Horizon 2020
European Union Funding
for Research & Innovation

ADLIFE

D7.2 - Patient Empowerment Materials and Interventions

Deliverable No.	D7.2	Due Date	31/July/2021
Description	This deliverable presents the sum of activities that has been performed on the topic of patient empowerment as part of task 7.2.		
Type	Report	Dissemination Level	PU
Work Package No.	WP7	Work Package Title	Empowerment of patient, caregivers and communities
Version	1.3	Status	Final

Authors

Name and surname	Partner name	e-mail
Anne Dichmann Sorknæs	OUH	Anne.dichmann.sorknaes@rsyd.dk
Natassia Kamilla Juul	OUH	Natassia.kamilla.juul@rsyd.dk
Søren Udby	OUH	Soren.udby@rsyd.dk
Janika Blömeke	OM	j.bloemeke@optimedis.de
Gökçe Banu Laleci Erturkmen	SRDC	Gokc@srdc.com.tr
Mert Baskaya	SRDC	baskaya@srdc.com.tr
Dolores Verdoy Berastegi	KRON	dverdoy@kronikgune.org
Ana Ortega Gil	KRON	aortega@kronikgune.org
Irati Erreguerena Redondo	KRON	ierreguerena@kronikgune.org

History

Date	Version	Change
16/07/2021	1.0	Initial version shared with reviewers
20/07/2021	1.1	Addition of formal content and formatting + incorporated feedback from the first reviewer
27/07/2021	1.2	Incorporated feedback and comments from reviews
30/07/2021	1.3	Final revision

Key data

Keywords	Patient empowerment, empowerment tools
Lead Editor	Anne Dichmann Sorknæs
Internal Reviewer(s)	Fritz Arndt (OM/Gesunder) and Omar Khan (WARWICK)

Abstract

ADLIFE aspires to create an outcome-based personalized care model that achieve gains in patient health status and improves Patient Reported Outcomes, through a large-scale pilot study involving seven pilot sites: Osakidetza (Spain), NHS Lanarkshire (United Kingdom); Odense University Hospital (Denmark), FALKHOSP Lower Silesia (Poland), Werra-Meißner Kreis (Germany), Region Jämtland-Härjedalen (Sweden), and Assuta Ashdod Hospital and Maccabi Healthcare Services Southern Region (Israel).

In the ADLIFE project, patient empowerment is facilitated through a suite of tools each designed for the purpose of making empowerment opportunities available for those patients who seek it. One of the primary empowerment tools is the integration of Patient Reported Outcome Measures (PROMs) into the Patient Empowerment Platform (PEP). The application of Patient Reported Outcomes (PRO) and PROMs is based on the work described in Deliverable 7.1 - ADLIFE Patient Reported Outcome Measures. In addition to PRO and PROMs, other empowerment tools include learning mechanisms, nudging, Just-in-Time-Adaptive-Interventions (JITAIs), self-management & self-assessment, and educational materials. Together, these tools are capable of empowering patients to take charge of their lives and care plans should they aspire to do so. The facilitation of empowerment is delivered through a series of seemingly disparate interventions, however, the sum of these interventions have the potential to increase the patients' individual level of empowerment. The empowerment tools are primarily integrated directly into the ADLIFE Toolbox's platforms.

Deliverable 7.2 starts with a comprehensive analysis of what defines patient empowerment followed by an in-depth literature review examining some of the most commonly applied tools used for empowering patients through certain interventions including specific considerations for the primary ADLIFE patient groups with COPD and CHF respectively. The review segues into patient empowerment and patient empowerment tools in the context of the ADLIFE project followed by a presentation of each of the empowerment tools. This deliverable will form the baseline for the final selection and development of empowerment tools to be used in the ADLIFE Intervention Study later on in the project.

Statement of originality

This deliverable contains original unpublished work except where clearly indicated otherwise. Acknowledgement of previously published material and of the work of others has been made through appropriate citation, quotation or both.

Table of contents

List of tables

List of figures

Definitions and acronyms

Patient empowerment

Empowerment is defined as the capacity of individuals, groups and/or communities to take control of their circumstances, exercise power and achieve their own goals, and the process by which, individually and collectively, they are able to help themselves and others to maximize the quality of their lives [1].

The World Health Organization defines patient empowerment as "a process through which people gain greater control over decisions and actions affecting their health" [2].

1.1 Terms and acronyms

Term or acronym	Explanation
PU	Public
CDM	Chronic disease management
CHF	Chronic heart failure
COPD	Chronic obstructive pulmonary disease
CRD	Chronic respiratory diseases
D7.2	Deliverable 7.2
DoA	Description of Action
GOLD	Global Initiative for Chronic Obstructive Lung Disease
JITAI	Just-in-Time Adaptive Intervention
KRON	Kronikgune
NICE	National Institute for Health and Care Excellence
NYHA	New York Heart Association
OUH	Odense University Hospital
PCPMP	Personalized Care Plan Management Platform
PEP	Patient Empowerment Platform
Pilot site	Hospital participating in the intervention study
PREMs	Patient reported experience measures
PRO	Patient reported outcomes
PROMs	Patient reported outcome measures
SRDC	Software Research and Development Consultancy

WP	Work package

2 Purpose, context and scope of the deliverable

The work which supports the production of this deliverable (D7.2) has been completed within Task 7.2 "Patient Empowerment Intervention", led by Odense University Hospital (OUH) as described in the Description of the Action (DoA) in the framework of Work Package (WP) 7 "Empowerment of patient, caregivers and communities" also led by OUH.

OUH has been responsible for organising the research, design, and development of the primary output for D7.2 such as the Just-in-Time Adaptive Interventions (JITAIs) in close collaboration with Software Research & Development Consultancy (SRDC) and the Pilot Sites for inclusion into the Patient Empowerment Platform (PEP) developed in WP4. A special thank you goes to Dr Janika Blömeke from the Werra-Meißner Kreis pilot site in Germany for contributions to the literature review on patient empowerment and to the reviewers.

2.1 Purpose of the deliverable

ADLIFE aims to develop innovative digital health solutions to support the healthcare planning and care delivery for patients over 55 years old with advanced (severe) long-term conditions such as chronic obstructive pulmonary disease (COPD) and/or heart failure (CHF).

The purpose of this deliverable is to present the activities that have been conducted as part of the ADLIFE Task 7.2 such as researching patient empowerment validated tools and techniques, identifying relevant educational materials for patients, and developing the framework for producing suitable JITAIs. All these outputs will be included in the Patient Empowerment Platform that will be used by the ADLIFE pilot sites.

The deliverable describes the concept of patient empowerment through an in-depth literature review defining what patient empowerment is and what the goal of patient empowerment is. This review is then placed in the context of the ADLIFE project taking into consideration socio-cultural, medical, and psychological aspects of empowering patients across national and cultural borders. The deliverable continues with an analysis of patient empowerment tools and techniques in the context of the ADLIFE project describing selected techniques such as PRO and PROMs, their purpose and usage along with examples of for both a generic and COPD-specific test. This is followed by a comprehensive analysis of the concept and development of JITAIs including an overview and review of the JITAIs developed specifically for ADLIFE. Finally, the deliverable concludes with recommendations and guidance for approaching patient empowerment in the ADLIFE project.

2.2 Context of the deliverable

ADLIFE is divided into 11 different WPs, three transversal (WP1, WP2, WP10) and seven technical ones. WP7, along with WP6, is devoted to changing the care model and empowering patients so they can take part in decisions about their treatment and lifestyle with a chronic disease, while WP3, WP4, WP5 are devoted to the technical development of the ADLIFE toolbox. These five WPs will allow completing the Phase 1 ("Organizational issues and Information and Communications Technology [ICT] platforms implementation") and lead to obtaining the ADLIFE toolbox and model that will be implemented in Phase 2 (WP8) and evaluated in seven different health systems (WP9) in Phase 3.

All issues dealt with in this document are aligned with WP6 on the ADLIFE care model, WP4 on technical specifications of the PEP, WPs 3, 4 and 5 on ICT specifications, WP8 on pilot implementation, and WP9 on evaluation framework.

WP7 is responsible for the identification, collection, and analysis of patient and care professional needs, wishes and requirements to ADLIFE in order to improve the empowerment of both parties. Therefore, the objective of WP7, in close collaboration with WP4, is to enhance patients' and caregivers' quality of life and level of empowerment. WP4 develops the PEP as the technical infrastructure that will assist patients and their caregivers through the care plan where all the interventions designed in WP7 will be delivered. The joint aim of the WPs is both to support and empower patients and, furthermore, to enhance the patients and their caregivers' quality of life by means of the PEP.

As stated before, WP7 is intended to change the care model and empower patients and their caregivers. This is a complex enterprise involving clinical, technical, and organizational aspects. A key aspect of empowering patients revolves around the use of PRO and PROMs in a combination with the utilisation of JITAIs to motivate, educate and support the patients in the right way during the intervention study (WP8) by adapting to each patients' individual behaviour and contextual state. JITAIs are underpinned by increasing technological capability of current healthcare technologies, particularly mobile healthcare technologies and sensors available to patients for use in their own homes, which facilitates a rapid, dynamic, and timely response to deliver personalised JITAIs. The overall aim is to promote the patients' self-management skills and competence to deal with their diagnosis in a more empowered manner.

Task 7.2 - Patient Empowerment Intervention is connected to the ADLIFE project milestone M6 - Tools for empowerment delivered and ready to be tested in WP8, and the completion of this deliverable is the culmination of verifying the completion of this milestone. However, despite the completion of milestone 6 and this deliverable, the continuing work and development in the other work packages in ADLIFE project towards the start of the intervention study may result in additional patient empowerment tools being identified or existing tools modified, which may require an update to the final list of patient empowerment tools proposed by this deliverable.

2.3 Approach of this deliverable

ADLIFE aims to provide personalised, integrated care to improve the health situation, deliver more appropriate targeted and timely care for patients over 55 years old with Advanced Chronic Diseases with special focus on COPD and CHF. ADLIFE's technology innovations will be deployed, used, and evaluated in seven healthcare environments in Spain, UK, Sweden, Germany, Poland, Denmark, and Israel.

The approach for delivering this document has been to research patient empowerment as a concept and bring this understanding into the very specific context of the ADLIFE project and the target patient groups with the goal of developing a set of empowerment tools that are feasible, suitable, and acceptable for use within the framework of the ADLIFE project. Patient empowerment tools will be integrated into the ADLIFE Toolbox to further strengthen the focus on patient-centric care by providing achievable targets, trigger descriptions, and intervention content.

3 Introduction to Patient Empowerment

Introduction

In moving towards collaborative models of health care and patient-centred care, the concept of patient empowerment has gained increased recognition in healthcare in the last decades [3] [4].

The goal with patient empowerment is to increase the patients' knowledge about their health condition. Empowered patients have the confidence to manage their health within their ability and to maintain their health by seeking information and performing health promoting behaviours.

The importance of involving patients more proactively in their treatment is especially important with regard to the growing number of people living with chronic conditions who have rising medical needs [5]. Particularly patients with chronic diseases face challenges regarding managing their own health and deciding between various treatment options, which requires a good knowledge about healthcare and health care services [6]. Hence, successful long-term management of patients with chronic conditions requires active patient self-management and a proactive involvement of patients in their healthcare and treatment [7]. This requires a patient-provider partnership in which the patient and the provider work actively together within an integrated system of collaborative care, including self-management, education and follow-up [8].

3.1 Background

3.1.1 Chronic disease

Chronic diseases are the main cause of death and disability in the world, contributing around two thirds of the global burden of disease with enormous healthcare costs for societies and governments [9].

Approximately 50% of all people have a chronic physical condition, receiving some form of treatment. Beyond the physical impact, a chronic disease may have extensive psychological, emotional, and social consequences. Specifically, patients with chronic respiratory diseases often perceive breathlessness as one of the most important symptoms resulting in multidimensional consequences (e.g. effecting patients' daily life, social environment, etc.) and perceive adaptations due to their disease as increasingly challenging. Furthermore, 98% of these patients suffer from one or more comorbidities, leading to multiple drug therapies. This multi-morbidity and polypharmacy leads to poor health outcomes and poses a challenge for patients, their loved ones, and the health-care professionals involved in the disease management. Accordingly, appropriate management of chronic diseases, including the management of comorbidities and polypharmacy, may improve health outcomes [10].

Chronic disease commonly refers to non-infectious diseases such as cardiovascular conditions, respiratory conditions, type 2 diabetes and cancer, but also includes infectious diseases such as hepatitis and HIV/AIDS that persist and require care over time [11]. Population ageing is a global phenomenon, and living longer may mean living with one or more chronic diseases [11].

Internationally, the increasing prevalence of chronic disease among older adults creates significant financial, social and psychological burden for patients, families and healthcare systems. International data indicate over 90% of older adults aged 65 and over live in their own homes in communities [11]. Driving forces such as the shifting of health care from hospital

to community settings and older adults' desire to remain in their homes present new challenges for chronic disease management (CDM). While home is viewed as a desirable location for persons requiring chronic care, CDM is a complex process requiring ongoing sources of care, expertise and support from health, community and social providers.

3.1.2 Chronic respiratory diseases

Chronic respiratory diseases are diseases of the airways and other structures of the lung, [12]. The Forum of International Respiratory Societies considers pneumonia, asthma, COPD, lung cancer, and tuberculosis the five most important lung diseases worldwide from a prevalence standpoint.

Chronic respiratory diseases remain a leading cause of disability and death worldwide. The global prevalence in 2017 was around 7.1%, with the highest prevalence (10–11% of the population or higher) observed in high-income regions. In 2017, an estimated 544.9 million individuals worldwide had a chronic respiratory disease, equivalent to a 39.8% increase compared with the number of individuals affected in 1990.

Much of this burden is the result of premature mortality. There were 3,914,196 deaths due to chronic respiratory diseases in 2017 globally, an increase of 18.0% since 1990. These deaths, in aggregate, accounted for 7.0% of total all-cause deaths globally, ranking chronic respiratory diseases as the third leading cause of death in 2017, just behind cardiovascular diseases (31.8% of all deaths) and neoplasms (17.1%). Each year, it is estimated that 4 million people die prematurely from chronic respiratory diseases.

Health-care costs for respiratory diseases are an increasing burden on the economies of all nations. In 2019, among 28 EU member states, costs of about €380 billion annually were attributable to the care of patients with chronic respiratory diseases alone. Included in this estimate are the costs of direct primary and inpatient health care (the latter estimated to be at least €55 billion), the costs of lost productivity (at least €42 billion), and the monetised value of disability-adjusted life-years (DALYs) lost (at least €280 billion) [12].

In general, progress has been modest in alleviating chronic respiratory disease burden over the past 30 years. However, from 1990 to 2017, the prevalence, mortality, and DALY rates per 100,000 people dropped by 14.3%, 42.6%, and 38.2%, respectively, if we adjust for population growth and ageing. These sharp declines might be the result of a long list of factors, including global or regional success in tobacco control measures, paired with reductions in environmental pollution in cities, more electric cars, cleaner working environments, better information and prevention with regard to allergens, better treatment of respiratory and non-respiratory comorbidities, and reductions of universally high rates of underdiagnoses of chronic respiratory diseases.

Risk factors for chronic respiratory diseases are common. At least 2 billion people are exposed to the toxic effects of biomass fuel use, 1 billion are exposed to outdoor air pollution, and 1 billion are smokers who expose a near-equal magnitude of people to the ill-effects of second-hand smoke. Although occupational respiratory conditions are a well characterised risk factor, their magnitude is ill-defined; on the basis of the few analyses that exist, around 2 million work-related deaths annually are estimated to occur because of work-related exposures relevant to respiratory conditions [12].

Although chronic respiratory diseases are not curable, various forms of treatment can help to control symptoms, increase patients' quality of life, and prevent adverse outcomes (including exacerbations) that are associated with substantial morbidity, increased health-care use, [12].

3.1.3 Chronic obstructive respiratory disease (COPD)

COPD remained the most prevalent disease-specific chronic respiratory disease among men and women, with crude prevalence rising globally in absolute terms worldwide in 2017. COPD was most prevalent in central Europe. It was the most common cause of chronic respiratory disease-attributable deaths, at 41.9 deaths per 100,000 individuals. Estimates were composed of six risk factors for COPD (smoking, second-hand smoke, household air pollution, ambient particulate matter, ozone, and occupational particulates, which include coal dust).

COPD is a slowly progressive disorder characterized by obstruction of the airways which does not change markedly over several months. COPD is a disabling disease with poor prognosis and no cure. As stated by Oliver, despite the palliative nature of the disease, little in the way of terminal care or support is available for this group of patients. Current medical treatment relies on managing exacerbations and symptom control. The degree of respiratory impairment correlates poorly with the patient's ability to cope. Research and evidence in daily practice has supported the health care professionals' view that social factors and the patient's individual personality significantly affect how the long-term consequences of this disabling disease are managed by the patient. It is possible that poor self-esteem, loss of hope and fear experienced by these patients reduce their ability to be assertive and seek the support that they need. Individuals seen as sick or with chronic disease status have been identified as having a poorer value in society. These factors, compounded with the self-inflicted nature of COPD, result in social, psychological and medical crises in their illness progression. Research has identified the need to empower the patient and suggest that this can result in not only informed and effective decision making but also a significant improvement in patient satisfaction and treatment compliance. A good doctor-patient relationship is seen as an important component in the patient's ability to coop, yet there remains a disparity between the two groups' perceptions and expectations during consultations [12] [13].

3.1.4 Chronic heart failure (CHF)

Chronic heart failure (CHF) is a cardiovascular disorder with high prevalence and incidence worldwide [14]. The European Society of Cardiology (ESC) guidelines defines CHF as a 'a clinical syndrome characterized by typical symptoms (e.g. breathlessness, ankle swelling and fatigue) that may be accompanied by signs (e.g. elevated jugular venous pressure, pulmonary crackles and peripheral oedema) caused by a structural and/or functional cardiac abnormality, resulting in a reduced cardiac output and/or elevated intra-cardiac pressures at rest or during stress' [9]. CHF affects approximately 1–2% of the adult population worldwide [15]. The incidence of CHF remains stable worldwide while the prevalence has increased over the recent decades. Global deaths from cardiovascular disease are increasing as a result of population growth, the aging of populations, and epidemiologic changes in disease.

Global deaths from cardiovascular disease increased by 41% between 1990 and 2013 despite a 39% decrease in age-specific death rates; this increase was driven by a 55% increase in mortality due to the aging of populations and a 25% increase due to population growth. Only in Central Europe and Western Europe did the annual number of deaths from cardiovascular disease actually decline.

The course of CHF is characterized by periods of stability and instability. Deterioration of CHF is associated with frequent and prolonged hospitalizations and it worsens the prognosis for the disease and increases cardiovascular mortality among affected patients [15].

There is a high rate of CHF-related admissions and readmissions and subsequent financial expenditures. This is associated with decompensation of the disease due to a poor adherence to medical therapy, volume overload, natural course of disease, etc. The management of HF

patients undergoing standard care includes scheduled office visits, scheduled follow-ups and readmissions due to decompensation.

Intensive follow-up by means of remote monitoring is currently presented by structured telephone support, telemedicine, remote monitoring with implanted therapeutic and monitoring-only devices. Remote monitoring systems prevent potential unfavourable cardiovascular events among CHF patients.

High prevalence, poor quality of life, high risk of disability, poor prognosis, high rate of hospitalizations and readmissions and high level of associated financial cost make CHF a significant public health problem. Poor adherence to medical therapy, inadequate medical therapy, changes in diet, poor self-care and inadequate patient support, as well as the natural course of the disease are the main factors responsible for decompensation of CHF. Factors, such a volume overload and persistent high filling pressures usually accelerate the natural course of disease. Approximately 70% of CHF related costs are due to hospitalization. Hence, CHF is considered as a significant socioeconomic problem, partly due to a substantial direct and indirect related cost. CHF decompensation worsens the prognosis for the disease and increases cardiovascular mortality among affected patients. Besides, readmissions are associated with substantial financial cost. Hence, efforts should be made to accomplish the early detection of CHF progression and the possible prevention of life-threatening conditions by timely intervention and appropriate management of the patients' treatment.

Possible early prediction and prevention of CHF decompensation may play a crucial role in improving the overall survival rate among CHF patients, a reduction of readmission rates and substantial saving on costs associated with in-hospital treatment, costly interventions and lead to an improvement of quality of care [16].

Recent guidelines recommend a multidisciplinary care approach to the management of CHF patients [9] [17]. The multidisciplinary CHF care approach includes a standard care (i.e. in-person follow-up visits) and alternative approaches, most of which have been presented recently (i.e. regularly scheduled structured telephone contact between patient and health care specialist (i.e. trained nurse practitioner, physician), electronic transfer of physiological data using remote access technology via external, wearable, or implantable electronic devices [18].

These alternative approaches may potentially provide remote disease management by continuous or frequent assessment of some CHF related physiological parameters. It may decrease the number of office visits and increase the efficiency of treatment through early detection and timely management of worsening CHF.

3.1.5 Health systems

As shown, chronic diseases are seen as a sustainability challenge for European health systems. Health systems struggle to cope financially with chronic conditions and the ageing population, and many governments cannot cope with the escalating disease burden and costs [9].

According to Epping, financing of the health system plays a role (e.g. chronic underfunding, lack of adequate numbers of healthcare professionals), but often the system challenge has more to do with the way healthcare is delivered and services organised [9]. We need to make better use of the resources already available.

Most patients who do not adhere to treatment have poorer health outcomes. In developed countries only around half of the people prescribed treatments for chronic conditions actually

take their medicines. Healthcare providers can do more to engage patients in managing their own conditions and to use treatments properly:

- Policymakers should help to transform health care, moving away from systems focused on episodic care for acute illness. Some governments and healthcare systems are already making the switch.

- Strategies to improve clinical care and outcomes for chronic conditions

- Develop health policies and legislation to support comprehensive care

- Reorganise healthcare finance to facilitate and support evidence based care

- Coordinate care across conditions, healthcare providers, and settings.

- Enhance flow of knowledge and information between patients and providers and across providers

- Develop evidence based treatment plans and support their provision in various settings Educate and support patients to manage their own conditions as much as possible

- Help patients to adhere to treatment through effective and widely available interventions

- Link health care to other resources in the community Monitor and evaluate the quality of services and outcomes

These strategies are based on the WHO's review of innovative best practice and affordable healthcare models [9].

From a patient's perspective, the health systems are often unable to cope well with chronic conditions because they do not meet patients' needs. *Patients are experts by lived experience, whose perspective on disease and care is unique. This implies the empowerment of patients and their involvement at every level in the health system, ensuring active patient involvement in policy-making and in co-designing care services to meet their needs more effectively -* Epping.

Some of the reasons why patient participation is still absent in some key health areas, and not strong enough in others include lack of awareness and recognition of patient empowerment;

- Slow pace in sharing and adopting good practices

- Lack of resources in the health system but also of patient organisations

- Poor know-how on how to meaningfully involve patients and patient organisations

- Patient communities with very different levels of capacity and different priorities across the EU.

A frequent topic in the general debate on patient empowerment is the misrepresentation that patient empowerment is a "consumer choice", which effectively reduces empowerment to the ability to choose a healthcare provider based on information that enables a patient to compare different options. It is important to distinguish between patient empowerment and patient involvement, if involvement only means one-way information from the health professionals to the patients.

The importance of involving patients more proactively in their treatment is especially important with regard to the growing number of people living with chronic conditions who have rising medical needs [5]. Empowered patients with knowledge about their health condition are confident to manage their health within their ability and to maintain their health by seeking information and performing health promoting behaviours.

Thus, there is growing awareness that patients should be more active in managing their own health and health care and study findings support that empowered and activated patients achieve better health outcomes, which consequently contributes to reduced health care costs [19]. Particularly patients with chronic diseases face challenges regarding managing their own health and deciding between various treatment options, which requires a good knowledge about healthcare and health care services [6]. Hence, successful long-term management of patients with chronic conditions requires active patient self-management and a proactive involvement of patients in their healthcare and treatment [7]. This requires a patient-provider partnership in which the patient and the provider work actively together within an integrated system of collaborative care, including self-management, education and follow-up [8].

Embracing empowerment means making a paradigm shift that is often difficult because the traditional approach to care is learned early in the training and socialisation of most health care professionals [20].

In contrast to the traditional approach, empowerment is not something one does to patients but rather a reciprocal dynamic that can develop only when the provider acknowledges that the patient is ultimately in control of his or her own care [9]. Under this paradigm, the physician's role is to provide the patient with the necessary information and tools to take charge of the disease or their cardiovascular risk factor management [20]

3.2 Definitions of Patient Empowerment

Patient empowerment is difficult to define and conceptualize because it can be seen both as a process and outcome. It is best understood within the context of chronic disease management where it refers to the patient's ability to participate in health care decisions and the patient's abilities to improve self-management, well-being and self-efficacy [21].

In ADLIFE we use the definition from Adams: Empowerment can be defined as *"the capacity of individuals, groups and/or communities to take control of their circumstances, exercise power and achieve their own goals, and the process by which, individually and collectively, they are able to help themselves and others to maximize the quality of their lives"* [1].

