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1 Executive Summary

This report focuses on the report of the online survey results (D4.2) from Work Package 4 of the AFFIRMO project.

We worked closely with our partners, AdvPha, UNIPD, UMU, EuGMS, UCSC, UMCFD and A-A, to develop and distribute the online survey. AdvPha helped in developing the online survey platform, while UNIPD, UMU, EuGMS, UCSC, UMCFD and A-A helped with the distribution of the survey to patients, caregivers and healthcare professionals in their respective countries.

Some of the results from the online survey formed the basis for the list of needs, quality performance indicators and outcomes presented in the Delphi process (T4.5). The survey was distributed to participants in five countries (UK, Italy, Spain, Romania and Denmark) between 31 May 2022 and 31 January 2023. A total of 1,305 participants were recruited (UK n=436, Italy n=260, Spain n=308, Romania n=272, Denmark n=29). Characteristics of the sample were (n; mean (SD) age, years; % female): Patients: 659; 70.9 (10.2) years, 52.8% female; Caregivers: 201, 58.3 (15.2) years, 73.1% female; HCPs: 445, 47.4 (10.6); 57.2% female. In the patients' group, there were significant sex differences related to health status, with women reporting greater impairments in mobility and usual activities, and higher pain/discomfort, while men reported a better overall QoL (VAS score: 60.0 (50.0-80.0) vs. 70.0 (50.0-80.0)) (all $p<0.05$). Sex differences were also evident in patient's engagement, with men showing more engagement than women (3.0(2.0-3.0) vs. 3.0(2.0-3.0)) ($p<0.05$), and in the perception of quality of care, with men more satisfied than women (5.16 (3.83-6.33) vs 4.16 (3.00-6.00), respectively). Age was significantly associated with quality of life in four of the five domains of the EQ-5D-3L, with patients aged >65 years reporting greater impairment ($p<0.05$).

In the caregiver group, women reported more pain/discomfort than men, whilst men reported fewer negative life changes than women (BCOS score: 63.5 (57.5-85.0) vs (62.0 (52.7-73.0)). Caregivers aged <65 years reported greater impairment in mobility and usual activities than those aged ≥65 years, and those aged <50 years reported more anxiety/depression. Caregivers aged <75 years reported significantly greater negative life changes than those aged ≥75 years. Quality of life was higher in Romania compared with Spain and Italy, with less impairment in self-care and lower reported anxiety. Caregivers from Spain reported less negative life changes compared to caregivers from other countries included in the survey. Caregivers with further education level reported better overall quality of life and greater negative life changes compared to caregivers with lower levels of education.

Engagement personas were characterised based on the results of the ACE and PHE-s® scales. For patients, using the PHE-s® scale, highly engaged personas were defined as being male, being as <75 years old, educated at secondary level or above, and having <3 co-morbidities; country of recruitment did not differ significantly between those with high and low engagement levels. For the ACE scale, highly engaged personas were classified as <65 years old, educated at degree level or above, from Northern Europe and having <3 co-morbidities; there were no significant differences between high and low engagement in men and women.

For the caregivers' group, no significant differences were found between high and low engagement levels by age group, sex, country of recruitment or level of education.

Fifty-three items were identified from the online survey, including 27 key needs, nine quality performance indicators and 17 key outcomes. This list of items formed the basis for the Delphi process and has been reported in detail in Deliverable 4.4.

2 Introduction

Purpose of Deliverable and Overview of structure

Work Package 4 of the AFFIRMO project is a mixed-methods study, which aims to assess the needs of patients, caregivers, and healthcare professionals (HCPs) for the comprehensive management of multimorbidity including atrial fibrillation (AF), and to examine ways of optimising care and self-management. This will lead to the development of a patient-centred approach for older multimorbid AF patients in the clinical practice. In addition, the results of the Delphi process will inform the outcomes of the clinical trial in WP7.

Objectives of the study are: (i) to ascertain the experience of living with (patients and caregivers) or managing AF and multimorbidity (patients, caregivers, HCPs) and to assess patient/caregiver needs; **(ii)** to identify what outcomes patients, caregivers, and HCPs consider as measures of effectiveness and indicators of quality of care (QPIs); **(iii)** to evaluate whether the empowerment level of patients and caregivers may modify their perceived needs and burden of diseases.

Figure 1 shows a summary of the study procedures for WP4.

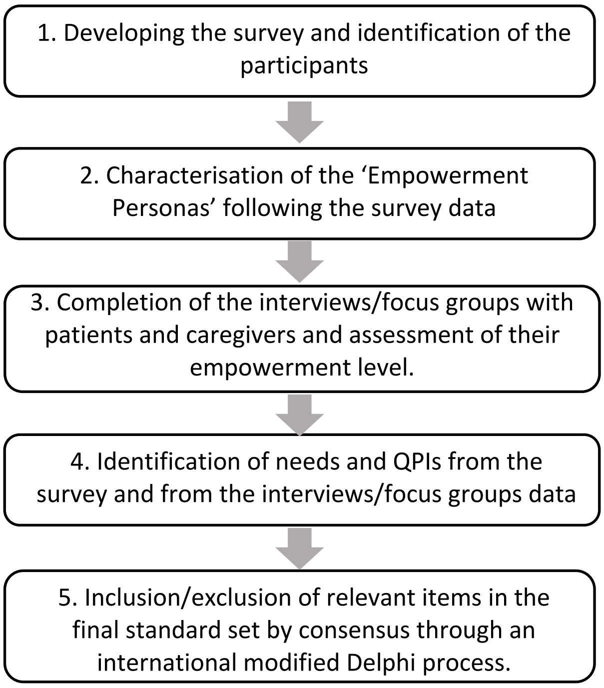


Figure 1: Study procedures for WP4.

This Deliverable report (D4.2) summarises the results of the survey conducted in five countries (Italy, Spain, Denmark, Romania, and the UK) to identify the needs and key quality performance indicators of patients and carers, and healthcare professionals, in relation to managing AF and multimorbidity.

3 Methods

The online platform hosting the survey was developed by AdvPha, with UoL, UNIPD and UCSC developing the content of the survey. AdvPha translated the survey into the other four languages (Italian, Romanian, Spanish and Danish) from English and the translated versions of the online survey were approved by the respective country leads.

