
<td><strong>Capabilities needed</strong></td>
</tr>
<tr>
<td>Smoking cessation</td>
<td>Smoking cessation instructor with knowledge about COPD</td>
</tr>
<tr>
<td>Dietary advice</td>
<td>Nutritionist with knowledge about COPD</td>
</tr>
<tr>
<td>Exercise</td>
<td>Physiotherapist or occupational therapist with knowledge about COPD</td>
</tr>
<tr>
<td>Medical treatment/supervision</td>
<td>Doctor or nurse with special expertise within COPD</td>
</tr>
<tr>
<td>Patient education</td>
<td>Health professional with special expertise within COPD</td>
</tr>
<tr>
<td>Psychosocial support</td>
<td>Health professional with special expertise within COPD</td>
</tr>
<tr>
<td>----------------------</td>
<td>--------------------------------------------------------</td>
</tr>
</tbody>
</table>

**Table 3.4b**

**CLINICAL WORKFLOW IN COPD LEVEL 2b (NON-STABLE PHASE) [15]**

<table>
<thead>
<tr>
<th>Activities</th>
<th>Capabilities needed</th>
<th>Responsibility</th>
</tr>
</thead>
<tbody>
<tr>
<td>Smoking cessation</td>
<td>Smoking cessation instructor with knowledge about COPD</td>
<td>Region (hospital)</td>
</tr>
<tr>
<td>Dietary advice</td>
<td>Nutritionist with knowledge about COPD</td>
<td>Region (hospital)</td>
</tr>
<tr>
<td>Exercise</td>
<td>Physiotherapist or occupational therapist with knowledge about COPD</td>
<td>Region (hospital)</td>
</tr>
<tr>
<td>Medical treatment/supervision</td>
<td>Doctor or nurse with special expertise within COPD</td>
<td>Region (hospital)</td>
</tr>
<tr>
<td>Patient education</td>
<td>Health professional with special expertise within COPD</td>
<td>Region (hospital)</td>
</tr>
<tr>
<td>Psychosocial support</td>
<td>Health professional with special expertise within COPD</td>
<td>Region (hospital) Municipality (network groups)</td>
</tr>
</tbody>
</table>

**Table 3.4c**

**CLINICAL WORKFLOW IN COPD LEVEL 3 [15]**

<table>
<thead>
<tr>
<th>Activities</th>
<th>Capabilities needed</th>
<th>Responsibility</th>
</tr>
</thead>
<tbody>
<tr>
<td>Smoking cessation</td>
<td>Smoking cessation instructor with knowledge about COPD</td>
<td>Region (hospital)</td>
</tr>
<tr>
<td>Dietary advice</td>
<td>Nutritionist with knowledge about COPD</td>
<td>Region (hospital)</td>
</tr>
<tr>
<td>Exercise</td>
<td>Physiotherapist or occupational therapist with knowledge about COPD</td>
<td>Region (hospital). Follow up at municipal level – possibly in the patient’s home</td>
</tr>
<tr>
<td>Medical treatment/supervision</td>
<td>Doctor or nurse with special expertise within COPD</td>
<td>Region (GP or hospital)</td>
</tr>
<tr>
<td>Patient education</td>
<td>Health professional with special expertise within COPD</td>
<td>Region (hospital)</td>
</tr>
<tr>
<td>Psychosocial support</td>
<td>Health professional with special expertise within COPD</td>
<td>Region (hospital) Municipality (network groups)</td>
</tr>
</tbody>
</table>
3.3.2 Clinical Workflow in MCI (Denmark)

3.3.2.1 Agreements regarding the clinical workflow in dementia in the North Denmark Region

The assessment of dementia is conducted in collaboration between the GP and a dementia nurse at municipal level. A memory clinic is also part of this collaboration securing interdisciplinary specialized visitation and diagnosing.

The GP refers patients to the memory clinic in the following cases [13]:

• Early and unclear cases of dementia
• Cases when the type of dementia is unclear
• Difficult and complicated cases
• Cases when medical treatment is necessary.

3.3.2.2 Clinical Workflow in the North Denmark Region

The clinical workflow within the dementia patient care in the North Denmark Region is shown below.

Throughout the continuity of care [13]:

<table>
<thead>
<tr>
<th>Activity</th>
<th>Capabilities needed</th>
<th>Responsibility</th>
</tr>
</thead>
<tbody>
<tr>
<td>Facilitator/coordinator</td>
<td>Dementia professional *</td>
<td>Municipality</td>
</tr>
</tbody>
</table>

* This would typically be a nurse who is specialized within dementia

Prior to diagnosis [13]:

<table>
<thead>
<tr>
<th>Activity</th>
<th>Capabilities needed</th>
<th>Responsibility</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical effort</td>
<td></td>
<td>GP</td>
</tr>
<tr>
<td>Activity offers</td>
<td></td>
<td>Municipality</td>
</tr>
</tbody>
</table>

The period of diagnosing [13]:

<table>
<thead>
<tr>
<th>Activity</th>
<th>Capabilities needed</th>
<th>Responsibility</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosing</td>
<td>Dementia professional and GP</td>
<td>Municipality and GP</td>
</tr>
<tr>
<td>Supplementary diagnosing (unclear cases)</td>
<td></td>
<td>Memory clinic at regional level</td>
</tr>
<tr>
<td>Social medical follow-up interview</td>
<td>Dementia professional and GP</td>
<td>Municipality and GP</td>
</tr>
</tbody>
</table>

The chronic phase [13]:

<table>
<thead>
<tr>
<th>Activity</th>
<th>Capabilities needed</th>
<th>Responsibility</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical effort and follow-up</td>
<td>Dementia professional and GP</td>
<td>Municipality and GP</td>
</tr>
<tr>
<td>Follow-up interview, min. 1 pr. Year</td>
<td>Dementia professional and GP</td>
<td>Municipality and GP</td>
</tr>
<tr>
<td>Social offers for people with</td>
<td></td>
<td>Municipality</td>
</tr>
<tr>
<td>dementia, support for relatives, practical help etc.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>---------------------------------------------------</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
4 Italy

4.1 Patient Pathways (Italy)

4.1.1 Patient Pathways in COPD

Following recent guidelines, in Italy the organizational network to take charge of respiratory diseases should be based on the principle of integration, which allows decentralizing operations and creating interaction skills, optimizing the use of resources with minimum waste.

A key role in contrast to the risk factors is usually done by the primary care: general practitioners (GP) and paediatricians.

These professionals are the ones most frequently called upon to provide interventions for early diagnosis in order to identify those at risk (due to a medical condition), directing them to the specialist.

The specialist must provide for the classification in the different stages of the disease and implement a treatment aimed at delaying the progression to more severe forms.

The severity of the disease should be assessed on the basis of the following, also summarized in Table 4.1:

1. Symptoms (dyspnoea, cough and expectoration) evaluated by questionnaires like modified Medical Research Council Breathlessness scale (mMRC), CAT= COPD Assessment Test (CAT), and Clinical COPD Questionnaire (CCQ);

2. Measures of the degree of bronchial obstruction evaluated by spirometry (FEV)

3. Number of exacerbations

<table>
<thead>
<tr>
<th>Patient</th>
<th>FEV1</th>
<th>mMRC</th>
<th>CAT</th>
<th>Exacerbations</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>&gt;50% (GOLD 1-2)</td>
<td>0-1</td>
<td>&lt;10</td>
<td>0-1</td>
</tr>
<tr>
<td>B</td>
<td>&gt;50% (GOLD 1-2)</td>
<td>≥ 2</td>
<td>≥ 10</td>
<td>0-1</td>
</tr>
<tr>
<td>C</td>
<td>&lt; 50% (GOLD 3-4)</td>
<td>0-1</td>
<td>&lt; 10</td>
<td>≥ 2</td>
</tr>
<tr>
<td>D</td>
<td>&lt; 50% (GOLD 3-4)</td>
<td>≥ 2</td>
<td>≥ 10</td>
<td>≥ 2</td>
</tr>
</tbody>
</table>

The general practitioner (GP) delivers respiratory symptoms in the personal history of his client also making use of questionnaires and proposes appropriate diagnostic investigations: especially (but not only) spirometry and/or specialist visit.