Four components have been reported as being fundamental to the process of patient empowerment:

1) Understanding by the patient of his/her role

2) Acquisition by patients of sufficient knowledge to be able to engage with their healthcare provider

3) Patient skills

4) The presence of a facilitating environment.

Based on these four components, empowerment can also be defined as:

A process in which patients understand their role, are given the knowledge and skills by their health-care provider to perform a task in an environment that recognizes community and cultural differences and encourages patient participation - WHO.

Besides this definition, various terms like self-management, patient participation, patient activation, patient involvement or self-efficacy are used interchangeably to patient empowerment [22] [23].

Facilitators to empowerment

Different outcome indicators of empowerment were found in the reviewed studies, including skill and knowledge improvement, quality of life, self-efficacy, improvement in physical symptoms and self-management. Thus, a clear outcome of empowerment interventions for patients with chronic conditions is hard to define.

Patient empowerment through self-monitoring of symptoms, shared decision making with the physician, and easily accessible education are important features extending the reach of mHealth technology beyond traditional care.

The market of mobile health (mHealth) technology is rapidly evolving, making new mobile technologies potentially available for healthcare systems. Sleurs et al [24] found that a variety of one hundred and twelve apps are available for patients with chronic respiratory diseases (CRDs) of which only few were developed by or jointly with medical doctors. The majority of these apps include self-monitoring tools, but only few also provide personalized feedback, which is needed to adopt these apps into daily care [24].

A multimodal individualized approach is essential for a successful empowerment intervention. Educational interventions (e.g. health education of the condition and skills to manage symptoms, coping skill development to achieve self-control and self-determination) are needed to improve knowledge, self-efficacy and self-management behaviour. Educational interventions need to be supplemented with behavioural components which focus on the development of behavioural abilities to implement a new behaviour, to support self-management and to increase motivation and self-awareness [25]. Often interventions on self-care improvement for patients with chronic conditions such as heart failure or COPD target behavioural changes through educational activities using cognitive behavioural or informational strategies or a combination of both [26] [27].

The gained knowledge is important to change self-care behaviours, however, patients also need to apply the gained knowledge in their daily life and need to connect it with their personal experiences. Hence, patients' preferences and other environmental and social factors, like family caregivers, need to be considered. Furthermore, healthcare professionals need to understand the patients' personal level of performance, expectations, and importance of empowerment interventions. They must consider what the patients think about self-care and to what extent the patient wants to be involved in his or her own care [28]. For this, the patient needs to be able to define disease related problems, which will be addressed in the individually tailored self-management program.

Furthermore, the patient needs to understand the role as an active patients, which mainly depends on the socioeconomic status, as patients with a higher socioeconomic status are more likely to participate in their own health care [29].

If patients are less autonomous in their health management, family caregivers play an essential role in supporting the patient's self-management. Engagement of family members

and informal caregivers can be increased through caregiver education [30]. Additionally, social support through peers can motivate and encourage patients [25].

Most of the empowerment interventions in the literature were delivered in person, through specialized nurses or other health care professionals who are sympathetic and have skills to understand people in order to build a strong relationship with the patient [31] [32]. However, written information, communication technologies, or a combination of in-person and telephone calls were also beneficial to facilitate empowerment in patients with chronic conditions. Especially in follow-ups, digital formats can be considered, which are useful to support long term effects and knowledge gain in the patients [33] [25]. Although technologies can be used to deliver interventions, or supplement non-technical intervention approaches, it is important to consider that technologies are not an alternative for the patient-provider relationship, which is fundamental to implement effective empowerment strategies [34]. Health care professionals have an important role in supporting empowerment through providing knowledge and building trusting relationships with the patient to facilitate empowerment. Therefore, they should have a positive attitude towards empowerment and should encourage the patient to take an active role in managing his or her healthcare [25].

From the patient perspective the following contextual factors can influence patient empowerment:

1) The level of patient participation (the patient clearly understands the role as an active patient. This mainly depends on the socioeconomic status, as patients with a higher socioeconomic status are more likely to participate in their own health care)

2) The level of health literacy (the patient receives enough information to make rational decisions on health and has a sense of health responsibility

3) The level of self-efficacy and health awareness (the patient is able to be fully involved in self-care practices because of a profound knowledge) [29].

However, patient empowerment is not only dependant on factors that are related to the patient and the health care providers. Due to its complexity, cultural and societal aspects might also influence patient empowerment [35].

Self-management interventions are very diverse which limits the comparability across studies and interventions. Thus, it is difficult to conclude which intervention provides the best outcome for the patients.

Barriers to Patient Empowerment [24] [20]

There are several potential barriers to patient empowerment and risk communication, some of which exist at the provider level. If healthcare professionals experience a fear of a loss of control, have worries about the expenditure of time for patient education or experience a lack of training in patient empowerment, a successful patient empowerment approach might be hindered [22].

A barrier is the difficulty in keeping current with frequently changing guidelines. Some patients may feel that the addition of another medication to lower the systolic blood pressure may not be worth the potential benefit if the concept of the number of needed to treat (NNT) is explained to them. Frequently shifting recommendations represent a moving target for patients and providers, and are frustrating for patients to make sense of, even with guidance from experienced clinicians [20].

Patient factors such as health literacy, education, and access to healthcare and resources also pose significant barriers to empowerment. In the simplest scenario, patients may lack knowledge about etiology, consequences, and preventive strategies relevant to their disease.

Other scenarios present more challenges; for instance, patients may possess incorrect or fragmented knowledge based on experiences of close friends and relatives and may be reluctant to part with these views due to the salience of their experiences. No less daunting is when patients hold a fatalistic view of cardiovascular disease as an unavoidable phenomenon governed by genetics or fate, pre-determined by past lifestyle choices, and beyond personal control in the present.

Another barrier to patient empowerment is the less tangible phenomenon of risk perception, which is both idiosyncratic and challenging to define and address in the context of clinician-patient interactions. For instance, it has often been said that hypertension is a silent killer. Patients who demonstrate over-reliance on concrete sensory feedback may fail to recognize the negative impact of uncontrolled blood pressure or cholesterol, as these conditions are typically asymptomatic and the consequences are not immediately apparent.

Risk perception is also influenced by a combination of factors unique to each patient, such as experiences of disease in the family, age, and sex. Based on personality and past experiences, some patients may associate disease with inevitably poor outcomes. Convinced of the futility of risk reduction strategies, these patients may deliberately avoid objective evaluation of their own risk factors.

3.2.1 Future of Patient Empowerment

Kambhampati et al [20] gives their bid for the patient empowerment of the future:

A growing body of evidence suggests that the foundation of improved health outcomes, better care, and lower costs is built upon engaged patients who are active participants in their care. Patient empowerment can be supported in technological advancements and better access of patients to these technologies. Early studies have shown that patient access to medical records improves communication, adherence, and patient empowerment. Thus, healthcare organizations are now focusing on inviting patient engagement through electronic means.

Randomized controlled studies assessing the effects of electronic medical records have demonstrated that access to patient portals improves outcomes in chronic diseases such as diabetes, hypertension, and depression. Systematic reviews examining the effects of patient portals have shown significant improvements in self-management of chronic diseases, as well as improvements in the quality of care provided by clinicians. These advances have partly been a by-product of more numerous opportunities for clinician-patient communication and education afforded by patient portals. As the burden of chronic diseases continues to grow globally, the impact of non-adherence becomes more significant.

Healthcare practices are increasingly relying on mobile technologies to enhance communication and education with the goals of improving adherence and quality of life and promoting cost effective health care. A systematic review of the literature to evaluate effectiveness of mobile health in supporting patient adherence to treatment plans found that in 40 % of the studies, short message service was the most commonly used mobile adherence tool. Approximately 60 % of the studies found high usability, feasibility, and acceptability of mobile interventions and a significant improvement in adherence behaviours and disease specific clinical outcomes [20].

Barriers to the use of patient portals include limited interest or in some cases lack of access in patients (generally those over the age of 70) who do not use the Internet. These factors are

strongly influenced by demographic and personal characteristics such as age, ethnicity, education, health literacy, health status, and role as caregiver. About 40 % of papers reported improvements in medication adherence, disease awareness, and self-management of disease, as well as decreased frequency of office visits, increased utilization of preventive medicine, and more frequent extended office visits at the patient's request for the purpose of providing additional information.

Conclusion

Knowing that empowered patients achieve better health outcomes, it needs to be examined how to empower patients and what kind of models, interventions, or mechanisms enhance empowerment in patients with chronic conditions. Therefore, we have made a review which aims to presents which empowerment strategies or interventions are the most beneficial and which contextual parameters are important for a beneficial empowerment strategy in patients with chronic conditions, especially in patients suffering from Chronic Obstructive Pulmonary Disease (COPD) and/or Chronic Heart failure (CHF) which are two of the most common chronic conditions.

4 Literature review on patient empowerment

Overview of Effective Empowerment Interventions in People with COPD or CHF
By Dr Janika Blömeke, OptiMedis.

(This review was written within the scope of ADLIFE Work Package 7 task 7.2)

Summary:

This report aimed to review the literature about the current models and theories around patient and caregiver empowerment in chronic patients, especially in patients suffering from Chronic Obstructive Pulmonary Disease (COPD) and/or Chronic Heart Failure (CHF). Further, it aimed to show which empowerment strategies or models are the most beneficial and which contextual parameters are important for a beneficial empowerment strategy. The search was conducted in PubMed in October and November 2020. Inclusion and exclusion criteria were defined a priori. The results are mainly based on 9 interventional studies on empowerment interventions for people with COPD or CHF. Further articles were included to underpin the results. The results show that interventions that aim to improve empowerment are complex. Most important in promoting empowerment of patients with chronic diseases such as COPD or CHF are to improve self-management and self-efficacy through educational interventions. Furthermore, behavioural strategies, social support from family caregivers and reinforcement through follow up calls or home visits need to supplement educational strategies and can optimize outcomes. An environment in which the patient is encouraged to participate actively in managing his or her healthcare is also important.

Introduction

In moving towards collaborative models of health care and patient-centred care, patient empowerment gained increased recognition in healthcare in the last decades [3] [4]. According to the World Health Organization, patient empowerment is defined as "a process through which people gain greater control over decisions and actions affecting their health" [2]. Besides this definition, various terms like self-management, patient participation, patient activation, patient involvement or self-efficacy are used interchangeably to patient empowerment [22] [23].

Patient empowerment is difficult to define and conceptualize because it can be seen as a process and outcome. It is best understood within the context of chronic disease management where it refers to the patient's ability to participate in health care decisions and the patient's abilities to improve self-management, well-being and self-efficacy [21].

The importance of involving patients more proactively in their treatment is especially important with regard to the growing number of people living with chronic conditions who have rising medical needs [5]. Empowered patients with knowledge about their health condition are confident to manage their health within their ability and to maintain their health by seeking information and performing health promoting behaviours. Thus, there is growing awareness that patients should be more active in managing their own health and health care and study findings support that empowered and activated patients achieve better health outcomes, which consequently contributes to reduced health care costs [19]. Particularly patients with chronic diseases face challenges regarding managing their own health and deciding between various treatment options, which requires a good knowledge about healthcare and health care services [6]. Hence, successful long-term management of patients with chronic conditions

requires active patient self-management and a proactive involvement of patients in their healthcare and treatment [7]. This requires a patient-provider partnership in which the patient and the provider work actively together within an integrated system of collaborative care, including self-management, education and follow-up [8].

Knowing that empowered patients achieve better health outcomes, it needs to be examined how to empower patients and what kind of models, interventions, or mechanisms enhance empowerment in patients with chronic conditions. Therefore, this review aims to presents which empowerment strategies or interventions are the most beneficial and which contextual parameters are important for a beneficial empowerment strategy in patients with chronic conditions, especially in patients suffering from Chronic Obstructive Pulmonary Disease (COPD) and/or Chronic Heart failure (CHF) which are two of the most common chronic conditions.

4.1 Method

1. *Eligibility criteria*

Peer-reviewed studies in English or German published up to 2020 that reported current models and theories around patient and caregiver empowerment in chronic patients, especially in patients suffering from COPD and/or CHF were retrieved.

2. *Information sources*

This literature search was conducted in PubMed in October 2020. Furthermore, the references of the included papers served as an additional information source and were included in the review if relevant.

3. *Search strategy*

Search terms were identified beforehand to address the four components of the research question: (1) empowerment, (2) chronic condition, (3) aging population, (4) intervention. Based on the four components further search terms that are related to these key terms were identified (see table 1). Boolean operators were used to connect the search terms in various combinations.

Table 1 - Search terms

Empowerment	Chronic condition	Aging population	Intervention
Patient participation	COPD	Elderly	Empowerment interventions
Patient engagement	Chronic heart failure	Adults	Empowerment strategies
Health participation			Patient empowerment program

Patient activation			Empowerment model
Self-management			Empowerment elements

From the various terms listed in table 1, the final search term that was formulated:

(Empowerment OR "patient participation" OR "patient engagement" OR "Health participation" OR "Patient activation" OR "self-management") AND (COPD OR "chronic heart failure" OR "chronic obstructive pulmonary disease" OR CHF) AND (adults OR elderly) AND ("Empowerment intervention" OR "empowerment strategies" OR "patient empowerment program" OR "Empowerment model" OR "Empowerment elements" OR "Empowerment program")

4.   Search and study selection

After running the search, a title screening was conducted followed by an abstract screening. The following inclusion and exclusion criteria were applied:

Inclusion criteria:

- Publications in English or German
- Studies focusing on patients with chronic conditions and in particular on COPD or CHF
- Studies focusing on interventions or approaches fostering empowerment in patients with COPD or CHF/HF
- Studies focusing on adults and/or elderly
- Articles published in peer-reviewed scientific journals
- Randomized controlled trials (RCT) or other experimental studies are preferred, however, other studies were also considered if important aspects concerning empowerment interventions were described.

Exclusion criteria:

- Validation studies
- Measurement instruments of patient empowerment
- Study protocols
- Abstracts from congresses or meetings etc.

4.2 Presentation of results

Articles that potentially met inclusion criteria through abstract review were reviewed in full. First, all interventional studies (e.g. RCT, experimental studies) that incorporated empowerment programs and measured the related effects were selected and carefully reviewed to provide a summary of the interventions that promote empowerment in patients with COPD or CHF. Data including the reference, study design, condition, intervention, and main result were extracted and summarized in a chart and the results of the interventional studies narratively described and summarized. Subsequently, all other studies that reported on empowerment in patients with COPD or CHF were included in the results and important aspects that refer to empowerment interventions summarized.

Results

Search Results

The initial search on PubMed yielded 78 articles in total. After a title and abstract screening 21 studies remained that were reviewed in full. From these, 7 were RCT's or other experimental studies, 8 reviews and 6 studies of another study type (e.g. cross-sectional, qualitative studies). After RCT full text review, 3 additional RCTs were added from the reference list of the previously included studies and included in this review. 8 studies were excluded because they did match the inclusion criteria, leaving 9 interventional studies (e.g. RCT), 1 feasibility study and 5 literature reviews. The results of this literature review focus mainly on the findings of the interventional studies (9 studies). Relevant aspects of the other identified articles were used to underpin the results. Additionally, 12 other articles that were not identified in the initial search but from the reference lists of included papers and were relevant for this topic, were included as well, to underpin the results. Figure 1 displays an overview about the selection process.
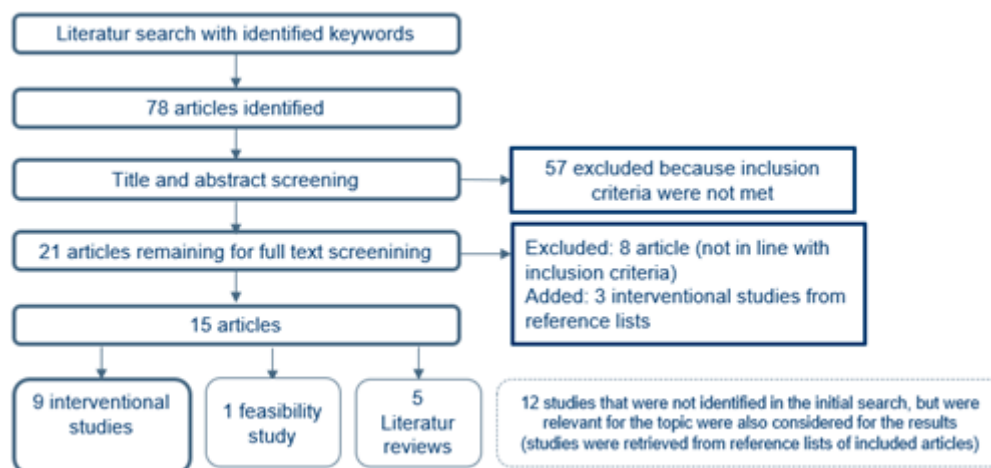
Figure 1 - Search strategy and results

Main Results

Different outcome indicators of empowerment were found in the reviewed studies, including skill and knowledge improvement, quality of life, self-efficacy, improvement in physical symptoms and self-management. Thus, a clear outcome of empowerment interventions for patients with chronic conditions is hard to define.

Several empowerment programs which tested educational interventions that aimed to support patient self-management and self-efficacy turned out to be effective in changing the behaviour of the patients and to empower patients. Besides focusing on knowledge gain to support self-management, educational interventions should also focus on the development of behavioural abilities to implement a new behaviour [36] [34]. Also, it is important to consider the patient's preferences and the individual condition of the patient to assist the patient in problem solving and to gain self-efficacy. For this, the patient needs to be able to define disease related problems, which will be addressed in the self-management program [37]. Furthermore, peer education in terms of teaching and sharing health information, values and behaviour with

others that have a similar social background is recommended to support engagement in empowerment programs.

Besides educational interventions, a working patient-provider relationship and healthcare professionals who promote an engagement culture are key elements in the ideal care of chronic conditions. It offers the opportunity to involve patients more actively in their treatment and to manage their own health. Having an informed patient through proper educational interventions and a good patient-provider relationship is fundamental for the interaction between physicians and patients [8] [34] [38]. Hence, also training for healthcare providers to increase knowledge about effective approaches for patient empowerment and the integration of case managers to facilitate empowerment need to be considered [38]. The efficacy of empowerment interventions can also be supported by promoting engagement of family members and informal caregivers towards patients' health care. Providing emotional support and counselling as well as caregiver education supports the caregiver in becoming an active part of the healthcare team [34].

The following paragraphs summarize the results of the identified empowerment interventions focusing on patients with COPD and CHF. An overview can be found in table 2 on page 30.

4.3 Empowerment Interventions that focus on patients with COPD

Educational interventions that are delivered through audio-visual techniques (e.g. in form of a video) seem to improve the ability to manage COPD and related exacerbation more than when patients receive written material (e.g. self-management leaflet). The improvement in self-management skills was especially high, when clinicians or other professionals provided the information on self-management strategies in the video [39].

Also, the results of a recent experimental study support the effectiveness of educational interventions for patients with COPD. The authors concluded that an educational intervention which is based on social cognitive theory (SCT) significantly contributes to improvement in self-efficacy, patient's awareness and skills and knowledge. Furthermore, the patient's motivation to learn was raised throughout the program [36]. SCT is based on the interaction of individual, behavioural, and environmental factors and is considered to achieve better behavioural outcomes [40]. The intervention consisted of lectures, group discussions, question and answer sessions in four training group sessions with 5 – 6 participants for 40 minutes. The sessions started with raising the awareness of the patient for their disease, which was followed by improving patient self-efficacy and skills. Subsequently, family caregivers were included and trained to increase their support for the patients. A detailed overview about the educational sessions is shown in the annex of table 1 which is taken from the article [36].

Educational interventions are more effective when delivered in a digital format (e.g. videos) or face-to-face cannot be clearly answered and both formats seem to be effective to increase self-management. This is also reported by a RCT which compares the efficacy of an internet-based self-management program with a face-to-face self-management program focusing on dyspnoea in patients with moderate to severe COPD [41]. In detail, the face-to face self-management program (fDSMP) consisted of education and skills training for dyspnoea management, comprising individualized tailored exercise planning, self-monitoring of respiratory symptoms and exercise, as well as personalized reinforcement and feedback for exercising and the use of dyspnoea self-management strategies. The internet-based program (eDSMP) additionally incorporated technologies to support early detection of symptom

degradation (e.g. real-time monitoring and prompt feedback). The program was delivered in four core components, starting with a face-to-face consultation (in person or online) led by an advanced practice nurse, to assess the patient's current level of exercise and experience with dyspnoea through motivational interviewing techniques and to build a relationship with the patient. Afterwards an individualized exercise plan was developed which included a combination of endurance (walking, cycling, or swimming) and arm strengthening (biceps curls, triceps curls, side arm raises, and upper arm raises) exercises. The patients were encouraged to complete endurance exercises at least 4 times per week (30 minutes per session) and the arm strengthening exercises at least 3 times per week independently at home. The exercise sessions were followed by reinforcement telephone calls or emails, education of dyspnoea management strategies, skills training, peer interactions in face-to-face group sessions or interactive web modules. Details of the program are listed in the annex of table 2 which was taken from the article [41].

These results and others clearly demonstrate that empowerment interventions for COPD patients are on the one hand needed to reduce exacerbations and prevent hospitalization and on the other hand to improve self-efficacy and quality of life [42]. Especially interventions which focus on disease-specific education (e.g. teaching how to manage breathlessness, inhaler technique, working with oxygen machines etc.) support patients to become more empowered [43] [44].

Besides knowing that educational interventions are useful to increase empowerment in people living with COPD, barriers and facilitating factors for empowerment in elderly with COPD need to be considered to plan effective interventions. A qualitative study on Iranian elderly with COPD concluded that the nature of aging including the degree of disability and co-morbidities hinder a successful empowerment process. Furthermore, the difficult nature of COPD itself needs to be carefully considered when planning empowerment interventions. Elderly suffering from COPD often lack physical ability and are forced to forgo activities due to breathing difficulties. Additional barriers of empowerment for COPD are depression, helplessness, and hopelessness which should be an essential part of the disease management in order to improve empowerment and should be addressed by the healthcare provider. In summary, empowerment of patients with COPD is mainly affected by social factors and personal resources and by the health care system itself. Apart from these barriers, a trustful relationship with the healthcare staff, incentives and an encouraging environment facilitates empowerment [45] [46].

4.4 Empowerment Interventions that focus on patients with chronic heart failure

Similarly to the interventions presented for patients with COPD, empowerment interventions that were designed for patients with heart failure also focused mainly on educational elements that target self-care behaviour such diet, adherence to medication, physical activity, daily weighting, monitoring and management of signs and symptoms [26]. A heart failure management program which included a one hour education session with an educational booklet showed reduced rates of hospitalization or death and improved knowledge, self-care behaviour and self-efficacy compared to a control group which received a general heart failure education pamphlet. The educational booklet in the intervention group also contained an individual management plan for the patient. In addition, follow-up calls were used to motivate and reinforce the educational sessions [47].

Besides educational elements, individual interviews were considered to be important to determine the problems from the patient's perspective and to motivate patients in their participation in empowerment programs prior to the intervention. Based on the results of the interviews, individual goals can be derived for the intervention. An 8 week empowerment self-management program which implemented this approach with additional use of virtual learnings and telephone follow-up or educational booklets showed a greater increase in self-efficacy, self-awareness and autonomy in patients with coronary artery diseases, compared to a control group which received routine care in a health centre [48].

Positive benefits of follow-up strategies on the educational session, were also noted in a recent RCT which examined the effects of an educational intervention program on the level of heart failure knowledge, self-care and behaviour. In the program, face-to-face educational sessions with a nurse resulted in improvement in knowledge in short-term compared to the control group which received usual care. Additional biweekly phone calls from the same nurse to reassure content validity and an audiotape with the education session, also improved knowledge, self-care and self-behaviour in the long-term. The authors concluded that educational sessions which reinforce knowledge and self-care strategies need to be repeated yearly, to maintain and enhance the effects of the intervention over a longer period [33]. The positive effect of structured follow-up approaches with either home visits or via, phone, or e-mail which helped to facilitate self-management was also noted in other studies [49] [50] [51]. Also the use of reminders in the form of prompts that are given to the patients to perform specific tasks related to the care of their condition were associated with significant improvement in disease control [52].

When implementing effective empowerment strategies, care managers such as specialized nurses can help to monitor the patient's condition, can provide necessary information, and can show and support how to implement behavioural changes. Using care managers in addition to a patient empowerment program has a positive impact on patients' self-efficacy, coping ability, self-monitoring, healthy lifestyle, clinical outcomes, quality of life, and especially on the patient's physical activity [31]. Also the home-based patient empowerment program KronikON for older patients with chronic conditions in the Basque country used nurses to provide essential information and to help the patients to understand their condition and to explore and agree on the best method of self-care. This intervention resulted in improved health outcomes (e.g. BMI, blood glucose, and oxygen saturation level) and fewer hospital and emergency visits. The patients felt more empowered to manage their health and were more satisfied after four 20 to 30-minute sessions led by the nurses [32].