The survey focussed on identifying the needs and quality performance indicators (QPIs) of each group (patients with AF and multimorbidity, caregivers, and healthcare professionals) in relation to managing multimorbidity, their views on current care pathways, barriers/enablers of self-management, and quality of life. To better identify needs and QPIs for specific categories of patients and caregivers, the survey also recorded data on multimorbidity (in terms of type and severity of diseases), socioeconomic status (e.g., educational attainment, living arrangements, proxies of economic level, current or previous occupation), and empowerment level (low, moderate, and high). The survey also included a number of questionnaires listed in section 3.1. Annex B contains the English version of the surveys.

The survey was open to patients with AF and one or more concomitant chronic health conditions (multimorbidity), and their caregivers (dyads and non-dyads), and to HCPs managing patients with AF and one or more concomitant chronic health conditions. Participants were recruited from the five partner countries (UK, Italy, Spain, Denmark, Romania) from 31 May 2022 to 31 January 2023, with a target of 300 participants for each country (n=100 patients, n=100 caregivers, n=100 HCPs), resulting in a total target of 1,500 participants.

AdvPha provided a weekly report (anonymised, only showing number of recruited participants for each group – patients, caregivers, and HCPs by country) to UoL to monitor recruitment. Anonymised online data collected in the survey were transferred from AdvPha to UoL by secure file transfer once recruitment was concluded.

3.1 Questionnaires

3.1.1 Patients' questionnaires

Patients were asked to fill in the following questionnaires as part of the online survey:

- **EQ-5D-3L**[1]: is a health-related quality of life measure. It comprises five dimensions related to (i) mobility; (ii) self-care; (iii) usual activities; (iv) pain/discomfort; and (v) anxiety/depression. Each of these dimensions can be scored by ticking one of the three level options available: (i) no problems; (ii) some problems; and (iii) extreme problems. Additionally, the EQ Visual Analogue Scale (VAS) included in the questionnaire allows the patients to score their health based on their own perception, from "best imaginable health status" to "worst imaginable health status" on a scale of 0 (worse health) to 100 (best health). Higher scores on each domain indicate better quality of life.

- **Healthcare Climate Questionnaire (HCCQ)**[2]**:** can be used to assess patients' perception of the degree to which their specific doctor or team of healthcare providers is autonomous and supportive. The survey utilised the short version (6-items), scored by averaging the individual item scores. Scores range from 1 (strongly disagree) to 7 (strongly agree), with a higher score demonstrating greater patient satisfaction.

- **Altarum Consumer Engagement (ACE) Measure™ [3]:** it is a validated questionnaire licensed by Altarum that measures the engagement level of an individual in making health and healthcare decisions. The 12-item version was employed. It uses a 5-point response scale (rated 0 to 4). To report the values with the original 25-item version (scale 0 to 100), the average score of the 12-item version has to be multiplied by 6.25. A higher score represents greater patient engagement. Scores in the top 50% (median and above) were classified as 'high engagement' and those in the bottom 50% as 'low engagement'.

- **FRAIL questionnaire[4]:** assesses frailty using five components: *Fatigue* (Are you fatigued?); *Resistance* (Cannot walk up 1 flight of stairs?); *Aerobic* (Cannot walk 100 m?); *Illness* (Do you have more than 5 underlying diseases?); *Loss of weight* (Have you lost more than 5% of your body weight in the past 6 months?), scored as 'Yes=1' and 'No=0'. Scores range from 0-5, with a higher score indicating greater frailty (defined with at least three out of five criteria).

- **5-item Medication Adherence Report Scale – MARS-5[5]:** is a 5-item validated assessment tool used to measure patients' non-adherence behaviours towards medication (e.g., forgetting or deliberately missing doses). Total scores range from 5 to 25, with higher scores indicating greater medication adherence.

- **The Patient Health Engagement scale (PHE-s®)[6]:** is a validated tool designed for patients to assess their engagement in healthcare. It includes items scored on a 7-point scale, designed to identify specific psycho-social needs that may be potential targets to deliver personalised supportive actions. Scores of ≥3 were categorised as 'high engagement' and scores <3 as 'low engagement'.

3.1.2 Caregivers' questionnaires

Caregivers were asked to fill in the following questionnaires as part of the online survey:

- **EQ-5D-3L [1]:** a health-related quality of life measure. See previous section for detail on this questionnaire.

- **The Caregivers Health Engagement Scale (CHE-s®)[7]:** is a validated tool designed for family and caregivers to monitor aspects of the caregiving functions that are important to them, and to assess their engagement in healthcare. It includes items scored on a 7-point scale, designed to identify specific psycho-social needs that may be potential targets to deliver personalised supportive actions. Scoring was undertaken by converting the scores in a scale 1-4 and then calculating the median, with higher scores showing greater engagement. Scores of ≥3 were categorised as 'high engagement' and scores <3 as 'low engagement'.

- **Bakas Caregiving Outcomes Scale (BCOS)[8]:** is a 10-item unidimensional scale to measure life changes in family caregivers of persons with chronic illness. The items are scored on a 7-

point scale, which ranges from -3 (changed for the worst) to +3 (changed for the best). Scoring is done by giving a value from 1 to 7 to each score (where -3=1 and +3=7), and then summing the individual score of each item, with a higher score showing positive changes, and lower scores showing negative changes.

3.2 Engagement personas

One of the fundamental pillars on which AFFIRMO is based is the importance of patient empowerment. "Engaging and empowering people & communities" and constitutes the first of the five strategies of the "Framework on integrated people-centred health services"[9] reported by the World Health Organization (WHO).