GP is also responsible for the active search for new cases, through the use of questionnaires.

The flow chart in Fig. 4.1 shows a model for the diagnostic path.
4.1.1.1 COPD Rehabilitation

In the event of an exacerbation, patients with severe COPD should be hospitalized and treated according to an optimal standard evidence-based and in relation to the severity of respiratory failure developed. After the acute phase and obtained the stabilization of the clinical condition discharge is programmed. It is desirable that the discharge of the patient is always agreed in advance with the general practitioner, so that the patient does not see itself forced to deal with the post-discharge, outside of a path known and shared. In the framework of a program of home care there are many possible professional interventions. In addition to the respiratory specialist and the general practitioner, the complexity of patients with respiratory failure require the intervention of other health professionals like Professional nurse specialist, pulmonary rehabilitation therapist, psychologist, nutritionist.

The respiratory rehabilitation (RR), integrated into the individual treatment of the patient, has the aim to reduce symptoms, optimize functional status, increase participation and reduces the consumption of health care resources, through the stabilization or improvement of the disease.

In patients with COPD, the main objectives of the RR are the improvement of dyspnoea, exercise tolerance and quality of life. Minor evidence is available for other outcomes, such as prevention of complications and exacerbations, slowing the progression of the condition and improvement of survival. A fixed starting point for COPD rehabilitation is the following:

- Smoking Cessation
- Physical exercise

Fig. 4.1 Model for a COPD diagnostic path in Italy.
• Pharmacological treatment
• Nutritional education
• Psychological support

During the hospitalization phase, the rehabilitation programs include: physical exercise, pharmacological treatment, and nutrition control.

The home rehabilitation programs to follow during post-hospitalization from exacerbations are tailored on the patient’s needs and would normally last about 3 months.

Patients are scored before and after rehabilitation program using the following methods:

• Assessment scales:
  • mMRC (Modified Medical Research council); Borg; 6MW (Six minutes walking); Barthel index.
• Instrumental assessments
  • Spirometry; blood gas; pulse oximetry.

The physical activity is a fundamental step in the post-rehabilitation therapy for COPD patients to maintain over time the results reached during the hospitalisation. Following the guidelines of the respiratory rehabilitation division of IRCCS San Raffaele Pisana, we can conclude that it is essential:

- To perform at least 30 minutes of daily home care rehabilitation program
- To perform physical activity away at least two hours from meals
- To undergo recurrent medical checks

The total duration in minutes of the exercises is defined by the medical personnel with respect to the patient’s condition.

The daily home care rehabilitation program includes a set of exercises to perform on a gym mat with or without a rod, a set of exercises to perform seated or standing, and activity on treadmill and/or bike.

4.1.2 Patient Pathways in MCI (Italy)

Despite the international guidelines, in Italy there is no approved action plan for dementia. Only a few institutions at the local level have given a priority to this issue by publishing some guidelines.

In most cases, the family members notice the presence of amnestic or behavioural disorders and refer the patient to the doctor. Even more rarely, the suspicion of dementia emerges during a clinical interview started for some other reasons and without a reporting of the cognitive symptoms. The problem of assessing the presence or absence of dementia arises even in the case of the definition of the level of competence of an elderly person for medical-legal reasons. The clinical approach to the patient with cognitive impairment is based on a multi-stage evaluation. The first objective is to
determine whether there is a cognitive impairment and whether this meets the criteria for dementia. If a syndrome is identified, the second step is the evaluation required to determine the etiology of dementia. For the purposes of setting drug and rehabilitation treatment and planning assistance actions, it is also necessary to assess the severity of cognitive impairment, functional and behavioural changes, and family, social, and environmental situation. Finally risks and complications are estimated (e.g. security issues of housing, nutritional status, risks of falls).

Fig. 4.2 summarized graphically the algorithm for the diagnostic path of a patient with suspected MCI.

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Fig. 4.2 Diagnostic path algorithm for MCI patients in Italy.
4.2 **Clinical Workflows (Italy)**

4.2.1 **Clinical Workflow for COPD**

The institutional definition of the organizational structure (which translates into the programmatic guarantee that the right to be cared is assured for every patient) must be accompanied by professional-technical definition of processes, or operating modes in which each professional involved must refer.

Fig. 4.3 shows a visualization of the organizational context of COPD treatment.

![Organizational context of the COPD treatment in Italy.](image)

**Fig. 4.3 Organizational context of the COPD treatment in Italy.**

4.2.2 **Clinical Workflow in MCI**

Despite the international guidelines, in Italy there is no approved action plan for dementia, only a few institutions at the local level have given the priority to this issue by planning an integrated network for dementia.

The construction of an integrated network aims to achieve an organization of the practice for the person with dementia and his family, which facilitates and simplifies the sharing of information between all stakeholders, to ensure a more skilled assistance and a shorter response time, paying attention to the economies of scale and to avoid a duplication of efforts, particularly with regard to the social assistance and the complex and expensive diagnostic laboratory tests.
**General practitioner (GP)**
As part of the Integrated Network, the role attributed to the general practitioner (GP) is strategic:

a) Screening / early identification of patients with dementia or cognitive impairment
b) Advise dedicated regional specialized clinics
c) Monitoring the clinical course / management therapies
d) Participation in the development of an appropriate home care
e) Monitoring the evolution of the disease / management of complications.

**Dedicated regional specialized clinics**
Dedicated regional specialized clinics ensure:

a) experienced staff dedicated medical specialist
b) Continuity of care with intervals of follow-up (clinical and / or neuropsychological) not exceeding six months.
c) possibility to access the service in no more than 15 days in the case of adverse events, complications, or changes in therapeutic
d) direct telephone access with dedicated time slot
e) information / training for caregivers and family members
f) liaison with health services
g) Cooperation with institutional bodies, local and / or regional and / or national epidemiological and clinical studies.

**Centre for Dementia**
In addition to the features already provided by the dedicated regional specialized clinics, these facilities guarantees:

a) Possibilities for day hospital or inpatient for invasive or complex diagnostic needs, or for therapeutic reasons and / or rehabilitation.
b) the possibility of multi-disciplinary expert advisory for the diagnosis and treatment of secondary dementias or rare dementia
c) activities of multidimensional assessment including neuropsychological and / or neurological -cognitive assessment
d) psychological counselling and taking charge of any relational problems
e) rehabilitation and / or cognitive stimulation in outpatient and / or under the hospitalization
f) Training / information for GPs, junior doctors, medical specialists, non-medical personnel.