Besides nurses that provide support to the patients, the family is an important source of social support and can help to support behavioural changes in self-management programs [53]. However, often family caregivers are lacking knowledge on how to best support patients in their disease management and self-care behaviour [54]. Results of the implementation of a family supportive intervention showed improvement of self-care behaviour in patients and thus highlighted the importance to engage family members in the care of patients with chronic conditions. The family supportive intervention consisted of three weekly group educational sessions with the caregivers which lasted 1 to 1.5 hours. In the first session, the caregivers were educated about the disease and the importance of self-care behaviour. A booklet was distributed to be able to re-read the information, to inform other family members and if necessary, to write down questions. In the second session, upcoming questions were evaluated and the importance of family in disease control and efficient communication skills were explained, followed by group discussions and role plays to empower and adopt learning skills. A booklet on practical and emotional support was provided. In the third session, experiences on communication skills and supportive strategies of the patients were shared.

Lastly, indications about the manner of self-care were explained and a contact number for further upcoming questions provided [55].

To improve caregiver confidence for a heart failure home management and to decrease the caregiving burden, a telephone coaching program for family caregivers can be helpful, as shown in a study that evaluated the feasibility of a coaching heart failure home management program for family caregivers. In detail, the coaching program for family caregivers consisted of four telephone sessions which were administered by a nurse. The sessions included: preparing the caregiver for home care; working with the patient's health care team to develop problem solving skills and self-management routine; preventing strain and burnout; and preparing the caregiver for emergencies. Additionally, each caregiver received a guidebook and handouts [30].

4.5 Discussion

The results show that a multimodal individualized approach is essential for a successful empowerment intervention. Educational interventions (e.g. health education of the condition and skills to manage symptoms, coping skill development to achieve self-control and self-determination) are needed to improve knowledge, self-efficacy and self-management behaviour. Educational interventions need to be supplemented with behavioural components which focus on the development of behavioural abilities to implement a new behaviour, to support self-management and to increase motivation and self-awareness [25]. Often interventions on self-care improvement for patients with chronic conditions such as heart failure or COPD target behavioural changes through educational activities using cognitive behavioural or informational strategies or a combination of both [26] [27].The gained knowledge is important to change self-care behaviours, however, patients also need to apply the gained knowledge in their daily life and need to connect it with their personal experiences. Hence, patients' preferences and other environmental and social factors, like family caregivers, need to be considered. Furthermore, healthcare professionals need to understand the patients' personal level of performance, expectations, and importance of empowerment interventions. They must consider what the patients think about self-care and to what extent the patient wants to be involved in his or her own care [28]. For this, the patient needs to be able to define disease related problems, which will be addressed in the individually tailored self-management program. Furthermore, the patient needs to understand the role as an active patients, which mainly depends on the socioeconomic status, as patients with a higher socioeconomic status are more likely to participate in their own health care [29]. If patients are less autonomous in their health management, family caregivers play an essential role in supporting the patient's self-management. Engagement of family members and informal caregivers can be increased through caregiver education [30]. Additionally, social support through peers can motivate and encourage patients [25].

Most of the empowerment interventions were delivered in person, through specialized nurses or other health care professionals who are sympathetic and have skills to understand people in order to build a strong relationship with the patient [31] [32]. However, written information, communication technologies, or a combination of in-person and telephone calls were also beneficial to facilitate empowerment in patients with chronic conditions. Especially in follow-ups, digital formats can be considered, which are useful to support long term effects and knowledge gain in the patients [33] [25]. Although technologies can be used to deliver interventions, or supplement non-technical intervention approaches, it is important to consider that technologies are not an alternative for the patient-provider relationship, which is fundamental to implement effective empowerment strategies [34]. Health care professionals have an important role in supporting empowerment through providing knowledge and building trusting relationships with the patient to facilitate empowerment. Therefore, they should have

a positive attitude towards empowerment and should encourage the patient to take an active role in managing his or her healthcare [25]. However, if healthcare professionals experience a fear of a loss of control, have worries about the expenditure of time for patient education or experience a lack of training in patient empowerment, a successful patient empowerment approach might be hindered [22].

From the patient perspective the following contextual factors can influence patient empowerment: (1) the level of patient participation (the patient clearly understands the role as an active patient. This mainly depends on the socioeconomic status, as patients with a higher socioeconomic status are more likely to participate in their own health care), **(2)** the level of health literacy (the patient receives enough information to make rational decisions on health and has a sense of health responsibility, **(3)** the level of self-efficacy and health awareness (the patient is able to be fully involved in self-care practices because of a profound knowledge) [29]. However, patient empowerment is not only depending on factors that are related to the patient and the health care providers. Due to its complexity also, cultural societal aspects might influence patient empowerment [35].

The results of this review show that self-management interventions are very diverse which limits the comparability across studies and interventions. Thus, it is difficult to conclude which intervention provides the best outcome for the patients. To tackle this issue, a recent study aimed to develop a taxonomy for self-management interventions to identify key characteristics of interventions and to facilitate comparison of different interventions. The taxonomy consists of various components, which are classified in four major domains: intervention characteristics, expected patient (or caregiver) self-management behaviours, type of outcomes for measuring self-management interventions, and target population characteristics. Using this taxonomy could help to compare effectiveness of interventions and thus to improve patient empowerment. Furthermore, it provides a clear structure of intervention categorization and might help to structure the development of interventions [56].

Limitations

Although this review provides evidence for effective empowerment interventions, it needs to be noted that the search was only conducted in one database with predefined search terms. Hence, this overview is not exhaustive, but represents most of the studies that address empowerment interventions in CHF or COPD. Furthermore, it needs to be noted that the study selection was only conducted by one person and might be influenced by subjective manners.

4.6 Conclusion

Empowerment is an umbrella concept and closely relates to patient participation, patient activation, self-management, shared decision making and other concepts in the field of patient centred care. Most important in promoting empowerment of patients with chronic diseases such as COPD or CHF are to improve self-management and self-efficacy through educational interventions. However, education alone is not enough to maintain positive effects of self-management and self-care behaviours which impact empowerment. Behavioural strategies, social support from family caregivers and reinforcement through follow up calls or home visits need to supplement educational strategies and can optimize outcomes.

Table 2 - Overview of studies found in literature search

Title	Authors	Study Design	Year	Condition	Intervention	Main Result
Assessing the effect of culturally specific audio-visual educational interventions on attaining self-management skills for chronic obstructive pulmonary disease in Mandarin- and Cantonese-speaking patients: a randomized controlled trial	Poureslami I. et al.	RCT	2016	COPD[1]	Culturally specific educational intervention of self-management skills	Audio-visual interventions showed the greatest improvement inhaler technique and self-management practices
The effect of empowerment program based on the social cognitive theory on the activity of daily living in patients with chronic obstructive pulmonary disease.	Aliakbari, F. et al.	two-group, quasi-experimental study	2020	COPD[1]	Cognitive theory-based empowerment program	Patients' awareness, skill, empowerment, and self-efficacy increased.
Randomized Controlled Trial of an Internet-Based Versus Face-to-Face Dyspnoea Self-Management Program for Patients With Chronic Obstructive Pulmonary Disease: Pilot Study	Nguyen, HQ. et al.	RCT	2008	COPD[1]	Internet-based and face-to-face dyspnoea self-management program	6-month, face-to-face or an Internet-based dyspnoea self-management showed clinically and statistically meaningful improvements in dyspnoea with ADL and self-efficacy for managing dyspnoea

The effects of an empowering self-management model on self-efficacy and sense of coherence among retired elderly with chronic diseases: a randomized controlled trial	Hourzad A, et al.	RCT	2018	diabetes, hypertension, coronary artery disease	Empowering self-management model based on self-efficacy and sense of coherence (SOC).	8 week implementation program led to a significant greater increase in self-efficacy and sense of coherence.
Impact of the CareWell integrated care model for older patients with multi-morbidity: a quasi-experimental controlled study in the Basque Country	Mateo-Abad, M. et al.	Quasi experimental controlled study	2020	COPD[1], CHF[2], Diabetes	Patient empowerment program KronikON	Fewer hospital admissions and emergency visits in the intervention group. Also, the program had a positive effect on clinical outcomes (e.g. BMI, blood glucose).
Feasibility and effectiveness of a disease and care management model in the primary health care system for patients with heart failure and diabetes (Project Leonardo).	Ciccone, MM. et al.	Pre-post feasibility study	2010	CVD[3], Diabetes, CHF[2]	Disease and management model and of the introduction of care managers	Self-efficacy, coping, ability to access social support, self-monitoring significantly improved. Health lifestyle behaviours were positively supported
Effects of an educational intervention on heart failure knowledge, self-care behaviours, and health-related quality of life of patients with heart failure: Exploring the role of depression	Hwang B. et al.	RCT	2020	HF[4]	Educational intervention program	Improvement in HF knowledge in short-term. Long-term effects were observed in the group that received the intervention with additional telephone contacts. Self-care also increased.

Effects of a family support program on self-care behaviours in patients with congestive heart failure	Shahriari M. et al.	Pre-post-test case and controlled clinical trial	2013	HF[4]	Family supportive intervention which consist of 3 group educational sessions with caregivers	The family supportive intervention led to promotion of self-care in HF patients.
A heart failure self-management program for patients of all literacy levels: a randomized, controlled trial	DeWalt, DA. et al.	RCT	2006	HF[4]	Heart failure management program for use by patients with a variety of literacy levels	The self-management program reduced the rate of hospitalization or death. Improvement in knowledge, self-care behaviour and self-efficacy in the intervention group were also observed.

[1] Chronic obstructive Pulmonary Disease, [2] Chronic Heart Failure, [3] Cardiovascular Disease, [4] Heart Failure

5 Patient empowerment in the context of the ADLIFE project

As has been shown in D7.2 so far, there is an increasing number of patients with chronic diseases, e.g. justified by increasing life expectancy, and living with a severe, chronic disease as COPD and CHF has a major impact on the patients but it also affects the caregiver's life and life-quality.

More care and treatment takes place in the home, and this requires that patients (and their caregivers) be trained to be able to make decisions in relation to their lifestyle and illness. They must be able to handle illness and treatment in collaboration with health professionals. This requires that patients have the knowledge, abilities and desire to meet the challenges.

The prioritisation of patient-centred care in health care has resulted in an increased focus on patient empowerment, which is considered to facilitate patient independence, self-management, and self-efficacy. As shown in the literature, patients who are able (empowered) to manage their own illness and treatment have a better quality of life, better adherence and are less frequently hospitalized.

In ADLIFE, empowerment is defined as the capacity of individuals, groups and/or communities to take control of their circumstances, exercise power and achieve their own goals, and the process by which, individually and collectively, they are able to help themselves and others to maximize the quality of their lives.

ADLIFE approaches empowerment as a process; the mechanism by which people, organisations, and communities gain mastery over their lives. ADLIFE uses Patient Reported Outcomes as means to guide health care, and adaptive interventions and Shared Decision-Making as some of the empowerment tools.

The patients with COPD and CHF targeted by the ADLIFE project are among the most frail and vulnerable patient groups and they would benefit significantly from receiving support through the tele-medicine platform to increase their level of empowerment.

The use of the Patient Empowerment Platform (PEP) is intended to both support and empower the patients and furthermore to enhance the patients and their caregivers' life quality. Therefore, the PEP is the main focus for facilitating tools for patient empowerment.

6 Patient empowerment tools in the ADLIFE project

Introduction to patient empowerment tools in the ADLIFE project

As described in the previous sections about the concept of patient empowerment, facilitating patient empowerment is a complex and challenging endeavour that requires a broad set of tools to transfer power from the clinicians to the patients or indeed enhance the level of empowerment experienced by the patients. In the ADLIFE project, a series of five tools have been investigated, evaluated, and implemented for their suitability in consideration for the primary patients groups with severe COPD and CHF diagnoses. These tool all share the common characteristic of enabling a multimodal individualised approach for empowering the patients through different manners of interventions. A major part of the ADLIFE project is the tele-medicine platform called the ADLIFE Toolbox, which consists of two key components; the Personalised Care Plan Management Platform (PCPMP) and the Patient Empowerment Platform (PEP). These platforms provide the technological foundation for 'distributing' the selected patient empowerment tools to the patients through the digital interactions between clinicians and patients. This is a key driver in the ADLIFE project to provide the means for patients to use the opportunities provided in the ADLIFE Toolbox to increase their level of empowerment not only when talk directly with the relevant clinicians, but also in the periods of time between consultations where patient would otherwise be left to their own devices.

The six patient empowerment tool are:

- Reinforcing learning mechanisms
- Nudging
- PRO and PROMs
- JITAIs
- Educational materials
- Self-assessment and self-management

Some of these tools overlap in purpose and are considered to be supplementary in nature and to the overall mission of empowering patients.

The following sections cover each tool in turn.

7 Reinforcing learning mechanisms

As presented in sections 3 and 4, patient empowerment consists of a number of elements whose sum produces a meaningful context for the patients to act within. A major element within the science of patient empowerment is learning and learning systems that increase the patient's capacity to make choices and transform their choices into effective actions and outcomes.

The purpose of any learning system is to impart new knowledge, information, and encouragement to the target user groups with the goal of increasing their level of empowerment and self-awareness. Psychological aspects and implications aside, the empowerment of patients in everyday practice relies heavily on the application and use of technology. At the heart of the learning system is the ability to provide patients with access to relevant educational materials, which will be covered in more detail in section 6/7 of this deliverable. However, technology also provides opportunities for new ways of connecting patients and clinicians and facilitate communication, knowledge exchanges, and critical thinking. In ADLIFE, the Patient Empowerment Platform (PEP) will be the main driver for reinforcing learning directly to the patient groups by providing access to a wealth of information relevant to the patient, both in relation to the generic concept of the diagnoses and to the individual, personalised care plan specific for each patient. The PEP has been developed with several mechanisms for reinforcing learning:

- Real-time video conferencing - Enables the direct exchange of information and knowledge between patient and clinician.
- PRO - Integrated questionnaires provide patients with opportunities to provide detailed information specific to their situation.
- PROMs - Results of measurements with relevant statistics and comparisons, which puts the patient's situation into a broader context that expands the awareness of what may be common and uncommon etc.
- JITAIs - The messages generated by the JITAI engine provides learning through performance updates, motivational messaging, and status declarations.
- Overview of activities - Including goals, achievements and deviations.
- Feedback - Ask questions, get advice, or provide commentary directly to clinicians and other peers/patients in a dedicated, moderated message forum.

In the context of ADLIFE and the PEP, the reinforcement aspect of learning is based on established concepts of behavioural psychology, where reinforcement is a consequence applied to promote future behaviour in a positive manner. Negative reinforcement is considered a form of punishment and will not be a part of the ADLIFE project. The sum of the learning mechanisms integrated into the PEP translates into a framework of interventions that are not only designed to empower patients through learning, they enable patients to actively seek out and self-manage their learning to suit their individual needs and promote self-sufficiency. By facilitating these interventions through the regular interaction with the PEP, patients are exposed to a steady stream of behavioural modifiers that promotes learning through a series of paradigms:

- Educational materials
- Remote access to information, generic and personalised

- Other patients as information sources
- Access to reliable advice in a moderated forum
- Access to their own data
- Influence on decision-making by answering questionnaires and reporting outcomes

Caveat

It is important to recognise that learning for the purpose of empowerment cannot and should not be imposed forcefully on all patients in a top-down manner. Some patients may choose not to participate actively in the learning processes for different reasons. Some may feel too overwhelmed by the whole situation and prefer to delegate the decision-making to a healthcare professional. Others may decide to not receive any treatment for their condition. For these reasons, the learning mechanisms applied in ADLIFE via the PEP are all available on an opt in/opt out basis. No patients are considered 'beyond' empowerment, but some patients will require different levels of support during the processes. This premise is an integral part of the Shared Decision-Making concept.

8 Introduction to nudging

The human brain processes billions of bits of information daily. With such a massive influx of information it is little wonder that people have difficulties in making the best decisions and the ideal choices. Everybody, even highly trained clinicians, make poor decisions from time to time. For patients whose quality of life and well-being are at stake based on a number of potentially obtuse decision-points it can be very stressful and intimidating to make the harder choices regarding their own health. This is where the concept of nudging has a significant role to play in empowering, supporting, and motivating patients to take charge of their own health and care. For the context of this deliverable, nudging is considered to be a positive altruistic technique, which can be used to elicit a behaviour that is beneficial for the patient while respecting their individuality, preferences and freedom of choice. Although there is no established definition of nudging that defines the roles, relationships, and boundaries, forceful negative nudging is considered irrelevant in this specific context.

A nudge can be anything, a tool, a piece of information, an interaction or an intervention that alters the behaviour of the patient in an efficient albeit predictable manner without restricting any options or incentives for the patient. We are all being nudged many, many times every day by family members, co-workers, bosses, and advertisements in some form or another. All to make us make a decision in one way or another. Nudges must be easy to ignore and avoid otherwise it becomes coercion. The power of nudging is found to be so substantial that former British Prime Minister David Cameron created a so-called Nudge Unit to improve the UK government's efficiency in planning their economic policies.

For nudges to be effective there must be a clear and understandable purpose that is deemed desirable in the specific context. For example, if the desired behaviour is to enable patients to more easily choose a generic medicinal product over a branded medication to make the treatment of a related condition more available for patients with lower income, then the nudge could be that the generic medication was offered as the standard option over the branded product in the Medication Database from which the clinicians prescribe to the patients. This example also highlights the caveat that every nudge is also only applicable in the contextual situation for which it has been designed. One of the most famous examples of nudging is the use of a tiny sticker resembling a fly being placed towards the centre of a urinal bowl in a public lavatory. Studies found that men would try to 'wash the fly down the drain' while urinating, which actually unconsciously nudged them to aim better while urinating thus reducing the amount of urine getting on the floor, which in turn reduced the cost of cleaning public lavatories.

In the case of ADLIFE, one of the main aims is to have the recruited patients use the bespoke Patient Empowerment Platform (PEP). For some of these patients using a new digital platform for managing their health and care is a new concept, and there are many instances and opportunities for the patients to make decisions for how they want to deal with their diagnosis (and in some cases diagnoses) and care plan. Aside from the adoption of the digital PEP as a tool, the user interface, the graphic communication within the platform, is the primary driver for enabling nudging of the patients directly. This type of digital nudging can take many forms. Typical examples include simplification of information (making it easier to understand and reducing information bias), decision staging (breaking down complex decisions into more palatable bites), default settings, and positive reinforcement (framing messages). These are all interventions in one form or another.

One nudging tool that is being utilised strategically in the ADLIFE project is the Just-In-Time-

Adaptive-Interventions (JITAIs), which is also covered in more technical details in section 6 of this deliverable. JITAIs are essentially automated messages that are triggered by the occurrence of one or more pre-set events and delivered to the patients. The purpose is to provide support, encouragement, and motivation to the patients with the aim of inspiring them to put in additional effort to achieve a desirable goal or outcome. These goals and outcomes can be physical (exercise), or psychological (mood and mental health) in nature. With JITAIs it becomes possible to monitor changes to a patient's behavioural, physical and mental states over time for the purpose of delivering the right support at the moment it is needed. As such, JITAIs are an advanced form of nudging that adapts more to patients' individual preferences and needs. Further information about the relationship between nudging and JITAIs will be covered in section 7 of this deliverable.

9 PRO and PROMs

Introduction

There has been a marked shift internationally in thinking about what health is and how it is measured. Over the course of several decades, clinical, health services, and social sciences researchers have produced thousands of validated instruments that facilitate consistent and reliable measurement of patient-reported health [57]. Patient perspectives on their health outcomes can now be measured in most clinical areas [57]. Traditional clinical ways of measuring health and the effects of treatment are increasingly accompanied by, or indeed replaced by, PROMs. PROMs are tools for capturing the patient's perspective on the outcomes of their own treatment and care [58].

The main thing about a PROM is that health is assessed by the person experiencing it, not by a doctor or anyone else.

This shift in focus is most evident in the appraisal of new health care technologies, where products and practices are subject to rigorous evaluation.

This chapter is inspired on the work presented on the "D7.1 ADLIFE Patient Reported Outcomes Measurements". The information presented here is relevant for the understanding of the Patient Empowerment interventions described in the following chapters.

9.1 Key definitions

Health outcomes

There are a number of definitions for health outcomes. In Australia the following operational definition is used.

A health outcome is a change in the health of an individual, or a group of people or population, which is wholly or partially attributable to an intervention or series of interventions [58].

9.1.1 Patient-reported outcomes (PROs)

There is growing interest internationally in the routine integration of PRO information into these evaluation and decision-making activities at levels of health system beyond the clinical consultation. This has potential advantages for engaging clinicians, increasing the relevance of the data collected, building large-scale or national datasets efficiently and ultimately improving patient care [58].

PRO can be defined as follows:

A PRO is directly reported by the patient without interpretation of the patient's response by a clinician or anyone else and pertains to the patient's health, quality of life, or functional status associated with health care or treatment [59].

The reliance on PROs is driven by the view that patients are the best judge of their own welfare [58]. The clinicians' task is to evaluate and react on the patients' reported outcomes.

Patient-reported outcomes (PROs) encompass a wide range of measurable outcomes of care from the patient's perspective, including symptoms, quality of life and functional status [58].

The most common method for measuring PROs is asking the patients to complete standardised, validated questionnaires so that they self-assess their own wellbeing and

functional status [58]. Patients are asked to rate their health by responding to a series of items, which are then combined to represent an underlying construct such as pain, symptom severity, function or quality of life.

Importantly, PRO data needs to be presented in a way that is useful to providers and patients. Providers need to be able to use PRO data to know what and how to improve [58].

PRO use the PROMs instruments to measure patient reported outcomes.

9.1.2 Patient Reported Outcome Measures (PROMs)

Patient Reported Outcome Measures (PROMs) capture quality-of-life issues that are the very reasons that most patients seek care: to address a bothersome symptom, limited function, or ailing mental health (Integrated personalized care for patients with advanced chronic diseases to improve health and quality of life p. 12).

PROMs can be defined as:

Patient Reported Outcome Measures (PROMs) are a means of collecting information on the effectiveness of care delivered to patients as perceived by the patients themselves.

In general, analysis of PROMs focuses on the change in scores following a health intervention, such as surgery or a course of treatment.

9.2 What is Patient Reported Outcome Measures

Patient Reported Outcome Measures (PROMs) are tools for capturing the patient's perspective on the outcomes of their own treatment and care [58]. Typically using questionnaires and device measurements.

The name is fairly self-explanatory: PROMs are completed by the *patients* themselves. The purpose of PROMs is to get patients' own assessment of their *health* and *health-related quality of life.* It is *patients* who answer the questions. PROMs are rarely used in the clinical context as stand-alone measures, but are often used alongside other indicators.

The questions can be asked by paper and pencil questionnaires, interviews, or, increasingly commonly, by electronic means (e.g., via a computer, or a handheld electronic device). PROMs questionnaires do not ask about patients' satisfaction with or experience of health care services, or seek their opinions about how successful their treatment was.

Internationally, the healthcare environment is receptive to patient-reported outcome measures (PROMs) as a mechanism to incorporate patient perspectives in quality improvement, electronic data collections, value-based payments and shared decision making.

PROMs must be clearly linked with clinical guidelines and pathways and knowledge translation expertise is needed to help patients, professionals and the public to access and use this information effectively. It is important to use valid, reliable and appropriate instruments when selecting PROMs and minimise the burden on patients and healthcare teams in data collection.

Any implementation of PROMs should have built-in systems for monitoring, evaluation and iterative development. In order to implement PROMs successfully and realise the potential

benefits, information and communication systems are required to ensure that the data can be collected easily and accurately. New information technologies can support the electronic capture of PRO data and facilitate real-time feedback to clinicians providing routine care. The integration of PROMs into electronic health records can also support data collection at an aggregate level and inform system-wide quality improvement and population surveillance.

9.2.1 Why should we use PROMs?

There are three primary reasons cited in the literature for the adoption of PROMs:

- Patients are the best judges of the impact of their treatment and can be most accurate in describing their own symptoms, pain, function and quality of life [58].

- PROMs are a valuable support for patient-centred care and can be used in clinical settings to support shared decision making and patient-centred care [58].

- When collected systematically across providers (e.g. via clinical registries), PROMs generate valuable data on treatment effectiveness, adverse events and variations in healthcare delivery and outcomes to inform efforts to improve quality and safety [58].

PROMs can contribute to the provision of person-centred care [60].

Using PROMs has the potential to improve clinician-patient communication. In the context of clinical consultations, PROMs are being used to:

- Help patients to raise concerns with their clinicians (for example, changes in mental health while receiving treatment)

- Sensitise patients to health issues (for example, symptoms) related to their underlying health conditions and associated treatments that they may not have thought to discuss with their clinicians

- Assist in the identification of health issues that may require further investigation and management

- Facilitate the tracking of health outcomes over time

- Enable comparisons to be made between an individual patient's outcomes with those of other patients with the same health conditions

- Promote shared decision-making when information is available on the effects of alternative treatments on patient-reported outcomes [61] [62] [63].

9.2.2 How do PROMs measure health?

There is a plethora of different PROM questionnaires or instruments, differing in terms of the wording and nature of the questions asked, the number of questions asked, and how the answers are scored or summed up [57]. The quality of these instruments, in terms of their reliability and validity, also varies considerably [57]. It is important to use valid, reliable, and appropriate instruments when selecting PROMs and minimize the burden on patients and healthcare teams in data collection.