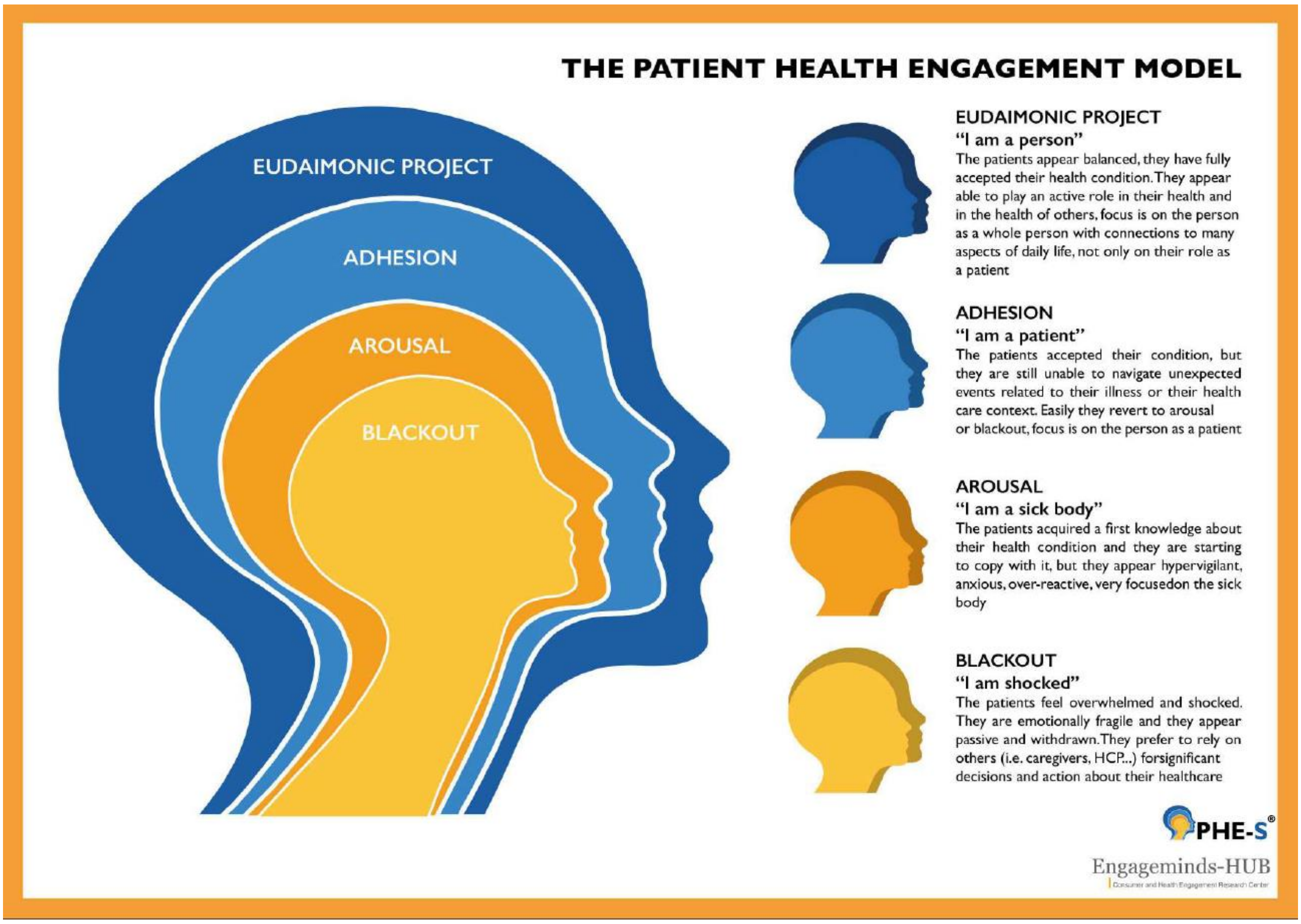
Empowered patients/ caregivers have the necessary knowledge, skills, attitudes, and self-awareness about their condition to understand their lifestyle and treatment options, make informed choices about their health and have control over the management of their condition/health in their daily life[10]. The levels of patient empowerment are also the basis of their meaningful engagement in the healthcare journey. Current scientific debate defines **patient empowerment** as a process that help patients in gain control over their lives, increasing their capacity to act on issues that they themselves define as important. A process through which patients individually and collectively are able to express their needs, present their concerns, devise strategies for involvement in decision making and take action to meet those needs (Adapted from European Union Network on Patient Safety and Quality of Care, PaSQ 2012[11]). Whereas in the AFFIRMO project, we define **patient engagement** as the situation in which patients take an active role in activities or decisions that will have consequences for the patient community, because of their specific knowledge and relevant experience as patients (adapted from EPF project "Value+" 2009[12]).

Since both dimensions of the patient experience are crucial for AFFIRMO, in this survey we described engagement personas on the basis of two validated measurement: the PHE® which describes the psychological readiness of patients to get involved in their healthcare journey and the ACE to measure the level of patients' activation.

The Patient Health Engagement model (PHE model)

As stated in the previous section, the Patient Health Engagement model (PHE model) describes patient engagement as a process, which depends on the psychological readiness of the patient to play an active role in his/her own health management, comprising all of the emotional and motivational processes underlying this assumption of proactivity[13].

The PHE model describes four phases of patient engagement (Figure 2), each phase characterised by a different way that the patient copes with his/her condition, a different level of elaboration of what the health condition entails, and thus different needs or preferences a patient may have.



EUDAIMONIC PROJECT
"I am a person"
The patients appear balanced, they have fully accepted their health condition. They appear able to play an active role in their health and in the health of others, focus is on the person as a whole person with connections to many aspects of daily life, not only on their role as a patient

ADHESION
"I am a patient"
The patients accepted their condition, but they are still unable to navigate unexpected events related to their illness or their health care context. Easily they revert to arousal or blackout, focus is on the person as a patient

AROUSAL
"I am a sick body"
The patients acquired a first knowledge about their health condition and they are starting to copy with it, but they appear hypervigilant, anxious, over-reactive, very focusedon the sick body

BLACKOUT
"I am shocked"
The patients feel overwhelmed and shocked. They are emotionally fragile and they appear passive and withdrawn. They prefer to rely on others (i.e. caregivers, HCP...) forsignificant decisions and action about their healthcare

PHE-S®
Engageminds-HUB
Consumer and Health Engagement Research Center

Figure 2: The PHE-s® model

The four phases described by the PHE model are[13, 14]:

