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D6.2 Recommendations for change management in integrated personalized care delivery

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Abstract

Change management is complex and is important in many different areas of any project. In this deliverable we want to describe not only the work done in WP 6, Task 6.4, but also other activities related to change management.

Chapter 1 describes the scope of change management in the project and the focus areas to make changes agreed by the consortium.

Chapter, 2, contains the report from the study preformed in WP 6, Task 6.1. “Integration and coordination of care for advanced chronic diseases in existing health-care services”. In this study professionals, patients and informal caregivers were interviewed in the different pilot sites. This report has set a baseline for the present care deliverance model and level of care integration at the pilot sites before the intervention.

Chapter 3 describes the work on change management carried out in Task 6.4 and connections to other work packages.

One of the focus areas, Shared decision making, is described in Chapter 4 which contains of a summary of work done in WP7 and detailed in D7.3 Shared Decision-Making tool requirements (Deliverable submitted on July 2021 and of confidential nature).

Training material to support change management is another topic that has had work done not only in WP6 but in many of the work packages. Chapter 5 contains a summary of those activities.

Chapter 6 summarises the content of the Deliverable and shows the conclusion, and Chapter 7 describes the next steps.

In chapter 2, one of the pilot sites in the study is Szpital Specjalistyczny im a Falkiewicza we Wroclawiu (Falkiewicz), in Poland. As of September 2021, they have left the project for reasons related to the impact of the pandemic caused by COVID-19 in its organization and care deliverance. University Hospitals Coventry and Warwickshire National Health Service trust (UHCW) in UK, has come in to the project as a new pilot site in the fall of 2021. Thus, the number of the pilot sites still the same, seven, but the number of the countries are six. The pilot sites in UK are situated in different parts, one in England and one in Scottland.

The fourth stage of the change management process will not be described in this deliverable, since WP10 “Exploitation” is leading the ongoing work with interviews of clinicians and management at the pilot sites, as part of their work on implementation. The baseline analyses with relevant stakeholders aim to evaluate the contextual factors that are relevant for the translation of the innovation action into routine practice in each site.

To describe all of the fifth stage will be possible after the intervention is done, and we aim to do so in D8.2 “Report on ADLIFE pilot execution”, due by Month 50 (Feb 2024), at the end of 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.

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Abbreviations and acronyms

Abbreviation/Acronym	Definition
AMCA	Assuta Ashdod LTD
CAT	COPD assessment test
COPD	Chronic obstructive pulmonary disease
DOA	Description of Action
EHR	Electronic Health Records
FALKIEWICZ	Szpital specjalistyczny im a Falkiewicza we Wroclawiu
GESUNDER	Gesunder Werra-Meissner-Kreis GMBH
GP	General Practitioner
IDT	Interdisciplinary team
KRONIKGUNE	Asociación instituto de investigación en servicios de SALUD-KRONIKGUNE
MACCABI	Maccabi Sheirutei Bruit Foundation
MDT	Multidisciplinary team
NHS	National Health Service
OSAKIDETZA	Servicio Vasco de Salud Osakidetza
OUH	Odense University Hospital
PCPMP	Personalized Care Plan Management Platform
PEP	Patient empowerment platform
RJH	Region Jämtland Härjedalen
UHCW	University Hospitals Coventry and Warwickshire National Health Service trust

1. Scope of Change Management

The ADLIFE project aims to improve the quality of life of older people with advanced chronic diseases by providing innovative integrated intelligent personalised care via a digitally enabled holistic and integrated supportive care ICT Toolbox. The ADLIFE intervention will be set across seven different pilot sites: Basque Country (Osakidetza), United Kingdom (National Health Service Lanarkshire and University Hospital Coventry & Warwickshire - National Health Service Trust), Denmark (Odense University Hospital), Germany (Gesunder Werra-Meißner Kreis), Sweden (Region Jämtland Härjedalen) and Israel (Assuta Ashdod Hospital - Maccabi Healthcare Services Southern Region) involving healthcare professionals, care services and patients and caregivers.

Work package WP6 “Evidence-based personalized care delivery” is devoted to changing the care model for severely ill patients’ chronic patients, through the design of the features of digital-based personalized care plans that promote and facilitate holistic case management addressing the multidimensional nature of their diseases. Change management strategies will be designed and implemented for the successful implementation and scaling up of digital integrated care.

The objective of Task 6.4 “Change management for personalized integrated care delivery” is to design a change management strategy that will be implemented in WP8 “Pilot design and implementation” as a significant part of the preparation for implementation of the pilots. This includes analysing barriers and critical success factors for implementation and recommendations for organizational change management. The intent is not only to implement changes for purposes of the pilots but to facilitate change that will be sustainable in real life after the project’s end. When this report is written, the project is about halfway timewise, and close to 6 months remain before start of the intervention. Change management will continue to be an important task in the project forwards as well.

In this first chapter the scope of change management and the content of the rest of the deliverable is described.

1.1 Stages in the change management process

The change management working group agreed upon a process of five stages:

Stage 1: Defining the focus and scope of the change at project level

Stage 2: Defining the overall approach at project level

Stage 3: Assessment of the change needed at pilot site level

Stage 4: Assessment of the readiness for change and implementation at pilot site level

Stage 5: Making and managing the change

1.2 Focus areas in change management

The pilot partners reached a consensus on the overall approach which is to focus on making changes in three main areas:

- The communication, joint decision making and care planning between the hospital and primary care staffs
- The role of the Nurse Care Coordinator/Care manager
- Shared decision-making of professionals with the patient and his family

2. Integration and coordination of care for advanced chronic diseases in existing health-care services

2.1 Introduction

One objective within WP6 is the integration of the unconnected care tasks performed in different levels and settings addressing the multidimensional nature of the conditions of patients with advanced chronic disease. Task 6.1 *Integration and coordination of care for advanced chronic diseases in existing health-care services* carried out an exhaustive analysis on present care deliverance model and level of care integration at each pilot site for patients with chronic severe diseases (COPD and/or chronic heart failure - CHF), using interviews and focus groups.

The interviews aimed to identify the most relevant improvement areas related to organizational aspects that could hinder the implementation, and lack of seamlessness in existing care deliverance from the patient's perspective. Special emphasis was made on working conditions of involved health care and social care providers, considering multi-disciplinary teams and coordination. The gathered information, both regarding present and future wished-for situation, will be used to co-design pathways for integrated supportive care in the Personalized Care Plan (PCP) module.

2.2 Purpose

The purpose of the task was to identify the issues that ADLIFE could address and improve in each site. To do that, in order to have the overview of the present care deliverance model and level of care integration at each pilot site, the input of the main stakeholders involved was collected and analysed. Each pilot site identified improvement areas required to enable the delivery of care proposed in ADLIFE. As some pilot sites were already using telemedicine in their health care system, the analysis also aimed to find key success factors for the existing use of telemedicine. The improvement areas and success factors will be used by ADLIFE technology partners, WP8 and Local Clinical Reference Groups in designing and developing the ADLIFE tool and implementation strategy.

2.3 Method

To examine the present care model and improvement areas, a qualitative method was chosen, as this method is suitable for describing experiences.

The seven pilot sites were asked to arrange interviews or focus groups with three stakeholder groups, 5-7 persons in each group. The three stakeholder groups were (1) patients with chronic diseases, (2) carers such as relatives, volunteers, near ones and (3) health care professionals. All pilots have been strongly affected by the Covid-19 situation, which both influenced the patients being in a risk group, and the availability of health care professionals. Six of the seven pilots could deliver their result within the proposed timeline. Their content is included in this analysis. The seventh pilot was unable to proceed with their interviews due to Covid-19.

The interviews were performed in native language, following a joint template with semi-structured questions. The template was developed by WP6 and decided by all participants. The document was presented in English and translated to native language by each pilot site. The arranged interviews were initiated by introducing the ADLIFE project and the main purpose of the task to the participants according to information included in the template. The stakeholders were asked to use their previous experiences and observations about health care situations in general, and care of COPD and/or chronic heart failure in particular. The questions focused on how the health care works, what can be improved, and actual suggestions on how it can be improved. This was repeated for all four dimensions of the holistic case management mentioned above: physical, psychological, social, and spiritual aspects of care. The participants were informed that the results would be used to design and develop a care tool, which would be tested in their regions later. No participants were promised access to the results. Ethical application was submitted in some pilot sites, according to local regulations.

After a first round of interviews in two pilots, the template was further developed with more describing examples of the care dimensions (physical, psychological, social, and spiritual). As well, one extra question about current telemedicine was added. The participants were also asked about their attitude of telemedicine for the four dimensions: would new technique be appropriate in their opinion? The following interviews used this adjusted template. All interviews, by both versions, were used in the analysis, which is a weakness in the work. The weakness consists in that ideally all interviews would be done with the same template. In this study, the potential win of change in the templet was considered bigger than the weakness of making changes in the template after those first two interview rounds. After performing the interviews and focus groups, the pilot sites made a summary of their results, first in native language and then in English. This summary was sent to Task 6.1 lead, Region Jämtland Härjedalen (RJH), to be used in the analysis.

A deductive-inductive approach to qualitative content analysis was used according to Graneheim, Lindgren and Lundman [1-3]. This aims to describe variations by identifying differences and similarities in the content. From the summaries, sentences were extracted and condensed, to reduce the wording without losing its purpose. The condensed units were abstracted to codes, capturing the significance of the text. The codes were chosen ahead of the analysis, using an ADLIFE framework structured in areas and dimensions (). This ADLIFE model is based on ICHOM standard sets for Heart Failure and Older People and will be used throughout the ADLIFE project as described in D7.1 ADLIFE Patient Reported Outcome Measures and ADLIFE Research Protocol latest version (v0.28). As this model is focusing on the patients' perspective, three more areas had to be added: ICT, Organizational culture, and Organizational structure. The organizational culture reflects the mentality, work ethic and values of management and employees. The term "organizational structure" refers to the actual framework of a company or organization and has a direct impact on the way day-to-day operations are handled.

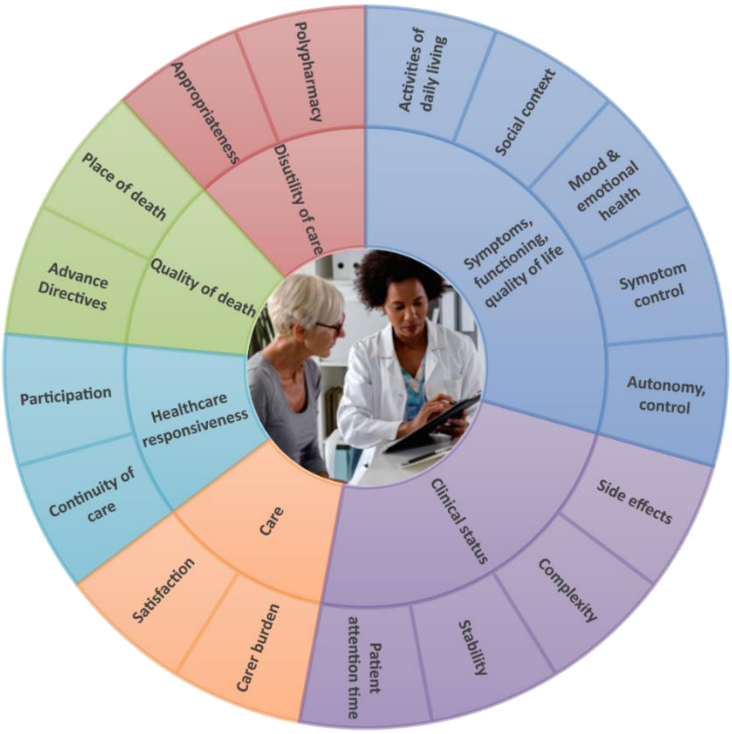

Figure 1 - ADLIFE conceptual data framework

The author of the analyses had experience of the patient category as a physiotherapist but had not been in a position as care giver for the participants. Some of the interviewed health care professionals in the local Region Jämtland Härjedalen pilot site are former colleagues to the author. A weakness in the analysis is that the analyses process in Region Jämtland Härjedalen was done by one person only. However, the results of the analysis were reviewed by the responsible researcher in RJH. Another weakness is the multiple translations to and from English, in which details and nuances in wording may be diminished. The accuracy of the content is also affected as the analysis was done on the pilot sites summaries, instead of their original content. Due to this, the report summarizes other summaries, which can affect the result. The result is validated by having the pilot sites study this report and give feedback.