Depending on the target, PROMs can be generic, disease-specific, or condition-specific [58]. When used together, generic and disease-specific PROMs can provide complementary information [58].

Advances in data science have contributed to the development of computerized adaptive testing, a predictive model that identifies the correct subset of questions selected from the full questionnaire to ask each patient based on his/her previous responses [64]. This approach of administering a questionnaire minimizes the time and effort required by the respondents to complete a test [58]. Being available in both computerized adaptive testing and traditional versions, PROMs can help to evaluate and improve the quality of healthcare services [58].

9.2.3 Generic PROMs

The advantage of generic PROMs is that they allow comparison of outcomes across conditions [65].

Generic PROMs usually measure either single aspects of health (e.g. pain) or cover multiple dimensions of health status[6]. These multidimensional questionnaires generally include items on physical functioning, role functioning, psychological symptoms, and pain [58]. Some questionnaires extend to additional domains such as sleep, social functioning, and sexual functioning [66].

If the goal of using a generic PROM is to estimate relative costs and benefits of different treatments, as in comparative effectiveness research, a range of multidimensional indices (also known as multi-attribute utility measures) is available [66]. These are short health questionnaires designed to generate a single index value for the health state being measured [58]. This single index or number can then be used to derive quality-adjusted life years (QALYs) with which cost data can be associated. There are a number of recent reviews that provide guidance on selecting a generic PROM instrument that is fit for purpose [66] [67].

As PROMs are often used to measure changes in function for a cohort of patients following treatment [68] or variation among patients receiving different treatments, sensitivity to small differences is an important psychometric characteristic of these instruments [58].

9.2.4 Disease-specific PROMs

Compared with generic instruments, disease-specific PROMs provide far more detailed information about a patient's experience of key symptoms across the trajectory of treatment and recovery for the disease. They are often adopted by disease-specific clinical registries [58]. Some of these instruments incorporate generic elements such as perceived health status or health-related quality of life [58]. Although this may seem an efficient approach, measurement errors can result from including both types of measures in one instrument (e.g. inadequate item representation on generic domains) and valid comparisons across conditions cannot then be made. Increasingly, such 'blended' instruments are being displaced by modular packages, which combine a general health profile and a complementary disease-specific instrument as well as relevant clinical indicators and information such as demographics and comorbidities [66].

There are a larger number of disease-specific PROMs, but they can only be completed by those with the specific disease.

Disease-specific PROMs (e.g. for a type of cancer) measure patient-reported health in a way that is particular to a disease, a set of conditions, or part of the body [57]. These have been called condition-specific measures (they are sometimes also referred to as disease-specific measures) [57]. The questions in these instruments measure the severity of a particular condition or some specific aspect of health, as viewed by the patient [57]. The questions focus on the particular sorts of limitations or problems that people can experience as a result of a very specific condition, or a wider set of conditions that affect a body part [57].

Disease-specific PROMs are used with other disease-specific indicators, which include clinical and physiological measures (e.g. blood pressure, serum cholesterol) and outcome-related performance indicators (e.g. time to receive treatment variables, complications, and adverse events) [58].

9.2.5 Condition-specific PROMs

Condition-specific instruments are relevant to patients who suffer, or are suspected of suffering, from health problems [57]. They are not usually used in population health surveys. Condition-specific PROMs do not focus on a particular disease but on a broader health condition or state [58]. They include a range of functional status or disability measures used to assess the health of a particular population group such as the elderly or those with mental health problems [58] [66]. Thus, 'condition-specific' apply to a service sector, such as rehabilitation or mental health services or a population segment such as the elderly. The European Heart Failure Self-Care Behaviour Scale [69] is an example of a condition-specific PROMs for measuring the behaviour of heart failure patients to maintain life, healthy functioning, and well-being.

9.2.6 Outcome measurement suites

Recently, outcome measurement suites have been developed for conditions (e.g. chronic disease management, dementia, incontinence conditions, mental health, assessment and monitoring of the elderly and asthma) and for particular situations (e.g. assessment and monitoring in primary and community care) [58]. These are collections of PROMs and other items that are seen as relevant for the outcomes monitoring of these conditions. They usually contain patient information, medical history, medication use, service use, clinical indicators, and generic and disease or condition-specific measures [66]. It is the case of the standardized datasets of ICHOM for health outcomes measurement across a range of diseases for population groups.

9.2.7 PROMs in clinical research and evidence

Research on patient-reported outcome measures (PROMs) has evolved over three decades [70] [60]. During this time, hundreds of PROMs have been developed [60]. The development of PROMs originally came from researchers looking to incorporate the perspectives of patients in their work [71].

PROMs often provide resource-efficient and standardised ways of collecting information on complex outcomes, such as daily functioning [72]. More recently, there has been increased interest in PROMs among clinicians, healthcare providers, and health system-level policy developers.

In broad terms, PROMs comprise a series of structured questions that ask patients about their health from their point of view. Patient-reported outcome measures (PROMs) ask patients to assess elements of their own health, quality of life, and functioning. The resulting data can be used to show how healthcare interventions and treatments affect these aspects of a person's day-to-day life [58].

The impact of PROMs on clinical consultations is an emerging field of research. Initial evidence has confirmed that using PROMs in daily practice can improve communication between patients and clinicians [73] [74]. When summaries of PROMs responses are made available to clinicians, patients tend to report that health-related quality of life issues are discussed more frequently during consultations.

Evidence to support the use of patient-reported outcome measures (PROMs) to inform quality improvement is growing internationally. The evidence is strongest for their use in understanding variation in clinical practice, as they can help in determining the relative effectiveness of different treatments and interventions. There is also good evidence that the use of PROMs enhances processes within the patient-clinician interaction [58].

PROMs have been used extensively in research and are increasingly being used in clinical registries and quality improvement activities. PROMs responses from many patients can be analysed together to generate information on:

- The comparative effectiveness of treatments
- The effectiveness of quality improvement activities
- Variations in care, costs, and outcomes among healthcare providers [61] [75].

This knowledge can be used to:

- Inform shared decision-making between clinicians and patients about treatment options
- Identify examples of best practice that can be promoted to facilitate learning and continuous improvement
- Inform future quality improvement activities
- Compare healthcare providers [61] [62] [57] [76].

PROMs have long been included in clinical trials to assess the health outcomes of interventions, but are increasingly used as a quality improvement tool. Tools can be completed in order to monitor outcomes of individual care or to feed into 'registries' of clinical data that assist in identifying effective health care practice and benchmarking the performance of healthcare providers.

PROMs are routinely used in trials of clinical interventions, such as medications and medical devices. Information derived from PROMs can be useful in assessing the benefits and harms of preventing, diagnosing, treating, and monitoring clinical conditions [77].

There is also the potential to use this information to support shared decision-making [61]. Patients may find this information helpful when deciding whether or not to have treatment or in choosing between treatment options.

9.3 PROMs in ADLIFE

As described in the previous section, PROMs are questionnaires completed by patients to ascertain perceptions of their health status, level of impairment, disability and health-related quality of life [78]. They allow the measurement of outcomes in relation to clinical interventions from the patients' perspective and represent a means of assessing clinical effectiveness and safety [79] [80]. Since ADLIFE will follow an outcome-based and patient-centred approach, PROMs represent an especially valuable tool to evaluate the outcomes addressed in this project.

In ADLIFE, PROs will be used for both care improvement and/or personalized care plans assessment. PROMs will allow evaluating the most recent patients' clinical context, constituting a supportive tool for the health status assessment, the decision-making process, and the definition of care goals and activities according to the patients' specific needs.

The definition of the specific PROMs that will be relevant for ADLIFE (i.e. PROMs that will be useful to measure the health outcomes described in the ADLIFE conceptual framework) is a crucial step of this project. The list of PROMs chosen for outcome measurement in the ADLIFE project is described in section 6.4.11 and in-depth in deliverable 7.1.

9.3.1 List of PROMs to be used in ADLIFE

(For a thorough review of PROMs to be used in ADLIFE please refer to D7.1)

Table 3 - Updated list of PROMs to be used in ADLIFE

ADLIFE areas	ADLIFE dimensions	PROMs
Symptoms, functioning quality of life	Autonomy, control	EQ-5D-5L
	Symptom control	EQ-5D-5L
	Mood and emotional health	EQ-5D-5L, HADS
	Social context	EQ-5D-5L
	Activities of daily living	EQ-5D-5L, Lawton IADL, Barthel Index

Clinical status	Complexity (i.e. hurdle, severity)	CAT, mMRC, KCCQ
Healthcare responsiveness	Participation	Shared decision making: "Ask 3 questions"
Care	Satisfaction	PCQ-P
	Carer burden	ZBI-22, WEMWBS

9.3.1.1 Description of PROMs

This section provides a brief summary of the questionnaires initially proposed in the ADLIFE project. Each one of the PROM descriptions includes a brief summary of the questionnaire, the authorship, its intended use, its format and number of questions, availability of translations, evidence of its validation, conditions of use, and a reference to an annex with the complete questionnaire in English. The wellbeing questionnaire will not be described in this section since at this stage of the project as no specific version had been chosen.

"Ask 3 questions" (Shared Decision-Making)

"Ask 3 questions" is part of a campaign launched to encourage patients to participate in the decision-making process by asking three questions to their clinicians [88]. This short questionnaire represents the conversation that takes place between a patient and his/her health professional to reach a healthcare choice together. This approach improves the quality of the information received by patients, helps physicians to make better decisions, strengthens patient-physician communication, and improves safety and quality of care [89].

Barthel Index

The Barthel Index is a scale used to measure the capability to perform basic activities in daily life, reflecting the ability to function independently [98]. The questionnaire measures the degree of assistance required by an individual by asking about mobility and self-care activities [98]. Time taken and physical assistance required to perform each activity are used to assess the independence of the patient [98].

The COPD Assessment Test (CAT)

The CAT is a questionnaire developed for its use in clinical practice to measure the impact of COPD on the patients' health status [85]. It was designed through a rigorous scientific development process, to provide a simple and reliable measure of health status in COPD as a supportive instrument to evaluate patients and enhance the communication between patients and clinicians [86].

EQ-5D-5L (EuroQol 5 Dimensions 5 Levels)

The EQ-5D-5L is a standardized instrument for examining the health-related quality of life [90].

The EQ-5D family of instruments has been designed to describe the health status across a wide range of disease areas. Each tool comprises a short questionnaire that provides a simple descriptive profile of the patient's health status, and a visual scale in which the patient rates his perceived current health [91].

Hospital Anxiety and Depression Scale (HADS)

HADS is a generic PROM that assesses both anxiety and depression, which commonly coexist. Anxiety is poorly recognized by clinicians, and it often precedes depression in response to stressors [99]. The anxiety and depression subscales are also useful to measure the severity of the emotional disorder [100]. HADS focuses on non-physical symptoms, avoiding somatic symptoms of illness, such as fatigue and insomnia or hypersomnia. Thus, it can be used for the detection of anxiety and depression in people with physical health problems, including old and chronic patients[82]. However, HADS does not include all of the diagnostic criteria of depression or all those required by the Health and Work Development Unit National Depression and Long Term Sickness Absence Screening Audit. For this reason, additional questions on appetite, sleep and self-harm/suicidal thoughts have to be asked [99].

Kansas City Cardiomyopathy Questionnaire (KCCQ)

The KCCQ is a questionnaire designed to measure the health status perceived by patients with heart failure. To do so, this tool quantifies, in a disease-specific fashion, physical function, heart failure symptoms (frequency, severity, and recent change), impact on social function, self-efficacy and knowledge, and quality of life [92] [93] [94]. The concepts quantified in the KCCQ are designed to be relevant and appreciable by all heart failure patients specified in the qualified context of use.

Lawton Instrumental Activities of Daily Living Scale (IADL)

The Lawton IADL evaluates the ability of patients to perform tasks that are required to live independently in the community, such as using a phone, shopping, or cooking [95] [96].

Aging, worsening chronic illnesses, and hospitalization usually contribute to a decline in the ability to perform this kind of activities [96]. The functional assessment of patients helps to identify their needs and to provide personalized care [96]. The Lawton IADL can be used to assess independent living skills and to detect early signals of functional decline that need further assessment [94] [95].

Modified Medical Research Council Dyspnoea Scale (mMRC)

The mMRC is a questionnaire used to quantify the disability attributable to dyspnoea in patients with respiratory diseases [87]. Thus it is useful to measure how breathlessness impacts the daily activities of the patients and helps to characterize dyspnoea [87].

Person-centred Climate Questionnaire – patient version (PCQ-P)

The PCQ is one of the most well-documented and widely tested scales available for evaluating the person-centred quality of the care environment within institutional settings [82]. The questionnaire measures how the climate care setting is perceived as person-centred [83] [84].

The Warwick-Edinburgh Mental Wellbeing Scales (WEMWBS)

The Warwick-Edinburgh Mental Wellbeing Scales was designed to monitor the mental wellbeing of the general population and for the evaluation of projects, programs, and policies that aim to improve mental wellbeing [101].

Zarit Burden Interview: 12-item version (ZBI-12) or 22-item version (ZBI-22)

ZBI is a questionnaire aimed to assess the level of burden experienced by the caregivers of older people with senile dementia and disabled patients [81].

10 Just-in Time Adaptive Interventions (JITAIs)

(With kind contributions from SRDC)

Behaviour change interventions are defined as 'coordinated sets of activities designed to change specified behaviour patterns' [102] of individuals. Sticking to healthy behavioural patterns, such as quitting smoking, following a balanced diet, to become more physically active has a direct effect on in people's health. NICE guideline on 'Behaviour change' [103], reports that 'there is overwhelming evidence that changing people's health-related behaviour can have a major impact on some of the largest causes of mortality and morbidity, and to alter current patterns of chronic diseases'.

In order to be able to implement effective behaviour change implementations and also enable the standard based evaluation of results of these interventions, the potentially active ingredients of content of interventions are defined via Behaviour Change Techniques (BCTs). A behaviour change technique (BCT) is defined as an "observable, replicable, and irreducible component of an intervention designed to alter or redirect causal processes that regulate behaviour"; that is, a technique is proposed to be an 'active ingredient' [104]. Michie et al. have defined 93 BCTs clustered into 16 groups as the definition of interventions to change a person's lifestyle behaviour [104]. These categories and some example BCTs for each category are presented in Table 4.

Table 4 - BTC Categories

BTC Categories	Example BTCs
1. Goals and planning	**Goal setting**: Set or agree a goal defined in terms of the behaviour to be achieved. *E.g.: Agree a daily walking goal (*e.g. 3 miles*) with the person and reach agreement about the goal.* **Goal setting (outcome):** Set or agree a goal defined in terms of a positive outcome of wanted behaviour. *E.g. Set a weight loss goal (*e.g. 0.5 kilogram over one week*) as an outcome of changed eating patterns.* **Action planning:** Prompt detailed planning of performance of the behaviour (must include at least one of context, frequency, duration and intensity). Context may be environmental (physical or social) or internal (physical, emotional or cognitive). *E.g. Prompt planning the performance of a particular physical activity (*e.g. running*) at a particular time (*e.g. before work*) on certain days of the week.* **Review behaviour goal(s):** Review behaviour goal(s) jointly with the person and consider modifying goal(s) or behaviour change strategy in light of achievement. This may lead to re-setting the same goal, a small change in that goal or setting a new goal instead of (or in addition to) the first, or no change*. E.g. Examine how well a person's performance corresponds to agreed goals (*e.g. whether they consumed less than one unit of alcohol per day*) and consider modifying future behavioural goals accordingly (*e.g. by increasing or decreasing alcohol target or changing type of alcohol consumed*).*

	Discrepancy between current behaviour and goal: Draw attention to discrepancies between a person's current behaviour (in terms of the *form, frequency, duration,* or *intensity* of that behaviour) and the person's previously set outcome goals, behavioural goals or action plans (goes beyond self-monitoring of behaviour). E.g. Point out that the recorded exercise fell short of the goal set. **Review outcome goal(s):** Review outcome goal(s) jointly with the person and consider modifying goal(s) in light of achievement. This may lead to re-setting the same goal, a small change in that goal or setting a new goal instead of, or in addition to the first. *E.g. Examine how much weight has been lost and consider modifying outcome goal(s) accordingly (*e.g., by increasing or decreasing subsequent weight loss targets*).*
2. Feedback and Monitoring	**Feedback on behaviour**: Monitor and provide informative or evaluative feedback on performance of the behaviour (e.g. *form, frequency, duration, intensity*). *E.g. Inform the person of how many steps they walked each day (as recorded on a pedometer) or how many calories they ate each day (based on a food consumption questionnaire).* **Self-monitoring of behaviour**: Establish a method for the person to monitor and record their behaviour(s) as part of a behaviour change strategy. E.g. *Ask the person to record daily, in a diary, whether they have brushed their teeth for at least two minutes before going to bed. Give patient a pedometer and a form for recording daily total number of steps.* **Feedback on outcome(s) of behaviour**: Monitor and provide feedback on the outcome of performance of the behaviour. *E.g. Inform the person of how much weight they have lost following the implementation of a new exercise regime.*
3. Social support	**Social support (unspecified):** Advise on, arrange or provide social support (*e.g. from friends, relatives, colleagues,' buddies' or staff*) or non-contingent praise or reward for performance of the behaviour. It includes encouragement and counselling, but only when it is directed at the behaviour**.** *E.g. Give information about a self-help group that offers support for the behaviour.*
4. Shaping knowledge	**Instruction on how to perform the behaviour:** Advise or agree on how to perform the behaviour *E.g. Advise the person how to use a BP Monitoring device.*
5. Natural consequences	**Information about health consequences:** Provide information (*e.g. written, verbal, visual*) about health consequences of performing the behaviour. *E.g. Explain that not finishing a course of antibiotics can increase susceptibility to future infection.* **Salience of consequences:** Use methods specifically designed to **emphasise** the consequences of performing the behaviour with the aim of making them more memorable (goes beyond informing about consequences).

	*E.g. Produce cigarette packets showing pictures of health consequences (*e.g. diseased lungs*) to highlight the dangers of continuing to smoke.*
6. Comparison of behaviour	**Demonstration of the behaviour:** Provide an observable sample of the performance of the behaviour, directly in person or indirectly (*e.g. via film, pictures, for the person to aspire to or imitate*), includes **'Modelling'**. *E.g. Demonstrate to nurses how to raise the issue of excessive drinking with patients via a role-play exercise.* **Social Comparison:** Draw attention to others' performance to allow comparison with the person's own performance
7. Associations	**Prompts/cues:** Introduce or define environmental or social stimulus with the purpose of prompting or cueing the behaviour. The prompt or cue would normally occur at the time or place of performance. *E.g. Put a sticker on the bathroom mirror to remind people to brush their teeth.*
8. Repetition and Substitution	**Behaviour substitution:** Prompt substitution of the unwanted behaviour with a wanted or neutral behaviour. **Graded tasks:** Set easy-to-perform tasks, making them increasingly difficult, but achievable, until behaviour is performed. *E.g. Ask the person to walk for 100 yards a day for the first week, then half a mile a day after they have successfully achieved 100 yards, then two miles a day after they have successfully achieved one mile.*
9. Comparison of outcomes	**Pros and cons:** Advise the person to identify and compare reasons for wanting (pros) and not wanting to (cons) change the behaviour (includes '**Decisional balance**'). *E.g. Advise the person to list and compare the advantages and disadvantages of prescribing antibiotics for upper respiratory tract infections.*
10. Reward and threat	**Social reward:** Arrange verbal or non-verbal reward if and only if there **has been** effort and/or progress in performing the behaviour (includes '**Positive reinforcement**'). *E.g. Congratulate the person for each day they eat a reduced fat diet.*
11. Regulation	**Pharmacological support:** Provide, or encourage the use of or adherence to, drugs to facilitate behaviour change.
12. Antecedents	**Restructuring the physical environment:** Change or advise to change the physical environment in order to facilitate performance of the wanted behaviour or create barriers to the unwanted behaviour (other than prompts/cues, rewards and punishments). *E.g. Advise to keep biscuits and snacks in a cupboard that is inconvenient to get to.*
13. Identity	**Identification of self as role model:** Inform that one's own behaviour may be an example to others. *E.g. Inform the person that if they eat healthily, that may be a good example for their children.*
14. Scheduled Consequences	**Reduce reward frequency:** Arrange for rewards to be made contingent on increasing duration or frequency of the behaviour (includes '**Thinning**'). *E.g. Arrange reward for each day without smoking, then each week, then each month, then every 2 months and so on.*

15. Self-belief	**Focus on past success:** Advise to think about or list previous successes in performing the behaviour (or parts of it). *E.g. Advise to describe or list the occasions on which the person had ordered a non-alcoholic drink in a bar.*
16. Covert learning	**Imaginary reward:** Advise to imagine performing the **wanted** behaviour in a real-life situation followed by imagining a pleasant consequence. *E.g. Advise the health professional to imagine giving dietary advice followed by the patient losing weight and no longer being diabetic.*

The NICE Guidelines recommends including 'goals and planning' and 'feedback and monitoring' and 'social support techniques' as behaviour change interventions [105].

Apart from identifying the 'right' content for the BCIs via selected BCTs, it is also important to select the 'best possible means' to deliver the interventions. Besides, delivering these interventions at regular follow-up appointments encouraging healthy behaviours, digital interventions can be utilized as a follow-up support to empower the patients for carrying out self-management activities following face-to-face encounters. NICE Guidelines also recommends 'delivering interventions remotely via digital means such as the telephone, text messaging or apps [105].

Recent technological advances have enabled delivery of behavioural change interventions via mobile devices in a real time manner. The Just-in-time Adaptive Intervention (JITAI) concept is introduced by Nahum-Shani et al. [106], and is defined as 'an intervention designed to address the dynamically changing needs of individuals via the provision of the type/amount of support needed, at the right time, and only when needed'.

Naughton et al. [107] presents that JITAIs have two distinctive key features:

- It is possible to provide behavioural support via JITAIs when the user is at risk of engaging in a negative health behaviour or has an opportunity to engage in a positive behaviour momentarily.

- The content or timing of behavioural support can be tailored according to input collected by the system. Behavioural support is triggered when an opportune moment has been detected by the system, instead of manually triggered by the user.

Several different systems delivering JITAIs have been developed for supporting healthy behaviours addressing the needs of eating disorders, obesity and weight management, sedentary lifestyle [106] and smoking cessation [108].

10.1 JITAIs in the context of the ADLIFE project

Purpose of JITAIs for the ADLIFE project

The ADLIFE Project, aims to provide an integrated care solution targeting early detection and assessment of deterioration, advanced and well-coordinated care planning, and supportive care for patients with advanced chronic diseases, namely, heart failure and COPD. These advanced chronic diseases introduce demanding challenges for the patients: long term conditions necessitate continuous and complex management. Diseases and treatment requirements change with time requiring continuous adjustments at the patient side as well. Patients need to engage in several different self-management activities, they need to adhere to their prescription plans, they need to adapt often more than one healthy behaviour at a time such as complying with dietary plans, performing physical

exercises, and they need to carry out several different tasks assigned to them, such as self-conducted blood pressure measurements and filling-in questionnaires to report symptoms and provide Patient Reported Outcome Measures (PROMs).

In the ADLIFE architecture, our aim is to support the patients in their self-management journey, via Just-in-time Adaptive Interventions, to remind them the activities that are assigned to them as a part of their care plan, and to motivate them to reinforce their adherence. Studies have shown that such interventions addressing common behavioural risk factors for chronic diseases such as tobacco smoking, poor diet, and physical inactivity and supporting behaviour change for the effective self-management of chronic conditions can positively contribute to health and well-being of the patients with chronic conditions [108].

10.2 Brief overview of JITAI Delivery mechanisms in ADLIFE architecture

In the ADLIFE architecture, via the Personalised Care Plan Management Platform (PCPMP) a shared care plan for the patient is created during an encounter with the presence of both the physician and the patient. Within this care plan, the physician and the patient can set goals and agree on a set of activities for the patient such as adhering to a medication plan, following a healthy diet and physical exercise regimens, carrying out self-measurement activities such as Blood Pressure monitoring, symptom reporting and filling in PROM questionnaires.

When these activities are added to the care plan by the physician, the physician by discussing with the patient, can select whether a JITAI should be assigned for this activity. For an activity that has a specific due date, a 'Reminder' can be set. For periodic activities, that needs to be carried out a certain number of times daily, weekly, or monthly, 'Motivational Messages' can be sent as JITAIs to the patient. We have categorized these 'Motivational Messages' as follows:

- General Reinforcement: General motivational messages such as 'Good work! You reached your goal for the day'.

- Positive Comparison with self: Here, we compare patient's recent performance in carrying out the assigned activity, with one of his/her previous performance. E.g.: 'That was a good day, you are 50% better than last Tuesday (your best day last week) in Blood glucose monitoring.'

- Positive Comparison with other patients in the cohort: Here, we compare patient's recent performance in carrying out the assigned activity, with the average performance of the patient cohort, to motivate the patient. E.g.: 'Good work! Your performance in daily exercise is better than 60 % of other patients in the cohort this week.'