1. **Blackout:** this phase mainly occurs when the patient experiences feelings of psychological vulnerability, often with a very recent diagnosis or a relapse. Patients in this phase often appear blocked, incapable of taking autonomous decisions and to take care of themselves, generally relying on caregivers (formal and informal) for decisions and management. Their own diagnosis and the change in lifestyle required by it are often seen by blackout patients as conflicting with their way of living, and these risks leading to non-adherence and feelings of sadness or anger. Patients in this phase need to elaborate the diagnosis, become more aware of what happened and accept it. They need to be helped in acknowledging the health behaviours expected from them, and to resume the knowledge regarding their health condition. Given their psychological state, this type of patients is very difficult to engage in activities that require at least a certain level of engagement.
2. **Arousal:** patients in the Arousal state have started to acknowledge and accept their own health condition, but still have a very superficial knowledge on how to effectively self-manage. Thus, their difficulty to adapt their lifestyle, the amount of information presented to them, and the uncertainty they have to face, leads to feelings of anxiety: these patients often report feeling hypervigilant, and strongly concerned whenever they feel something different. For instance, an arousal patient might feel something that is expected as a side effect, and be concerned that it is not "normal" or that it is a new symptom. Patients in this position need to organise their knowledge regarding their condition and their medications, become more aware of their self-efficacy, and thus assume a more positive mindset regarding what they can do day-by-day.

3. **Adhesion:** patients in the Adhesion phase have generally succeeded in the process of regulating their negative emotions regarding their health condition and have thus developed a good acceptance of their disease. They have a good awareness of what is happening to them, and of what they have, and what they can do to manage it. However, patients in adhesion are not fully autonomous: they still perceive themselves as “patients” (as opposed to “persons”), and their illness as something rather external to them (as opposed to something that is part of their current life). Thus, they need to be supported in maintaining the correct health behaviours, as these are not necessarily part of their daily routine: health behaviours are perceived as something they *have to* do, but not as something that is the new “normality”. In particular, changes or atypical situations might constitute triggers for non-adherence. Patients in Adhesion need to be supported in building a solid daily routine and in becoming more autonomous (e.g., be supported in accomplishing simple tasks in self-management or in information-seeking behaviours, without direct prompts, and with tools to set up a daily routine of self-care).
4. **Eudaimonic Project:** from the Greek word εὐδαιμονία, which literally translates as “good spirit” (or, in modern terms, “happiness and wellbeing as the purpose of life”), this is the group of patients with the highest level of engagement. Patients in this phase have become fully aware of their condition, to the point where this awareness has become part of their own personality, and health-related behaviours are part of their normal lives. Health and disease management are now part of their own life goals, which allows these patients to have a more positive perspective towards their disease, and thus a more satisfactory life. Nevertheless, patients can also “go back” in positions (due to relapses, new symptoms, or other events in their lives): it is thus fundamental to maintain their level of engagement and support them with tools that allow them to self-manage effectively. Patients in Eudaimonic Project need to have access to networks of peers, they need to further improve and maintain those sets of personal skills that allow an effective self-management and be supported in overcoming those barriers (physical or social) that make it difficult to reach their life goals.

Caregiver engagement was measured using the Caregivers Health Engagement Scale (CHE_s®)[15]. The Caregiver Health Engagement Model configures a multidimensional experience that helps determine the caregiver's involvement in the patient's care path. The focused dimensions are as follows:

- Process the change emotionally

- Mature a proactive and balanced role in the care process

- Relate effectively with operators and the health system

- Manage the care and assistance needs of your loved ones

Based on these dimensions, the research identified four incremental levels of caregiver involvement expressed in the following profiles:

Denial and escape. The caregiver finds him/herself in a situation of emotional shock, overwhelmed by negative emotions, tends to implement defensive mechanisms (avoidance, denial, anger), has difficulty understanding and anticipating the needs of assistance and care of their loved one. Tends to distance themselves from the role of caregiver and delegate every decision to others.

Hyperactivation. Even in the face of an initial understanding and acceptance of the current state of their loved one, the caregiver reports a state of emotional alarm and hyperactivation, is careful to monitor every clinical sign and symptom, but has difficulty empathizing with the patient's psychological difficulties. For clinical decisions he/she still prefers to rely on the referring clinicians.

Abnegation and drowning. The caregiver has managed to develop adaptive strategies for efficient management of care activities, is more organised, capable of understanding the care needs of his/her loved one and responding effectively to them. He/she becomes more engaged in conversations with carers, but is still insecure and tired on a psychological level and unable to integrate the role of caregiver in a balanced way with his own life and self-expression needs.

Balance and equilibrium. The caregiver shows full autonomy in responding to the essential needs of their loved one. He perceives himself as more capable, effective and confident in his own skills, and has managed to consolidate a good partnership relationship with the healthcare provider team in which he/she participates with greater proactivity and collaboration. He/she has managed to find a greater balance and a more harmonious integration of the different life tasks and the various roles that he/she is called to perform.

The Altarum Consumer Engagement Measurement (ACE)

The ACE Measure[3] is a scientifically-validated patient engagement assessment tool that looks at several aspects of the engagement process, such as patterns of seeking information about the healthcare process and options, or the willingness of participating in treatment decisions. The ACE aims to identify factors encouraging the adoption of patients' involvement in the management of their own health, and also evaluating programs aiming to encourage patient decision-making. The domains of engagement assessed by the ACE are:

- **Commitment**: which examines the patients’ commitment to everyday health behaviours. This allows prediction of the patient overall health, of patient adherence to medical guidance, and to patient success in the management of the chronic disease.
- **Informed Choice**: measures the patients’ desire to learn more about their health, choosing adequate providers and opting for informed procedures. This domain predicts the patient interest in “Shared Decision Making” and the patient’s ability to make comparisons between healthcare options.
- **Navigation**: measures patients’ skills and experience in using healthcare benefits. This domain predicts the patient ability to successfully use benefits of the healthcare process.

3.3 Data analysis

The data was tested for normality using the Shapiro-Wilk test, with *p<.0001* indicating that the data was not normally distributed. Non-parametric tests were used for data analysis. The Mann-Whitney U test was used to test for sex-related differences in questionnaires scores. The Kruskal-Wallis test was used to test for differences in questionnaire scores among age groups. A post-hoc test was conducted to identify differences between groups, using a pairwise comparison with significance values adjusted by the Bonferroni correction. P-values <.05 were considered statistically significant. A partial correlation analysis was performed to test for correlation (p<.05) between PHE-s®, ACE and FRAIL scores, with age and sex.