2.4 Pilot sites

In the following the pilot sites whose data is used in the study describe their site.

2.4.1 Assuta Ashdod Hospital together with Maccabi Healthcare Services Southern Region, Israel

The patients who were interviewed were, at the time for the interview, hospitalized in the Maccabi Integrated Care Unit in Assuta Ashdod Hospital. Carers were family members of patients who were or had been recently hospitalized in Assuta Ashdod Hospital. Professional staff of Assuta and Maccabi participated in focus groups, including hospital doctors (internal medicine, cardiology, pulmonology, and emergency medicine), family physicians, nurses, a social worker, a physical therapist, a nutritionist and IT staff. Overall, both patients and carers clearly perceived the main locus of care to be in the community and in the hands of the family doctor. Convalescence care is available after hospitalization.

There is a level of data exchange between the hospital and the community with some limitations. The doctors in the hospital can access selected medical information on a hospitalized patient or a patient being treated in an outpatient clinic in two ways. Through the Maccabi Portal or through the National Electronic Health Record (EHR) exchange. Thus, a doctor (or senior nurse) in the hospital can access information from the patient's community Electronic Medical Record (EMR) including diagnoses, test results and medications. Likewise, the family physician is notified as a pop-up in his EMR when his patient is discharged from the Emergency Room (ER) or hospitalized. He also gets a copy of the ER and hospital discharge summary.

A characteristic of the Israeli system is that there are many specialists who have clinics in the community and consequently, family doctors will frequently refer their patients to these specialists, rather than to refer then to the specialist in the outpatient department of the hospital. These specialists are all using the Maccabi EMR and consequently, all the data entered by specialists in the EMR, including text, is transparent and available to the family doctor.

Maccabi owns a network of complementary medicine clinics. Because of the multicultural nature of the Israeli population, Maccabi is very sensitive to and adapts its services and how they are delivered to the specific cultural and spiritual needs of its diverse populations. For example, they have a translation service that can be accessed during a visit if language is a barrier. Another example, the ultraorthodox population requires same sex clinicians, and modest dress so services for these populations adhere to these strictures. Maccabi has cultural coordinators for these subpopulations who make sure that there is awareness, and the special needs and sensitivities of these subgroups are addressed.

Social services are provided by the health or social care system, from the Maccabi Social Worker. The National Social Security Institute is responsible for the provision of domiciliary services (home care) as well as pensions and subsidies.

2.4.2 Szpital Specjalistyczny im a Falkiewicza we Wroclawiu – Falkiewitz, Poland

Patients receive care at base level at the POZ primary health care providers. If there is a need for more support more entities are involved. Patients in need of more attentive care are entitled to patient-centered physical and social care in care homes and in hospital settings. General practitioners have limited time to assess the state of social needs of chronic patients. As well, little time is allowed for spiritual needs within context of primary care.

A diversity of competencies presents considerable challenges for effective coordination of activities across the health system. The coordination of primary care is achieved through introduction of interdisciplinary primary care teams to coordinate care pathways, but there is still room for improvement. There is weak coordination between inpatient and outpatient care, including poor access to diagnostics.

2.4.3 Odense University Hospital-OUH, Denmark

Patients with COPD who are discharged from care following an exacerbation, and need care consecutively, can get telehealth counselling solutions with nurses for 7-10 days after discharge.

A tablet combined with wireless pulse oximetry and spirometry is used for video consultations. There is a well-functioning collaboration with an external supplier regarding delivery, training, pick-up, cleaning, and calibration of the device. There is also good technical support.

The collaboration between the different actors in health care varies a lot. There is a general lack of cross-specialty interest within this area. The doctors are mostly solving different ad hoc tasks but are not interested in the telehealth solution because there is a lack of evidence on the subject. After the first telehealth counselling days, the commune usually is informed, in consent with the patient. The commune also has COPD nurses in their organization, who will assess whether care should proceed in their organization after the telehealth session.

2.4.4 Gesunder Werra-Meißner Kreis-GWMK, Germany

There is communication and interaction between family doctors and specialists in the county. The interaction of medical care with other relevant actors can still be improved in the district, there is a lack of awareness of health care or social services outside the medical sector. Neither the actors know each other nor do those affected know the actors they can turn to.

Most care services in the county are sparsely populated, and care providers work as lone wolfs in the outpatient sector. There are pneumologists in the district, but too few, which means that some patients must turn to pneumologists outside the county. Alternative treatment options are not or only to a limited extent offered on an outpatient basis. A further gap in care is reflected in the lack of guaranteed mental health care.

2.4.5 Osakidetza, Basque country

In primary care, assistance is either face-to-face or at home, and sometimes by telephone. In the hospital, care is delivered face-to-face (in some cases, with specific consultations, monographic of a certain pathology-COPD) and by telephone, as well as with the intervention of the advanced practice nursing; closer follow-up is done. In one of the centers there is a telemedicine program for the control and monitoring of patients with COPD who are re-admitted, as well as rehabilitation.

The physical dimension is addressed in a more global way from primary care, while specialists need to have access to that more global assessment carried out in primary care. Treatment is also monitored.

As for the psychological dimension, less assessment is carried out than it should be, also taking into account that patients demand it; there is a lack of psychologists in the health system and therefore the response of the system is slow to these symptoms. In primary care, medication is monitored and in specialist care some psychological health assessment tools are also used (in the specific case of COPD, for example, COPD Assessment Test (CAT) is used) and psychological support is provided in specific situations.

The socio-health aspect is the great forgotten one and yet it is very important, given that it sometimes generates admissions and avoidable consultations. From primary care there is communication with the social services and an annual register is made of interventions of this type. Acute specialized care calls for a screening of the social situation of the patients, which does exist in the medium-stay centres; and in this assessment, the role of the caregivers should also be included. It is proposed to give greater prominence to patient associations, which bring patients and caregivers together, and offer services that are highly valued, such as support groups or talks.

The existential dimension is addressed only when there are situations of terminal care or in very specific cases, and the follow-up is more systematic if the patient has signed the advance directive.

There is communication and coordination between professions, both within the same level of care and between primary and specialized care, and for this purpose different tools are used, such as video calls, telephone, non-face-to-face consultations, although more tools are needed to promote this communication or for those that exist to function correctly.

2.4.6 Region Jämtland Härjedalen, Sweden

Patients with COPD and/or heart failure have their primary care in health care centres. There should be a solid care contact, one person who coordinates the care, but it's not always the fact. For diagnostics, more advanced tests and during exacerbations, the care is given in the county hospital. Both primary care and hospital use the same EHR system, Cosmic.

The municipality have health care professionals who are responsible for patients with bigger needs, like help with getting dressed, eating, daily hygiene or to move. All eight municipalities have different EHR systems, no one has the same as primary care/hospital. There is a system for information regarding hospital visits: Cosmic Link. In this system, messages are sent to affected organizations when a patient is enrolled/discharged from hospital. The organizations/professionals are added manually. Patients can read their EHR in a site called 1177.se which is national. Here, health information is given, and all inhabitants are told to look for advice here (web site/call center) first, then primary care, and only in emergencies: the ER.

Another branch of the municipality is responsible for social services. This is under another jurisdiction, and sometimes the health care and social care services are inconsistent. The responsibilities of each health care organization in the county are described in an agreement which is often debated: there is a risk that managers are more into economical boarders than what is best for the individual patient.

2.5 Results

The results are described in (1) dimensions, (2) areas and (3) themes, confirmed by quotes with pilot site numbers. The pilot site numbers are in no specific order, to anonymize the quotes. The analysis presents nine categories/areas with results in eight of them, as no content could be encoded into the category/area "Quality of death".

- Disutility of care,
- Quality of death,
- Healthcare responsiveness,
- Care,
- Clinical status,
- Symptoms, functioning, quality of life,
- ICT,
- Organization culture, and
- Organization structure

Under these areas, 18 dimensions can be seen. The theme for the analysis is "Improvement areas for using digital tools like ADLIFE", with sub theme "Key success factors for using digital tools like ADLIFE". The analysis is based on the stakeholder's experiences, describing what they can see works and is good in their health care systems, and what does not work and need improvement.

Table 1: Example of analysis from Sentence to Area.

Pilot site	Sentence	Condensed sentence	Dimension	Area
#1	Patients with heart failure have adopted to their disease --- accepting their low level of functioning in daily life	Patients accept low level of Activities of daily living (ADL)functioning	Activities of daily life	Symptoms, functioning, quality of life

Area 1: Disutility of care

The first category includes the codes/dimensions "Autonomy, control" and "Polypharmacy". In this, experiences of adverse or harmful effects, even minor, are collected. This category/area had few contributions.

Table 2: Example from Area 1: Disutility of care

Pilot site	Sentence	Condensed sentence	Dimension	Area
#1	I want to know, very clear, when a medication is switched to something else. Sometimes I get that information at the drugstore - a bit late I think.	If a medication is changed, patients want to know about it	Polypharmacy	Disutility of care

The participants describe a wish for regular reviews of their medications. For example, patients are asking for more co-ordination between the health care and the pharmacists/drug stores.

"The family doctor should stabilize pain, stop constantly changing meds"
#6

"I would like the health care to coordinate their work with the drugstore, about medications. They change names and looks all the time! I want it to be clearer" #1

Area 2: Quality of death

No results.

Area 3: Healthcare responsiveness

The area "Healthcare responsiveness" includes two codes/dimensions: "Participation" and "Continuity of care". In all pilot sites, these codes/dimensions received a lot of material. The continuity is highly connected to the latter category/area "Organization structure" since a good structure will enhance continuity. Many participants also mentioned the cultural side of organizations: if there are regular and positive relationships, the patients receive better health care. This goes for all care levels. Two issues are common: the importance of follow ups, and the (constant) referrals. Both patients and carers want a stable multi-disciplinary team, who knows the patient's background and deals with problems in depth, instead of "just referring the patient". Instead of referrals, family doctors should consult their colleagues in the hospitals.

In some pilot sites, telehealth is already in use. The use of distance technique gives an obvious possibility in participating in your own care, as the patient's strength can be used for talking, not travelling. The technique demands experienced nurses, with knowledge in both ICT and the diagnoses. The majority describes the home monitoring as positive. Both patients, carers and health care professionals express their satisfaction with the technique, and some even miss it when the program is done:

Table 3: Example from Area 3: Healthcare responsiveness

Pilot site	Sentence	Condensed sentence	Dimension	Area
#7	I actually miss it (the tablet). I can (still) get in touch with them (the nurses) but it's not the same way.	Telemedicine is an easy way to get in touch with nurses.	Participation	Healthcare responsiveness

Patients highlights the ease of using the tablet, that it takes "no time", and that texting their nurses gives them quick response. They also recognize the value of not having to travel to the hospital.

"We don't need to see each other. As long as it (the measurements) is on this level, it's approved" #7

Even though using a tablet seems to enable the patient's participation in their own care, the importance of participation is seen regardless of technique. It is also mentioned in pilot sites with traditional care, face to face:

"*Usually, I participate in decisions about my health care. It feels good*!" #1

In the code/dimension "Continuity of care" health care staff see a lot of improvement areas in follow ups, a need of better relations and cooperation and more teamwork. They also highlight the many referrals to different specialists. Specific suggestions of improvement are to engage care coordinators/case managers to support all actors, and to "consult instead of refer":

"A care coordinator equipped to deal with the patient holistically could provide guidance and someone to turn to - both for patients and carers" #6

The carers, as the patients, are mostly satisfied with the participation and continuity of care. There are some issues though, about bureaucracy: both regarding lab tests but also in applying for social care.

> *“Carers think the care is coordinated - despite this there were complaints about the bureaucratic process, particularly in getting post-discharge tests done in the community” #6*

Area 4: Care

The “Care” area consists of two codes/dimensions: “Satisfaction” and “Carer burden”. The needs of the carers are described both as mental support, for example about grief and suffering since their near ones are chronically ill, but also as opportunities to enhance their physical capacity, since caring for another can be physically challenging. It is also highlighted that carers often want to be involved in care plans and should be encouraged to interact with health care services.