In the following table, we present how we map the ADLIFE Patient Empowerment activities, including care planning and JITAI delivery can be mapped to The BCT taxonomy defined by Mitchie et al. [104]. In this table, we also present how different ADLIFE components take role to deliver these behavioural change interventions.

Table 5 - Mapping of ADLIFE Patient Empowerment activities

BTC Categories defined by Mitchie et. al[3].	Mapping of ADLIFE Patient Empowerment activities including JTAIs to BCT categories
1. Goals and planning	**Goal setting**: In ADLIFE PCPMP, it is possible to set a goal defined in terms of the behaviour to be achieved after discussing this with the patient. *E.g.: 'Increasing physical activity'.* This goal, then will be presented to the patient via PEP. **Goal setting (outcome):** In ADLIFE PCPMP, it is possible to set a goal defined in terms of a positive outcome of wanted behaviour after discussing this with the patient. *E.g. 'Set a weight loss goal (*e.g. 0.5 kilogram over one wee*k) as an outcome of changed eating patterns.'* This goal, then will be presented to the patient via PEP. The patient will also be enabled to see his/her performance in achieving this goal, if s/he regularly logs in his/her weight measurements via PEP. **Action planning:** In ADLIFE PCPMP, it is possible to assign concrete activities to be carried out by the patient as a part of his/her care plan. While these activities are assigned, the frequency, duration, due date of them can also be set within the care plan. *E.g. 'Carrying out moderate physical activity (*e.g. walking*) for half an hour three times a week.'* **Review behaviour goal(s) & Review outcome goal(s):** Both in ADLIFE PEP, and also in PCPMP, the patient and the physician will be able to see the patient's achievements related with the goal via dashboards. Based on these, during care plan review meeting, they will have a chance to discuss and update the goals accordingly. **Discrepancy between current behaviour and goal:** In ADLIFE PEP, the patients will have a chance to mark the activities as performed (for some of the activities, such as self-measurements or PROM questionnaires, this will be automatically performed by the system). Patient's daily, weekly and monthly performances in performing the periodic activities will be calculated automatically by the system. While the activity is assigned to the patient as a part of a care plan, an action plan is also determined to indicate the quantity/duration and frequency for activity. For example, if a BP Measurement activity is assigned to be performed 3 times a week, the JTAI Engine as a part of PEP, listens for BP Measurement Observations recorded by PEP, and checks whether 3 activities have been performed each week. This, then, will be recorded as a performance of 100%. These will be presented at PEP, and also in PCPMP as dashboards. In addition to these, as presented below, based on these performance monitoring *Motivating Messages (General reinforcement, positive comparison with self, positive comparison with others)* will be sent to patients.

2. Feedback and Monitoring	**Feedback on behaviour**: As presented above, patient's progress in achieving the planned behaviour in comparison to the prescribed *form, frequency, duration, intensity* will be continuously monitored by the system. This will be visible in PEP dashboards. In addition to these, patients will receive *Motivating Messages (General reinforcement, positive comparison with self, positive comparison with others)* related with these. E.g. *'Well done you are doing a great job! You have successively logged your symptoms for the last 3 days.'* Or *'You are almost there for the week! Just keep up your good work, and you will exceed your last week's performance by 30%.'* **Self-monitoring of behaviour**: In ADLIFE PEP, some of the activities will marked as 'completed' by the system. For example, when a patient fills in a questionnaire, or records a BP measurement via PEP, this will be automatically marked as 'completed'. For some other activities, such as 'taking medication 3 times a day', these will be marked as 'completed' by the patient via PEP. **Feedback on outcome(s) of behaviour**: Patient's progress in achieving the targeted outcome (such as loosing 3kgs in 3 months) will be monitored by the systems, and patient's current achievement will be presented to the patient via PEP.
3. Social support	**Social support (unspecified):** In ADLIFE PCPMP, it will be possible to assign an activity to '*check self-help group for a specific condition that offers support to the patients.*
4. Shaping knowledge	**Instruction on how to perform the behaviour:** As a part of patient's care plan, training material can be assigned to the patient in PEP, which might be about 'H*ow to use a BP Monitoring devices' for self-measurement activities. These can be reviewed by the patient via PEP.*
7. Associations	**Prompts/cues:** In ADLIFE, once the care plan is finalized at PCPMP, it will be shared with the patient via PEP. For the activities assigned to the patient, a physician can set 'reminder messages' to be delivered via PEP. This selection can also be turned on/off via PEP by the patient. An example reminder that can be delivered to the patient as a JTAI could be: *'Just to remind you; You have an upcoming blood pressure monitoring point scheduled before noon.'*
9. Comparison of outcomes	**Pros and cons:** In PCPMP, Decision Aids can be assigned to patient, so that s/he can examine them at home via PEP. In these decision aids, the patient is reminded to review the advantages/disadvantages (pros/cons) of alternative treatment options, which might include lifestyle changes.
10. Reward and threat	In ADLIFE, we have designed several JITAI content presenting verbal rewards when there has been effort and/or progress in performing the behaviour. Patient's progress has been continuously monitored and *Motivating Messages (General reinforcement, positive comparison with self, positive comparison with others)* are being delivered to the patient.

	E.g. 'You are almost there for the week! Just keep up your good work, and you will exceed your last week's performance by 30%.'

In ADLIFE architecture, JITAIs are designed to be delivered when an opportune moment is detected to remind and motivate the patient. The JITAIs are triggered after certain events are detected by the platform:

- Whenever a planned activity in the patient's care plan has happened, for example the patient logged a walking exercise, his/her current performance to achieve his daily/weekly/monthly goal is calculated, and he is provided positive feedback and reinforcement.

- Whenever a planned activity missed, e.g. the patient has missed to record his daily BP measurement, his/her current performance to achieve his daily/weekly/monthly goal is calculated, and he is provided positive feedback and reinforcement.

- Before planned events, especially when the activity is not a periodic one, instead a singular activity to be carried out at a certain time slot, e.g. control appointment with his GP, the patient is provided reminder messages.

As explained in Table 4, the system will continuously monitor patient's activities at PEP at the background, to catch a convenient moment to send reminders and motivational messages as interventions. The system calculates patient's performance daily/weekly/monthly in the background and categorizes them as follows:

TARGET ACHIEVED: Patient achieves daily, weekly or monthly target (X% of the targeted activities. E.g. 100%)

TARGET SUCCESSIVELY ACHIEVED: Patient successively reached his daily, weekly or monthly targets for a number of times

TARGET CLOSE TO ACHIEVE: Patient is very close to achieve his daily, weekly or monthly target (s/he has achieved X% of the targeted activities. E.g. 70%)

TARGET IN PROGRESS: Patient has completed a certain percentage of his targeted activities but has not yet completed it. Example: Patient needs to walk three times a week, has performed some exercise (s/he has walked two times this week), the week is not over yet, and the patient has still time to meet his/her weekly target

TARGET ALMOST ACHIEVED: Patient could not meet his/her targets for the day/week/month but was very close to achieve. Example: Patient needs to walk three times a week, has performed some exercise (s/he has walked two times this week), yet, the week is over.

TARGET NOT ACHIEVED: Patient could not meet his/her targets for the day/week/month, and s/he was not close to achieve it.

Based on these, different JITAI content templates have been prepared, so that, the achievement percentages can be individually calculated, and the content is adapted individually for the patient dynamically.

Another type of personalization is the frequency of delivering JTAI messages to the patient. We have defined the following frequencies:

Each Time (Always): For each planned action for a specific time the intervention will be delivered. e.g. If patient selects "mandatory" for "reminders" for "BG monitoring goal", a reminder will be sent for each planned action (once after breakfast, once after lunch, etc.).

Frequently: The intervention will be delivered 70% of the time among the times an action is planned.

Occasionally: The intervention will be delivered 30% of the time among the times an action is planned.

Rarely: The intervention will be delivered 10% of the time among the times an action is planned.

Never: The intervention will never be sent.

These frequencies can be selected by the physician during a care plan review meeting by discussing with the patient, and also by the patient via PEP.

In this way, in ADLIFE, it is possible to tailor the intervention delivery strategies dynamically in terms of intervention type, timing and frequency, in compliance with people's action plans, changing physical / psychological contexts as well as their changing preferences over time.

10.3 Proposed JITAIs for the ADLIFE project

In ADLIFE, in relation to the disease we target to address (COPD, CHF and their selected comorbidities including Dementia, Mild Cognitive Impairment, Hypertension, Diabetes and Renal Failure), we have currently identified the following behaviour types, we have considered to provide motivational messages to increase their adherence in following the pre-set plan in the care plan:

Table 6 - Proposed JITAIs

Behaviour Type	Activities /Targets Related with these behaviour
Self-measurement of selected clinical parameters and vital signs	Self-measurement of blood pressure Self-measurement of oxygen saturation Self-measurement of pulse Self-measurement of weight Self-measurement of spirometry Self-measurement of blood glucose
Symptom recording	E.g.: Self-registration of changed dyspnoea, Self-registration of more/less cough, Self-registration of the colour, quantity, viscosity od sputum, Self-registration of possible adverse effects of
Completing PROM questionnaires	EQ-5D-5L mMRC PCQ-P ZBI-22, ZBI-12 WEMWBS HADS

	Lawton IADL, Barthel Index CAT
Exercise Monitoring	Walking, Running, # of Steps

In the following sections, we present the JTAI Content proposed for these selected behaviour types:

10.3.1 JITAI Content for Self-Measurement Activities

Table 7 - JITAI content for self-measurement activities

	Trigger	Rules	Main BCT Technique	Intervention Content ([lang=en])	Examples
MOTIVATIONS	Whenever a related Patient Activity is recorded from PEP/ and at the end of the day, week or month	TARGET ACHIEVED	General Reinforcement	Good work! You reached your target for the ${target_temporal}.	Good work! You reached your target for the day.
			Positive comparison with self	That was a good ${target_temporal}, you are ${comparison_value}% better than ${comparison_temporal} in self blood pressure monitoring!	That was a good day, you are 30% better than last Tuesday (your best day last week) in self-blood pressure monitoring.
			Positive comparison with others	Good work! Your performance is better than ${comparison_population_percentage}% of others ${comparison_temporal}.	Good work! Your performance is better than 40 % of others this week.
			General Reinforcement	Thank you sending in your readings, it is much appreciated	Thank you sending in your readings, it is much appreciated
		TARGET SUCCESSIVELY ACHIEVED	General Reinforcement	Well done you are doing a great job! You have successively achieved your Blood Pressure monitoring target for last ${streak_value} ${streak_temporal}s.	Well done you are doing a great job! You have successively achieved your Blood Pressure monitoring target for last 3 days.
		TARGET CLOSE TO ACHIEVE	General Reinforcement	You are almost there for ${target_temporal}! If you can adhere your remaining Blood Pressure monitoring tasks you will reach your target.	You are almost there for the week! If you can adhere your remaining Blood Pressure monitoring tasks you will reach your target
			Positive comparison with self	You are almost there for ${target_temporal}! Just keep up your good work, and you will exceed your ${comparison_simulation_temporal}'s performance with ${comparison_simulation_value}%.	You are almost there for week! Just keep up your good work, and you will exceed your last week's performance with 30%.

Trigger	Rules		Main BCT Technique	Intervention Content ([lang=en])	Examples
			Positive comparison with others	You are almost there! Just keep up your good work and you will exceed ${comparison_simulation_population_percentage} of others ${comparison_simulation_temporal}.	You are almost there! Just keep up your good work and you will exceed 20% of others this month.
			Positive comparison with self	You are almost there! Complete your remaining Blood Pressure monitoring task and you will exceed your ${comparison_simulation_temporal}'s performance with ${comparison_simulation_value}%	You are almost there! Complete your remaining Blood Pressure monitoring task and you will exceed your last days performance with 30%
		TARGET ALMOST ACHIEVED	Positive comparison with self	Almost there for the ${target_temporal}! Still, you are ${comparison_value}% better than ${comparison_temporal} in Blood Pressure monitoring. Keep up the good work and you will reach your targets.	Almost there for the day! Still, you are 30% better than last Tuesday in Blood Pressure monitoring. Keep up the good work and you will reach your targets.
			General Reinforcement	Almost there for the ${target_temporal}! Keep up the good work and you will reach your targets next time.	Almost there for the day! Keep up the good work and you will reach your targets next time.
			Positive comparison with others	Almost there for the ${target_temporal}! Still your performance is better than ${comparison_population_percentage}% of others ${comparison_temporal}.	Almost there for the day! Still your performance is better than 40% of others this week.
		TARGET NOT ACHIEVED	Positive comparison with self	It seems, you missed your last Blood Pressure monitoring task. No problem, if you can complete your remaining tasks, still you will be ${comparison_simulation_value}% better than ${comparison_simulation_temporal}.	It seems, you missed your last Blood Pressure monitoring task. No problem, if you can complete your remaining tasks, still you will be 30% better than your worst performance.
			General Reinforcement	It seems, you missed your last Blood Pressure monitoring task. Focus on your remaining tasks and still you will be close to achieving your targets.	It seems, you missed your last Blood Pressure monitoring task. Focus on your remaining tasks and still you will be close to achieving your targets.

	Trigger	Rules	Main BCT Technique	Intervention Content ([lang=en])	Examples
			General Reinforcement	"You made so much progress lately! This was not your best day, but you are working hard lately!"	"You made so much progress lately! This was not your best day, but you are working hard lately!"
			General Reinforcement	Too bad you did not make it today! Tomorrow might be a better day!	Too bad you did not make it today! Tomorrow might be a better day!
			Positive comparison with self	Too bad you did not reach your target for the ${target_temporal}! Still this is not your worst performance; it is ${comparison_value}% better than your ${comparison_temporal} performance and you are improving.	Too bad you did not reach your target for the day! Still, this is not your worst performance; it is 30% better than your worst day performance and you are improving.
			Positive comparison with others	You did not have the best ${target_temporal}. Still, you worked hard and you perform ${comparison_population_percentage}% better than others ${comparison_temporal}.	You did not have the best day. Still, you worked hard and you perform 30% better than others this month.
REMINDERS	Before each planned activity	None	Simple reminder	Just to remind you; You have an upcoming ${action_name} scheduled (${action_time})	Just to remind you; You have an upcoming blood pressure monitoring scheduled before noon.
		TARGET CLOSE TO REACH	Simple reminder	Just to remind you; You have an upcoming planned ${action_name} scheduled (${action_time})! If you can complete it, you will reach your target today	Just to remind you; You have an upcoming planned blood pressure monitoring scheduled before bed! If you can complete it, you will reach your target today
			Positive comparison with self	Just to remind you; You have an upcoming ${action_name} scheduled (${action_time})! If you can complete it, your performance will be ${comparison_simulation_value}% better than ${comparison_simulation_temporal}.	Just to remind you; You have an upcoming blood pressure monitoring scheduled after lunch! If you can complete it, your performance will be 30% better than yesterday.

Trigger	Rules	Main BCT Technique	Intervention Content ([lang=en])	Examples
		Positive comparison with others	Just to remind you; You have an upcoming ${action_name} scheduled (${action_time})! If you can complete it, your performance will be better than ${comparison_simulation_population_percentage}% of others ${comparison_simulation_temporal}.	Just to remind you; You have an upcoming blood pressure monitoring scheduled after breakfast! If you can complete it, your performance will be better than 10% of others this week.
			Just to remind you; You have an upcoming ${action_name} scheduled (${action_time}) and you are very close to extend your streak (successive target reach) to ${streak_value} ${streak_temporal}s.	Just to remind you; You have an upcoming blood pressure monitoring scheduled after breakfast and you are very close to extend your streak (successive target reach) to 13 days.

10.3.2 JITAI Content for Exercise Monitoring

Table 8 - JITAI content for exercise monitoring

	Trigger	Rules	Main BCT Technique	Intervention Content ([lang=en])	Examples
MOTIVATIONS	Whenever a related Patient Activity is recorded from PEP/ at the end of the day, week or month	TARGET MORE THAN ACHIEVED	General Reinforcement	Great success! You are performing better than your target for the ${target_temporal}.	Great success! You are performing better than your target for the week.
			Positive comparison with self	Excellent ${target_temporal}, you are ${comparison_value}% better than ${comparison_temporal} in your exercises.	Excellent week, you are 30% better than last week in your exercises.
			Positive comparison with others	Great job! Your performance is better than ${comparison_population_percentage}% of others ${comparison_temporal}.	Great job! Your performance is better than 40% of others this week.
		TARGET ACHIEVED	Positive comparison with self	Congratulations, you have successfully completed your planned exercise session! You perform ${comparison_value}% more than ${comparison_temporal} in this session.	Congratulations, you have successfully completed your planned exercise session! You perform 25% more than yesterday in this session.
			Positive comparison with self	That was a good ${target_temporal}, you perform ${comparison_value}% more than ${comparison_temporal}.	That was a good week, you perform 20% more than last week
			General Reinforcement	Great success, you successively achieved your target for last ${streak_value} ${streak_temporal}.	Great success, you successively achieved your target for last 3 weeks.
			General Reinforcement	Good work! You have successfully completed your planned exercise session.	Good work! You have successfully completed your planned exercise session.
			General Reinforcement	Congratulations! You reached your target for the ${target_temporal}.	Congratulations! You reached your target for the week.
			Positive comparison with others	Congratulations, that was a good ${target_temporal}, you perform more than ${comparison_population_percentage}% of others ${comparison_temporal}!	Congratulations, that was a good month, you perform more than 60% of others this month!

Trigger	Rules	Main BCT Technique	Intervention Content ([lang=en])	Examples
		TARGET IN PROGRESS	Positive comparison with self	Good work! You performed ${comparison_value}% more than ${comparison_temporal} in this session.	Good work! You performed 25% more than last Saturday in this session.
			General Reinforcement	Good work! You now have ${target_remaining} minutes of exercises to reach your weekly target	Good work! You now have 80 minutes of exercises to reach your weekly target
		TARGET CLOSE TO ACHIEVE	General Reinforcement	You are almost there for ${goal_temporal}! If you can adhere your remaining exercise sessions you will reach your goal.	You are almost there for the week! If you can adhere your remaining exercise sessions you will reach your goal.
			Positive comparison with self	You are almost there! Continue your exercise today just ${goal_remaining} more and you will exceed your ${comparison_simulation_temporal}'s performance with ${comparison_value}%.	You are almost there! Continue your exercise today just 20 minutes more and you will exceed your last Sunday's performance with 25%.
			Positive comparison with self	You are almost there for ${goal_temporal}! Just keep up your good work, and you will exceed your ${comparison_simulation_temporal}'s performance with ${comparison_simulation_value}%.	You are almost there for week! Just keep up your good work, and you will exceed your this week's performance with 10%.
			Positive comparison with others	You are almost there! Just ${goal_remaining} more minutes within this ${goal_temporal} and you will exceed ${comparison_simulation_population_percentage}% of others ${comparison_simulation_temporal}	You are almost there! Just 20 minutes more minutes within this day and you will exceed 25% of others today
		TARGET ALMOST ACHIEVED	General Reinforcement	Almost there for the ${target_temporal} exercise session! Perform your exercise ${target_remaining} minutes more than last time, and you will reach your target.	Almost there for the daily exercise session! Perform your exercise 20 minutes more than last time, and you will reach your target.
			General Reinforcement	Almost there for the ${target_temporal}! Keep up the good work, and you will reach your target next time.	Almost there for the week! Keep up the good work, and you will reach your target next time.
			Positive comparison with self	Almost there for this ${target_temporal}! Still, you are ${comparison_value}% better than ${comparison_temporal} in exercise adherence.	Almost there for this week! Still, you are 20% better than last week in exercise adherence.

	Trigger	Rules	Main BCT Technique	Intervention Content ([lang=en])	Examples
			Positive comparison with others	Almost there for this ${target_temporal}! Still, you are ${comparison_population_percentage}% better than others ${comparison_temporal} in exercise adherence.	Almost there for this week! Still, you are 30% better than others this week in exercise adherence.
		TARGET NOT ACHIEVED	General Reinforcement	You made so much progress in your exercise sessions! This was not your best day, but you are working hard in general!	You made so much progress in your exercise sessions! This was not your best day, but you are working hard in general!
			General Reinforcement	Too bad you did not complete your exercise session this time! Tomorrow might be a better day!	Too bad you did not complete your exercise session this time! Tomorrow might be a better day!
			Positive comparison with self	Too bad you did not complete your exercise sessions ${target_temporal}! Still this is not your worst performance. Yo are (${comparison_value}% better than ${comparison_temporal}) and you are improving.	Too bad you did not complete your exercise sessions this week! Still this is not your worst performance. You are 25% better than last week and you are improving.
			Positive comparison with others	You did not have the best ${target_temporal}. Still, you worked hard and you perform ${comparison_population_percentage}% better than others ${comparison_temporal}.	You did not have the best day. Still, you worked hard and you perform 25% better than others today.
REMINDERS	Before each planned activity	None	Simple reminder	Just to remind you; You have an upcoming ${action_name} scheduled (${action_time})	Just to remind you; You have an upcoming walking exercise scheduled today
		TARGET CLOSE TO REACH	Simple reminder	Just to remind you; You have an upcoming planned ${action_name} scheduled (${action_time})! If you can complete it, you will reach your target today	Just to remind you; You have an upcoming planned walking exercise scheduled today! If you can complete it, you will reach your target today

Trigger	Rules	Main BCT Technique	Intervention Content ([lang=en])	Examples
		Positive comparison with self	Just to remind you; You have an upcoming ${action_name} scheduled (${action_time})! If you can complete it, your performance will be ${comparison_simulation_value}% better than ${comparison_simulation_temporal}.	Just to remind you; You have an upcoming walking exercise scheduled today! If you can complete it, your performance will be 25% better than last week.
		Positive comparison with others	Just to remind you; You have an upcoming ${action_name} scheduled (${action_time})! If you can complete it, your performance will be better than ${comparison_simulation_population_percentage}% of others ${comparison_simulation_temporal}.	Just to remind you; You have an upcoming walking exercise scheduled today! If you can complete it, your performance will be better than 30% of others today.
		General Reinforcement	Just to remind you; You have an upcoming ${action_name} scheduled (${action_time}) and you are very close to extend your streak (successive target reach) to ${streak_value} ${streak_temporal}s.	Just to remind you; You have an upcoming walking exercise scheduled today and you are very close to extend your streak (successive target reach) to 14 days.

10.3.3 JITAI Content for Symptom Reporting Questionnaires

Table 9 - JITAI content for symptom reporting questionnaires

	Trigger	Rules	Main BCT Technique	Intervention Content ([lang=en])	Examples
MOTIVATIONS	Whenever a related Patient Activity is recorded from PEP/ at the end of the day, week or month	TARGET ACHIEVED	General Reinforcement	Good work! You have logged your symptoms for the ${target_temporal}.	Good work! You have logged your symptoms for the day.
			Positive comparison with self	That was a good ${target_temporal}, you are ${comparison_value}% better than ${comparison_temporal} in symptom reporting!	That was a good week, you are 30% better than last week in symptom reporting!
			Positive comparison with others	Good work! Your performance is better than ${comparison_population_percentage}% of others ${comparison_temporal}.	Good work! Your performance is better than 40 % of others today.
		TARGET SUCCESSIVELY ACHIEVED	General Reinforcement	Well done you are doing a great job! You have successively logged your symptoms for last ${streak_value} ${streak_temporal}s.	Well done you are doing a great job! You successively logged your symptoms for last 3 days.
		TARGET CLOSE TO ACHIEVE	General Reinforcement	You are almost there for ${target_temporal}! Continue to log your symptoms, and you will reach your target for the ${target_temporal}! .	You are almost there for the week! Continue to log your symptoms, and you will reach your target for the week.
			Positive comparison with self	You are almost there for ${target_temporal}! Just keep up your good work, and you will exceed your ${comparison_simulation_temporal}'s performance with ${comparison_simulation_value}%.	You are almost there for week! Just keep up your good work, and you will exceed your last week's performance with 30%.
			Positive comparison with others	You are almost there! Just keep up your good work and you will exceed ${comparison_simulation_population_percentage} of others ${comparison_simulation_temporal}.	You are almost there! Just keep up your good work and you will exceed 20% of others this week.
			Positive comparison with self	You are almost there! Complete your remaining symptom reporting task and you will exceed your ${comparison_simulation_temporal}'s performance with ${comparison_simulation_value}%	You are almost there! Complete your remaining symptom logging task and you will exceed your last weeks performance with 30%

	Trigger	Rules	Main BCT Technique	Intervention Content ([lang=en])	Examples
		TARGET ALMOST ACHIEVED	Positive comparison with self	Almost there for the ${target_temporal}! Still, you are ${comparison_value}% better than ${comparison_temporal} in symptom logging. Keep up the good work and you will reach your targets.	Almost there for the week! Still, you are 30% better than last week in symptom logging. Keep up the good work and you will reach your targets.
			General Reinforcement	Almost there for the ${target_temporal}! Keep up the good work and you will reach your targets next time.	Almost there for the week! Keep up the good work and you will reach your targets next time.
			Positive comparison with others	Almost there for the ${target_temporal}! Still your performance is better than ${comparison_population_percentage}% of others ${comparison_temporal}.	Almost there for the week! Still your performance is better than 40% of others this week.
		TARGET NOT ACHIEVED	Positive comparison with self	It seems, you missed your last symptom logging task. No problem, if you can complete your remaining tasks, still you will be ${comparison_simulation_value}% better than ${comparison_simulation_temporal}.	It seems, you missed your last symptom logging task. No problem, if you can complete your remaining tasks, still you will be 30% better than last week.
			General Reinforcement	It seems, you missed your last symptom logging task. Focus on your remaining tasks and still you will be close to achieving your targets.	It seems, you missed your last symptom logging task. Focus on your remaining tasks and still you will be close to achieving your targets.
			General Reinforcement	Too bad you did not make it today! Tomorrow might be a better day!	Too bad you did not make it today! Tomorrow might be a better day!
			Positive comparison with others	You did not have the best ${target_temporal} for symptom logging. Still, you worked hard and you perform ${comparison_population_percentage}% better than others ${comparison_temporal}.	You did not have the best day symptom logging. Still, you worked hard and you perform 30% better than others this week.
REMINDERS	Before each	None	Simple reminder	Just to remind you; You have an upcoming ${action_name} task.	Just to remind you; You have an upcoming symptom logging task.