Characteristics of the engagement personas were assessed grouping the scores on the PHE_s® and ACE to quantify the engagement level of patients, and the scores of the CHE-s were used to quantify the engagement level of caregivers. Level of engagement was divided into low and high (cut-off PHE_s®: score <3 and ≥3; ACE: bottom 50% and top 50%, respectively), and the personas were analysed by age, sex, level of education, country of recruitment and number of comorbidities. A chi-squared test was used to test for differences between low and high engagement groups. A pairwise Z-score test adjusted for Bonferroni correction was conducted to identify differences between groups. The Mann Whitney U test was used to assess the effect of age on the engagement level (high and low groups).

Given the low recruitment rate of patients in Denmark (n=3) and to allow for between country comparisons, Danish patients were grouped with those from the UK. Comparisons were made between patients from Northern Europe (UK and Denmark), Eastern Europe (Romania), and Southern Europe (Spain and Italy). There was also a low recruitment rate for caregivers in both the UK and Denmark. Therefore, comparison of the data for caregivers between countries was restricted to Italy, Spain and Romania.

4 Results

The online survey opened simultaneously in all five participating countries on 31 May 2022 and closed on 31 January 2023. This deliverable was delayed due to challenges in obtaining the ethics and regulatory approvals in all five countries.

4.1 Demographic and groups characteristics

A total of 1,305 participants completed the online survey (n, mean (SD) age, years; % male): **Patients:** 659; 70.9 (10.2) years, 52.8% female; **Caregivers:** 201, 58.3 (15.2) years, 73.1% female; **HCPs:** 445, 47.4 (10.6); 57.2% female. Figure 3 shows the country distribution for each participant group. Most patients were recruited from the UK (n=358, 54.3%), while the caregivers were mainly from Spain, Romania, and Italy. HCPs were mainly recruited from UK, Italy, Spain, and Romania.

Table 1 presents the characteristics of the patients who completed the online survey. Level of education among patients varied, with degree level or above being the most common (42.5%). Most patients were currently retired (78.5%), married/had a partner (68%), and lived at home with family without assistance (63.6%). When assistance was required, it was mainly informal (92.7%). Patients reported different co-morbidities; the most common was hypertension (59%). Most patients reported having more than two co-morbidities (45%), with 10% having more than five co-morbidities.

Table 2 presents the characteristics of the caregivers who participated. Most caregivers reported spending less than 6h/day in caring activities (50.2%). Most were informal caregivers (91.5%), with more than five years as a caregiver (44.8%), mainly assisting a parent (36.8%), spouse/partner (27.9%) or other relative (25.4%). Less than half (46.8%) lived with the assisted person. The person they cared for had two or more comorbidities, predominantly cardiovascular conditions. Most assisted persons were taking more than five medications (70.6%), were able to walk independently (60.7%), but required assistance with some activities of daily living.

Table 3 presents the characteristics of the HCPs that completed the online survey. Most HCP respondents were medical doctors (73.5%), either cardiologists (45.2%) or geriatricians (31.7%). Years of practice varied from less than five years (23.6%) to more than 30 years (20.9%). Most worked in secondary (36%) or tertiary care (38.7%) and managed two to five patients with AF per week, and the most common comorbidities were cardiovascular diseases (92.6%).

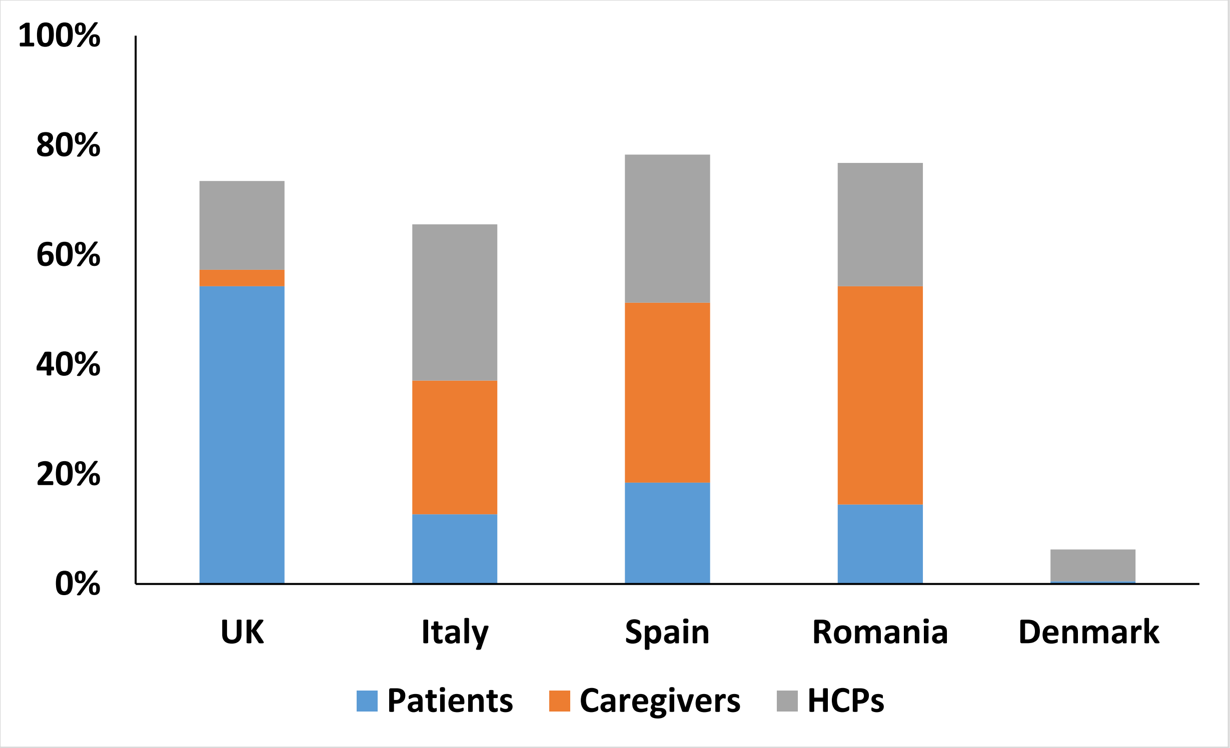


Figure 3: Percentage of participants recruited for the survey, divided by group and country.