Many patients describe that they are satisfied with their traditional care, that the telephone can be a barrier (in contrast to physical meetings) and that they want face to face help with emotional symptoms. One carer also mentioned the physical aspect of being able to hold hands, or comfort, in a physical meeting, that won’t be done on screen. Other pilot sites, where telehealth is used already, are very positive with their experiences and have high satisfaction with leaving the hospital faster, no need to commute, and comfortable communication on the patient's premises and describes an advantage of digital consultations in vulnerable cases. It seems like the type of meeting is not crucial for the satisfaction of care.

Regardless of the type of care – traditional or telehealth – the satisfaction is negatively affected by lack of information, unknown purpose of the visit, uncertainty if primary care is “as good as” hospital care, and if no follow ups are done. Some patients report that they use internet for information, but mostly the doctor is the primary source of information.

Table 4 Example from Area 4: Care

Pilot site	Sentence	Condensed sentence	Dimension	Area
#3	Also, carers are affected by death and suffering, they should get more support concerning grief and bereavement.	Carers need support about grief and suffering	Carer burden	Care

Several patients valued availability as most important – regardless if it was by phone, video or chat. A need to know that someone answers. Patients are confused and worried if the information given is unclear or missing. An informed patient will most likely comply better with his treatment, and not ask for unnecessary visits.

> *“My atrial fibrillation was discovered at a regular check up on my pacemaker in the hospital. Nevertheless, they referred me to primary care. I don’t know why?” #1*

Two conflicting views on telehealth can be seen. Maybe it is a personal point of view, or it is hard to envision how it will work before you have actually tried it. The interviews are both positive and negative about telehealth as it comes to satisfaction:

> *“There are advantages of digital consultations - the patients feel pleased, especially in the first few vulnerable days after being discharged” #7*

“The patients insist that face to face care is preferable, especially when dealing with more sensitive issues, as it helps them feel more secure” #4

Some carers describe frustration, both because of lack of solutions to the patient’s conditions (which affects his near ones too), but also because they don’t always feel appreciated or as a part of the care team. They have a hard time getting an overview of medications and contacts. Other carers have no specific needs or expectations, they feel safe in the traditional care system. The carers who have tried telehealth solutions, highly recommend it compared with traditional care.

“It’s absolutely amazing, the machine (iPad). (Previously) a home nurse arrived 6 times a day. It was a nightmare” #7

“The caregivers feel safe in the present health care system. They mention that care provided at home has been even more positive” #4

Area 5: Clinical status

In the fifth area “Clinical status”, there are four dimensions: “Side effects”, “Complications”, “Survival” and “Patient attention time”. In this part, the participants see how early detection can be improved by asking simple questions in primary care, how malnutrition must be dealt with both in hospital and at home, and the need of focusing on comorbidities such as stroke/aphasia.

Table 5 Area 5: Clinical status

Pilot site	Sentence	Condensed sentence	Dimension	Area
#5	A lung function test should be introduced in regular health check-ups at the family doctor’s office, to detect illness in good time.	Include lung function test in regular health check ups	Complications	Clinical status

As for the four dimensions of health, the physical dimension is often taken care of – but not always in time. A lung function test in regular health check-ups and regularly asking patients if they are out of breath, if they avoid stairs, slopes, and household chores as vacuuming, could improve early detection.

“The physical dimension is assessed in primary care where also treatment is monitored” #4

“Early detection can be made better. Today many patients are hypoxic without knowing it. They think they are overweight, or untrained, and feel ashamed. They also get used to their shortness of breath and seek help 10 years too late” #1

The carers meet most engagement from the health care system when it comes to medications and prescriptions. However, they “never” hear anyone talking about the importance of food, although the “know it in the gut”:

> *"Nutrition is often forgotten by the doctors, although we all know it means a lot for health and healing. Don't we?" #1*

Area 6: Symptoms, functioning, quality of life

This is a broad area with five underlying codes/dimensions: "Activities of daily living", "Social context", "Mood & emotional health", "Symptom control" and "Autonomy, control". As for being active both in daily living and active in training, there is a view of patients accepting, and getting used to, a low level of ADL functioning, and decline training as it is too exhausting just to travel to the session. But there is also a big awareness of the benefits of training. From several pilot sites, there are wishes for more physical therapy appointments, physical activity as prescription, and for rehab programs to proceed longer in time.

Regarding social context, pilot sites state that many patients are lonely and there is a need for social support, either for practical help, company or for economic support. There is a need to focus on social needs and screen the social situation – also in a proactive way.

Within "Mood and emotional health", both patients, staff and carers are positive about screening mental health and raise the question of low mood. There is a clear distinction though between mental health (as in depression, anxiety, helplessness, low confidence) and spiritual/existential worries. The latter is seldom talked about – and both patients and health care professionals reflect if this is "outside" health care services. The issue is often referred to churches or palliative care teams. To make this better in the future, it is described as essential to train professionals in existential dimensions and communication skills, to gain closeness and the trust of the patient.

Table 6 Example from Area 6: Symptoms, functioning, quality of life

Pilot site	**Sentence**	**Condensed sentence**	**Dimension**	**Area**
#3	Patient screening tools should be more widely used to identify patients with changes in their emotional well-being. During visits, a set of questions should be asked, integrated in the consultation.	Use screening tools for emotional health	Mood & emotional health	Symptoms, functioning, quality of life

The patients speak highly about different social associations and suggest that health care professionals are active in suggesting this to the patient. This could be a way to organize exchanges between patients, being able to talk to others in the same situation.

> *"The possibility of patient associations, where patients can share experiences and participate in activities, is highly valued" #4*

The connection between physical health, ability to be part of daily life activities and emotional state is described by several pilot sites, as well as the autonomy that comes with medical aids:

> *"Providing the patient with compact portable oxygen to enable greater patient mobility would improve the patient's emotional state" #6*

> *"We work with both thoughts and action. The focus is to make the patients interpret and experience their symptoms in a different way - to dare more and be active. This way the anxiety goes down. As physiotherapist, I encourage physical activity – it's not dangerous to be out of breath." #1*

> *"Physical problems, such as pain, adds on to the patient's COPD, and limit them in their daily life activities. The patients follow the physical exercise recommendations given, and feel better when they exercise" #4*

Several carers indicate that patients suffer from some level of depression or low mood. Although the patients don't have any diagnosed pathologies, the caregivers can notice a lower mood, sometimes associated with admissions. This group also makes a distinction between psychological issues and spiritual issues. The carers are critical of medications and referrals as the main vectors of care, as they know problems not being dealt with can give depression.

> *"Carers claimed no one in the system talks about these things (existential issues) or seems to be interested in the patient's "spiritual" well-being" #6*

> *"They were depressed (because) they felt that their problem was not being dealt with, instead they were prescribed medications or referred, or spending too much time in the hospital" #6*

Area 7: ICT

The area "ICT" was added to the ICHOM framework, as many comments concerned technical issues. Many comments are positive and confirms the use of telehealth. As key success factors they mention an ease to use the devices: "just press one button". There were also persons who could not deal with the device – it was too hard to figure out. Most patients are very interested in following their own values and ask the nurse for both medical and technical advice.

Not only do the patients need good equipment – so do the professionals. In some hospitals, the technical equipment is not enough to perform telehealth, even if they want to. Many share desks and do not have a quiet place to conduct the meeting in. To be successful, the professionals must know the user interface as well as their own view and they need to be confident with the approach. Another advice is to use a well-defined agenda on what to discuss, and to make sure the meeting is not interrupted.

Table 7 Example from Area 7: ICT

Pilot site	Sentence	Condensed sentence	Dimension	Area
#7	The functioning of the wireless pulse oximetry and spirometry is a challenge because patients are often very interested in getting the numbers. Much time is spent on supporting technical issues. The care provider needs to know the user interface very well too, to support	Much time is spent on technical issues. The nurse needs to know the user interface too.	ICT	ICT

	unexpected difficulties during the consultation.			

The technique is not suitable for all patients. Those already engaged in their health will probably use the tool best. There is also a need for wireless network in the house, and good support. On the web site, plain wording is requested, also for the diagnoses.

“Technical issues regarding connection, sound, picture quality and wireless equipment makes patients frustrated. A solid wireless network is pre-requisite” #7

“We have a well-functioning collaboration with an external supplier regarding delivery, training, pick-up and cleaning (calibrating) the device. We have good technical support” #7

Health care professionals see a need to share care plans within the system and with external service providers in the area. To do this at the best, the electronic documentation must be coordinated and standardized. There is also a need to know more about other caregivers in the region, to give the patients advice on who to turn to. They also suggest notifications to know when their patients are enrolled or discharged, and chat options between professionals.

“(Need) standardized protocols for effective communications in IDT” #3

“A clearing up of the participants and their services in the circle would be meaningful. Also, there should be a list of physiotherapists who offer respiratory therapy. The representation of care in the circle, with links to actors, would be optimal to visualize the care” #5

Some staff are sceptical in how their patients will be able to use new technique.

“I wonder though… these patients are old, and I see their old mobile phones by their beds... Who will help them out?” #1

Carers are often invited to join telehealth meetings, which can be hard on a small screen:

“It would be better if the patient had a larger screen, so relatives and homecare assistants can join. But it would also take more space in their homes” #7

Area 8: Organization culture

This area is in close relationship with both “Satisfaction” and “Continuity of care”. Within the culture lies co-operation and collaboration, both between care levels and between professions. Interestingly, working remote can be used as an excuse for bad collaboration: it is easier to not take your responsibility behind a screen than in real life.

Table 8 Example from Area 8: Organization culture

Pilot site	Sentence	Condensed sentence	Dimension	Area
#7	There is a general lack of cross-specialty interest within this area. Doctors are not interested in telehealth solutions because of lack of evidence. We need prioritization and support from the management. Maybe have the attendance of a doctor to some consultations.	Lack of interest from doctors and management.	Organization culture	Organization culture

Most patients are satisfied with the care, but some have reacted:

> *"If many professionals and caregivers are involved, we (the patients) have to repeat a lot of information. They all seem to write so much in the EHR, but nobody reads the written stuff?" #1*

Health care professionals experience a lack of teamwork and clear responsibilities, both regarding medications, medical aids, and oxygen treatment. They also mention a lack of interest from management perspective on telehealth.

Many sites mention a need of mentoring, discussions with colleagues, communicating and getting to know each other – but they also mention lack of time for doing this.

> *"I would like to meet other physiotherapists in the region, to talk about this (patient) group. I am asked to visit primary care to discuss the guidelines, but I don't have time. The waiting-list is haunting me" #1*

There is a need to talk about telehealth to improve the solution, both within the specific specialty, but also cross-sectional. There is also a need to inform each other on different care services in the region, both health care services and social services outside the medical sector. The actors don't know each other, and the affected don't know who they can turn to. Other suggested areas to improve are the patient centered work, add comfort and competence in addressing spiritual needs, and fill general knowledge deficits:

> *"General practitioners must be sensitized to the diagnostic process to avoid false or delayed diagnoses" #5*

There are examples of good interaction, but they can be improved, and more proactive.

> *"It is sometimes difficult to know who can decide on prescriptions and other things out-of-bounds for nurses" #7*

Most carers find that there is a coordination between professionals. Instead, they would like to be more involved in care plans:

> *"Families and carers usually want to be involved in care plans. Provide them with opportunities for shared decision making and encourage interaction" #3*

Area 9: Organization structure

This last area is also an addition to ICHOM. Under this category there are many suggestions on how the health care can be improved. The suggestions are connected to the ICHOM framework, for example they aim to enhance participation and continuity of care, which are dimensions in the area "Healthcare responsiveness".

Table 9 Example from Area 9: Organization structure

Pilot site	Sentence	Condensed sentence	Dimension	Area
#3	Coordination between inpatient and outpatient care is challenging. There is a need for a collaborative care model with particular attention to patients who need several care providers working according a mutual care plan.	The care model must include a mutual care plan	Organization structure	Organization structure

Patients and carers do not see the structural needs as clear as the professionals do. In each individual case, the care often works fine.