Trigger	Rules	Main BCT Technique	Intervention Content ([lang=en])	Examples
planned activity	TARGET CLOSE TO REACH	Simple reminder	Just to remind you; You have an upcoming planned ${action_name} task scheduled (${action_time})! If you can complete it, you will reach your target today	Just to remind you; You have an upcoming planned symptom logging task scheduled today! If you can complete it, you will reach your target today
		Positive comparison with self	Just to remind you; You have an upcoming ${action_name} task scheduled(${action_time})! If you can complete it, your performance will be ${comparison_simulation_value}% better than ${comparison_simulation_temporal}.	Just to remind you; You have an upcoming symptom logging task scheduled today! If you can complete it, your performance will be 30% better than last week.
		Positive comparison with others	Just to remind you; You have an upcoming ${action_name} task scheduled (${action_time})! If you can complete it, your performance will be better than ${comparison_simulation_population_percentage}% of others ${comparison_simulation_temporal}.	Just to remind you; You have an upcoming symptom logging task scheduled today! If you can complete it, your performance will be better than 10% of others this week.
			Just to remind you; You have an upcoming ${action_name} task scheduled (${action_time}) and you are very close to extend your streak (successive target reach) to ${streak_value} ${streak_temporal}s.	Just to remind you; You have an upcoming symptom logging task scheduled today and you are very close to extend your streak (successive target reach) to 13 days.

10.3.4 JITAI Content for PROM Questionnaires

Table 10 - JITAI content for PROM questionnaires

	Trigger	Rules	Main BCT Technique	Intervention Content ([lang=en])	Examples
MOTIVATIONS	Whenever a related Patient Activity is recorded from PEP/ at the end of the day, week or month	TARGET ACHIEVED	General Reinforcement	Good work! You have finished your ${action_name} for the ${target_temporal}.	Good work! You have finished your Activities for Daily Life questionnaire for the month.
			Positive comparison with self	That was a good ${target_temporal}, you are ${comparison_value}% better than ${comparison_temporal} in ${action_name}!	That was a good month, you are 30% better than last week in Activities for Daily Life questionnaire!
			Positive comparison with others	Good work! Your performance is better than ${comparison_population_percentage}% of others ${comparison_temporal}.	Good work! Your performance is better than 40 % of others today.
		TARGET SUCCESSIVELY ACHIEVED	General Reinforcement	Well done you are doing a great job! You have successively completed ${action_name} for last ${streak_value} ${streak_temporal}s.	Well done you are doing a great job! You have successively completed Activities for Daily Life questionnaire for last 3 months.
		TARGET CLOSE TO ACHIEVE	General Reinforcement	You are almost there for ${target_temporal}! Continue to complete your ${action_name}, and you will reach your target for the ${target_temporal}! .	You are almost there for the week! Continue to complete Activities for Daily Life questionnaire, and you will reach your target for the week.
			Positive comparison with self	You are almost there for ${target_temporal}! Just keep up your good work, and you will exceed your ${comparison_simulation_temporal}'s performance with ${comparison_simulation_value}%.	You are almost there for month! Just keep up your good work, and you will exceed your last month's performance with 30%.
			Positive comparison with others	You are almost there! Just keep up your good work and you will exceed ${comparison_simulation_population_percentage} of others ${comparison_simulation_temporal}.	You are almost there! Just keep up your good work and you will exceed 20% of others this month.
			Positive comparison with self	You are almost there! Complete your remaining ${action_name} task and you will exceed your ${comparison_simulation_temporal}'s	You are almost there! Complete your remaining Activities for Daily Life questionnaire task and you will exceed your last month's performance with 30%

			performance with ${comparison_simulation_value}%	
	TARGET ALMOST ACHIEVED	Positive comparison with self	Almost there for the ${target_temporal}! Still, you are ${comparison_value}% better than ${comparison_temporal} in completing ${action_name}. Keep up the good work and you will reach your targets.	Almost there for the week! Still, you are 30% better than last month in completing Activities for Daily Life questionnaire. Keep up the good work and you will reach your targets.
		General Reinforcement	Almost there for the ${target_temporal}! Keep up the good work and you will reach your targets next time.	Almost there for the week! Keep up the good work and you will reach your targets next time.
		Positive comparison with others	Almost there for the ${target_temporal}! Still your performance is better than ${comparison_population_percentage}% of others ${comparison_temporal}.	Almost there for the week! Still your performance is better than 40% of others this month.
	TARGET NOT ACHIEVED	Positive comparison with self	It seems, you missed your last ${action_name} task. No problem, if you can complete your remaining tasks, still you will be ${comparison_simulation_value}% better than ${comparison_simulation_temporal}.	It seems, you missed your last Activities for Daily Life questionnaire task. No problem, if you can complete your remaining tasks, still you will be 30% better than last month.
		General Reinforcement	It seems, you missed your last ${action_name} task. Focus on your remaining tasks and still you will be close to achieving your targets.	It seems, you missed your last Activities for Daily Life questionnaire task. Focus on your remaining tasks and still you will be close to achieving your targets.
		Positive comparison with others	You did not have the best ${target_temporal} for ${action_name} task. Still, you worked hard and you perform ${comparison_population_percentage}% better than others ${comparison_temporal}.	You did not have the best month for Activities for Daily Life questionnaire task. Still, you worked hard and you perform 30% better than others this month.

REMINDERS	Before each planned activity	None	Simple reminder	Just to remind you; You have an upcoming ${action_name} task.	Just to remind you; You have an upcoming Activities for Daily Life questionnaire task.
		TARGET CLOSE TO REACH	Simple reminder	Just to remind you; You have an upcoming planned ${action_name} task scheduled (${action_time})! If you can complete it, you will reach your target today	Just to remind you; You have an upcoming planned Activities for Daily Life questionnaire task scheduled this month! If you can complete it, you will reach your target this month
			Positive comparison with self	Just to remind you; You have an upcoming ${action_name} task scheduled(${action_time})! If you can complete it, your performance will be ${comparison_simulation_value}% better than ${comparison_simulation_temporal}.	Just to remind you; You have an upcoming Activities for Daily Life questionnaire task scheduled this month! If you can complete it, your performance will be 30% better than last month.
			Positive comparison with others	Just to remind you; You have an upcoming ${action_name} task scheduled (${action_time})! If you can complete it, your performance will be better than ${comparison_simulation_population_percentage}% of others ${comparison_simulation_temporal}.	Just to remind you; You have Activities for Daily Life questionnaire! If you can complete it, your performance will be better than 10% of others this month.
				Just to remind you; You have an upcoming ${action_name} task scheduled (${action_time}) and you are very close to extend your streak (successive target reach) to ${streak_value} ${streak_temporal}s.	Just to remind you; You have Activities for Daily Life questionnaire and you are very close to extend your streak (successive target reach) to 3 months.

10.3.5 International and social considerations and adaptations

Social and cultural considerations can also be a factor in choosing the right content for JTAIs. As presented, we have identified 4 different types of JITAIs:

- Reminders

- General reinforcement

- Positive comparison with self

- Positive comparison with others

For each of them, we have identified a number of alternative messages. Each pilot site will be asked to localize these contents, and also translate them to their language. At this stage, they will also be able to update the proposed templates, to alter the 'tone' of the message intended to be delivered to the patient. In addition to these, pilot sites can also choose to not to utilize certain types, e.g. in Danish pilot site, the current inclination is to use only Reminders and General Reinforcement Messages and not the ones that includes comparison with self or others. It is also a fact that, due to personality traits, patients can react differently to different types of JITAIs. For this purpose, we have designed the system to enable the physician to choose suitable content for his/her patient individually via PCPMP.

10.3.6 Links between JITAIs and PROMs

In ADLIFE JITAIs are delivered to remind and motivate patients to carry out the activities that have been assigned to them as a part of their care plan. These activities are usually lifestyle changes, and health living adaptations. In addition to these, several tasks can be assigned to the patient, such as filling in questionnaires to report symptoms regularly, or periodically complete PROM questionnaires. In this context, JITAIs can be utilized to increase patient's adherence to complete PROM questionnaires regularly. In addition to these, PROMs can be utilized to carry out scored assessment about patient's changing physical / psychological context. This information can also be utilized to adapt the frequency and content of the JITAIs. For example, if the patient is stressed and depressed, it might be better to present 'general reinforcement' messages instead of 'positive comparison with others.

11 Educational materials for patient empowerment

One key aspect of patient empowerment is health literacy. However, empowerment is much more than patients being informed. It is fundamental that patients have access to the right information and the right resources. Health literacy is also more than just information. It covers people's knowledge, motivation and competences to access, understand, appraise and apply health information in order to make judgments and make decisions concerning health and care options to maintain or improve their quality of life.

Well-informed, health literate people are more discerning about their health, they are in a position to make more informed choices and decisions, and they are more likely to seek earlier diagnosis and recover faster. The inverse is also true. From a patient's perspective, the knowledge and competence gained through health literacy leads to the strength and empowerment needed to manage a disease and its impacts on quality of life well.

Health literacy begins with sound, easily understandable information; information is not enough in itself but a tool towards improved health literacy. Targeted health literacy interventions are often necessary, and they can be particularly useful to reach out to specific vulnerable groups, such as target patient groups in ADLIFE. Therefore, the pilot sites have been asked to identify, collect and organise relevant material suitable for empowering the patients through increased knowledge and understanding about their conditions and treatment options. Aside from the direct purpose of empowering the patients, the collection of educational material also facilitates self-management, which is a key element in patient-centric care. For patients with chronic conditions, the management of the condition is mostly handled by the patients themselves at home and in the community. Self-management can be understood as a partnership between patients and the healthcare team; the team supports patients in "living with" their conditions and in managing the conditions and their physical, psychological, emotional and social impacts. Through self-management support, patients can develop the confidence, self-efficacy and skills to be in control of their daily life and attain the greatest possible quality of life and health outcomes.

11.1 Identification of local educational materials for each pilot site

The pilot sites have contributed to a list of materials deemed to be relevant for the ADLIFE patient groups and cover a wide range of topics including, but not limited to:

- General information about the disease and symptoms
- Tests and examinations
- Treatments and medications
- How to use medication correctly
- Side effects and how to deal with them
- Nutrition and diet
- Co-morbidities and complications
- Family and relatives
- Exercise and training
- Sexual health
- Mental and social well-being

- General health advice i.e. how to quit smoking etc.
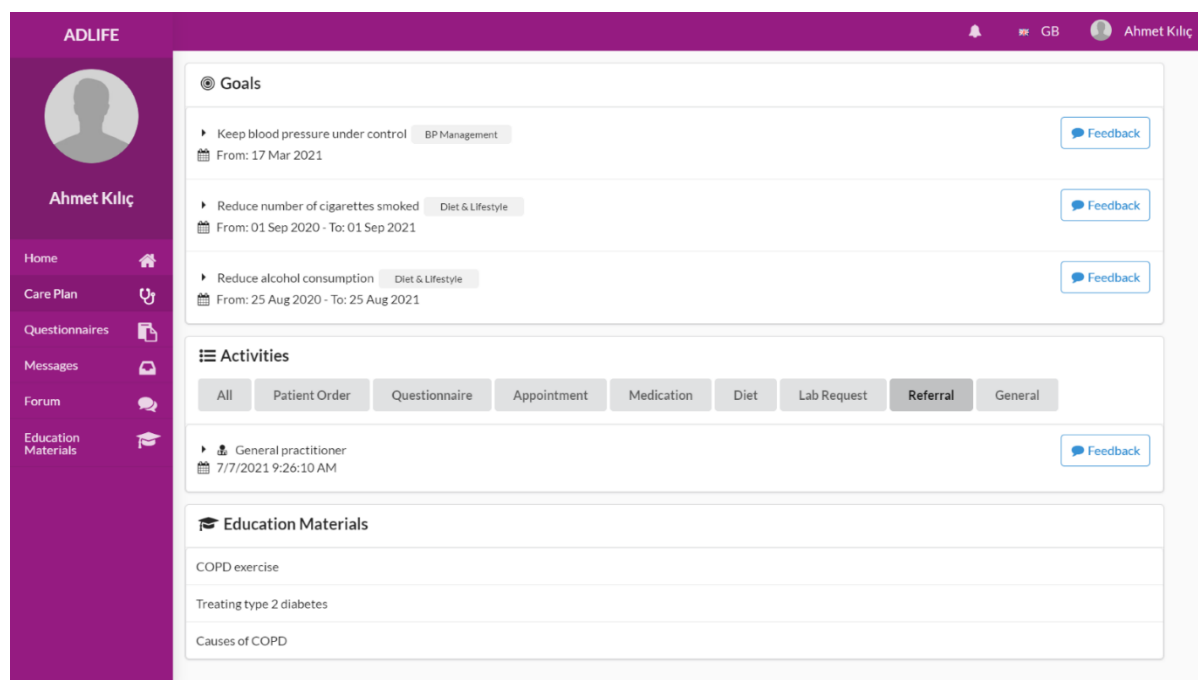- Patient rights

Each of the topics contains one or more pieces of materials, typically as either a PDF document or an online video.

The collected materials have been collated into an organised database, where each item is tagged in both English and the original language (if different from English) to enable implementation into the PEP, where clinician may prescribe a piece of educational material to a patient directly in the system. Educational materials may also be used to support a patient's care plan.

The full list of all the identified educational materials totals close to 1,000 entries, which are unsuitable for presentation here. The full table is available in Appendix 15.3.

11.2 Integration of educational materials into the PEP

The identified materials are implemented into the PEP in two manners. Firstly, clinicians may decide to 'prescribe' some educational materials to a patient in line with the patient's care plan. This allows clinicians to tailor the type and topic of materials for each patient while ensuring consistency across the broad spectrum of patients. Educational materials also may be recommended by the clinical decision support systems to the clinician in the care plan process. It is up to the clinicians to add the recommended materials to the care plan or not. Once added to the care plan, educational materials are presented to the patients in PEP as care plan activities. Screenshot below shows an example care plan view in PEP where educational materials assigned to the patient are listed at the bottom.
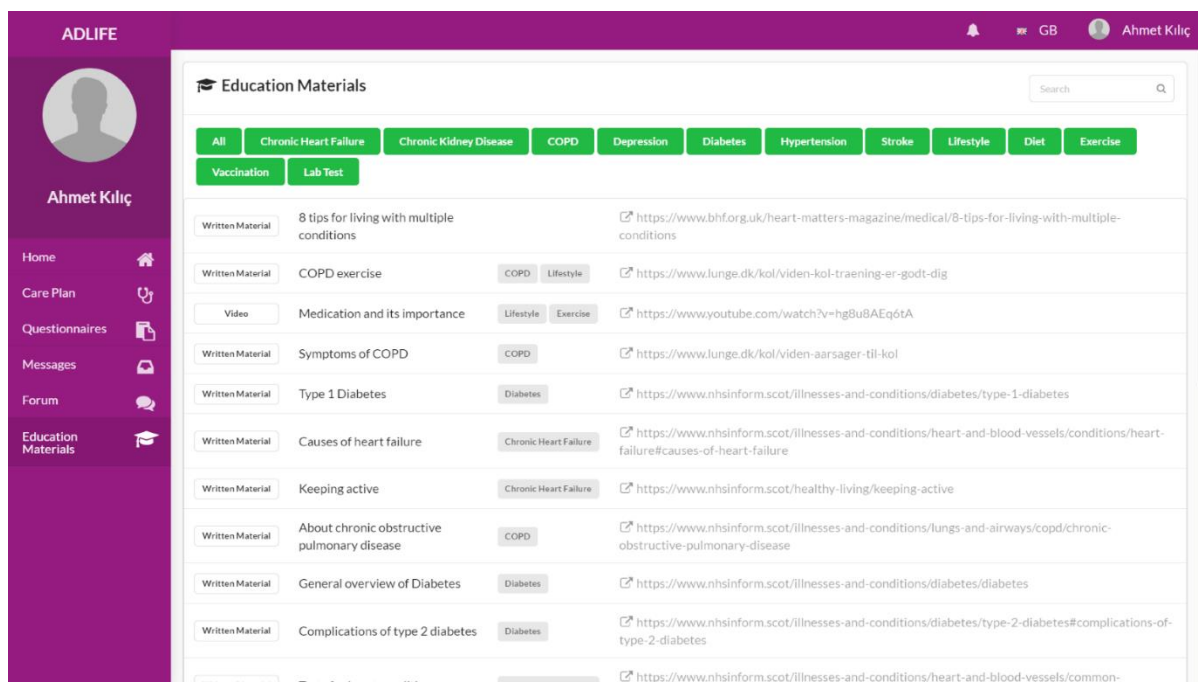

Figure 2 - PEP UI example #1

PEP also includes an educational material catalogue. In this catalogue, educational materials are presented to the patient with their content types (written material, video, etc.), categories, title and URL. Categories contain related morbidities and topics of the materials. In the catalogue, patients can list all the items identified by their pilot sites. The catalogue also provides filtering based on categories and search functionality by titles. Screenshot below shows an example catalogue view in PEP.

Figure 3 - PEP UI example #2

12 Self-assessment and self-management

Generally, patient self-assessments have been the more reliable assessments of subjective symptoms, which is one reason for a growing interest in subjective health status measures from the scientific community, clinical practitioners, and industry.

Self-assessed symptoms are used to predict declines in health status of patients. Their widespread use has been recommended to increase quality of care, and 30% of all new drug developments use patient-reported outcomes (PROs) as their primary or co-primary end-point.

The purpose of self-assessment tests is to enable patients to take care of their own lives taking into account the realities of the disease. Self-assessment tests can then help patients become empowered. When they repeatedly detect disease symptoms and make measurements that are intended to detect early signs of a worsening of the disease, patients gain knowledge and experience about where their disease symptom records and measurements usually lie, and thus they will become aware if their measurements change or they get more symptoms as a sign that there is an incipient worsening of the disease on the way. The patients will thus be able to detect a worsening early and be able to take their own precautions by, for example, starting a treatment according to a self-treatment plan, contacting a general practitioner or hospital. Early treatment of exacerbation can reduce (re)admissions and permanent exacerbation of the disease.

'Expert patients' or better 'the patient as a specialist of his/her own life' are those patients who take responsibility for the day-to-day decisions about their health, and who work with healthcare providers as collaborators and partners to produce the best possible health given the resources at hand. Those patients are not only consumers of healthcare but also producers of health'.

Expert patient programs 'developing the confidence and motivation of patients to use their own skills and knowledge to take effective control over life with a chronic illness' have been shown to be effective in decreasing symptoms, improving health behaviours, self-efficacy, and satisfaction with the healthcare system as well as reducing health-care utilisation.

The chronic disease at hand is part of the patient's entire life. Beyond coping with the disease, patients need to change and adapt their lifestyles and lives underlining the need for a holistic approach. For instance, breathlessness not only impacts the daily life of the patients but also the daily lives of their social environment, for example, family caregivers. Secondly, the responsibility of patients as specialists of their own lives is to express what's important in their lives and thereby, in collaboration with health-care providers, to specify relevant treatment goals helping them to live the lives they want to. Third, a specialist tries to solve a problem while an expert knows the solution and has expertise and skills on an expert level, often working in academic fields. Thus, the health-care professional might be the expert, the patient the specialist [10].

12.1 Self-management

Houben-Wilke et al [10] refers to self-management as *'the ability of the individual, in conjunction with family, community, and healthcare professionals, to manage symptoms, treatments, lifestyle changes, and psychosocial, cultural, and spiritual consequences of health conditions'.* Self-management might be facilitated by interactive counselling approaches actively involving patients in their disease management.

Self-management interventions have been shown to be associated with improved health status, reduced hospital admissions, and less symptoms of dyspnoea for patients with chronic respiratory diseases. Since enhancing self-management and empowering patients are important goals of ADLIFE, it represents a sustainable setting to facilitate the role of the patient as a specialist of his own life supported by an interdisciplinary treatment approach.

Novel concepts such as illness perception, locus of control, and emotional intelligence, may play an important role in treatment strategies to enhance illness understanding and self-management skills. In addition, self-management interventions targeting patients' (negative) illness perceptions might lead to improvements in health status.

Patients' empowerment challenges the paternalistic dominance of health-care professionals over patients, in a positive way. Participatory medicine is one of the four elements of P4 (predictive, preventive, personalized, and participatory) medicine, which supports a transition from the current reactive practice of medicine to a proactive empowerment of individuals to manage their health together with their healthcare professionals using systems medicine approaches to attack the disease.

The concept of a patient as a specialist of his own life further supports the concept of shared decision-making, an important component of patient-centred care.