Table 1. Patients' characteristics

Mean (SD), n (%)	**Patient group (n=659)**
Age (years)	70.9 (10.2)
Women	348 (52.8)
Ethnicity	
White	645 (97.9)
Hispanic or Latino	6 (1.1)
Country	
UK	358 (54.3)
Italy	84 (12.7)
Spain	122 (18.5)
Romania	92 (14.0)
Denmark	3 (0.5)
Level of Education	
None	17 (2.7)
Primary	77 (12.0)
Secondary	51 (7.7)
High School*	158 (24.0)
Apprenticeship/Professional training/vocational training*	57 (8.6)
Degree level or above	280 (42.5)
Other/prefer not to say	19 (2.9)
Employment status	
Employed	102 (15.5)
Unemployed	20 (3.0)
Retired	517 (78.5)
Disability Allowance	20 (3.0)
Marital status	
Single/Never married	39 (5.9)
Married/Partnered	448 (68.0)
Widowed	111 (16.8)
Separated/Divorced	61 (9.3)
Living arrangements	
Living at home alone with no assistance	168 (25.5)
Living at home with family with no assistance	419 (63.6)
Living at home with part-time assistance	50 (7.6)
Living at home with full-time assistance	19 (2.9)
Living in long-term care facilities	3 (0.5)
If assistance is required, the caregiver is	
Formal	48 (7.3)
Informal	611 (92.7)
Smoking status	
Current	33 (5.0)
Former	281 (42.6)
Never	345 (52.4)
Comorbidities (n, %)	
Hypertension	389 (59.0)
Cardiovascular disease	399 (60.5)
Diabetes mellitus	108 (16.4)
Thyroid disease	108 (16.4)
Chronic obstructive pulmonary disease	41 (6.2)

Gastrointestinal diseases	128 (19.4)
Chronic liver disease	19 (2.9)
Kidney disease	62 (9.4)
Previous stroke	57 (8.6)
Parkinson’s disease	8 (1.2)
Multiple sclerosis	3 (0.5)
Dementia	2 (0.3)
Cognitive decline	46 (7.0)
Osteoarthritis	165 (25.0)
Osteoporosis/previous hip fracture	51 (7.7)
Rheumatoid arthritis	29 (4.4)
Chronic pain	77 (11.7)
Vision problems	119 (18.1)
Hearing problems	105 (15.9)
Cancer	40 (6.1)
Other	182 (27.6)
Number of comorbidities	
None	27 (4.0)
1-2 comorbidities	270 (41.0)
3-5 comorbidities	297 (45.0)
>5 comorbidities	66 (10.0)
Hospital visits per year, median (IQR)	0.0 (0.0-1.0)

IQR, interquartile range; SD, standard deviation

**in subsequent analyses, High school and Apprentice/Professional Training/Vocational Training were included in the ‘Secondary level’ education group*

Table 2. Caregivers' characteristics

Mean (SD), n (%)	**Caregiver group (n=201)**
Age (years)	58.3 (15.2)
Women	147 (73.1)
Ethnicity	
White	199 (99.0
Other	2 (1.0)
Country	
UK	6 (3.0)
Italy	49 (24.4)
Spain	66 (32.8)
Romania	80 (39.8)
Denmark	0 (0.0)
Level of Education	
None	2 (1.0)
Primary	23 (11.4)
Secondary	22 (11.0)
High School	40 (20.0)
Apprenticeship/Professional training/vocational training	15 (7.5)
Degree level or above	77 (35.0)
Other/prefer not to say	22 (11.0)
Time spent caregiving	
Full-time	43 (21.4)
Less than 6 h/day, daily	57 (28.4)
Less than 6h/day, not daily	101 (50.2)
Person assisted – if informal (n=184)	
Spouse/partner	56 (27.9)
Father	31 (15.4)
Mother	43 (21.4)
Any other relative	51 (25.4)
A friend	3 (1.5)
Living with assisted person	94 (46.8)
Type of caregiver	
Formal	17(8.5)
Informal	184(91.5)
Years being caregiver	
≤1 year	50 (24.9)
2-4 years	61 (30.3)
≥5 years	90 (44.8)
Comorbidities of the assisted person	
High blood pressure	124 (61.7)
Heart disease	171 (85.1)
Diabetes	66 (32.8)
Thyroid problems	38 (18.9)
Chronic obstructive pulmonary disease	24 (11.9)
Gastrointestinal diseases	32 (15.9)
Chronic liver disease	7 (3.5)
Kidney disease	38 (18.9)
Previous stroke	31 (15.4)
Parkinson's disease	5 (2.5)

Multiple sclerosis	1 (0.5)
Dementia	11 (5.5)
Cognitive decline	29 (14.4)
Osteoarthritis	41 (20.4)
Osteoporosis/previous hip fracture	22 (10.9)
Rheumatoid arthritis	14 (7.0)
Chronic pain	22 (10.9)
Vision problems	41 (20.4)
Hearing problems	42 (20.9)
Cancer	22 (10.9)
Other	27 (13.4)
Number of comorbidities of the assisted person	
None	5 (2.5)
1-2 comorbidities	79 (39.3)
3-5 comorbidities	87 (43.3)
>5 comorbidities	30 (15.0)
Number of medications taken by the assisted person	
None	5 (2.5)
1 to 2	10 (5.0)
3 to 4	44 (21.9)
5 or more	142 (70.6)
Mobility level of the assisted person	
Can walk independently	122 (60.7)
Walk with a cane/walking stick	37 (18.4)
Walk with a walker/Zimmer-frame	28 (13.9)
Moves around with a wheelchair	5 (2.5)
Confined at home, mostly lying on the bed	9 (4.5)
Activities that requires assistance	
Eating	37 (18.4)
Bathing	81 (40.3)
Dressing	45 (22.4)
Toileting	35 (17.4)
Transferring	141 (70.1)