> *"Carers find home services and health care staff to coordinate their work quite well, in the community. There is a bigger gap to the hospital" #1*

Many specific improvement areas are suggested by the health care professionals: for example, to arrange a COPD-school for patients, to provide more home visits, to enable a one-stop-shop for services and tests and to practice communication skills.

> *"It is essential to train professionals in existential dimensions and communication skills, to gain closeness and the trust of the patient" #4*

Other suggestions are emergency consultation hours to relieve the burden on General Practitioners (GPs) and specialists, creating self-help groups, less bureaucracy for home services, less fragmentation of governance and management and prioritizing creating care plans. IDT, interdisciplinary teams, are suggested by many, and by this, also a review of the team participants: should "new" occupations as pharmacists, instructors and chaplains be added? When psychological and social help is not given/given too slow, this should be enhanced.

2.6 Conclusion

In general, many patients and carers are satisfied with the care they receive, and how it is organized. This might be because they are dependent on the care given, and not in the position to make demands. It can also be because new techniques and new ways of providing health care is not commonly known by the public yet. It's hard to ask for something unknown.

The health care professionals often see structural needs, with more coordination and integration of systems. Their suggestions are strongly linked to local organization, both structure and culture. A need for a more holistic and team-based care can be seen, where traditional hierarchy is replaced by a person-centred approach. Also, the scope of health care must be broader: alternative treatment is seldom offered, the socio health aspect is often forgotten, and psychological issues are less assessed.

As for the sub-theme, key success factors for using digital tools like ADLIFE, user friendliness and experienced and engaged professionals are clear factors. New techniques are more likely to be tried and used if a pedagogic approach is used, with both calming and encouraging feedback. Another success factor is for the health care/digital tools to inquire for results and self-monitoring measures. If no one asks how it's going, many patients will stop measuring/training/taking self-care.

The main theme improvement areas for using digital tools like ADLIFE describes things to be done better in all areas. Many are connected to relations: a solid multi-disciplinary team which know the patient and his/her near ones, follows him/her over time and gets to know each other, is a safety for continuity of care. If the IDT-team is well represented, there is also less need of referrals, an activity that many describe as problematic.

In future tasks like this one, we propose the analysis to be done on original material instead of on summaries. Also, even though ADLIFE framework based on ICHOM standard sets is used, we suggest doing qualitative analysis without fixed areas in future work. Since some sentences cannot fit into any of the predetermined areas, the author is forced to encode it into the least bad option. Thus, as a fixed framework can affect the result in a negative way compared to the freedom of creating areas during the process.

3. Change management in ADLIFE

At the start of the project, it was stated that a strategy for change management would be designed. Change management has been on the agenda on a range of different meetings. Now, when pilot sites and other partners have worked with the topic for more than two years, the chosen strategy is to present a framework with a change management process and three focus areas for change.

There are many differences between the pilot sites, so the plan for change management needs to be on pilot site level. Osacideza has developed a strategy described in 3.4.1

3.1 Stages in the change management process

The change management working group agreed upon a process of five stages as described in section 1.1:

Stage 1 – Defining the focus and scope of the change at project level

Stage 2 – Defining the overall approach at project level

Stage 3 - Assessment of the change needed at pilot site level

Stage 4 - Assessment of the readiness for change and implementation at pilot site level

Stage 5 – Making and managing the change

3.1.1 Current status

Stage 1 and 2, defining the focus, scope of the change, and overall approach on project level, are done. All of the pilots (with the exception of the newest partner, University Hospital Coventry & Warwickshire (UHCW) NHS Trust) have also taken a step further in stage 1 and defined the focus and scope of the change required at pilot level.

Stages 3 and 4 - Assessment of the change needed and assessment of the readiness for change and readiness for implementation at pilot site level overlaps with the implementation assessment that has been the focus of the activities in WP10. Therefore, we have created a joint working group with WP 10, WP9 and WP 8 to coordinate so that we will be using the same tools for assessing readiness and planning the change management process in each pilot site. In addition, meetings including interview, focus groups and work sessions have been held with representatives of all of the stakeholder groups; doctors, nurses, social workers, patients and caregivers as part of the co-design process for the intervention, as well as the change management process.

3.1.2 Next step

The next steps will be an assessment of readiness to change, identification and prioritization of potential problems and obstacles and developing a plan to handle them. The implementation of the survey developed in WP10 will be an integral part of this process. Pilots will be encouraged to follow the strategy developed by Osakidetza (3.4) to guide them in developing their change management intervention plan.

3.2 Focus areas for change management

The changes that need to be made in each of the focus areas are changes in roles and relationships among the various actors, changes in processes and changes in work-flow, changes in communication and exchange of information- all using the ADLIFE toolkit to support the changes and identifying useful and easy to use tools for each stage

3.2.1 Communication and joint decision making

This focus area is aiming at communication, join decision making and care planning between the professionals in primary care (Health Care centres and municipality care) and secondary care (specialised care, as hospital care and specialised open care).

3.2.2 Nurse Care Coordinator

The nurse case manager/care coordinator is very central in all of the sites, when they are describing the change management. This role is already existing in several of the pilot sites. Those existing rolls differs a lot from each other, for example due to differences in laws and regulations.

3.2.3 Shared Decision Making

This focus area is described in Chapter 4.

3.3 Activities

3.3.1 Chronology on Change management work

The following are not to be seen as a complete list of what is done in the topic, even if the aim has been to present it as thorough as possible, could some activities have been overseen.

Table 10 Chronology on Change management work

Kick-off meeting in Bilbao January 21-22 2020	Plan presented: In WP6 a change management strategy will be designed (to be implemented in WP8).
1st plenary meeting October 20, 2020	Report of Main results: Storyboards from all pilots
1st meeting for the Change Management working group, consisting mainly of the pilot partners. February 9, 2021	Described the scope of Change Management in the ADLIFE project. There was consensus on the overall approach presented.
2nd meeting for the Change Management working group April 27, 2021	

2nd plenary meeting May 4-5, 2021	Presentation on Change management (Appendix A)
3rd plenary meeting November 16-17, 2021	Report from WP8: Continued alignment activities between WP8, WP9 and WP 10 on the topic: Readiness to change
Biweekly regular meetings WP8 from January 2022 – ongoing	Pilot sites working with plans for the intervention
4th Plenary meeting June 8-9 2022 in Sweden	Report from WP6: T 6.4 Review of previous work on Change management (lead by AMCA Presentation and workshop on Internal recommendations of change management Appendix B

3.3.2 Other meetings

Change management has been on the agenda at a range of other meetings to, such as regular meetings in WP6, and meetings between leaders of WP 6, WP 7, WP 8, WP 9 and WP 10 in different constellations, as the topic is key for the project and cross transversal to many tasks.

3.4. Change management in different ADLIFE contexts

The pilot sites that have been involved in the project since the beginning and still are have been asked to describe their work with change management in short.

3.4.1 Strategy developed by Osakidetza, Basque country

Osakidetza is the Basque health service provider in Basque Country. The Basque Public Health Service is made up by 13 Integrated Care Organizations (OSIs). The Integrated Care Organizations are integrated governance bodies between primary care regions and hospital, with a defined population catchment area. In Osakidetza, ADLIFE will be piloted at Integrated Care Organizations (OSIs): They involve four University Hospitals and several Primary Care Health Centers. Altogether 126 patients will be recruited for intervention. In each of the OSIs, an interdisciplinary team involving GPs, Nurses and Specialists will be established, comprising four settings (Primary Care, Hospital, Community Care and Home).

Following the Change management strategy proposed in Task 6.4, Osakidetza has designed and executed in some extent, its local change management strategy in order to ensure the adequate operation of ADLIFE toolbox in its pilot. This local strategy will be the basis for the pilot processes in Basque Country. To date, the following activities have been carried out to assess the change needed in Osakidetza: the definition of the expected scope of the change on the site, the estimation of the number of employees impacted by the intervention, the methodology for the identification and prioritization of the required changes and the assessment of the amount of change required from where we are.

Scope of the change

In Basque Country, the change aims the healthcare units that will take place in the ADLIFE intervention. They are the Integrated Care Organizations (OSIs) taking part in the project with the support and collaboration of the Sub-Directorate of Informatics and Information Systems (Subdirección de Informática y Sistemas de Información) and the Directorate of Health Care (Dirección de Asistencia Sanitaria, DAS) of Osakidetza.

Impact of the intervention

The intervention will have an impact on an extensive and diverse group of stakeholders. We have identified 25 different roles at various levels and different roles: Managers, Healthcare professionals, Social Workers, Mental health supporters, Volunteers, IT staff, Patients and Caregivers.

Change management strategy

As agreed upon by the consortium, ADLIFE approach in change management will focus on three specific areas: i) the communication, joint decision making and care planning between the hospital and primary care, ii) the role of the Nurse Care Coordinator/Care manager and 3) the endorsement of the shared decision-making of professionals with the patient and his family in the routine practice.

Following the general approach, each pilot site has adapted it to its local variation. Osakidetza has developed a comprehensive change management strategy and plan for the ADLIFE application, including the methodology. The following sections draft the methodology and show the results till now.

Identification and prioritization of the intervention topics in Osakidetza

Local working teams from the pilot site comprising representatives and selected experts are analysing the three areas of change management in the project. Currently, they are being assessed from the process, technology, organisation, job roles and strategy perspectives. As an example of the area focused on the collaboration between professionals at different levels, from the technological point of view, Osakidetza has already facilitated the interoperability of the electronic health record with ADLIFE and aims to integrate the local appointment management system, prescription system and lab request systems.

Action plan for the prioritized topics

In terms of assessing the change needed, we are examining the implications and highlight the gaps that need to be filled in order to arrive at new ways of working. The action plan will guide the set-up of the process for implementing the necessary actions on the identified key intervention topics. The objective of the plan is to describe in detail what actions will be taken and how and when the suggested changes will be implemented in order to roll out the pilot phase of the Project. The plan includes the definition of the specific objectives to be achieved, the development of the "change package" that encompasses the actions required for implementation and the definition of the key performance indicators.

Implementation of the action plan

The implementation of the action plan started at the beginning of the project with the presentation of the ADLIFE project in Osakidetza and with the involvement of the critical stakeholders of the organization. In January 2020, ADLIFE was presented to the managers of all OSIs in Osakidetza. In March 2020, the local Clinical Reference Group was constituted by an interdisciplinary team joining professionals from several settings, levels and OSIs, which has been given support to the definition of the ADLIFE care model in ADLIFE. The COVID-19 pandemic in March 2020 impacted the project, especially in the sites. Even so, this group has provided expert advice, support, and guidance on the project. In addition, local IT teams have been involved from the very beginning to support the integration and interoperability of the ADLIFE with the local sites. As a result, all the actions, tasks and achievements have been accepted and aware of the organization.

A PDSA (Plan-Do-Study-Act) process has been designed to implement the action plan. The "Plan" phase includes identifying the leader who will promote and lead the transformation (champion), setting up the appropriate inter-disciplinary team, communicating the mission to key stakeholders, designing the change processes and supporting tools, involving users, ensuring the availability of resources and the commitment of the implementation supports (organisation, relevant departments, people). The "Do" phase will consist of implementation. The "Study" phase will do periodic monitoring. The "Act" phase will make the necessary changes and adjustments based on monitoring and feedback.

Next steps

Osakidetza has provided the basis for its change management strategy. Osakidetza will finalise the identification and execution of the intervention topics which require implementing changes to enable the ADLIFE pilot application to work in the Basque pilot site. The plan's implementation should be carried out according to the process described above. The strategy will be adapted to current local needs. Following the pilot roll-out, lessons learned will be drawn to help healthcare organisations plan for a smooth and successful adoption of digital and integrated supportive care.

3.4.2 Assuta Ashdod Hospital together with Maccabi Healthcare Services Southern Region, Israel

Baseline plans

To identify the key stakeholders directly involved in the change for purposes of the pilot and to identify the stakeholders indirectly involved in order to provide support as well as to facilitate sustained change beyond the pilot.

To engage these stakeholders by regular updates in face-to-fae as well as virtual meetings supported by slides which then remain with the stakeholders.