Below we have chosen to show an example of a COPD specific self-assessment test and an example of a generic self-assessment test that we are going to use partly in the ADLIFE project.
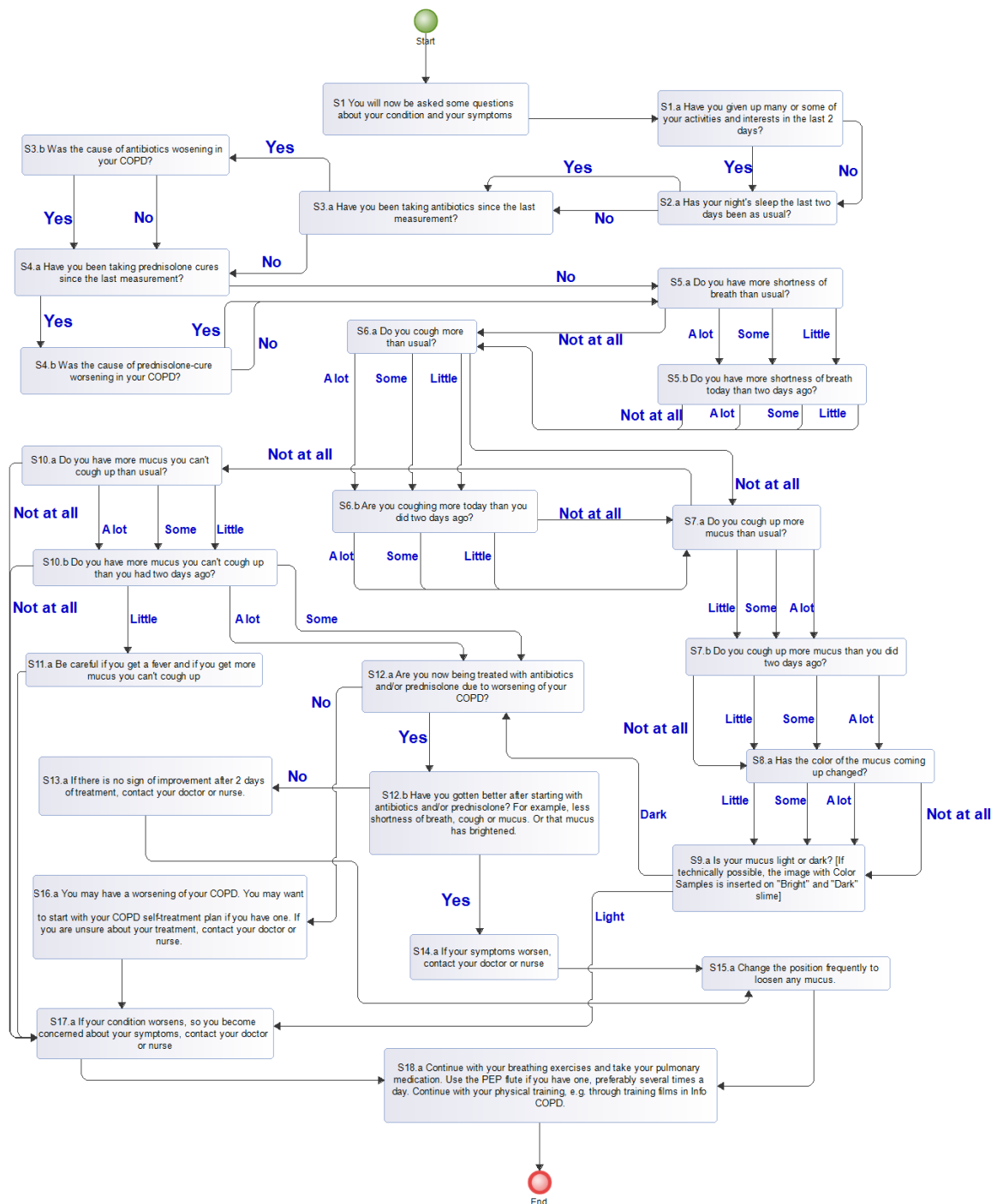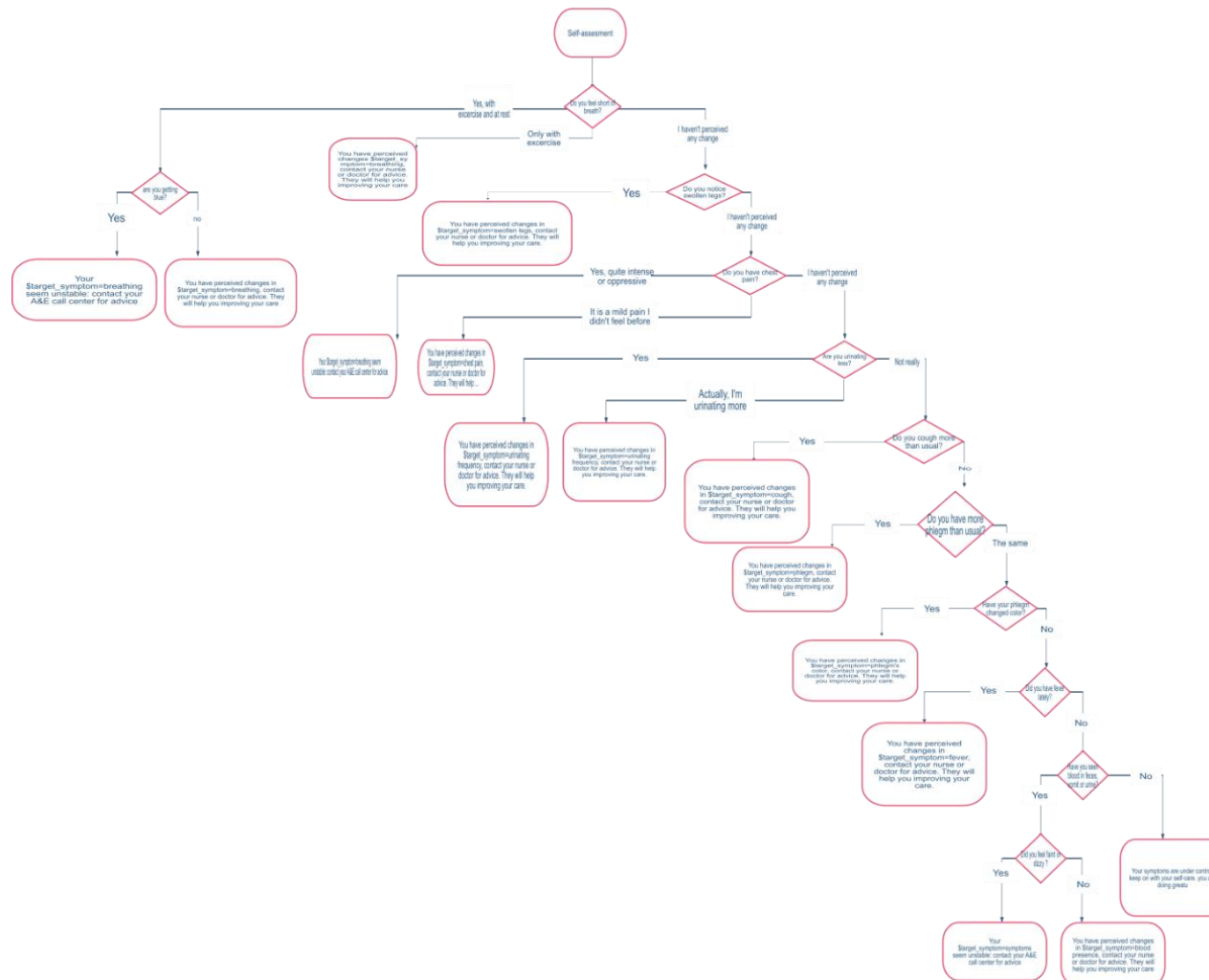
Figure 4 - COPD self-assessment test flowchart

The patient is asked the initial starting question and dependent on their answer given, the patient will progress through the self-assessment chart towards the end and produce an individual result that reflect their medical condition.

s

Figure 5 - Generic self-assessment test flowchart

Similarly, the patient will progress through the generic assessment test to build a profile of their medical condition.

The results from the self-assessment tests will contribute to empower the patients further as they gain a comparable insight into their current health and the course of their health. When patients frequently contemplate certain symptoms and data, which relate to their particular illness and condition, they become aware of which changes in their course of the disease are important to note and relate to. They thus learn to compare their own experiences of symptoms, what they themselves feel of symptoms and discomfort with what they can register by, for example, measuring their weight daily. They become aware of changes that occur from day to day and changes that occur over time. In the PEP, they have the opportunity to go back to previous registrations and thus follow the course of their own illness and symptoms. With the help of measurements, they get a number for how things are going objectively with their disease, which they can compare with their own subjective symptoms. This can help them to be empowered by gaining knowledge about when a deterioration is potentially on the way, what to do and possibly what can trigger an exacerbation, and of course what exactly they need to be specifically aware of in relation to the disease. This helps to empower patients as it increases their knowledge and drive.

In Task 7.2, we have, via evidence-based internationally recognized guidelines such as Nice and GOLD, investigated what is recommended by specific PROs and PROMs in relation to the chronic diseases with a focus on COPD and CHF, which ADLIFE deals with. Based on the Guidelines, we have made recommendations as to what questions and measurements the patients in the different disease groups should capture.

How often patients should register their symptoms depends in part on the patient's diagnosis and the severity of the individual patient's illness. The frequency of registrations is determined by a health professional, who individually determines the frequency of registrations in collaboration with the patient (Shared Decision-Making). The patient's registrations are recorded in the PEP. The registrations can be viewed in the PCPMP by a health professional with special knowledge within the individual disease, and the patient receives a response in the form of feedback from the health professional.

Measurements related to patients with CHF

Relevant measurement for patients with CHF includes:

- Body weight
- Oedema in legs, abdomen, and feet
- Shortness of breath,
- Dyspnoea
- Chest pain
- Dizziness

Measurements related to patients with COPD

Relevant measurement for patients with COPD includes:

- Shortness of breath
- Change in volume of sputum/mucus
- Colour and change of colour of sputum/mucus
- Changes in cough

12.2 Patient empowerment and Shared Decision-Making

Patient empowerment and Shared Decision-Making are two concepts that are inextricably linked. Patient empowerment is a prerequisite for Shared Decision-Making and occurs when a patient accepts responsibility for his or her health. Shared decision-making requires that patients have knowledge of the available options and their pros and cons about what they need to decide on in collaboration with health professionals.

Empowerment is an umbrella concept and closely related to patient participation, patient activation, self-management, shared decision making and other concepts in the field of patient centred care. Most important in promoting empowerment of patients with chronic diseases such as COPD or CHF are to improve self-management and self-efficacy through educational interventions. However, education alone is not enough to maintain positive effects of self-management and self-care behaviours which impact empowerment. Behavioural strategies, social support from family caregivers and reinforcement through follow up calls or home visits need to supplement educational strategies and can optimize outcomes.

13 Conclusion and next steps

Empowerment is an umbrella concept and closely relates to patient participation, patient activation, self-management, shared decision making and other concepts in the field of patient-centred care.

It is important that clinicians and healthcare professionals receive training on empowerment techniques and tools - a paradigm shift away from the traditional patriarchal relationship between patient and doctors.

Empowerment entails a significant move that is often difficult to implement because the traditional approach to care is learned early in the training and socialization of most health care professionals. In contrast to the traditional approach, empowerment is not something one does to patients but rather a reciprocal dynamic that can develop only when the provider acknowledges that the patient is ultimately in control of his or her own care. Patient empowerment begins with the provider acknowledging that patients are ultimately in control of their care and aims to increase a patient's capacity to think critically and make autonomous, informed decisions about their health. Under this paradigm, the physician's role is to provide the patient with the necessary information and tools to take charge of the disease and their disease risk factor management.

Most important in promoting empowerment of patients with chronic diseases such as COPD or CHF is to improve self-management and self-efficacy through educational interventions. However, education alone is not enough to maintain positive effects of self-management and self-care behaviours which impact empowerment. Behavioural strategies, social support from family caregivers and reinforcement through follow-up calls and/or home visits need to supplement educational strategies to optimise outcomes.

Patient empowerment is also crucial to shared decision-making and occurs when a patient accepts responsibility for his or her own health. They are then enabled to better understand how to manage the challenges with information and support from professionals.

A series of tools have been identified that can facilitate the empowerment goal and the collaboration between the patients and the health professionals. These tools include:

- PROs and PROMs, which have become a vital tool in modern medicine and fully acceptable internationally by health care professionals.

- Patient symptoms score registrations, questionnaires, and measurements, which must always be decided in collaboration (Shared Decision-Making) between the patient and the health professional and the frequency of registration and method (PRO and PROMs) is determined based on individual considerations for the patient, his illness, cognitive, social and desires / abilities.

- Nudging, which can be a tool, a piece of information, an interaction, or an intervention that alters the behaviour of the patient in an efficient albeit predictable manner without restricting any options or incentives for the patient. In the ADLIFE project, digital nudging have been implemented into the PEP to encourage active engagement from patients to take charge of their own health.

- JITAIs, which are the primary behaviour intervention tool deployed in the PEP. The purpose of the various JITAIs are generally to motivate, support, and encourage patients to continue actively adhere to the goals set in their care plan. This is often manifested in the form of motivational messages and positive comparisons with one self or, in certain cases, others.

- Educational materials, a core element in patient empowerment. These materials facilitate health literacy for the patients enabling them to gain more knowledge, motivation and competences to access, understand, appraise and apply health information in order to make judgments and make decisions concerning health and care options to maintain or improve their quality of life.

- Self-assessment and self-management, tools for the patients to gain an insight into their medical condition and the changes, good and bad, in their condition over time. The awareness gained through the self-assessment and self-management evaluations empower the patients to become experts about their own health and care plan.

From the clinical perspective, patient empowerment moves a portion of the responsibility for the treatment and care plan from the clinicians to the patients themselves in a new approach towards collaboration.

From the patient perspective, empowerment tools support the patient in taking on this new responsibility to become master of their situation.

The process towards patient empowerment involves many different factors changing the mind set moving from compliance to adherence to achieve coherence. This ultimately leads to a new mind set implementing Shared Decision-Making, which is strongly linked to patient empowerment.

13.1 Next steps

The next steps on the road towards patient empowerment in the ADLIFE project is to fully integrate the selected tools into the PCPMP and PEP and have those tools trialled at the pilot sites in preparation for the upcoming intervention study. Based on the outcome of these tests, some of the tool may need to be revaluated or adjusted to suit the clinical practice.

14 References

[1] R. Adams, "Empowerment, participation and social work," New York, Palgrave Macmillan, 2008, p. xvi.

[2] WHO, "Health Promotion Glossary," World Health Organization, Geneva, 1998.

[3] N. Wallerstein, "What is the evidence on effectiveness of empowerment to improve health?," WHO Regional Office for Europe, Copenhagen, 2006.

[4] R. M. Anderson and M. M. Funnell, "Patient empowerment: reflections on the challenge of fostering the adoption of a new paradigm," *Patient Educ Couns,* 2005.

[5] P. Bravo, A. Edwards, P. J. Barr, I. Scholl, G. Elwyn and M. McAllister, "Conceptualizing patient empowerment: a mixed methods study," *BMC Health Serv Res,* 1 Jul 2015.

[6] J. James , "Health Policy Brief: Patient Engagement," *Health Affairs,* 2013.

[7] E. Monninkhof, P. van der Valk, J. van der Palen, C. van Herwaarden, M. R. Partridge and G. Zielhuis, "Self-management education for patients with chronic obstructive pulmonary disease: a systematic review," *Throax,* 2003.

[8] T. Bodenheimer, K. Lorig, H. Hlasted and K. Grumback, "Patient self-management of chronic disease in primary care," *JAMA,* 2002.

[9] J. Epping-Jordan, R. Bengoa, R. Kawar and E. Sabaté, "The challenges of chronic conditions: WHO responds," *BMJ,* 2001.

[10] S. Houben-Wilke, I. M. Augustin, B. B. Wouters, R. A. Stevens, D. J. Janssen, M. A. Spruit, L. E. Vanfleteren, F. M. Franssen and E. F. Wouters, "The patient with a complex chronic respiratory disease: a specialist of his own life?," *Expert Rev Respir Med,* 2017.

[11] WHO, "Global Health and Aging," World Health Organization, 2011.

[12] GDB Chronic Respiratory Disease Collaborators, "Prevalence and attributable health burden of chronic respiratory diseases, 1990-2017: a systematic analysis for the Global Burden of Disease Study 2017," *Lancet Respir Med,* 2020.

[13] S. M. Oliver, "Living with failing lungs: the doctor-patient relationship," *Fam Pract,* 2001.

[14] G. A. Roth, M. H. Forouzanfar, A. E. Moran, R. Barber, G. Nguyen, V. L. Feigin, M. Naghavi, G. A. Mensah and C. J. Murray, "Demographic and epidemiologic drivers of global cardiovascular mortality," *N Engl J Med,* 2015.

[15] M. Martirosyan, K. Caliskan, D. A. Theuns and T. Szili-Torok, "Remote monitoring of heart failure: benefits for therapeutic decision making," *Expert Rev Cardiovasc Ther,* 2017.

[16] P. K. Lindenauer, D. Remus, S. Roman, M. B. Rothberg, E. M. Benjamin, A. Ma and D. W. Bratzler, "Public reporting and pay for performance in hospital quality improvement," *N Engl J Med,* 2007.

[17] S. A. Hunt, W. T. Abraham, M. H. Chin, A. M. Feldman, G. S. Francis, T. G. Ganiats, M. Jessup, M. A. Konstam, D. M. Mancini, K. Michl, J. A. Oates, P. S. Rahko, M. A. Silver, L. W. Stevenson and C. W. Yancy, "ACC/AHA 2005 Guideline Update for the Diagnosis and Management of Chronic Heart Failure in the Adult: a report of the American College of Cardiology/American Heart Association Task Force on Practice Guidelines (Writing Committee to Update the 2001 Guideli," *Circulation,* 2005.

[18] C. Klersy, A. D. Silvestri, G. Gabutti, F. Regoli and A. Auricchio, "A meta-analysis of remote monitoring of heart failure patients," *J Am Coll,* 2009.

[19] J. Greene and J. Hibbard, "Why does Patient activation matter? An examination of the relationship between patient activation and health-related outcomes," *J Gen Intern Med,* 2012.

[20] S. Kambhampati, T. Ashvetiya, N. J. Stone, R. S. Blumenthal and S. S. Martin, "Shared Decision-Making and Patient Empowerment in Preventive Cardiology," *Curr Cardiol Rep,* 2016.

[21] M. Dowling, K. Murphy, A. Cooney and D. A. Casey, "A concept analysis of empowerment in chronic illness from the perspective of the nurse and client living with chronic obstructive pulmonary disease," *J Nurs Health Chronic Iln,* 2011.

[22] Y. Longtin, H. Sax, L. L. Leape, S. Sheridan, L. Donaldson and D. Pittet, "Patient participation: current knowledge and applicability to patient safety," *Mayo Clin Proc,* 2010.

[23] I. Aujoulat, W. d'Hoore and A. Deccache, "Patient empowerment in theory and practice: polyseny or cacophony?," *Patient Edu Couns,* 2007.

[24] K. Sleurs, S. F. Seys, J. Bousquet, W. J. Fokkens, S. Gorris, B. Pugin and P. W. Hellings, "Mobile health tools for the management of chronic respiratory diseases," *Allergy,* 2019.

[25] R. Disler, J. Appleton, T. Smith, M. Hodson, S. Inglis, D. Donesky and P. M. Davidson, "Empowerment in people with COPD," *Patient Intelligence,* 2016.

[26] S. Boisvert, A. Proulx-Belhumeur, N. Goncalves, M. Doré, J. Francoeur and M. C. Gallani, "An integrative literature review on nursing interventions aimed at increasing self-care among heart failure patients," *Rev Lat Am Enfermagern,* 2015.

[27] V. V. Dickson, N. Nocella, H. Yoon, M. Hammer, G. Melkus and D. Chyun, "Cardiovascular Disease Self-Care Interventions. Nursing Research and Practice," *Nurs Res Pract,* 2013.

[28] L. S. Evangelista and M. A. Shinnick, "What do we know about adherence and self-care?," *Cardiovasc Nurs,* 2008.

[29] M. McGuckin, J. Storr, Y. Longtin and B. Allegranzi, "Patient empowerment and multimodal hand hygiene promotion: a win-win strategy," *Am J Med Qual,* 2011.

[30] U. Piamjariyakul, C. E. Smith, C. Rusell, M. Werkowitch and A. Elyachar, "The feasibility of a telephone coaching program on heart failure home management for family caregivers," *Heart Lung,* 2013.

[31] M. M. Ciccone, A. Aquilino, F. Cortese, P. Scicchitano, M. Sassara, E. Mola, R. Rollo, P. Caldarola, F. Giorgino, V. Pomo and F. Bux, "Feasibility and effectiveness of a disease and care management model in the primary health care system for patients with heart failure and diabetes (Project Leonardo)," *Vasc Health Risk Manag,* 2010.

[32] M. Mateo-Abad, N. González, Fullaondo, M. Meriono, L. Azkorgorta, A. Giné, D. Verdoy, I. Vergara and E. de Manuel Keenoy, "Impact of the CareWell integrated care model for older patients with multimorbidity: a quasi-experimental controlled study in the Basque Country," *BMC Health Serv Res,* 2020.

[33] B. Hwang, M. M. Pelter, D. K. Moser and K. Dracup, "Effects of an educational intervention on heart failure knowledge, self-care behaviors, and health-related quality of life of patients with heart failure: Exploring the role of depression," *Patient Educ Couns,* 2020.

[34] G. Graffigna, S. Barello, G. Riva, M. Corbo, G. Damiani, P. Iannone, A. C. Bosio and W. Ricciardi, "Italian Consensus Statement on Patient Engagement in Chronic Care: Process and Outcomes," *Int J Environ Res Public Health,* 2020.

[35] C. Reichardt and P. Gastmeier, "Patient Empowerment. Wie viel können Patienten zu einer verbesserten Compliance des Personals beitragen," *Krankenhaushygience up2date,* pp. 157-164, 2013.

[36] F. Aliakbari, F. Alipour, E. Tavassoli and M. Sedehi, "The effect of powerment program based on the social cognitive theory on the activity of daily living in patients with chronic obstructive pulmonary disease," *J Educ Health Promot,* 2020.

[37] D. Fischer, A. L. Stewart, D. Blcoh, A. Lorig, D. Laurent and H. Holman, "Capturing patient's view of change in clinical outcome measure," *JAMA,* 1999.

[38] M. E. Poitras, M. E. Maltais, L. Bestard-Denommé, M. Stewart and M. Fortin, "What are the effective elements in patient-centered and multimorbidity care? A scoping review," *BMC Health Serv Res,* 2018.

[39] I. Poureslami, S. Kwan, S. Lam, N. A. Khan and J. M. FitzGerald, "Assessing the effect of culturally specific audiovisual educational interventions on attaining self-management skills for chronic obstructive pulmonary disease in Mandarin- and Cantonese-speaking patients: a randomized controlled trial," *Int J Chron Obstruct Pulmon Dis,* 2016.

[40] K. Glanz, B. K. Rimer and K. Viswanath, Health Behavior and Health Education: Theory, Research, and Practice, London: John Wiley & Sons, 2008.

[41] H. Q. Nguyen, D. Donesky-Cuenco, S. Wolpin, L. F. Reinke, J. O. Benditt, S. W. Paul and V. Carrieri-Kohlman, "Randomized Controlled Trial of an Internet-Based Versus

Face-to-Face Dyspnea Self-Management Program for Patients With Chronic Obstructive Pulmonary Disease: Pilot Study," *J med Internet Res,* 2008.

[42] G. Moullec, K. L. Lavoie, K. Rabhi, M. Julien, H. Favreau and M. Labrecque, "Effect of an integrated care programme on re-hospitalization of patients with chronic obstructive pulmonary disease," *Respirology,* 2012.

[43] T. Effing, E. M. Monninkhof, P. D. van der Valk, J. van der Palen, C. L. van Herwaarden, M. R. Partidge, E. H. Walters and G. A. Zielhuis, "Self-management education for patients with chronic obstructive pulmonary disease," *Cochrane Database Syst Rev,* 2007.

[44] F. Blackstock and K. E. Webster, "Disease specific health education for COPD: a systematic review of changes in health outcomes," *Health Education Research,* 2007.

[45] Z. Fotoukian, F. Mohammadi Shahboulaghi, M. Fallahi Khoshknab and E. Mohammadi, "Barriers to and factors facilitating empowerment in elderly with COPD," *Med J Islam Repub Iran,* 2014.

[46] Z. Fotoukian, F. Mohammadi Shaboulaghi, M. Fallahi-Khoshknab and A. Pourhabib, "The empowerment of elderly patients with chronic obstructive pulmonary disease: Managing life with the disease," *PloS One,* 2017.

[47] D. A. DeWalt, R. M. Malone, M. E. Bryant, M. C. Kosnar, K. E. Corr, R. L. Rothman, C. A. Sueta and M. P. Pignone, "A heart failure self-management program for patients of all literacy levels: a randomized, controlled trial," *BMC Health Serv Res,* 2006.

[48] A. Hourzad, S. Pouladi, A. Ostovar and M. Ravanipour, "The effects of an empowering self-management model on self-efficacy and sense of coherence among retired elderly with chronic diseases: a randomized controlled trial," *Clin Interv Aging,* 2018.

[49] H. M. Krumholz, J. Amatruda, G. L. Smith, J. A. Mattera, S. A. Roumanis, M. J. Radford, P. Crombie and V. Vaccarino, "Randomized trial of an education and support intervention to prevent readmission of patients with heart failure," *J Am Coll Cardiol,* 2002.

[50] M. B. Harrison, G. B. Bowne, J. Roberts, P. Tugwell and A. Gafni, "Quality of life of individuals with heart failure: a randomized trial of the effectiveness of two models of hospital-to-home transition," *Med Care,* 2002.

[51] N. B. Shearer, N. Cisar and E. A. Greenberg, "A telephone-delivered empowerment intervention with patients diagnosed with heart failure," *Heart Lung,* 2007.

[52] S. R. Weingarten, J. M. Henning, E. Badamgarav, K. Knight, V. Hasselblad, A. J. Gano and J. J. Ofman, "Interventions used in disease management programmes for patients with chronic illness-which ones work? Meta-analysis of published reports," *BMJ,* 2002.

[53] G. J. Molley, D. W. Johnston and M. D. Witham, "Family caregiving and congestive heart failure. Review and analysis," *Eur J Heart Fail,* 2005.

[54] A. M. Clark, E. R. Margaret, E. M. Caroline, C. Simon, D. L. Murdoch and L. John, "The complex nature of informal care in home based heart failure management," *J Adv Nurs,* 2007.

[55] M. Shahriari, M. Ahmadi, S. Babaee, T. Mahrabi and M. Sadeghi, "Effects of a family support program on self-care behaviors in patients with congestive heart failure," *Iran J Nurs Midwifery Res,* 2013.

[56] C. Orrego, M. Ballester, M. Heymans, E. Camus, O. Groene, E. Niño de Guzman, H. Pardo-Hernandez, R. Suñol and COMPARE-EU-Group, "Talking the same language on patient empowerment: Development and validation of a taxonomy of self-management interventions for chronic conditions," *PLoS ONE,* 2020.

[57] N. J. Devlin and J. Appleby, "Getting the most out of PROMs: Putting health outcomes at the heart of NHS decision-making," The King's Fund, London, 2010.

[58] K. Williams, J. Sansoni, D. Morris, P. Grootemaat and C. Thompson, "Patient-reported outcome measures: Literature review," Australian Commision on Safety and Quality in Health Care, Sydney, 2016.

[59] T. Weldring and S. M. Smith, "Patient-Reported Outcomes (PROs) and Patient-Reported Outcome Measures (PROMs)," *Health Serv Insights,* 2013.

[60] E. C. Nelson, E. Eftimovska, C. Lind, A. Hager, J. H. Wasson and S. Lindblad, "Patient reported outcome measures in practice," *BMJ,* 2015.

[61] K. Williams and C. Thompson, "Patient-reported outcome measures: Stakeholder interviews," Australian Commision on Safety and Quality in Health Care, Sydney, 2018.

[62] J. M. Valderas, A. Kotzeva, M. Espallargues, G. Guyatt, C. E. Ferrans, M. Y. Halyard, D. A. Revicki, T. Symonds, A. Parada and J. Alonso, "The impact of measuring patient-reported outcomes in clinical practice: a systematic review of the literature," *Qual Life Res,* 2008.