Fig. 4.4 shows a flowchart for the recommended clinical workflow for MCI in Italy.
Fig. 4.4 Recommended clinical flow for MCI in Italy.
5 The Netherlands

5.1 Patient Pathways (The Netherlands)

5.1.1 Patient Pathways for COPD

5.1.1.1 Diagnosis and Assessment

A clinical diagnosis of COPD should be considered in any patient who has dyspnoea, chronic cough or sputum production, and a history of exposures to risk factors of the disease. Spirometry is required to make the diagnosis in a clinical context; the presence of a post-bronchodilator FEV1/FVC < 0.70 confirms the presence of persistent airflow limitation as shown in Table 5.1 [17]. Table 5.1 shows the classification of the airflow limitation severity in COPD, together with the prevalence for the Netherlands in COPD population.

<table>
<thead>
<tr>
<th>GOLD-stadium</th>
<th>FEV1/FVC</th>
<th>FEV1(% predicted)</th>
<th>Prevalence (now &gt; future)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I Mild</td>
<td>&lt; 0.7</td>
<td>≥ 80</td>
<td>28% &gt; + 120%</td>
</tr>
<tr>
<td>II Moderate</td>
<td>&lt; 0.7</td>
<td>50-80</td>
<td>54% &gt; + 27%</td>
</tr>
<tr>
<td>III Severe</td>
<td>&lt; 0.7</td>
<td>30-50</td>
<td>15% &gt; + 30%</td>
</tr>
<tr>
<td>IV Very severe</td>
<td>&lt; 0.7</td>
<td>&lt; 30 (of &lt; 50 with lung failure)</td>
<td>3% &gt; + 120%</td>
</tr>
</tbody>
</table>

This approximately resembles the groups as defined in the international GOLD guidelines [17] (group A – low risk, less symptoms, group B – low risk, more symptoms, and group C – high risk, less symptoms). Besides the lung function, dyspnoea (Medical Research Council Dyspnoea scale: MRC) and health status (Clinical COPD questionnaire: CCQ) are also assessed.

The goals of the COPD assessment are to determine the severity of the disease, its impact on the health status and the risk of future events (e.g. exacerbations) in order to guide the therapy. The assessment considers the following aspects:

- Current level of symptoms;
- Severity of spirometric abnormality;
- Exacerbation risk;
- Presence of comorbidities.

Recent guidelines recommend the use of a combined COPD assessment for treatment guidance. In the Netherlands, as described in the so-called ‘COPD care standard (zorgstandaard)’ [18], the following patient groups are defined, namely, patients with a mild, moderate or severe disease burden. This stratification is shown in Table 5.2.
The various patient groups are described in detail below.

- **Patients with mild disease burden:**
  
  Every patient with COPD, who according to the assessment (no longer) meets the criteria for further analysis (diagnostic issues or not achieving treatment goals). No severe complaints because of dyspnoea (MRC < 3) no serious adaptation problems, no impaired nutritional status, without frequent exacerbations, and disease burden is only slightly influenced by comorbidities. Follow-up at least once a year with a yearly basic assessment in primary care (anamnesis, exacerbation frequency, MRC/CCQ/BMI/FEV1).

- **Patient with moderate disease burden:**
  
  Every patient with COPD, who according to the assessment meets the criteria for further analysis (diagnostic issues or not achieving treatment goals). Treatment close to home is possible, but where infrequent, extensive monitoring (e.g. possible adjustment in treatment) in secondary care is needed. This group is best served by ‘shared’ care. Follow-up at least twice a year with a yearly basic assessment (anamnesis, exacerbation frequency, MRC/CCQ/BMI/FEV1). On indication more extensive assessment.

- **Patient with severe disease burden:**
  
  Every patient with COPD, who according to the assessment meets the criteria for further analysis (diagnostic issues or not achieving treatment goals) with intensive support in secondary or tertiary care (e.g. by means of multidisciplinary rehabilitation) is required. Follow-up at least twice a year with a yearly basic assessment (anamnesis, exacerbation frequency, MRC/CCQ/BMI/FEV1) in secondary care. On indication more extensive assessment.

On the basis of the above mentioned stratification, the pathway in the healthcare system is determined. This pathway is show in detail in Fig. 5.1. A referral from the GP to the chest physician takes place in case of a doubt on the diagnosis (e.g., comorbidities, complex lung function) and / or in the case of a discrepancy between the subjective complaints and the GOLD stage.

<table>
<thead>
<tr>
<th>Disease burden</th>
<th>GOLD</th>
<th>MRC</th>
<th>CCQ</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild</td>
<td>GOLD I / II, uncomplicated</td>
<td>&lt;3</td>
<td>&lt;2</td>
</tr>
<tr>
<td>Moderate</td>
<td>GOLD II, complicated or GOLD 3, uncomplicated</td>
<td>≥ 3</td>
<td>≥ 2</td>
</tr>
<tr>
<td>Severe</td>
<td>GOLD 3, complicated GOLD 4</td>
<td>&gt;3</td>
<td>&gt;2</td>
</tr>
</tbody>
</table>

Abbreviations: MRC: medical research council dyspnoea scale (score 1-5), CCQ: clinical COPD questionnaire
5.1.1.2 Treatment
If the COPD has been diagnosed with patient, then, an effective management should be based on an individualized assessment of the disease in order to reduce both, the current symptoms (i.e. relieve symptoms, improve exercise tolerance, improve health status) and the future risks (i.e. prevent disease progression, prevent and treat exacerbations, reduce mortality) [17]. A way to determine the severity of the diagnosed COPD is shown in Fig. 5.2.

Fig. 5.2 Determining COPD severity.
The following are the treatment aspects as stated in the ‘zorgstandaard’[18]:

1. **Information, awareness and education**
   
   It is crucial for patients to understand the nature of their disease, the risk factors for its progression and their role and that of their health care workers in achieving optimal management and health outcomes. Special attention should be for the possibility of fellow patient support. The aim of creating awareness and providing education is to support self-management of the patient.

2. **Smoking cessation**
   
   Smoking cessation is the intervention with the greatest capacity to influence the natural history of COPD.

3. **Physical activity**
   
   Physical activity is recommended for all patients with COPD.

4. **Nutrition**
   
   In case of severe weight loss or BMI < 21. Or BMI > 30.

5. **Management of dyspnoea, coughing and sputum**
   
   Using medication, breathing and relaxation exercises, mucus clearance.

6. **Pharmacologic treatment**
   
   Pharmacologic treatment is used to reduce symptoms, reduce frequency and severity of exacerbations, and improve health status and exercise tolerance. These include: flu/pneumococcal vaccination, short-acting bronchodilators, corticosteroids, antibiotics.

7. **Oxygen therapy**
   
   Regular oxygen therapy in case of chronic hypoxemia, at home. Or applied during exercise (if saturation < 90% for a long time).

8. **Lung rehabilitation**
   
   Defined as an integrated multidisciplinary treatment program for patients with lung problems that is individually designed, based on a complete assessment. The program focuses not only on physical condition, using medication and exacerbation management, but also contains different aspects of the physiological functioning and adaptation to the disease. It thus aims to optimize the general health status, participation and autonomy of the patient.

9. **Management of exacerbations**
   
   An exacerbation is an acute event characterized by a worsening of the patient’s respiratory symptoms that is beyond normal day-to-day variations and leads to a change in medication. The goal of treatment of exacerbations is to minimize the impact of the current one, and to prevent the development of subsequent exacerbations. Treated at home or in the hospital.

10. **Invasive treatment**
    
    Includes lung volume reduction and lung transplant.
11. **Non-invasive respiration**

In case of severe exacerbations Non-Invasive Positive Pressure Ventilation is applied, at intensive care or nursing ward.