Main achievements since then

AMCA has been faced by challenges of staff turnover and organizational changes both in AMCA itself as well as Maccabi. This has required many meetings for presenting ADLIFE and clarifying roles and responsibilities. We have updated all of the current actors and generated commitment to implementing ADLIFE. We worked closely with the key clinicians in the hospital and have identified the family doctors in Maccabi that we intend to recruit.

Current status

We have just completed a new round of meetings in both AMCA and Maccabi and have generated a higher level of commitment, both within the immediate pilot site management staff as well as the supporting staff in both organizations. We have agreed upon an incentive plan for Maccabi family doctors. We have also defined the role expectations of the Nurse case Manager

Plans for the next months

We will meet again with the hospital clinicians and will meet for the first time with the Maccabi family physicians to engage them and recruit them. We have identified candidates for the Nurse Care manager position and will bring them on board and train them. Together with the primary stakeholders, we will complete the final agreements on the ADLIFE processes, the supporting technology and prepare the training materials for professionals, patients and carers.

3.4.3 Odense University Hospital-OUH, Denmark

Baseline plans

To share information about the ADLIFE project with potential stakeholders and increase a sense of aware of the project and the benefits for clinical practice. We have a lot of experience with telemedicine solutions, and will draw on these experiences

Main achievements since then

OUH have already included and hired nurses who refers to the physicians. The health professionals have already been educated and informed through viewing a video and studied the inclusion and exclusion criteria. They have prepared lists with these criteria to be able to easier note relevant participants. The physicians and department management are highly involved in the process as well.

Current status

The health professionals in the departments that are taking part in ADLIFE have been informed about details about the pilot. OUH have started preparing the inclusion process (we ask patients if we can contact them when we will start including patients).

Plans for the next months

OUH will continue to choose possible and relevant participants to the pilot. OUH will start to train the clinicians to use of the PCPMP as soon as possible and also the PEP, so that they are able to assist the participants with the use of PEP

3.4.4 Gesunder Werra-Meißner Kreis-GWMK, Germany

Baseline plans

- Translate coordinating nurse context and requirements into case management offer for the region -> “GWMK Heart & Lung Health Guides” including core process descriptions
- Translate PEP, PCPMP, CDSS training material from English into German

- Win 5 ambulatory physician practices as test centre for ADLIFE intervention project

Main achievements since then

- Development of GWMK core processes (enrolment, stable phase, hospital & rehabilitation phase, ACP phase) that translate difficult to grasp ADLIFE requirements into German case management processes
- Introduction of the GWMK health care management team to the new role of heart and lung guides

Current status

- Programming of project electronic health record (ADLIFE ePA) with University of Kassel is on track
- Technical partners are provided with access and hardware to install German ADLIFE suite
- PEP translation completed
- PCPMP and CDSS rule card translation open

Plans for the next months

- Introduce hospital to project requirements
- Win over physicians with superior useable software that delivers added benefit to their work as well as the offer to outsource tasks to the new heart lung guide team

3.4.4 National Health Service Lanarkshire

Baseline plans as drafted in the spring of last year

To share information about the ADLIFE project with potential stakeholders and increase a sense of aware of the project and the benefits for clinical practice.

Main achievements since then

Given the stress that current health services are under in Scotland due to the global pandemic, any engagement from clinicians has to be viewed positively. Staff are facing huge challenges in relation to current workloads and, as such, it is a significant achievement that a group of secondary care clinicians have expressed interest in the project and are keen to explore in more depth how it can be implemented into their current services.

Interest from clinicians

Engagement with strategic and senior staff

Current status

A range of engagement meetings have been taking place between the local ADLIFE research team and local clinicians.

Plans for the next months

Continue with engagement with relevant nursing/medical specialities. Ensure robust infrastructure (locally agreed0) of support to clinicians is available

3.4.5 Region Jämtland Härjedalen, Sweden

Baseline plans

We believe that the test of ADLIFE is not a change in the true sense. At the same time, we know of several ongoing change projects such as Near Care, person centred care, and patient contracts, which we hope to be able to collaborate with, and maybe even facilitate.

Main achievements since then

A change in the organisation has brought a smoother way to meet and collaborate with management in departments important for the project. New members of the ADLIFE team have contributed with knowledge and experience from different ongoing changes in the region.

Current status

RJH has worked on internal relations on management level during spring of 2022. Parallel to that has more informal contacts among clinicians taken place.

Plans for the next months

Planning activities and translation of materials for a broader approach on dialog with clinicians and patients will take place during the summer month, to be ready for activities in September.

4. Shared Decision Making

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. In the ADLIFE project, shared decision-making is a core concept that has the purpose of giving patients, especially chronic patients, the opportunity and power to participate constructively and actively in the decision-making processes involved in managing their health and health condition. On the surface it may appear as a rather simple and straightforward technique, however, to get the optimal outcomes and intended results shared decision-making must be utilised in a new kind of equal partnership between the patient and the clinician, which traditionally has been more a prescription relationship where the clinician tells the patient what has been decided.

This section summarizes part of the work described in D7.3 Shared Decision Making tool requirements submitted on July 2022. More detailed information can be found in the referred document.

4.1 Introduction to Shared Decision-Making

The negative physical and psychological consequences of chronic disease can largely be reduced with optimal self-management. However, chronic disease management takes place at home, with patients and their loved ones making decisions as to whether treatments should be started or continued, often without consulting the health care team [5].

As such, patients may focus on their own experiences of health, finding externally specified disease management strategies, such as evidence-based guideline-directed care, inadequately compelling. The process and outcome of these decisions are described as adherence: the extent to which a person’s behaviour corresponds with agreed-upon recommendations from a health care provider.

It has been estimated that about 50% of patients do not take their long-term therapy for chronic conditions as prescribed [6-8].

Such non-adherence to medication is a major public health problem. It has significant negative consequences on both patients and providers, such as loss of treatment effectiveness and increases in healthcare costs. Consequently, in view of the increasing prevalence of chronic diseases, there is a clear need to tackle medication non-adherence [7].

Adherence in combination with persistence of treatment is necessary to achieve improved clinical outcomes [6].

Shared decision-making interventions has shown to have a positive effect of improving: adherence.

Shared decision-making is a process in which clinicians and patients work together to clarify treatment, management or self-management support goals, sharing information about options and preferred outcomes with the aim of reaching mutual agreement on the best course of action [9].

For patients with chronic conditions, SDM is expected to result in improved self-management using the term in a broad sense; that is, not only medicines management but also factors such as diet, exercise, self-monitoring, and participation in self-management education courses [10].

Shared Decision-Making is about cooperation between the patient and the clinician, when a decision has to be made. It is necessary to see the patient and the clinician as two equal experts, and make use of the knowledge of both of them.

- The clinician is the expert on the disease-specific knowledge, and informs the patient about treatment options, risks, pros and cons.
- The patient is the expert on his/her own life, and tells the clinician about lifestyle, experiences with the disease, preferences and priorities.

In order to be able to make the best decision for the individual patient, the decision has to consider both the professional and scientific angle, as well as the patient's values and shared decision-making may involve negotiation and compromise, but at its heart is the recognition that clinicians and patients bring different but equally important forms of expertise to the decision-making process.

The clinician’s expertise is based on knowledge of the diagnosis, likely prognosis, treatment and support options and the range of possible outcomes based on population data; the patient knows about the impact of the condition on their daily life, and their personal attitude to risk, values and preferences. In shared decision-making the patient’s knowledge and preferences are taken into account, alongside the clinician’s expertise, and the decisions they reach an agreement with each other are informed by research evidence on effective treatment, care or support strategy preferences [9].

For shared decision-making to take place, both parties must commit to sharing information and decision-making responsibility, recognising the need for this and respecting each other’s point of view. They should also commit to a documented conversation about risk, which is formalised for surgical procedures by the process of gaining informed consent but is currently less rigorously implemented and documented when the decision concerns medication use or behaviour change.

All of this is in sharp contrast to the traditional approach to clinical decision making in which clinicians are seen as the only competent decision-makers, with an expectation that they will make decisions for rather than with patients. Patients rarely challenge this assumption because they defer to the clinician’s knowledge, with neither party explicitly acknowledging the legitimacy of the patient’s expertise and decision-making role [9].

This approach could be seen as an expression of a paternalistic and traditional way of thinking by clinicians.

SDM involves the provision of evidence-based information about options, outcomes and uncertainties, together with decision support counselling and a system for recording and implementing patients’ informed preferences [9].

Most consultations between clinicians and patients should evoke the spirit of shared decision-making. Shared decision-making explicitly recognises a patient’s right to make decisions about their care, ensuring they are fully informed about the options they face.

There are three essential components:

- Provision of reliable, balanced, evidence-based information outlining treatment, care or support options, outcomes and uncertainties
- Decision support counselling with a clinician or health coach to clarify options and preferences
- A system for recording, communicating and implementing the patient’s preferences.

There is compelling evidence that patients who are active participants in managing their health and health care have better outcomes than patients who are passive recipients of care.

Shared decision-making is also important for commissioners because it reduces unwarranted variation in clinical practice. Shared decision-making is the principal mechanism for ensuring that patients get the care they need and no less, the care they want, and no more [9]. Unfortunately, adoption of Shared Decision-Making into routine practice has been remarkably slow, despite 40 years of research and considerable policy support [11], and effective shared decision-making is not yet the norm and many patients want more information and involvement in decisions about treatment, care or support than they currently experience [9].

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4.2 Definition of Shared Decision-Making

There are different ways of defining Shared Decision-Making (SDM). The definition chosen for the ADLIFE project is made by one of the founders of Shared Decision-Making theory; Glyn Elwyn. He defines SDM as:

> *”An approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences” [4].*

4.2.1 What is the purpose/goal of Shared Decision-making?

The goal is to make sure that the patient feels fully involved in decisions about treatment and care. A key element of Shared Decision-Making is therefore cooperation between the patient and the healthcare professional, when a decision must be made.

The easiest way to explain the purpose of SDM from a patient perspective is with the following short sentence: “No decision about me, without me”

What shared decision-making involves

Shared Decision-Making is appropriate for decisions about whether to:

- Undergo a screening or diagnostic test
- Undergo a medical or surgical procedure
- Participate in a self-management education programme or psychological intervention
- Take medication
- Attempt a lifestyle change.

The clinician must inform the patient about options, risks, pros and cons, while the patient needs to tell the healthcare professional about lifestyle, experiences and priorities. In that way the decision can be made with sight of both the professional and scientific angle, as well as the patient's values and preferences. Both the patient’s and the healthcare professional’s knowledge is valuable, in order to make the right decision for the patient.

4.3 Literature review on Shared Decision-Making

WP7 have made a review on the current literature about the effects of Shared Decision-Making (SDM) in patients with long-term conditions, especially in patients suffering from Chronic Obstructive Pulmonary Disease (COPD) and/or Chronic Heart Failure (CHF). The review aims to provide evidence which SDM strategies or models are the most beneficial and demonstrate effect of SDM.

The search was conducted in PubMed and CINAHL in May up to July 2021. Inclusion and exclusion criteria were defined. With this review, WP7 found 15 articles that describe the effects and significance of Shared Decision-Making for patients with chronic disease.

The conclusions were drawn from 3 reviews and 5 RCTs and 7 other studies which demonstrate SDM effects for people with chronic diseases with focus on COPD and/or CHF.

The results show that SDM interventions are complex but most SDM interventions had a positive effect improving: adherence, knowledge, decision quality and chronic illness care, decisional conflict and decision self-efficacy, perceived health status, perceived symptom severity and have an economic benefit.

A clear outcome of Shared Decision-Making interventions for patients with chronic conditions is difficult to define, however, it appears that multi-factor programmes that involve different healthcare professionals and several approaches, such as various information material, consultations and follow-up, has the best effect.

4.4 Ethical considerations of Shared Decision-Making

There are increasing numbers of frail older patients with chronic diseases and multiple comorbidities which can be burdensome for the individual and results in an increasing economic cost for society. Shared decision-making has been proposed as a way of supporting patient-centred care and avoiding unwanted interventional treatments. However, it has also been suggested that the shared decision-making approach is simply a means towards minimizing the use of expensive healthcare resources.