[63] M. S. Donaldson, "Taking PROs and patient-centered care seriously: incremental and disruptive ideas for incorporating PROs in oncology practice," *Qual Life Res,* 2008.

[64] L. T. Kane, S. Namdari, O. R. Plummer, P. Beredjiklian, A. Vaccaro and J. A. Abboud, "Use of Computerized Adaptive Testing to Develop More Concise Patient-Reported Outcome Measures," *JBJS Open Access,* 2020.

[65] N. Black, "Patient reported outcome measures could help transform healthcare," *BMJ,* 2013.

[66] J. E. Sansoni, "Health outcomes: an overview from an Australian perspective," Australian Health Outcomes Collaboration, Wollogong, 2016.

[67] J. Richardson, A. Iezzi, M. A. Khan, G. Chen and A. Maxwell, "Measuring the sensitivity and construct validity of 6 utility instruments in 7 disease areas," *Med Decis Mak,* 2016.

[68] J. Dawson, H. Doll, R. Fitzpatrick, C. Jenkinson and A. J. Carr, "Routine use of patient reported outcome measures in healthcare settings," *BMJ,* 2010.

[69] T. Jaarsma, A. Strömberg, J. Mårtensson and K. Dracup, "Development and testing of the European Heart Failure Self-Care Behaviour Scale," *Eur J Heart Fail,* 2003.

[70] E. Basch, "New frontiers in patient-reported outcomes: adverse event reporting, comparative effectiveness, and quality assessment," *Annu Rev Med,* 2014.

[71] A. R. Tarlov, J. E. Ware Jr, S. Greenfield, E. C. Nelson, E. Perrin and M. Zubkoff, "The Medical Outcomes Study. An application of methods for monitoring the results of medical care," *JAMA,* 1989.

[72] Health and Public Policy Committee, American College of Physicians, "Comprehensive functional assessment for elderly patients. Health and Public Policy Committee, American College of Physicians," *Ann Intern Med,* 1988.

[73] S. Ishaque, J. Karnon, G. Chen, R. Nair and A. B. Salter, "A systematic review of randomised controlled trials evaluating the use of patient-reported outcome measures (PROMs)," *Qual Life Res,* 2019.

[74] G. Kotronoulas, N. Kearney, R. Maguire, A. Harrow, D. D. Domenico, S. Croy and S. MacGillivray, "What is the value of the routine use of patient-reported outcome measures toward improvement of patient outcomes, processes of care, and health service outcomes in cancer care? A systematic review of controlled trials," *J Clin Oncol,* 2014.

[75] D. C. Lavallee, K. E. Chenok, R. M. Love, C. Petersen, E. Holve, C. D. Segal and P. D. Franklin, "Incorporating Patient-Reported Outcomes Into Health Care To Engage Patients And Enhance Care," *Health Aff (Millwood),* 2016.

[76] J. Lipscomb, M. S. Donaldson and R. A. Hiatt, "Cancer outcomes research and the arenas of application," *J Natl Cancer Inst Monogr,* 2004.

[77] S. Ahmed, R. A. Berzon, D. A. Revicki, W. R. Lenderking, C. M. Moinpour, E. Basch, B. B. Reeve, A. W. Wu and International Society for Quality of Life Research, "The use of patient-reported outcomes (PRO) within comparative effectiveness research: implications for clinical practice and health care policy," *Med Care,* 2012.

[78] Monmouth Partners, "A Guide to Patient Reported Measures - Theory, Landscape and Uses," Monmouth Partners, London, 2018.

[79] C. Kingsley and S. Patel, "Patient-reported outcome measures and patient-reported experience measures," *BJA Educ,* 2017.

[80] N. Black, M. Varaganum and A. Hutchings, "Relationship between patient reported experience (PREMs) and patient reported outcomes (PROMs) in elective surgery," *BMJ Qual Saf,* 2014.

[81] The Health Foundation, "Case study: Developing the "Ask 3 Questions" campaign to raise people's awareness of shared decision making," The Health Foundation, United Kingdom, 2013.

[82] H. L. Shephard, A. Barratt, L. J. Trevena, K. McGeechan, K. Carey and R. M. Epstein, "Three questions that patients can ask to improve the quality of information physicians give about treatment options: A cross-over trial," *Patient Educ Couns,* 2011.

[83] Physiopedia, "Barthel Index," United Kingdom.

[84] P. W. Jones, G. Harding, P. Berry, I. Wiklund, W. H. Chen and N. Kline Leidy, "Development and first validation of the COPD Assessment Test," *Eur Respir J,* 2009.

[85] GlaxoSmithKline, "The COPD Assessment Test (CAT) For Healthcare Professionals & Researchers," GlaxoSmithKline Services Unlimited, England, 2018.

[86] EQ-5D, "EQ-5D-5L: About," EuroQol Research Foundation, The Netherlands, 2017.

[87] M. van Reenen, B. Jansen, E. Stolk, K. S. Boye, M. Herdman and M. Kennedy-Martin, "EQ-5D User Guide," EuroQol Research Foundation, The Netherlands, 2019.

[88] A. F. Stern, "The Hospital Anxiety and Depression Scale," *Occup Med,* 2014.

[89] A. S. Zigmond and R. P. Snaith, "The Hospital Anxiety and Depression Scale," *Acta Psychiatr Scand,* 1983.

[90] CV Outcomes Inc, "The Kansas City Cardiomyopathy Questionaire (KCCQ)," CV Outcomes Inc, Missouri, 2004.

[91] FDA, "Medical Device Development Tool (MDDT) Qualification Decision Summary For Kansas City Cardiomyopathy Questionaire (KCCQ)," Food and Drug Administration, United States, 2004.

[92] C. P. Green, C. B. Porter, D. R. Bresnahan and J. A. Spertus, "Development and evalution of the Kansas City Cardiomyopathy questionaire: A new health status measure for heart failure," *J Am Coll Cardiol,* 2000.

[93] M. P. Lawton and E. M. Brody, "Assessment of Older People: Self-Maintaing and Instrumental Activities of Daily Living," *Gerontologist,* 1969.

[94] R. Coyne, "The Lawton Instrumental Activities of Daily Living (IADL) Scale," *Best Pract Nurs Care to Older Adults,* 2019.

[95] C. Graf, "The Lawton Instrumental Activites of Daily Living Scale," *Am J Nurs ,* 2008.

[96] MDCalc, "Modified Medical Research Council Dyspnea Scale - MDCalc," MDCalc.

[97] M. Wilberforce, A. Sköldunger and D. Edvardsson, "A Rasch analysis of the Person-Centred Climate Questionaire - Staff version," *BMC Health Serv Res,* 2019.

[98] D. Edvardsson, P.-O. Sandman and B. Rasmussen, "Swedish language Person-centred Climate Questionaire patient version: Construction and psychometric evaluation," *J Adv Nurs,* 2008.

[99] D. Edvardsson, S. Koch and R. Nay, "Psychometric evaluation of the English langauge Person-centred Climate Questionaire - staff version," *J Nurs Manag,* 2010.

[100] Warwick Medical School, "About WEMWBS," Warwick Medical School, Coventry.

[101] ePROVIDE, "Zarit Burden Interview (ZBI)," Mapi Reseach Trust, Lyon, 2020.

[102] S. Michie, M. van Stralen and R. West, "The behaviour change wheel: a new method for characterising and designing behaviour change interventions," *Implement Sci,* 2011.

[103] NICE, "Behavior change: General approaches [PH6]," 2007.

[104] S. Michie, M. Richardson, M. Johnston, C. Abraham, J. Francis, W. Hardeman, M. P. Eccles, J. Cane and C. E. Wood, "The behavior change technique taxonomy (v1) of 93 hierarchically clustered techniques: building an international consensus for the reporting of behavior change interventions," *Annals of Behavioral Medicine,* 2013.

[105] NICE, "Behavior change: Individual approaches [PH49]," 2014.

[106] I. Nahum-Shani, S. N. Smith, B. J. Spring, L. M. Collins, K. Witkiewitz, A. Tewari and S. A. Murphy, "Just-in-Time Adaptive Interventions (JITAIs) in Mobile Health: Key Components and Design Principles for Ongoing Health Behavior Support," *Ann Behav Med,* 2018.

[107] F. Naughton, "Delivering "Just-In-Time" Smoking Cessation Support Via Mobile Phones: Current Knowledge and Future Directions," *Nicotine Tob Res,* 2016.

[108] OECD/EU, "Health at a Glance: Europe 2016," OECD Publishing, Paris, 2016.

15 Appendices

15.1 Educational sessions for patients with COPD

Educational sessions for patients with chronic obstructive pulmonary disease based on the social cognitive theory

Educational session	Session topic	Factors	Educational strategy
First session	Explain the study purpose, increased awareness about disease, and the importance of physical activity	Awareness	Lecture, group discussion, and question and answer
Second session	Training on how to breathe properly, using sprays and oxygen and practicing	Skill	View - View and repeat the show by individual
Third session	Raising motivation and strengthening the patient's emotional field for regular physical activity and daily activities	Self-ability	Lecture, group discussion, and question and answer
Fourth session	Training sessions with family caregivers of patients (training on how to care for patients) Understanding the associations and organs that help patients and how to get proper education in the disease	Reinforcing	Group discussion and brainstorming and group problem solving

Taken from: [36].

15.2 Dyspnoea self-management program

Dyspnea self-management program components

Core Components	fDSMP	eDSMP
1. Dyspnea and exercise consultation (1-1.5 hours)	Individual face-to-face	Individual face-to-face Training on website and PDA
2. Endurance (4 times/week, 30 min/session) and arm strengthening (3 times/week) exercise program	Unsupervised independent exercise	Unsupervised independent exercise
3. Collaborative self-monitoring of exercise and respiratory symptoms and reinforcement of dyspnea management strategies (weekly in month 1; biweekly in months 2-6)	Paper diaries Reinforcement telephone calls (5-10 min)	PDA and Web diary Reinforcement emails
4. Structured education of dyspnea management strategies, skills training, and peer interactions (six 1-hour sessions)	Paper modules Face-to-face group sessions	Interactive Web modules Live group chat sessions Bulletin board

15.3 Educational Materials

In this section are presented some examples of the educational materials collected by each ADLIFE pilot site.

The complete list is available in this public URL: https://drive.google.com/file/d/1T7sCx1-cw7lfBS1C1GtobWi40qcwezlS/view?usp=sharing

Sweden -RJH
(Region Jämtland Härjedalen)

Topic/description of the educatic	Sub-topic (In English)	Native language topic	Link	Category/type
COPD general information	COPD	KOL_allmän information	KOL – kroniskt obstruktiv lungsjukdom - 1177 Vårdguiden	Web page
Lungs and airways-Function	Lungs and airways	Lungor och luftvägar_funktion	Så fungerar luftvägar och lungor - 1177 Vårdguiden	Web page
Lung function tests	Lung function tests	Lungfunktionstest	Lungfunktionstest - 1177 Vårdguiden	Web page
Diabetes type 2 – starting page	Diabetes type 2 – starting page	Diabetes typ 2_allmän information	https://www.1177.se/Jamtland-Harjedalen/Fakta-och-	Web page Web page
General information on treatment of diabetes type 2	General information on treatment of diabetes type 2	Diabetes typ 2_behandling	https://www.1177.se/Jamtland-Harjedalen/Fakta-och-rad/Rad-om-	Web page
Food when having diabetes type 2	Food when having diabetes type 2	Diabetes typ 2_kost	https://www.1177.se/Jamtland-	Web page
Plasma-glucose	Plasma-glucose	Blodsocker-prov_information	https://www.1177.se/Jamtland-	Web page
HbA1c	HbA1c	HbA1c-prov_information	https://www.1177.se/Stockholm/Fakt	Web page
General information about	General information about	Hypertoni_allmän information	https://www.1177.se/Jamtland-	Web page
General information on drug treatment_hypertension	General information on drug treatment_hypertension	Hypertoni_läkemedelsbehandling	https://www.1177.se/Jamtland-Harjedalen/Fakta-och-rad/Rad-om-	Web page
Symptoms in hyperlipidemia	Symptoms in hyperlipidemia	Höga blodfetter_allmän	https://www.1177.se/Jamtland-	Web page
General information on treatment of hyperlipidemia	General information on treatment of hyperlipidemia	Höga blodfetter_läkemedelsbehandling	https://www.1177.se/Jamtland-Harjedalen/Fakta-och-rad/Rad-om-	Web page
Lifestyle A general information	A general information about	Livsstil_Fysisk aktivitet	Träning och fysisk hälsa - 1177	Web page and videos
Lifestyle_Nutrition	Lifestyle_Nutrition	Livsstil_Näringslära	Bra att veta om näring - 1177	Web page
Lifestyle Help to quit smoking –	Help to quit smoking – advices and	Livsstil_Hjälp att sluta röka	https://www.1177.se/Jamtland-	Web page
Lifestyle Obesity	Obesity	Livsstil_Fetma och övervikt	https://www.1177.se/Jamtland-	Web page
vaccination against influenza	vaccination against influenza	Vaccination_influensa	https://www.1177.se/Stockholm/Fakta-och-rad/Behandlingar/Vaccination-	Web page
vaccination against Covid-19	vaccination against Covid-19	Vaccination_Covid-19	Vaccination mot covid-19 - 1177 Vårdguiden	Web page
Informal caregivers_information	Informal caregivers	Anhörig_stöd och information	Anhörig – närstående - 1177	Web page
Depression - anxiety	Depression - anxiety	Ångest_allmän information	https://www.1177.se/Jamtland-	Web page

Basque Country (Osakidetza)

CONDITION	CATEGORY	Topic/description of the educational material	Sub-topic (In English)	Native language topic/title?	Link	Category/type (FORMAT?)
Diabetes	General Information	about the Diabetes Type 2 diseases in multi-morbid patients	General information about Diabetes Type 2.	Diabetes: Información general sobre diabetes	https://www.osakidetza.euskadi.eus/kronikon-programa/-/diabetes-paciente-cronico/	Webpage and video
Diabetes	Symptoms	Information about symptoms in Diabetes Type 2	Diabetes Type 2: what is and symptoms.	Diabetes: Qué es la diabetes y cuáles son sus síntomas	https://www.osakidetza.euskadi.eus/kronikon-programa/-/diabetes-paciente-cronico/	Webpage
Diabetes	Treatment & Interventions	Information about how patients with Diabetes Type 2 have to be care in relation to diet, exercise, alcohol, foot care and recommendations.	Diabetes Type 2: what can I do to take care of myself?	Diabetes: Qué puedo hacer para cuidarme	https://www.osakidetza.euskadi.eus/kronikon-programa/-/diabetes-paciente-cronico/	webpage
Diabetes	Treatment & Interventions	Information about when to go to the doctor	Diabetes Type 2: when to go to the doctor	Diabetes: ¿Cuándo debo llamar a mi médico o enfermera?	https://www.osakidetza.euskadi.eus/kronikon-programa/-/diabetes-paciente-cronico/	webpage
Diabetes	Related Diseases / Conditions	Information about symptoms in patients with hypoglycemia, & hyperglycemia	Diabetes Type 2 what hypoglycemia& hyperglycemia are and their symptoms.	Hipo e hiperglucemia en diabetes: Qué son y sus síntomas	https://www.osakidetza.euskadi.eus/kronikon-programa/-/diabetes-paciente-cronico/	webpage
Diabetes	Related Diseases / Conditions	Information about treatment in patients with hypoglycemia, & hyperglycemia	Diabetes Type 2: treatment in patients with hypoglycemia, & hyperglycemia	Diabetes Tipo 2: Tratamiento de la hipo e hiperglucemia	https://www.osakidetza.euskadi.eus/kronikon-programa/-/diabetes-paciente-cronico/	webpage
Diabetes	Related Diseases / Conditions	treatment in patients with hypoglycemia & hyperglycemia related to diet, exercise, medication,...	Diabetes Type 2 – how to avoid hypoglycemia & hyperglycemia	Hipo e hiperglucemia en diabetes tipo 2: Cómo evitarlas	https://www.osakidetza.euskadi.eus/kronikon-programa/-/diabetes-paciente-cronico/	webpage
Diabetes	Related Diseases / Conditions	Information about interventions in patients with hypoglycemia & hyperglycemia related to when to go to the doctor, alarm signals,...	Diabetes Type 2: When should I call my doctor or nurse if I have hypo- or hyperglycemia?	Diabetes: Cuándo debo llamar a mi médico o enfermera ante una hipo o hiperglucemia	https://www.osakidetza.euskadi.eus/kronikon-programa/-/diabetes-paciente-cronico/	webpage

Condition	Topic/description of the educational material	Sub-topic (In English)	Native language topic	Link	Category/type
			Denmark (Southern Denmark)		
COPD		What is COPD	Havd er KOL?	https://www.lunge.dk/kol	Written material
COPD	Generel information about the disease-anatomical and physiological	What happens when you get COPD	Hvad sker der ved KOL?	https://www.lunge.dk/kol/viden-det-sker-der-ved-kol	Written material
COPD		The risks by getting COPD	Risiko for at få KOL?	https://www.lunge.dk/kol/viden-risiko-kol	Written material
COPD		Causes of COPD	Årsager til KOL?	https://www.lunge.dk/kol/viden-aarsager-til-kol	Written material
COPD	What symptoms does the disease	Symptoms of COPD	Symptomer på KOL?	https://www.lunge.dk/kol/viden-aarsager-til-	Written material
COPD	Blood tests and other examinations (measurements)	Measuring lung capcity	Lungefunktionsmåling	https://www.lunge.dk/kol/viden-saadan-kan-	Written material
COPD		Measuring lung capcity	Lungefunktionsmåling	https://www.youtube.com/watch?v=rZ_bZvp	Video
COPD	Exacerbation	Exacerbation of COPD	Forværring af KOL	https://www.lunge.dk/kol/viden-forvaerring-	Written material
COPD		Treatment of exacerbated COPD	Behandling af forværring af KOL	https://www.lunge.dk/kol/viden-behandling-ved-forvaerring-af-kol	Written material
COPD		COPD care and treatment	KOL behandling	https://www.lunge.dk/kol/sektion-kol-	Written material
COPD		Oxygen therapy	Iltbehandling	https://www.lunge.dk/aandedraet/sektion-	Written material
COPD	How is the disease treated?	Non-invasive-Ventilation therapy	NIV behandling	https://www.lunge.dk/kol/viden-niv-og-respiratorbehandling-ved-kol	Written material
COPD		High-flow treatment	High-flow behandling	https://www.lunge.dk/lunger/nyheder-intensiv-lufttilfoersel-gavner-meget-syge-kol-patienter	Written material
COPD		Vaccination	Vaccination	https://www.lunge.dk/kol/viden-vaccination-og-kol	Written material
COPD		Medical care	Medicinsk behandling	https://www.lunge.dk/kol/viden-faa-styr-	Written material
COPD	Medical treatment and how to use it correct	Different types of inhalation medication	Forskellige typer inhalationsmedicin	https://www.sundhed.dk/content/cms/65/95865_oversigt-inhalatorer-20170828.pdf	Written material
COPD		Medication and its importance	Medicin og den betydning	https://www.youtube.com/watch?v=hg8u8AEq6tA	Video
COPD	Nutrition	Food and sustenance	Mad og måltider	https://www.lunge.dk/mad/sektion-mad-og-maaltider-til-dig-med-en-lungesygdom	Written material

United Kingdom (NHSL Lanarkshire)

Diagnosis	Category	Topic/description of the educational material	Sub-topic (In English)	Native language topic/title?	Link	Format/type
COPD	General Information	General overview of COPD	About chronic obstructive pulmonary disease	About chronic obstructive pulmonary disease	Chronic obstructive pulmonary - Illnesses & conditions | NHS inform	Written material
COPD	Symptoms	Symptoms of COPD, Flare-ups, Other signs of COPD	Symptoms of COPD	Symptoms of COPD	Chronic obstructive pulmonary - Illnesses & conditions | NHS inform	Written material
COPD	Causes	Things you can change, Things you cannot change	Causes of COPD	Causes of COPD	Chronic obstructive pulmonary - Illnesses & conditions | NHS inform	Written material
COPD	Diagnosis	Diagnosing COPD, Spirometry, Other tests, Further tests	Diagnosing COPD	Diagnosing COPD	Chronic obstructive pulmonary - Illnesses & conditions | NHS inform	Written material
COPD	Treatment and Intervention	Stop smoking, Inhalers, Short and long-acting bronchodilator inhalers, Steroid inhalers, Medicines, Other types of treatment	Treating COPD	Treating COPD	Chronic obstructive pulmonary - Illnesses & conditions | NHS inform	Written material
COPD	Recommendations	Living well with COPD, Support	Living well with COPD	Living well with COPD	Living well with COPD | NHS inform	Written material
COPD	Recommendations	Living well with COPD - Myths about COPD	Myths about COPD	Myths about COPD	Living well with COPD | NHS inform	Written material
COPD	Recommendations	Living well with COPD - Hints and tips	Hints and tips	Hints and tips	Living well with COPD | NHS inform	Written material
COPD	Recommendations	Living well with COPD - Exercising with COPD	Exercising with COPD	Exercising with COPD	Living well with COPD | NHS inform	Written material & Videos
COPD/Heart	Recommendations	Information on the benefits of quitting smoking & support				Written material

Israel (Maccabi Healthcare Services)

Topic/description of the educational material	Sub-topic (In English)	Native language topic/title?	Link	Format/type
COPD	COPD- General information	מחלת ריאות חסימתית כרונית- מבוא	https://www.maccabi4u.co.il/2791-he/Maccabi.aspx	
	COPD- Symptoms	מחלת ריאות חסימתית כרונית- סימפטומים	https://www.maccabi4u.co.il/2791-he/Maccabi.aspx?TabId=2793_2794_2796	
	COPD- Causes	מחלת ריאות חסימתית כרונית- גורמים	https://www.maccabi4u.co.il/2791-he/Maccabi.aspx?TabId=2793_2794_2797	
	COPD- Diagnosis	מחלת ריאות חסימתית כרונית- אבחון	https://www.maccabi4u.co.il/2791-he/Maccabi.aspx?TabId=2793_2794_2798	
	COPD- Treatment	מחלת ריאות חסימתית כרונית- טיפול	https://www.maccabi4u.co.il/2791-he/Maccabi.aspx?TabId=2793_2794_2799	
	COPD- Prevention	מחלת ריאות חסימתית כרונית- מניעה	https://www.maccabi4u.co.il/2791-he/Maccabi.aspx?TabId=2793_2794_2800	
	COPD- Information about AMCA's lung clinic	מכון הריאות אסותא אשדוד	https://www.assutaashdod.co.il/?catid=%7Bfcc2333a-f8bc-4bf8-bb16-17b48e886c2a%7D	
	CHF- General Information	אי ספיקת לב- מבוא	https://www.maccabi4u.co.il/11440-he/Maccabi.aspx	
	CHF- Symptoms	אי ספיקת לב- סימפטומים	https://www.maccabi4u.co.il/11440-he/Maccabi.aspx?TabId=11442_11443_11445	
	CHF- Causes	אי ספיקת לב- גורמים	https://www.maccabi4u.co.il/11440-he/Maccabi.aspx?TabId=11442_11443_11446	
			https://www.maccabi4u.co.il/11440-	

Germany (Werra- Meißner Kreis)

Diagnosis	Category	Topic/description of the educational	Sub-topic (In English)	Native language topic/title?	Link	Format/type
CHF	General information	General information about the disease - anatomical and physiological	What is CHF	Was ist Herzinsuffizienz/ Herzschwäche?	Herzschwäche | Gesundheitsinformation.de	Written material
CHF	General information		What is CHF 2.0	Herzschwäche kurz erklärt	https://youtu.be/unFX4oo7QIU	Video
CHF	General information		Causes of CHF	Ursachen von Herzschwäche	Herzschwäche: Die Ursachen sind vielfältig | Herzstiftung	Written material
CHF	General information		The risks of getting CHF	Risikofaktoren	https://youtu.be/fg9_cxVn14s	Video
CHF	Symptoms	What symptoms does the disease cause?	Symptoms of CHF	Symptome	Herzschwäche: Symptome sind oft unspezifisch | Herzstiftung	Written material
CHF	Examinations	Examinations	Overview	Wie wird eine Herzschwäche festgestellt?	Wie wird eine Herzschwäche festgestellt? — Patienten-Information.de (patienten-information.de)	Written material
CHF	Examinations		EKG	Echokardiogramm (EKG)	https://youtu.be/WfagPn4EzL0	Video
CHF	Treatment	How is the disease treated?	CHF care and treatment	Behandlung	Herzschwäche behandeln — Patienten-Information.de (patienten-information.de)	Written material
CHF	Treatment		Therapy in hospital	Behnadlung im Krankenhaus	Behandlung im Krankenhaus — Patienten-Information.de (patienten-information.de)	Written material
CHF	Treatment		Vaccination	Impfungen	https://www.patienten-information.de/patientenblaetter/herzinsuffizienz-impfungen	Written material
					Therapie der Herzschwäche: Worauf kommt es an? |	