12. **Complementary treatments**

E.g. homeopathy, acupuncture.

* see more detailed description in subsequent paragraphs

The integrated health status does not solely depend on physiological measures, but also to the degree the patient is adapted to the disease. Psychological factors are important: cognition, emotion and behaviour. These are strongly interrelated with each other and with the disease, and are also influenced by the social environment of the patient. In all the above-mentioned treatment modules, the adaptation plays an important role.

### 5.1.1.3 **Physical Therapy**

The provision of physical therapy is related to dyspnoea and a reduced exercise performance/physical activity and/or impaired mucus transport. Patients with COPD and those with dyspnoea (including non-diagnosed patients with COPD) are generally referred by a pulmonary physician or GP. Therapists providing ‘direct-access physical therapy’ should assess the patient’s GOLD stage and MRC score. The flow chart of Fig.5.3 shows the potential pathways for the treatment of a reduced exercise performance in two different modalities: a *multidisciplinary rehabilitation program* and a *physical activity program* supervised by a physical therapist in primary care.

The patients with mild to moderate COPD (GOLD stages 1 and II) and with mild impairment of the exercise capacity (MRC < 2) can be involved in regular physical (sports) activities. Patients with more advanced disease (GOLD III and IV) should be seen by a pulmonary physician for further multidisciplinary assessment and treatment. Patients with mild disease but with more impaired functional performance (MRC ≥ 2) or increased risk for cardiovascular diseases (age, smoking, low physical activity) should have formal exercise evaluation to further assess their impaired exercise capacity as well as their ability to safely perform exercise training. Fig. 5.3 shows further the continuity of the integrated care for patients with COPD. After a multidisciplinary rehabilitation, the exercise training should be continued in relevant physical activity programs. Alternatively, the patients participating in physical activity programs might need further multidisciplinary treatment when disease progresses or after severe acute exacerbations.
Fig. 5.3 Dyspnoea, impaired physical activity and physical fitness (KNGF guideline, 2009) [19].

5.1.1.3.1 Treatment Plan

The general goal of the treatment is to reduce or eliminate the patient’s body function impairments and to improve activities and participation, thereby improving quality of life. The most common treatment goals for physical therapy interventions are the following:

1. to reduce dyspnoea;
2. to improve exercise capacity and physical activity;
3. to improve mucus clearance;
4. to improve knowledge, self-management and self-efficacy.

The patient education - belonging to the domain of physical therapy - involves breathing strategies, bronchial hygiene techniques, benefits of the exercise and maintaining a physical activity level and anxiety and panic control including relaxation techniques.

In addition to those mentioned above, a patient might experience other health problems, which should be addressed by a multidisciplinary team comprising of a pulmonary physician, general practitioner, physical therapist, nurse, nutritionist, psychologist, social worker, and occupational
therapist, all qualified in respiratory disease and rehabilitation management. These teams will mostly be based in a secondary or tertiary health care facility, but can also be based in primary care.

5.1.1.3.2 Treatment in the Twente Region
In the Twente region, a large number of physical therapy practices are part of the COPE-Active association, specialized in the state-of-the-art treatment of patients with COPD. This association aims to treat COPD patients using state-of-the-art treatment, with a uniform quality and style of work. For this, physiotherapists are trained, guidelines are developed, and multidisciplinary collaborations are set up in both primary and secondary care. These physiotherapists are employed in primary and secondary care and contribute to scientific research that aimed to investigate the effect of physical therapeutic exercise programs in COPD, including telemedicine research.

5.1.1.4 Lung Rehabilitation
Pulmonary rehabilitation is defined as “a comprehensive intervention based on a thorough patient assessment followed by patient-tailored therapies that include, but are not limited to, exercise training, education, and behaviour change, designed to improve the physical and psychological condition of people with chronic respiratory disease and to promote the long-term adherence to health-enhancing behaviours” [20].

The symptom burden, functional impairment, and impaired quality of life in patients with chronic respiratory disease are not simply consequences of the underlying physiological disorder, but also depend on the patient’s adaptation to the illness, its comorbidities, and its treatments. Problems with activities and participation can only be assessed when looking at patients from various perspectives, approaches and treatments, i.e. somatic, psychological, communicative and social aspects. As stated in the ATS/ERS statement on pulmonary rehabilitation: pulmonary rehabilitation is implemented by a dedicated, interdisciplinary team, including physicians and other health care professionals; the latter may include physiotherapists, respiratory therapists, nurses, psychologists, behavioural specialist, exercise physiologists, nutritionists, occupational therapists, and social workers. The intervention should be individualized to the unique needs of the patient, based on initial and ongoing assessments, including disease severity, complexity, and comorbidities. Although pulmonary rehabilitation is a defined intervention, its components are integrated throughout the clinical course of a patient’s disease. Pulmonary rehabilitation may be initiated at any stage of the disease, during periods of clinical stability or during or directly after an exacerbation. The goals of pulmonary rehabilitation include minimizing symptom burden, maximizing exercise performance, promoting autonomy, increasing participation in everyday activities, enhancing (health-related) quality of life, and effecting long-term health-enhancing behaviour change [20].

Rehabilitation programs should include, at a minimum, exercise training, nutrition counselling and education. The educational component of pulmonary rehabilitation has gradually evolved from a traditional, didactic approach to the promotion of adaptive behaviour change, especially collaborative self-management [20].

The applied therapeutic components of lung rehabilitation include the following [21]:

- Medication (individual effects and self-management);
- Oxygen therapy;
- Smoking cessation;
- Education (on COPD, inhalation technique, self-management, social map);
• Upper / lower limb training;
• Inspiratory muscle training;
• Mucus clearance;
• Movement training (coordination, flexibility);
• Breathing exercises;
• Pace regulation;
• Energy balance / day schedule;
• ADL training;
• Ergonomics;
• Relaxation exercises;
• Speech regulation;
• Psychological counselling;
• Occupational therapy (work);
• Nutritional counselling;
• Respiratory support;
• Supporting aids;
• Organize follow-up process.

5.1.1.4.1 Treatment at Roessingh lung rehabilitation centre

The lung rehabilitation programme is an outpatient group treatment of 2 or 3 days a week, for 3 months. The groups consist of maximally 8 persons with a lung disease (not necessarily COPD). Treatment is aimed at breathing techniques, physical condition, sports / swimming, group meetings, assistance in educational opportunities, and work (re)integration. The partner of the patient is involved in the program.

There is a regular treatment team, consisting of a rehabilitation physician, specialist, physiotherapist, movement teacher, social worker, and dietician. If necessary an occupational advisor and a psychologist. The treatment team holds weekly meetings.

5.1.2 Patient Pathways for MCI (the Netherlands)

Commissioned by the Dutch ministry of Public Health, Wellbeing and Sports, the Netherlands has a Dutch ‘care standard for dementia’ (Dutch: “Zorgstandaard Dementie”) since July 2013 [23]. This guideline is unique because it covers not only the care, but also the wellbeing and the treatment, and has received contributions from over 30 organisations in The Netherlands. [23] describes a multidisciplinary and integral patient-centred approach and it is currently in the authorisation phase of The National Health Care Institute. This institute assesses care-standards for inclusion in the statutory insured package [24], [25]. The Care standard for dementia does not describe which professionals should deliver each specific care task, but the task allocation is delegated to the
regional care providers, such as the local governments and the care insurance companies to enable them to strive to optimal fulfilment of their care tasks.