In healthcare, four ethics principles are used:

- Autonomy
- Non-maleficence
- Beneficence
- Justice

Autonomy is the respect for individual decisions. Non-maleficence is avoiding causing harm. Beneficence pertains to relieving, lessening or preventing harm and providing benefits and balancing benefits against risks and costs. Justice ensures that benefits, risks and costs are fairly distributed (Ibid).

Shared Decision-Making is an invaluable tool for ethical medical practice, and could improve patient-perceived outcomes, while indirectly reducing non-adherence, thus benefitting the patient, the physician and the wider healthcare community [12].

4.5 Shared Decision-Making in the context of the ADLIFE project

In order to impart knowledge and competencies in Shared Decision-Making to all partners and clinicians in ADLIFE, OUH produced and hosted a webinar on the topic.

The webinar was held virtually in October 2020 and was subsequently recorded and shared with all partners as a spoken PowerPoint presentation, so each partner and pilot site has the opportunity to share the presentation with their clinicians.

The purpose of the webinar was to give all sites knowledge about what SDM is, which elements SDM contains, and how to practice SDM in clinical practice. OUH will support all pilot sites with knowledge on SDM, different education materials and how to train the health professionals during the project's lifetime and most importantly during the intervention.

4.5.1 Elements of Shared Decision-Making

The material OUH have presented to the project partners contained following elements:

What is Shared Decision-making?

SDM is based on three key elements:

- There must be a real choice to make, which means that there must be more than one option, and not just the option between treatment and no treatment
- There must be knowledge/ evidence enough about the options
- The conversation must lead to an agreed, active choice

It is important to remember that the patient should always have the opportunity to refrain from treatment even if it would be a choice that would lead to the patient's death.

Why is Shared Decision-making relevant?

For some decisions the choice is clear, and preferences play little or no role. This is often in acute situations where postponement of treatment is a danger to the patient's life or health. This could be situations where:

- A broken hip needs surgery (+/-)
- Coronary thrombosis needs treatment or
- Bacterial meningitis requires antibiotics

In such situations, there is only one right decision to make.

For most decisions, however, there is more than one sensible choice, including the option to refrain from treatment. This is for example situations like:

- Decision on treatment of renal failure (which type of dialysis treatment would the patient prefer?)
- Treatment of depression and
- Decisions about "End of life"

In such cases, it is highly relevant to involve the patient in the decision-making process, because there is not one decision that is better than the other. What is best depends on the patient's life and preferences.

To provide further insight into what the outcome of a situation may be, if patients are not involved in decisions regarding treatment options, an example from clinical practice was provided.

The silent misdiagnosis

The silent misdiagnosis is what might happen, if the patient is not involved in decisions. This might happen because healthcare professionals are not aware of how the patient lives his/her life and what his/her preferences are, and patients do not always know the possible treatment opportunities, effects and side effects of a treatment. This results in poor quality of the decision as shown in **Figure 2**.

Figure 2. Quality of decisions [13]

There are no healthcare professionals who want to proceed with a treatment that the patient does not want, but if the healthcare professional is not aware of the patient's preferences, situations like this one can easily happen.

4.6 Practising Shared Decision-Making

Shared Decision-Making is a special form of communication. In ADLIFE it has been decided to use the SHARE model [14] for structuring the conversation, which consists of five phases:

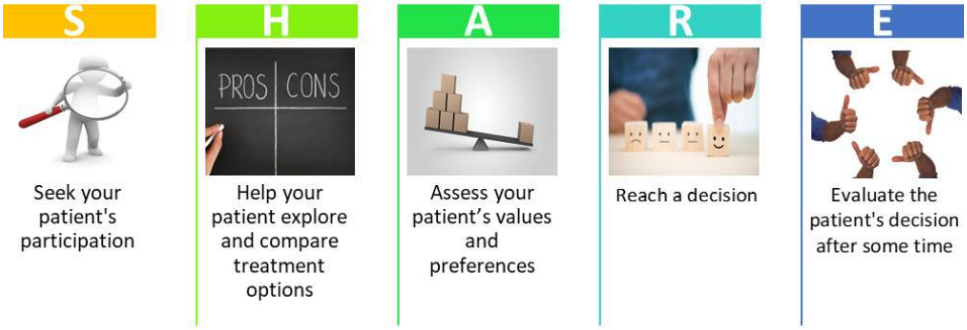

Figure 3. The SHARE model [14]

Phase 1: The conversation begins with examining the patient's wishes in relation to making a shared decision.

Phase 2: The healthcare professional helps the patient to explore and compare treatment options.

In phase 3: It is necessary to assess the patient's values and preferences and give the patient time to reflect

Phase 4: The patient and the healthcare professional reach a decision together

Phase 5: At last, the healthcare professional evaluates with the patient, if the patient still thinks the decision is the right decision, and allows the patient to change treatment choices if possible.

4.5.2 The SHARE model

The S in the SHARE model stands for: "Seek your patient's participation". To do that you have to:

- Summarize the patient's problem
- Explain that there are several options
- Make it clear that a decision needs to be made
- Invite the patient to participate into the decision
- Try to engage the patient to participate by explaining why patient participation is important
- Emphasize that all questions, inputs and considerations are welcome
- Ask which role the patient wants to play in the decision-making process

You could for example formulate yourself by saying: "The decision will affect your life and that is why it is important that we together find the treatment that suits you best. What do you think? How much do you want to be part of the decision?"

The H stands for: "Help your patient explore and compare treatment options". To do that you have to:

- Tell the patient about opportunities. It is important to provide equal and neutral information about ALL the options. Do not show what you might think is the best option, but spend equal time on each option
- Inform about the advantages, disadvantages and risks of the available options
- Explore what the patient's knowledge and perceptions are about the different options
- Create realistic expectations for, for example, treatment outcomes and consequences for the future
- Use absolute numbers
- Summarize options
- Check the patient's understanding - invite questions and ask the patient to retell

You could for example formulate yourself by saying: "To be sure I have explained your options well enough, tell me what you have noticed about the pros and cons of the options WP7 are talking about".

The A stands for: “Assess your patient’s values and preferences”. To do that you have to let the patient assess the possibilities:

- Tell again that the best treatment is the one that suits the patient's life and preferences best
- Examine the patient's preferences: How does your patient prioritize in life?
- Encourage the patient to express all preferences
- Help the patient to become aware of what influences the patient’s decision
- Discuss the "trade-off", that is in the situation in relation to the patient's preferences

You could for example formulate yourself by saying: "In order for us to find the right decision for you, it is important to understand what matters to you”

Remember to inform about the next step, which is to consider the possibilities, possibly together with relatives, and make clear that the decision does not necessarily have to be made right now. Agree when the decision will be made.

Is the patient ready to make a decision?

Perhaps the patient needs a break between talking about options and decision. Time for consideration and conversation with relatives and if the patient needs time to think, it is important to make an agreement on when the decision must be made.

Patients are different, and as the picture shows, they can have many different challenges, which have to fit in with the final decision. In such cases, it may be necessary to make room for reflection time.

The R stands for: “Reach a decision”. Before the patient and you can make a decision you have to:

- Examine whether the patient is ready to make a decision
- Summarize the possibilities briefly
- Ask for the patient's considerations and preferences
- Ask what is most important to the patient. You could ask, what makes it difficult to choose or what the patient needs to be able to make the decision
- Recognize or suggest an option based on the patient's preferences, and check if the patient agrees

Moreover, what is very important is to make the patient aware that it is possible to change the decision if needed, and then talk about the next step: what should the patient do and what do you do, to make sure that you agree on the agenda.

When the decision is made, you need to clarify the decision, by for instance saying: “What you have decided now is that you would rather…than… - is that correct?”

The E stands for: “Evaluate the decision together with the patient after some time”. You could arrange a 'trial period' with the patient if possible, and evaluate the patient's decision to make sure that it was the right decision.

You could for example formulate yourself by saying: ”How do you feel about the decision? Is it the right option for you?” If not, you probably must reconsider the decision and the possible other options in unison with your patient.

At most decision points there are a number of treatment, care or support possibilities to consider. In many clinical situations, clinical guidelines identify, summarise and evaluate the highest quality evidence in order to support decision-making. Most guidelines aim to support clinicians, not patients, in decision-making. But if the patient is to play a part in the decision-making process, they need clear, comprehensible information about the condition and the treatment or support options. This must be based on reliable research evidence, outlining outcomes, risks and uncertainties in a clear, comprehensible and unbiased manner.

Providing this verbally in a busy clinic can be extremely challenging. One solution is to ‘prescribe’ a decision aid that the patient can review and absorb at home, before returning to discuss their preferences and decide how to treat or manage their condition.

4.7 Decision aids for Shared Decision-Making

Patient decision aids are similar to clinical guidelines, in that they are based on research evidence, but they are designed not just to inform patients, but to help them think about what the different options might mean for them and to reach an informed preference.

The intention of decision aids is to help people engage in decision that require weighing the benefits and harms of treatment options [12]. They are different from more traditional patient information materials because they do not tell people what to do. Instead, they set out the facts and help people to deliberate about the options.

There are now a large number of patient decision aids available and many of them are listed on two websites, www.decisionaid.ohri.ca and www.thedecisionaidcollection.nl. Their use has been evaluated in randomised controlled trials and a Cochrane review has summarised the findings from this body of evidence [15].

In D 7.3 strategies for decision aids in the ADLIFE toolbox is described.

4.8 Concluding remarks – Implications for clinical practice

Embedding shared decision-making into clinical practice and systems, processes and workforce attitudes, skills and behaviours is a challenge, Shared Decision-Making requires a new attitude from the clinician away from the paternalistic approach to a shared decision-making approach. Shared Decision-Making will be implemented by the pilot sites and decision aids that are implemented in the ADLIFE solutions will be tested by all the Pilot sites.

The next steps on the road towards patient empowerment in the ADLIFE project is to fully integrate the selected tools into the ADLIFE solutions 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.

5. Training

ADLIFE's technology innovations will be deployed, used and evaluated in seven healthcare environments in Spain, UK, Sweden, Germany, Denmark and Israel. The stakeholder groups of the sites involved in the project have to be trained to participate in the intervention. The training has to ensure that key stakeholders have sufficient knowledge, confidence and practical understanding of both the study and the ADLIFE system to participate in, or to support, the study effectively.

A training strategy is being designed in the framework of WP6 and WP8 with the aim of delivering the adequate training and support to all stakeholder groups of the sites that will take part in the ADLIFE intervention. This section describes the activities performed in the initial phase of the training strategy. This phase covers the preparation of the basic set of core training materials, supporting the training of the end-users. These core training materials have been designed and developed collaboratively between the project partners, taken into account the target audience and aiming for simplicity and user friendliness.

The basic core set are aimed at end-users (patients and informal caregivers, and healthcare professionals –HCPs) and includes an Introductory Video, User Manual for Patient Empowerment Platform (PEP), User manual for Personalized Care Plan Management Platform (PCPMP), Walkthrough for PEP and Walkthrough for PCPMP.

For each material intended to end-users, an English version has been jointly created for use by all seven sites. Once it has been approved, each site has to translate it into their corresponding languages, insert screenshots, if required, in the pertinent language and make some minor modifications as appropriate. At the end, each site will have its own version (including translation and context adaptation).

The introductory video for intervention patients and carers have been developed in Task 2.2, (WP2). The video introducing ADLIFE project has been produced to approach patients, informal caregivers and health care professionals. Each site will have its own video in its language. The English version of the video can be accessed from the ADLIFE website. Currently there are videos in Danish, German and Spanish. The other sites are in the process of generating their own videos.

The user manuals include all the functionalities that the stakeholders are going to use during the intervention, providing comprehensive instructions on how to use the ADLIFE system. Two user manuals have been created, one for PEP platform to be used by patients and informal caregivers (developed in WP4 and to be reported in D4.2, due by June 2022) and other for the PCPMP to be used by HCPs (developed in WP3 and to be reported in D3.2, due by August 2022). The user manuals are based on the current versions of the platforms.