IQR, interquartile range; SD, standard deviation

Table 3. Healthcare professionals' characteristics

Mean (SD), n (%)	**Healthcare professional group (n=445)**
Age (years)	47.4 (10.6)
Women	257 (57.8)
Country	
UK	72 (16.2)
Italy	127 (28.5)
Spain	120 (27.0)
Romania	100 (22.5)
Denmark	26 (5.8)
Occupation	
Medical doctor	327 (73.5)
Nurse	110 (24.7)
Other	8 (1.8)
Specialty	
Cardiology	201 (45.2)
GP	17 (3.8)
Geriatrics/Elderly care	141 (31.7)
Haematology	8 (1.8)
Internal medicine	38 (8.5)
Other	40 (9.0)
Years of practice	
0 to 5	105 (23.6)
6 to 10	65 (14.6)
11 to 20	105 (23.6)
21 to 30	77 (17.3)
>30	93 (20.9)
Care sector	
Primary care	113 (25.4)
Secondary care	160 (36.0)
Tertiary care	172 (38.7)
University Hospital	
Yes	337 (75.7)
No	108 (24.3)
Regularly working with patients with chronic condition(s)	
Yes	430 (96.6)
Sometimes	13 (2.9)
No	2 (0.4)
Patients with AF managed per week	
0 to 1	45(10.1)
2 to 5	231 (51.9)
6 to 10	81 (18.2)
>10	88 (19.8)
Most frequently managed conditions	
Cardiovascular	412 (92.6)
Diabetes	172 (38.7)
Endocrinologic diseases	6 (1.3)
Respiratory diseases	136 (30.6)
Chronic liver diseases	7 (1.6)
Gastrointestinal diseases	13 (2.9)
Kidney diseases	73 (16.4)

Cerebrovascular diseases	71 (16.0)
Neurologic diseases	19 (4.3)
Minor/major cognitive disorders	86 (19.3)
Osteoarticular diseases	25 (5.6)
Rheumatologic diseases	9 (2.0)
Chronic pain	16 (3.6)
Vision problems	0 (0.0)
Hearing problems	0 (0.0)
Other	12 (2.7)
Most represented age group	
<60 years	11 (2.5)
60-70 years	108 (24.3)
71-80 years	201 (45.2)
>80 years	125 (28.1)
Assisted patients with AF and at least one other chronic condition	
0 to 10%	7 (1.6)
11 to 30%	28 (6.3)
31 to 50%	56 (12.6)
51 to 80%	141 (31.7)
>80%	213 (47.9)

AF, atrial fibrillation; SD, standard deviation

5 Analysis of the patients and caregivers' responses to questionnaires

5.1 Patients

5.1.1 Differences in quality of life, patient engagement, and self-reported medication adherence and frailty by sex and age.

Women reported greater impairment in mobility and usual activities, and more pain/discomfort impacting their quality of life compared to men (Table 4); with a trend towards more anxiety and depression among women. Men rated their overall quality of life higher than women.

There was significantly greater impairment in mobility, greater pain and discomfort, and more anxiety/depression reported in those aged 65 years and older compared to those <65 years (Table 4). Those aged 75 years and older reported significantly greater impairment in their ability for self-care than those <75 years. However, there was no overall significant difference in quality of life reported by age category.

Patient engagement assessed by the PHE-s® demonstrated a significant difference between men and women, with men reporting greater engagement in healthcare than women, however there were no differences by age group (Table 4). In contrast, younger adults (aged <65 years) reported significantly greater engagement in healthcare decisions than those aged ≥65 years, when assessed using the ACE questionnaire (Table 4) but there were no differences by sex.

There were no significant differences in frailty or self-reported medication adherence between men and women or between age groups.

There were significant differences between men and women and by age group regarding patient perceptions about quality of care. Women and all adults <65 years reported feeling better supported by their healthcare team (Table 4).

Table 4. Quality of life, patient engagement, and self-reported medication adherence and frailty: comparison by sex and age group.

Questionnaire Median (IQR)	Sex				Age groups			
	Overall N= 659	**Male N= 311**	**Female N=348**	**P value**	**18-64 years N= 156**	**65-74 years N= 237**	**75+ years N=266**	**P value**
Quality of Life (EQ-5D-3L)								
Mobility	1.0 (1.0-2.0)	1.0 (1.0-2.0)	2.0 (1.0-2.0)*	**<0.001**	1.0 (1.0-2.0)	2.0 (1.0-2.0)	2.0 (1.0-2.0)$^{+}$	**<0.0001**
Self-care	1.0 (1.0-1.0)	1.0 (1.0-1.0)	1.0 (1.0-1.0)	0.277	1.0 (1.0-1.0)	1.0 (1.0-1.0)	1.0 (1.0-2.0)$^{++}$	**0.002**
Usual activities	2.0 (1.0-2.0)	1.0 (1.0-2.0)	2.0 (1.0-2.0)*	**<0.0001**	1.0 (1.0-2.0)	2.0 (1.0-2.0)	2.0 (1.0-2.0)	0.215
Pain discomfort	2.0 (1.0-2.0)	1.0 (1.0-2.0)	2.0 (1.0-2.0)*	**<0.0001**	1.0 (1.0-2.0)	2.0 (1.0-2.0)$^{+}$	2.0 (1.0-2.0)	**0.006**
Anxiety/Depression	2.0 (1.0-2.0)	1.0 (1.0-2.0)	2.0 (1.0-2.0)	0.053	2.0 (1.0-2.0)	2.0 (1.0-2.0)	1.0 (1.0-2.0)$^{++}$	**0.008**
VAS[1]	70.0 (50.0-80.0)	70.0 (50.0-80.0)**	60.0 (50.0-80.0)	**0.007**	70.0 (50.0-80.0)	65.0 (50.0-80.0)	69.0 (50.0-80.0)	0.762
Perception of quality of care (HCCQ[2])	4.66 (2.84)	5.16 (3.83-6.33)	4.16 (3.00-6.00)*	**<0.0001**	5.41 (3.54-6.33)	4.17(3.0-6.0)$^{+}$	4.83 (3.5-6.2)	**0.018**
Medication Adherence (MARS-5[3])	24.00 (22.00-25.00)	24.00 (22.00-25.00)	24.00 (22.00-25.00)	0.373	24.00 (22.0-25.00)	24.00 (23.0-25.0)	24.00 (22.0-25.00)	0.791
Frailty (FRAIL)	1.00 (0.0-2.0)	1.0 (1.0-2.0)	1.0 (0.0-2.0)	0.641	1.0 (1.0-2.0)	1.0 (0.0-2.0)	1.0 (0.0-2.0)	0.709
Patient Engagement(PHE-s®[4])	3.0 (2.0-3.0)	3.0 (2.0-3.0)**	3.0 (2.0-3.0)	**<0.0001**	3.0 (2.0-3.0)	3.0 (2.0-3.0)	3.0 (2.0-3.0)	0.294