5.1.2.1 Diagnosis and Assessment

Dementia is a syndrome (a combination of symptoms), in which the brain function is disturbed. Alzheimer’s disease is the most prevalent type of dementia. Life expectancy with dementia is about eight years, of which for six years, the person with dementia is living at home [23]. However, the time course of the disease can vary strongly between individuals. In the Netherlands, there are about 250,000 people diagnosed with dementia. It is expected that this number will double up to half a million in 2050 [23].

Dementia is a progressive syndrome, which means that it would worsen over time. People with dementia will lose their ability to take care of themselves and their loved ones will slowly ‘lose the person with dementia – their character and memories’. A detailed information on the demographics, stages of dementia and the burden on the informal caregivers are described in Deliverables 2.1 and 2.2 of the eWall project [4].

The early diagnosis – in the early stage of dementia – is important, not only for the care, the practical and the emotional help, but also for all the legal and financial decisions that can relief the burden of ‘not knowing what is wrong?’. The Care Standard Dementia [23] mentions prevention via two routes, namely:

1. **Collective prevention.** Focus on the general population and specific risk groups. Providing general information on dementia symptoms, available care, care volunteers etc.

2. **Individual prevention.** Supporting professionals and volunteers to refer people with a ‘feeling of something is wrong’ (early warnings of dementia) to professional help (e.g., the signalling of early signs towards cognitive deficits and/or burden on the informal caregivers). A regional example is the preventive house visits for elderly over 75 years old.

5.1.2.1.1 Diagnosis

**General Practitioner (GP)**

Family members often notice the first symptoms of dementia. Together with the two prevention routes aforementioned, the person with possible dementia will often be referred to the general practitioner (GP). The GPs in the Netherlands are in charge of the first anamnesis and reference to the specific specialists, depending on his or her findings. The GP’s have their own standard of dementia care, the ‘NHG-Standaard Dementie’[26], [27], which is a manual describing three phases: 1) signalling, 2) diagnosis, and 3) evaluation. Details of these phases are given below.

1. **Signalling:** symptoms of possible dementia. Memory deficits, apathy, weight loss, walking difficulties, frequent visits with specific complaints.

2. **Diagnostics.** Exclusion of other causes of the symptoms. For example, such are hormonal disbalance, vitamin deficiency, wrong medication use and depression. These can be tested by blood and urine testing. Aphasia and other changes in the behaviour will be evaluated by consulting the close social environment, such as close family members living with the individual. To objectify the cognitive deficits, the Mini-Mental State Examination (MMSE) and the Clock Drawing Test (CDT) should be administered [28].
3. **Evaluation.** The diagnosis of dementia is based on the presence of the following three characteristics:

- Memory deficits;
- One or more cognitive deficits (aphasia, apraxia, agnosia, ADL difficulties);
- Impact on the daily functioning.

When further examination is needed for the diagnosis, the GP refers the patient to a specialist. The following possibilities are there:

- **Referral to a medical specialist:**
  When a GP presumes that the person has an Alzheimer’s disease, he or she often refers to a medical specialist for neurological and neuropsychological evaluation, sometimes extended with other examinations or tests such as an MRI scan. In the Netherlands, there are dedicated memory-policlinics (www.geheugenpoli.com), neurological departments in hospitals, GGZ or psychiatric centres. In the Netherlands, patients can only visit a specialist when they are referred by their GP.

- **Case manager**
  Independent case managers are available (in many regions in the Netherlands) for guidance and counselling during the whole dementia trajecy from the early signs, diagnosis, care adjustments, intramural care, until the decease of person with dementia.

### 5.1.2.1.2 Treatment

The treatment of dementia can consist of medication, adaptations of the environment and guidance for the person with dementia and his or her informal caregivers. Dementia care is complex and requires networked care of several care providers, which are changing over time when the individual needs are changing.

The treatment aspects of good dementia care as adopted in The Netherlands are summarized in Table 5.3 [23].

<table>
<thead>
<tr>
<th>Conditions of good Dementia Care</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Respectful contact</td>
<td>Care professionals will respect the capacities and dignity of person with dementia.</td>
</tr>
<tr>
<td>2 Clear and timely information</td>
<td>Providing information on early signs of dementia, diagnosis and possible treatment to support early diagnosis; and information after diagnosis on care, treatment and guidance.</td>
</tr>
<tr>
<td>3 Signalling and active referring to professional help</td>
<td>Professional care providers or local governmental domestic support (WMO-loket) can signal early signs of dementia and actively refer to professional help.</td>
</tr>
<tr>
<td>4 Fast and accurate diagnostics</td>
<td>Striving towards a diagnosis within 1 year after the first signs of dementia or feeling of 'something wrong'. Diagnosis can be done, depending on the situation, at home, in a general memory-policlinic</td>
</tr>
</tbody>
</table>
5 One case manager and one personal care plan

or in a specialized memory-clinic.

When dementia is expected on personal case manager will be assigned for guidance and as an independent contact for the person with dementia and his or her informal caregivers. Together with this case manager a personal care plan will be created consisting of all activities of and agreements with all care providers involved. The case manager will also consults the responsible medical specialist and other care professionals.

6 Treatment, help and guidance

Support will be the minimal necessary to minimize the effects of the dementia, and focusses on both the person with dementia and his or her informal caregivers. Support should complement personal wishes, habits and needs.

7 Activities matching personal lifestyle and capacities

Activities that the person with dementia are offered, should match his or her lifestyle, (learning) capacities and personal interests. And should provide day rhythm, regularity and meaning to life.

8 Temporary or full relief of care tasks

Informal caregivers often perceive a high care burden and can benefit from temporal relief of their care tasks by volunteers or care professionals either at their own home, or temporary in a care institute (Dutch: Respijtzorg). This enables informal caregivers to go on a holiday, visit a hobby club or read a book.

9 Safely and comfortably dwelling

Adaptations to the home such as reducing acoustic stimuli can help the person with dementia living comfortably at home. Also monitoring technologies can help to keep an eye on the person with dementia. When living at home is no longer safe or comfortable, other types of dwelling with care facilities are available such as small-scale group accommodations, caring homes, day or night care, and many others.

10 Crisis care

When the health status of the person with dementia or of the informal caregiver changes suddenly, crisis care is available 24/7 and will be brought into action by the ‘responsible care professional’. This care can be temporal admission into a caring home or crisis care at home. This, to prevent a permanent move into a care facility.

5.2 Clinical Workflows (The Netherlands)

5.2.1 Clinical Workflow for COPD

As stated in the guidelines, the effective and successful treatment of COPD patients is a team effort. A multidisciplinary team comprises a pulmonary physician, general practitioner, physical therapist, nurse, nutritionist, psychologist, social worker, and occupational therapist, all qualified in respiratory disease and rehabilitation management. These teams will mostly be based in a secondary or tertiary health care facility, but smaller teams (including general practitioner, nurse, physical therapist and nutritionist are also based in primary care [19].

The main actor of the COPD patient care is either the GP or the lung physician. In general, the clinical workflow for the patients with mild, moderate and severe disease burden, respectively, is as summarized below [18].

- **Clinical workflow for the mild COPD group**

  The mild group is treated close to home (after diagnostic consult) within 3 months. Main actor of the patient is the GP. Follow-up at least once a year with a yearly basic assessment in primary care.
• **Clinical workflow for the moderate COPD group**

The main actor of the patient is the GP and/or lung physician. If the moderate group is stable and the treatment goals have been reached, they are treated close to home after a 3-12-months follow-up. When the patients are not stable or do not reach the treatment guidelines, they are treated in a secondary care (chest physician and e.g. outpatient lung rehabilitation) or ‘shared care’ models. A follow-up of at least twice a year with a yearly basic assessment is performed. On indication, more extensive assessment can be done.