The walkthroughs for both PEP and PCPMP have been developed (in WPs 4 and 3 respectively) to support usability tests performed in the framework of WPs 4 and 3. The walkthroughs guide the users to gather feedback on the usability of the components of the ADLIFE platform from the perspective of the end user, prior to its deployment and use in the pilot sites. Pilot sites have to translate and localise the user manuals and walkthroughs as required according to the local deployment of ADLIFE and their integration with the local systems.

In this initial phase of training preparation, we have developed the basic set of materials for end-user (patients, informal caregivers and healthcare professionals) to facilitate their participation. In the next phase, the plan is to assess whether to expand the basic training set with other materials that reinforce the participation of end-users, such as leaflets and handbooks that provide a comprehensive reference about the project and the intervention. The next phase will also cover the production of training materials aimed at support users (local project team, local technical teams and local system administrators) of the intervention, such as Administrator guides for ADLIFE system aimed at the pilot site coordinator for the management of the system and the technical manuals to guide the pilot site local IT teams on how to use, manage and maintain the system, among others.

6. Conclusion

The seven pilot sites taking part in the ADLIFE project will use a new tool to create patient care plans based on each patient's baseline and most recent clinical data. ADLIFE toolbox promotes holistic case management, and supports integrated care at different levels of the health care system. Change management is an important issue in this process, to make sure that the ADLIFE Toolbox will be used and give value to the patients, informal caregivers and professionals.

The interview study early in the project shows that in general, many patients and carers are satisfied with the care they receive, and how it is organized. The health care professionals often see structural needs, with more coordination and integration of systems. Their suggestions of improvement are strongly linked to local organization, both structure and culture. Within the main theme improvement areas for using digital tools like ADLIFE, improvement areas could be found in all categories/areas. Many are connected to relations: a solid multi-disciplinary team which know the patient and his near ones, follows him/her over time and gets to know each other, is a safety for continuity of care. If the Interdisciplinary team (IDT) is well represented, there is also less need of referrals.

During this first half of the project change management has been a main topic in many activities and a side topic in many more. Five stages for change management (section 3.1) and three focus areas (section 3.2) are described. A strategy for change management is presented (section 3.4.1). The pilot sites have worked with the stages of change management on their own sites, and shared experiences among each other.

Shared Decision-Making as a focus area aims to empower patients. Embedding shared decision-making into clinical practice and systems, processes and workforce attitudes, skills and behaviours is a challenge, Shared Decision-Making requires a new attitude from the clinician away from the paternalistic approach to a shared decision-making approach.

Change management is difficult, and in need of a good support system. Training prepare participants for their involvement in the study. It includes informing, supporting, up-skilling and coaching activities. The training material (section 5) is part of that support system. ADLIFE has developed a set of training materials to date to support training events (Introductory Video and User Manuals for ADLIFE components).

7. Next steps

Change management will help sites to minimize as much as possible the barriers that could hamper the successful implementation of ADLIFE intervention. Pilot sites will continue their work on change management. During the fourth plenary meeting of the consortium, which took place in June 2022, the pilot sites shared their experiences so far in designing and implementing change management. In addition, the sites have set up regular meetings to discuss this issue along with the preparation and implementation of the pilot. During these meetings, the pilots will continue to share their experiences on the topic.

Change management is and will continue to be an essential issue in WP8, where the planning of the intervention is in an intense stage. D8.2 “Report on ADLIFE pilot execution”, due by Month 50 (Feb 2024), will collect the results of implementing the change management strategy, describe the organizational changes put in place before and during the site intervention and provide the guidelines on organizational change management to facilitate the implementation of ADLIFE care model in real life.

Before the intervention starts, participants in the seven sites will receive the appropriate training. The training should ensure that critical stakeholders have sufficient knowledge, confidence and practical understanding of the study and the ADLIFE system to participate in or support the study effectively. Pilot sites will define their training plan, create core training materials /tools to support training events, and localise the training materials (including translation and context adaptation).

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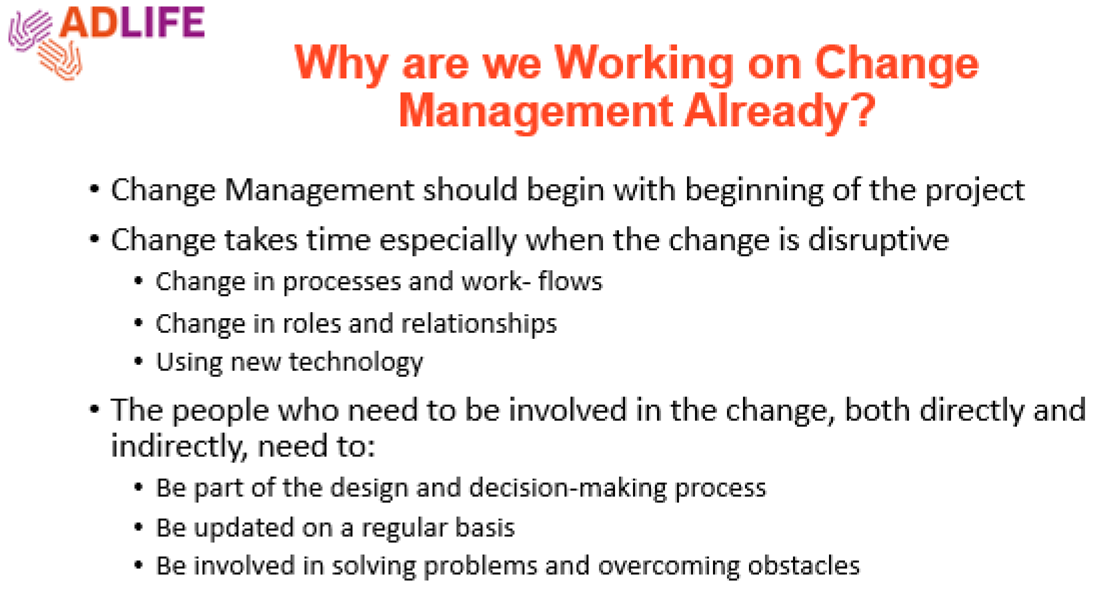
Appendix A

This project has received funding from the European Union's Horizon 2020 research programme under grant agreement No 875209.

Change Management
Second Plenary Meeting

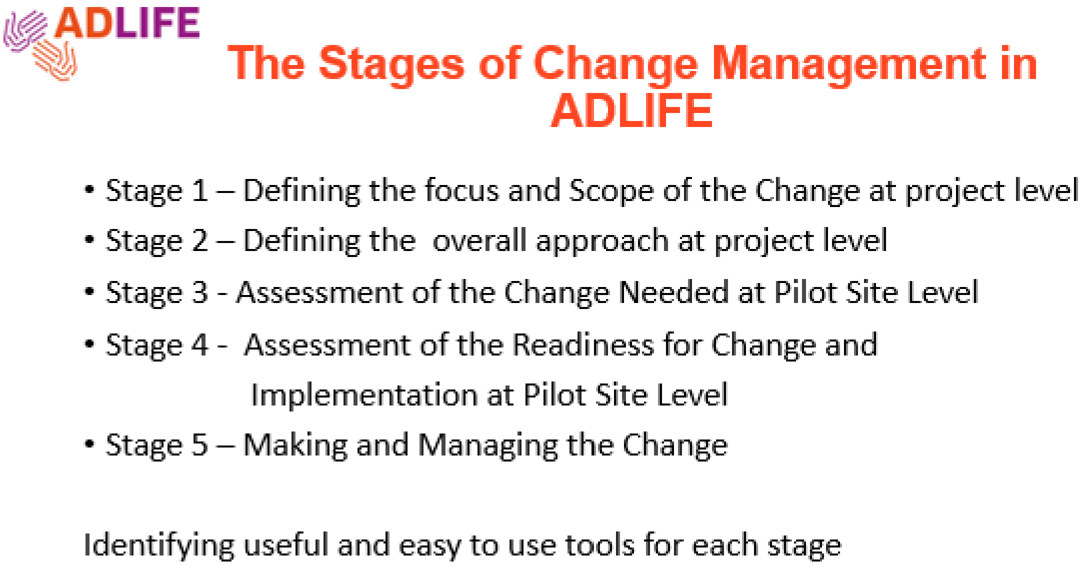
May 2021

@adlife_project



Why are we Working on Change Management Already?

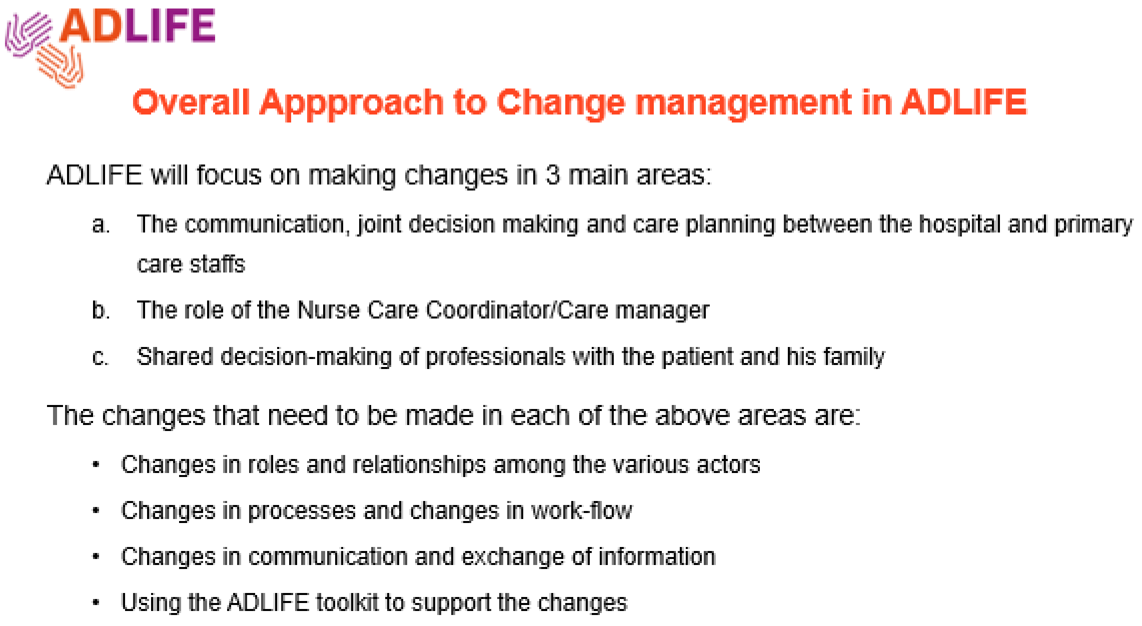
- Change Management should begin with beginning of the project
- Change takes time especially when the change is disruptive
    - Change in processes and work- flows
    - Change in roles and relationships
    - Using new technology
- The people who need to be involved in the change, both directly and indirectly, need to:
    - Be part of the design and decision-making process
    - Be updated on a regular basis
    - Be involved in solving problems and overcoming obstacles



The Stages of Change Management in ADLIFE

- Stage 1 – Defining the focus and Scope of the Change at project level
- Stage 2 – Defining the overall approach at project level
- Stage 3 - Assessment of the Change Needed at Pilot Site Level
- Stage 4 - Assessment of the Readiness for Change and Implementation at Pilot Site Level
- Stage 5 – Making and Managing the Change

Identifying useful and easy to use tools for each stage



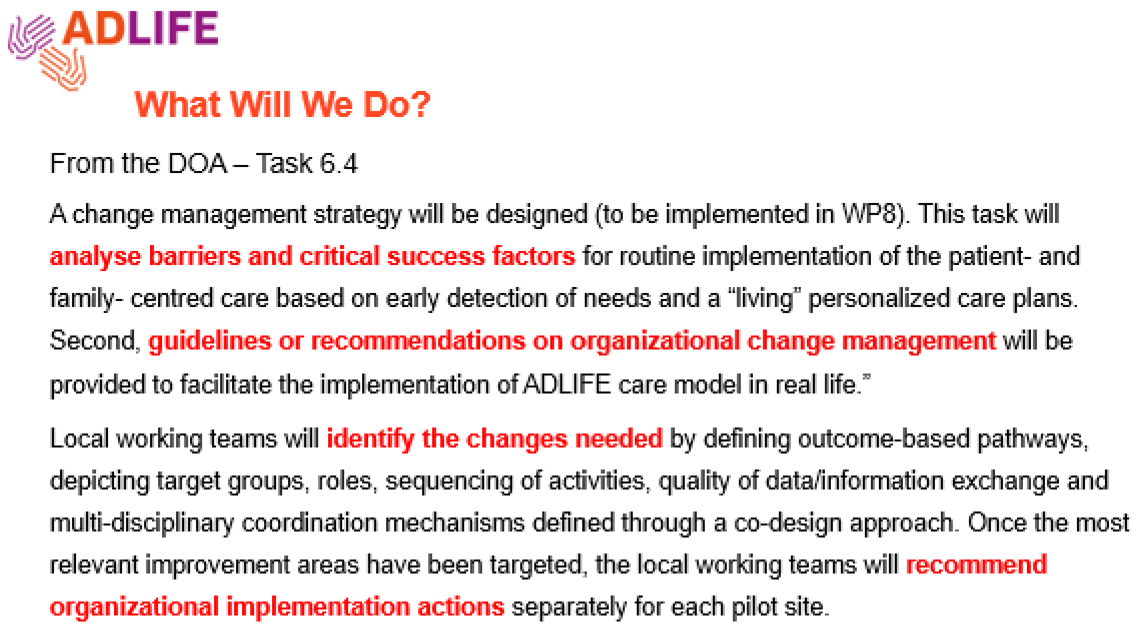
Overall Appproach to Change management in ADLIFE

ADLIFE will focus on making changes in 3 main areas:

a. The communication, joint decision making and care planning between the hospital and primary care staffs
b. The role of the Nurse Care Coordinator/Care manager
c. Shared decision-making of professionals with the patient and his family

The changes that need to be made in each of the above areas are:

- Changes in roles and relationships among the various actors
- Changes in processes and changes in work-flow
- Changes in communication and exchange of information
- Using the ADLIFE toolkit to support the changes



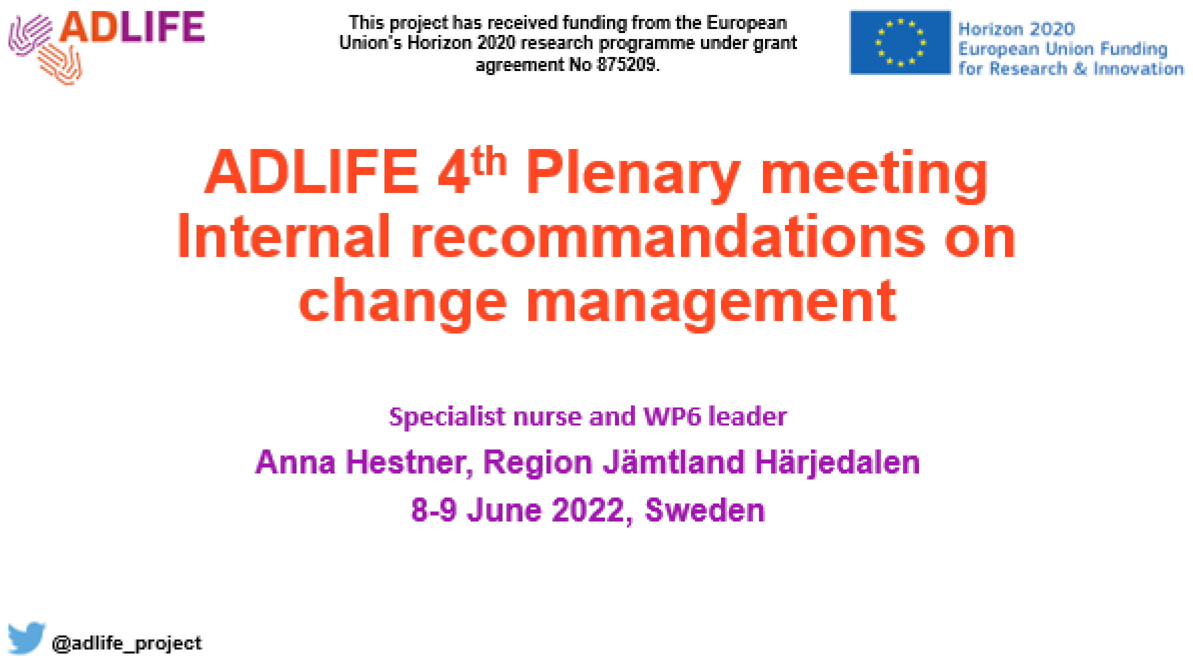
What Will We Do?

From the DOA – Task 6.4

A change management strategy will be designed (to be implemented in WP8). This task will **analyse barriers and critical success factors** for routine implementation of the patient- and family- centred care based on early detection of needs and a "living" personalized care plans. Second, **guidelines or recommendations on organizational change management** will be provided to facilitate the implementation of ADLIFE care model in real life."

Local working teams will **identify the changes needed** by defining outcome-based pathways, depicting target groups, roles, sequencing of activities, quality of data/information exchange and multi-disciplinary coordination mechanisms defined through a co-design approach. Once the most relevant improvement areas have been targeted, the local working teams will **recommend organizational implementation actions** separately for each pilot site.

Appendix B



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Horizon 2020
European Union Funding
for Research & Innovation

ADLIFE 4th Plenary meeting Internal recommendations on change management

Specialist nurse and WP6 leader

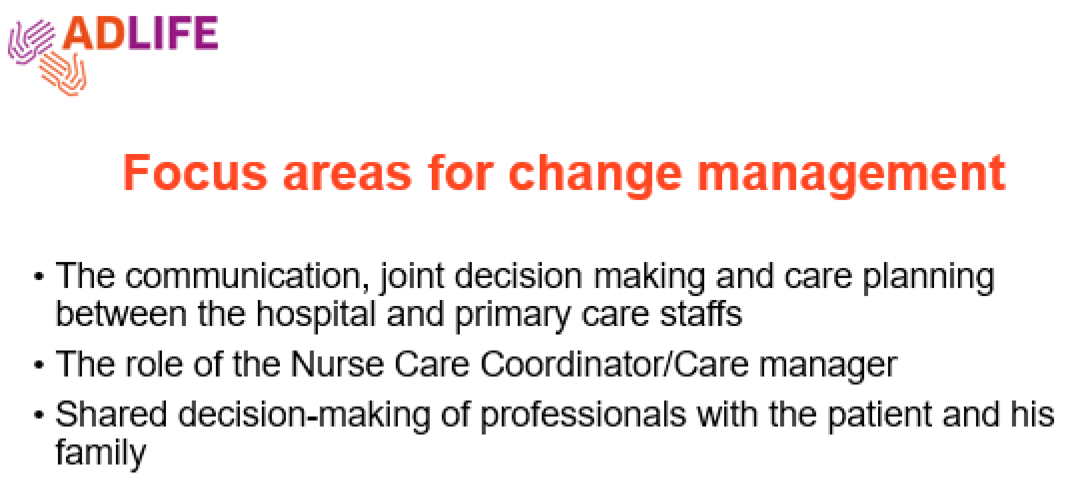
Anna Hestner, Region Jämtland Härjedalen

8-9 June 2022, Sweden

@adlife_project

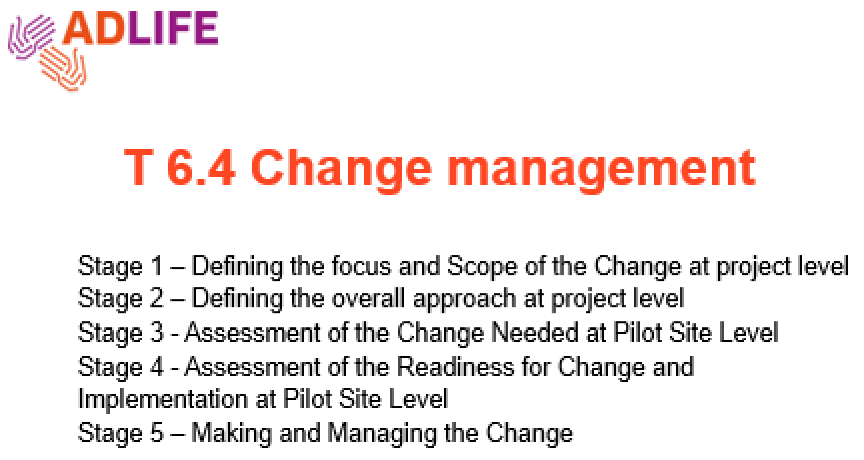
D 6.2 Recommendations for change management in integrated personalized care delivery

"The intent is not only to implement changes for purposes of the pilots but to facilitate change that will be sustainable in real life after the project's end."
Dr Rachelle Kaye in first review report on T 6.4



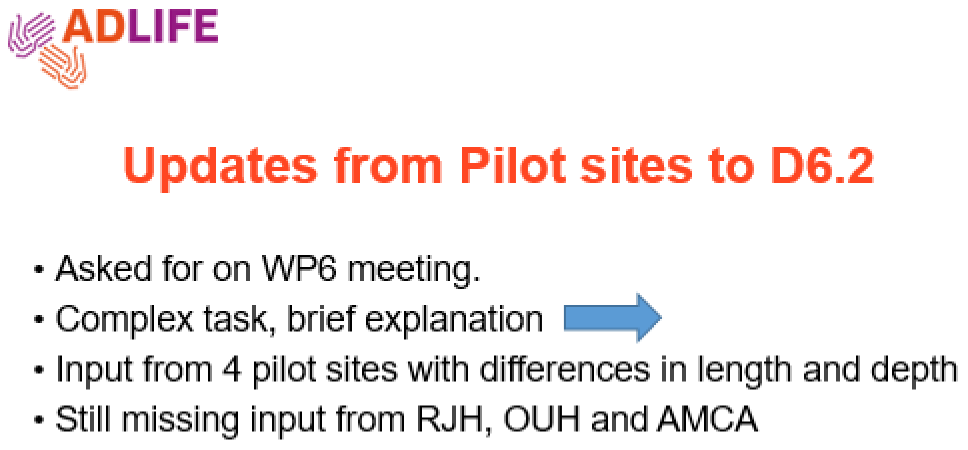
Focus areas for change management

- The communication, joint decision making and care planning between the hospital and primary care staffs
- The role of the Nurse Care Coordinator/Care manager
- Shared decision-making of professionals with the patient and his family



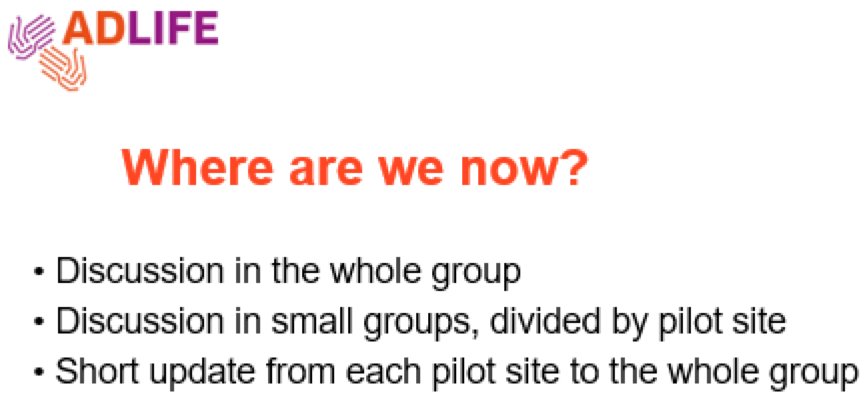
T 6.4 Change management

Stage 1 – Defining the focus and Scope of the Change at project level
Stage 2 – Defining the overall approach at project level
Stage 3 - Assessment of the Change Needed at Pilot Site Level
Stage 4 - Assessment of the Readiness for Change and Implementation at Pilot Site Level
Stage 5 – Making and Managing the Change



Updates from Pilot sites to D6.2

- Asked for on WP6 meeting.
- Complex task, brief explanation ➡
- Input from 4 pilot sites with differences in length and depth
- Still missing input from RJH, OUH and AMCA



Where are we now?

- Discussion in the whole group
- Discussion in small groups, divided by pilot site
- Short update from each pilot site to the whole group