• **Clinical workflow for the severe COPD group**

The severe COPD group is treated and followed in secondary care or in intensive multidisciplinary lung rehabilitation. Shared care is applied in the case of exacerbations. Once that the treatment goals have been reached after the lung rehabilitation, the patients are referred back to the chest physician. In the case of terminal care, the option is to choose for a care close to home, in agreement with the patient. Follow-up at least twice a year with a yearly basic assessment in secondary care. On indication more extensive assessment is done.

### 5.2.2 Care Organization

Table 5.3 shows the organization of the standard care of patients with mild or moderate disease burden, and when patients are treated in primary or secondary care. Patients are diagnosed, treatment is set (consisting of medication, smoking cessation, physical activity, nutrition, coping/adaptation), the treatment goals are evaluated and follow-up assessments are performed. In addition, patients are educated and are treated for exacerbations if necessary. Table 5.4 shows all the care professionals that are involved in the different treatment aspects.

<table>
<thead>
<tr>
<th>Treatment part</th>
<th>Involved care professionals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis</td>
<td>GP</td>
</tr>
<tr>
<td></td>
<td>Lung physician</td>
</tr>
<tr>
<td>Evaluation/Follow-up*</td>
<td>Practice assistant (POH)</td>
</tr>
<tr>
<td></td>
<td>Nurse practitioner</td>
</tr>
<tr>
<td>Smoking cessation**</td>
<td>Behavioural therapist</td>
</tr>
<tr>
<td></td>
<td>Group course</td>
</tr>
<tr>
<td></td>
<td>Smoking cessation clinic (hospital)</td>
</tr>
<tr>
<td></td>
<td>GP/POH</td>
</tr>
<tr>
<td>Physical activity / exercise</td>
<td>Physical therapist</td>
</tr>
<tr>
<td></td>
<td>Movement teacher</td>
</tr>
<tr>
<td>Dietary / nutrition***</td>
<td>Dietician</td>
</tr>
<tr>
<td>Pharmacologic treatment</td>
<td>GP</td>
</tr>
<tr>
<td></td>
<td>Lung physician</td>
</tr>
<tr>
<td></td>
<td>Pharmacist</td>
</tr>
<tr>
<td>Information, awareness and education</td>
<td>GP / Lung physician</td>
</tr>
<tr>
<td></td>
<td>POH / nurse practitioner</td>
</tr>
<tr>
<td></td>
<td>Physical therapist</td>
</tr>
<tr>
<td></td>
<td>Psychologist</td>
</tr>
</tbody>
</table>
The healthcare in case of an exacerbation can take place in primary or secondary care. This is illustrated in Fig. 5.5. In case of an emergency, patients can be hospitalized for an exacerbation. The organization of care and costs for exacerbations in primary care are in DBC M3 [21].
Fig. 5.5 Exacerbation work flow [18], [22].

5.2.3 Clinical Workflows for Dementia

5.2.3.1 Care Organization

In the Netherlands, a network of medical professionals would be involved in the dementia care. The GP is ‘in charge’ of the care path, as the medical specialists can only be consulted, after the GP’s referral of the patient. These medical professionals are the following:

- GP
- Specialized clinics / hospital
- Centres for dementia (inpatient care, day care)
- Case managers
- Homecare
- Alzheimer NL for information distribution via their website, public campaigns and Alzheimer cafés. These cafés are informal monthly meetings for all people interested in information on Alzheimer’s (both patients and/or their relatives) providing practical information and contact with fellow sufferers. These meetings are locally organized, currently at 228 locations throughout the Netherlands.
6 Romania

6.1 Patient Pathways (Romania)

6.1.1 COPD

• Ambulatory Monitoring in Romania
  Over two thirds of the COPD patients to the doctor are to their family physician (GP), largely for a prescription renewal; the vast majority of those consulting a lung physician are from the urban areas.

• Exacerbations in Romania
  Annually, over 80,000 hospitalizations are registered for COPD exacerbations, representing 1.76% of the hospitalizations in 2006 (DRG). There are no estimates for the ambulatory treatment of COPD. A recent study, based on COPD patient interviews, showed that they were subject to an average of 2.3 exacerbations per year, of which two thirds required hospitalization.

• COPD Hospitalizing Costs in Romania
  A retrospective study, based on observation/medical sheets of COPD hospitalized patients, showed an average hospitalization cost of EUR 727. Out of the overall annual direct medical costs for COPD (moderate and severe), the “exacerbation” component represented cca.83%, being the main component of the overall expenses for disease management.

• COPD Management Priorities
  The following recommendations should be considered a priority in the COPD management in Romania [29]:
  • COPD diagnosis;
  • Give up smoking;
  • Pharmaceutical/prescribed medication treatment;
  • Exacerbation management;
  • Patient awareness/education;
  • COPD management optimization.

The history and physical examination for COPD are somewhat unspecific, especially for the mild and moderate manifestations. For this reason, spirometry should be used to confirm the diagnosis, which additionally allows for an illness stage assessment. COPD diagnosing in the absence of spirometry is uncertain.

Obstruction of airways is defined as follows:

• MEVS < 80% of the predicted value,
• MEVS / FVC < 70% of the predicted value;
- MEVS – maximum expiratory volume in the first second
- FVC – forced vital capacity

Following a drug therapy, if the MEVS and the MEVS/FVC ratio normalize, the COPD diagnosis is not confirmed.

The COPD severity has four stages based on the percentage value of MEVS (out of the predicted value based on the age, the height and the gender) in accordance with GOLD (Global Initiative for Chronic Obstructive Lung Disease) [17].

The stratification for COPD in Romania is shown in Table 6.1.

<table>
<thead>
<tr>
<th>Stage/stadium</th>
<th>Criteria</th>
<th>Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>I  mild</td>
<td>MEVS/CVF&lt;70%</td>
<td>MEVS &lt;80%</td>
</tr>
<tr>
<td>II Moderate</td>
<td>50%&lt; MEVS &lt;80%</td>
<td></td>
</tr>
<tr>
<td>III Severe</td>
<td>30%&lt; MEVS &lt;50%</td>
<td></td>
</tr>
<tr>
<td>IV Very severe</td>
<td>MEVS &lt;30% or MEVS &lt;50% + chronic respiratory insufficiency</td>
<td></td>
</tr>
</tbody>
</table>

The patient pathway for a COPD patient in Romania is shown in Fig. 6.1.

The family physicians identify symptomatic patients suspected of COPD and direct them to a medical specialist (lung physician) for an adequate/competent assessment. Later on, the family physician monitors the evolution of the COPD diagnosed patient, who follows the chronic treatment as prescribed by the medical specialist. A reassessment of the COPD patient is performed by the medical specialist, after a period of 3-6 months for a severe and extreme COPD, and after 12 months for light and moderate COPD. If the symptoms and the quality of life do not improve significantly, the re-assessment by the medical specialist will be performed in a period not exceeding 3 months.

The moment in which an exacerbation occurs implies a compulsory evaluation by the medical specialist in order to readjust the treatment.
6.1.1.1 Criteria for COPD evaluation

The family physician requires a number of criteria for prescribing a medical specialist (pulmonary or internist) evaluation for a COPD patient, as follows:

- Suspicion of COPD;

- Consultations by medical specialists:
  - mild and moderate COPD - annually (includes clinical tests, spirometry, 6 min. walking test on a case by case basis);
  - severe and extreme COPD – every 6 months; 3 months for those presenting frequent exacerbations and/or severe symptoms (includes clinical examination, spirometry, arterial blood gas, ECG, hemoglobin and hematocrit level testing, 6 min. walking test on a case by case basis);

- Disease non-responsive to treatment:
  - persistent symptoms (cough, purulent expectoration, dyspnea);
  - frequent and/or severe exacerbations;
  - signs of disease complications (respiratory insufficiency, pulmonary heart, polyglobulia);

Fig. 6.1 Patient pathway for a COPD patient in Romania.
• Sleep apnea symptoms: daytime somnolence, wake-up at night sleep, apnea noticed by the partner;
• Assistance for tobacco withdrawal.

The criteria for directing a confirmed COPD patient to other medical specialists and departments are summarized as follows:

• Physiotherapy – patients with excessive or purulent expectoration – respiratory techniques;
• Nutrition counseling – patients with high or low BMI, or with considerable fluctuations;
• Occupational health specialist – patients with professional exposure;
• Social Services Department – patients with debilitating COPD;
• Multitasking teams for palliative care – terminal COPD patients, their families, and caretakers

6.1.1.2 COPD Assessment

The COPD patient assessment takes place during each visit to the medical specialist, optimally taking place at intervals of 3 - 6 - 12 months.

The stable COPD assessment includes:

• Smoking status: smoker/ex-smoker/non-smoker and the degree of tobacco intoxication (packs per year);
• Level of dyspnoea (degree of tolerance to physical exercise) – consider a 6 min. walking test;
• Associated symptoms (coughing, expectoration);
• Ventilation function through spirometry at least annually for mild and moderate COPD and at 3-6 month periods for severe and extreme COPD patients;
• Occurrence of complications (chronic respiratory insufficiency, chronic pulmonary heart disease);
• Frequency of exacerbations, hospitalizations, ER (emergency interventions).

6.1.2 Dementia

6.1.2.1 Current status and perspectives of the national strategy on dementia in Romania

Alzheimer’s disease, a concerning reality of today’s world, has both social and economic implications which are escalating as a result of an ageing population. Coordination between the EU (Parliament and Commission) and the national policies is paramount for the patients’ benefit of the best available treatment and care.

The issues to be solved have been identified as follows:

• Social integration of patients;
• Reducing pressures or constraints for families and close friends of the family;
• Access to efficient medication and/or treatment;
• An early stage treatment is particularly relevant to the prevention of a rapid brain neuron deterioration; hence the need for an early/timely diagnosis.

The Medical Practice Guide for Dementia [30], currently in use in Romania, aims at standardizing in the diagnosis and treatment of the most frequent forms of dementia. It is based on clinical studies that follow the principles of medicine based on the evidence, as well as the guidelines, laid out by the European Federation of Neurology (EFNS) and the American Academy of Neurology [31], [32]. A multidisciplinary approach by specialized services of any patient with cognitive impairment would be welcome – memory centres, whereby a multidisciplinary team would perform a complex assessment in order to issue a correct diagnosis.

The recently diagnosed patients should be reviewed after 2 months in order to determine their degree of tolerance, followed by a 6-months monitoring. Subsequent evaluations are needed for cognitive, functional and behavioural assessment monitoring (including the stabilization or slowing down of the disease’s evolution), as well as for possible side-effects or somatic/mental/neurological comorbidity.

In addition to a specific drug therapy, integrated medical services should be made available to the individuals affected by dementia so as to ensure primary care, home care, special daily services, specialized hospital/institution care and recovery, general hospital care, specialized mental health services, which would include local teams for mental health assessment, memory evaluation services, psychological and home-care therapies.

Table 6.2 summarizes the specifics of the disease and the available recommendations for how to handle those.

<table>
<thead>
<tr>
<th>Specifics of the disease</th>
<th>Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild/moderate cases</td>
<td>Structured programs for cognitive stimulation provided by adequately trained and qualified medical and social personnel.</td>
</tr>
<tr>
<td>Moderate/severe cases</td>
<td>permanent monitoring and care by the family or a specialized social worker (rights to an attendant)</td>
</tr>
<tr>
<td>Severe cases</td>
<td>hospitalization in specialized medical facilities is recommended for dementia patients in their last stages without a specific timeline since the individual is completely dependent - physically and psychologically - in this final stage of the illness</td>
</tr>
<tr>
<td>Behavioural and psychiatric symptomatology</td>
<td>behavioral and functional assessment by professionals with specific abilities, in order to evaluate the factors that could generate, aggravate, or ameliorate behavioral changes (pain often generates unexpected behavioral changes)</td>
</tr>
<tr>
<td>Patients with anxiety, regardless of the type or severity of dementia</td>
<td>access to specific procedures in accordance with personal preferences, abilities, and habits, as per their personal history. Such approaches include: memory therapy (recollections), psychomotor exercises, multi-sensorial stimulation, various forms of social/occupational therapy (e.g. through music, dance)</td>
</tr>
<tr>
<td>Individuals with dementia suffering</td>
<td>cognitive-behavioral therapy with active involvement of the specialized staff</td>
</tr>
</tbody>
</table>
There is currently no national strategy for handling the Alzheimer’s disease. The Romanian Alzheimer Society - Societatea Română Alzheimer- has sent letters asking for the development of a national plan to various government departments. In this respect, the outcome of eWALL can be a very valuable contribution for developing further this national plan.

Dementia has to be recognized as a priority public healthcare problem in Romania. In support of this worrying situation, The Romanian Alzheimer Society appeals to the relevant political and public authorities through its proposed National Plan for dementia: The Strategy and the National Plan if Action for the period 2014 - 2020.

Some specific objectives of the above action are the following:

a) Drawing-up a Register of certified individuals suffering of Alzheimer dementia, where a special note will apply to “social” cases (sick persons without family).

b) Establishment of a significant number of specialized units for the early diagnosis of dementia and Alzheimer disease, such as a Memory Center-“Centrul Memoriei”- able to process urgent assessment requests of individuals with cognitive confusions. Establishing such a center is of great importance as it would:

- allow for a differential diagnosis of dementia from other illnesses that can be treated and are potentially reversible;
- allow the patient and the family to take legal steps for protection before losing the capacity to make decisions;
- assist families with present and future financial planning;
- allow the patient to decide with the family on the most suitable form of treatment/care;
- allow the patient to be aware of his/hers life planning;
- ensure counselling and support for families currently caring for sick members.

Such medical units must be made part of the standardized medical network of healthcare and recognized as part of the public healthcare network.

c) Development of a network of basic services for individuals with dementia and carers.

Such services should offer a variety of options, be flexible, have ease of access, and ensure continuity of care. Types of such services are:

- cognitive assessment, diagnostic, and treatment;
- support services for initial stages of the illness;
- social services at the level of local communities and/or at home (permanent/long term, or temporary);
- boarding facilities – terminal illness hospital.
d) Designing public awareness and education programs on dementia and Alzheimer disease, aimed at early detection of the illness, shortening investigations for early diagnosis, as well as initiating steps towards adopting the relevant legislation for specific situations while ensuring access to treatment and services from the incipient/early stages.

e) Social campaign for social inclusion, removing the stigma surrounding individuals with dementia
7 Differences and similarities between countries

This section seeks to summarize the main differences and similarities between the patient pathways and clinical workflow in the different countries with a particular focus on the demonstration countries (Denmark, Italy and the Netherlands).

7.1 Differences/similarities in patient pathways in COPD

The patient pathways in COPD in the demonstration countries seem quite similar. The GP plays a key role in the diagnosis and in the following of the treatment of the patient. All patients are stratified into varying treatment paths depending on the severity of their disease. In the more severe COPD cases a more specialized lung physician will typically take over some of the responsibility for the treatment of the patient.

In all demonstration countries patients are offered COPD rehabilitation. The criteria for being included in COPD rehabilitation vary. However, the consensus seems to be that the COPD should have reached a certain level of severity before the patients are entered into rehabilitation. The rehabilitation programs contain more or less the same elements. As a minimum, the rehabilitation programs include the following elements:

- Exercise training;
- Education;
- Behaviour change.

All elements are designed to improve the physical and psychological condition and to promote the long-term adherence to health-enhancing behaviours.

The eWall system could therefore seek to assist COPD patients within the above areas – however, not necessarily only within these areas.

It should also be emphasised that in COPD treatment there is a focus on the health behaviour change, for example with regard to the physical activity. This is an important aspect in and after rehabilitation, but also in the earlier phases of the disease. The eWall system should rather be inspired by the scopes of rehabilitation in Europe coming up with a unique solution.

7.2 Differences/similarities in patient pathways in dementia

The patient pathways in dementia appear rather similar in the three demonstration countries. The first ones to notice the dementia are typically the immediate family members. The next step would typically be a visit to the GP. After that, the patient can be referred to a specialist for further evaluation. The GP will remain the patient’s primary contact within the health care system even after the referral to the medical specialist.

7.3 Differences/similarities in clinical workflow in COPD

Most often the GP is the key responsible during the entire treatment process in COPD with the exception of the more severe cases when a lung physician takes over as the primary responsible.
The treatment of the COPD patient is multidisciplinary and a variety of health care professionals take part in the patients care, including doctors, nurses, therapists etc. The treatment will typically take place in both primary and secondary care.

7.4 Differences/similarities in clinical workflow in dementia

It should be fair to say that patient pathways and clinical workflow are less structured and adequately described in dementia than in COPD in all demonstration countries. A reason for this may be the diversity of the patient paths and/or the lack of rehabilitation programs. The GP remains the key responsible for the treatment of the dementia patient. However, other people may be involved in the patients care – including both primary care, secondary care and relatives.

7.5 Maps of correspondence

The maps of correspondence have the objective to give an overview of the differences and similarities between the demonstration countries.

7.5.1 COPD Map of Correspondence

Table 7.1 gives the COPD map of correspondence.

<table>
<thead>
<tr>
<th>Area of interest</th>
<th>Denmark</th>
<th>Italy</th>
<th>The Netherlands</th>
</tr>
</thead>
<tbody>
<tr>
<td>Who does the diagnosis?</td>
<td>GP</td>
<td>GP(sometimes with consult of lung physician)</td>
<td></td>
</tr>
<tr>
<td>Sectors possibly involved in the patients care</td>
<td>GP Hospital</td>
<td>Hospitals/GP (for monitoring progress and management of symptoms)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Outpatient clinic</td>
<td>Physical therapy practices</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Municipality</td>
<td>Rehabilitation centers</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Other non-standard care (e.g. psychology practices)</td>
<td></td>
</tr>
<tr>
<td>Health care professionals possibly involved in the patients care in eWall</td>
<td>GP (would be ideal but could be challenging) Hospital doctors Lung specialist doctors Nurses (at all levels – including municipal).</td>
<td>GP/Specialist nurse/lung physician Rehabilitation physician Physical therapists Occupational therapists Movement teachers Social workers</td>
<td></td>
</tr>
<tr>
<td>Main actor/key person in the patients pathway</td>
<td>GP A case manager if the patient has complex needs</td>
<td>GP for mild to moderate COPD Lung physician for (very) severe COPD</td>
<td></td>
</tr>
<tr>
<td>Elements that should be included in rehabilitation</td>
<td>Smoking cessation</td>
<td>Exercise training</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Physical exercise</td>
<td>Education</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Medical treatment</td>
<td>Behaviour change (with regard to physical activity)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Nutrition education and treatment</td>
<td>Psychosocial support</td>
<td></td>
</tr>
<tr>
<td></td>
<td>COPD education</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Psychosocial support</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Duration of rehabilitation</td>
<td>7-12 weeks</td>
<td>12 weeks</td>
<td></td>
</tr>
</tbody>
</table>
### 7.5.2 MCI Map of Correspondence

Table 7.2 gives the MCI map of correspondence.

<table>
<thead>
<tr>
<th>Area of interest</th>
<th>Denmark</th>
<th>Italy</th>
<th>The Netherlands</th>
</tr>
</thead>
<tbody>
<tr>
<td>Who does the diagnosis?</td>
<td>GP (preliminary) Specialized units of dementia diagnosis</td>
<td>GP “Dementia professional” (typically a nurse who is specialized within dementia) at municipal level</td>
<td></td>
</tr>
<tr>
<td>Health care professionals possibly involved in the patients care in eWall</td>
<td>GP “Dementia professional” (typically a nurse who is specialized within dementia) at municipal level</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Key person</td>
<td>“Dementia professional” (typically a nurse who is specialized within dementia) at municipal level</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Elements that should be included in rehabilitation</td>
<td>No specific suggestions for health promoting activities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Duration of rehabilitation</td>
<td>n/a</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
8 Conclusions

This deliverable described the patient pathways and clinical workflows for the eWALL primary user groups, namely, patients suffering from COPD and MCI. The patient pathways and clinical workflows were described for the three main countries where eWALL will perform large scale real-user trials, as well as for Romania, for further comparisons. The crucial task here is to enable a feedback to the WP3, WP4, WP5 and WP6 that would guarantee a sustainability of the eWALL solution.

The eWall solution should aim at the following:

- Provide quick and easy access to complete patient information from across the care continuum;
- Improve the clinical decision making with built-in support tools enabled by the eWALL services, devices, and reasoning framework;
- Align to and enhance existing clinical workflows and patient pathways so that;
  - Administration and paperwork is reduced
  - Patient care and coordination across the care continuum is guaranteed;
  - Patient experiences and outcomes are very high quality
  - Strong privacy and consent compliance is provided.
- Focus on the COPD assistance and rehabilitation; also, the system could provide assessment within this area

The eWALL services and applications should fit seamlessly into the everyday clinician workflow. They should focus on the way clinicians work, and when and how information is needed resulting in solutions that are so intuitive that clinicians actually want to use them. A collaboration across eWALL work packages and WP2 tasks should benefit the real user trials by identifying the following key issues for the eWALL clinical workflows also mapped to patient pathways:

- Who uses the various eWALL devices? eWALL primary users? eWALL secondary users, such as physicians and nurses? Administrators?
- What eWALL applications would be accessed the most, and how do eWALL users get to them?
- Where is the eWALL device – a public or private location? What connectivity does it have?
- When and how do eWALL users access the device – is it shared or not, and do users change frequently and rapidly?
- Why do eWALL users use the device? How important is the device speed to this function? How critical is the security? How can we balance the speed and security for an ultimate user benefit?
- How to optimize the eWALL primary user’s self-management?
Bibliography


Abbreviations

MCI Mild Cognitive Impairment
COPD Chronic Obstructive Pulmonary Disease