Patient Engagement (ACE[5])	52.00 (46.67-58.67)	52.40 (46.67-58.00)	52.83 (46.67-58.67)	0.207	54.67 (49.33-61.33) [+]	52.00 (45.33-57.33)	52.00 (10.67)	**0.001**

[1] Visual Analogue Scale, [2] The Health Care Climate Questionnaire, [3] Medication Adherence Report Scale (5 items), [4] Altarum Consumer Engagement Scale, [5] Patient Health Engagement Scale.

**significantly different compared to men*

***significant compared to women*

[+] significantly different compared to 18-64 years age group.

[++] significantly different compared to 18-64 years age group and to 65-74 age group.

5.1.2 Differences in quality of life, patient engagement, and self-reported medication adherence and frailty by country

Patients from Southern Europe reported greater impairment in self-care than those from Eastern or Northern Europe (Table 5). There was no overall significant difference in mobility, usual activities, and anxiety/depression reported by country (Table 5). Preliminary analyses showed an overall difference in pain/discomfort and VAS score (Table 5) by region, however post-hoc pairwise comparisons adjusted by the Bonferroni correction, revealed no differences among groups.

Frailty varied by region, with patients from Eastern Europe emerging significantly frailer than patients from Northern Europe. Self-reported medication adherence was significantly higher among patients in Southern Europe compared to those from Eastern and Northern Europe.

The perception of quality of care provided was lower in Northern Europe compared to Southern and Eastern Europe, with the latter having the best perception of the quality of care provided.

Preliminary analysis showed overall differences in patient engagement (with both the ACE and PHE-s® scores) by region (Table 5), however after pairwise comparisons adjusted by the Bonferroni correction, no significant differences between groups were identified.

Table 5. Quality of life, patient engagement, and self-reported medication adherence and frailty: comparison by country

Questionnaire	Overall N=659	Eastern Europe N= 92	Northern Europe N= 361	Southern Europe N= 206	p-value
Quality of Life (EQ-5D-3L score)					
Mobility	1.0 (1.0-2.0)	1.0 (1.0-2.0)	1.0 (1.0-2.0)	1.0 (1.0-2.0)	0.580
Self-care	1.0 (1.0-1.0)	1.0 (1.0-1.0)	1.0 (1.0-1.0)	1.0 (1.0-2.0)$^{+}$	**<0.0001**
Usual activities	2.0 (1.0-2.0)	1.0 (1.0-2.0)	1.0 (1.0-2.0)	1.0 (1.0-2.0)	0.111
Pain discomfort	2.0 (1.0-2.0)	1.0 (1.0-2.0)	2.0 (1.0-2.0)	2.0 (1.0-2.0)	**0.025***
Anxiety/Depression	2.0 (1.0-2.0)	2.0 (1.0-2.0)	2.0 (1.0-2.0)	2.0 (1.0-2.0)	0.354
VAS	70.0 (50.0-80.0)	70.0 (50.0-80.0)	70.0 (50.0-80.0)	60.0 (50.0-80.0)	**0.046***
Perception of quality of care (HCCQ[1])	4.66 (2.84)	6.42 (5.67-6.83) $^{++}$	3.83 (2.50-5.00)	5.83 (4.16-6.33) $^{+++}$	**<0.0001**
Medication Adherence (MARS-5[2])	24.0(22.0-25.0)	24.0 (22.0-25.0)	24.0 (22.0-24.0)	25.0 (22.0-25.0) $^{+++}$	**<0.0001**
Frailty (FRAIL)	1.0 (0.0-2.0)	1.0 (1.0-3.0) $^{+}$	1.0 (0.0-2.0)	1.0 (0.0-2.0)	**0.013**
Patient Engagement (PHE-s®[3])	3.0 (2.0-3.0)	3.0 (2.0-4.0)	3.0 (2.0-3.0)	3.0 (2.0-3.0)	**0.031***
Patient Engagement (ACE[4])	52.00 (46.67-58.67)	53.33 (46.66-59.66)	53.33 (48.00-58.66)	50.70 (45.33-57.33)	**0.030***

[1]*The Health Care Climate Questionnaire,* [2]*Medication Adherence Report Scale (5 items),* [3]*Patient Health Engagement Scale,* [4]*Altarum Consumer Engagement Scale.*

$^{+}$significantly different compared to Northern Europe

$^{++}$significantly different compared to Northern and Southern Europe

$^{+++}$significantly different compared to Northern and Eastern Europe

**Post-hoc pairwise comparisons show no differences between groups*

5.1.3 Differences in quality of life, patient engagement, and self-reported medication adherence and frailty by level of education

There were some differences in quality of life by level of education. Patients with primary school level education only reported greater impairment in self-care and mobility compared to patients with secondary education or higher (Table 6). Overall QoL was rated significantly higher by patients with degree level or above education compared to those with primary or secondary education only (Table 6). There was no overall significant difference in usual activities, pain/discomfort, and anxiety/depression or frailty reported by level of education (Table 6).

Patient engagement was significantly different by level of education. Patients with degree level or above education reported greater engagement with healthcare assessed by the ACE score compared to patients with lower education, however there were no differences in patient engagement by educational level assessed by the PHE-s® (Table 6).

Medication adherence was significantly higher in those with primary level education compared to those with more years of education (Table 6). Preliminary analyses showed overall differences in the perception of quality of care by educational level, however pairwise comparisons adjusted by the Bonferroni correction, revealed no significant between group differences.

Nineteen patients did not report their level of educational attainment, however the results remained unchanged when this group was included in the analyses (Table 6).

Table 6. Differences in quality of life, patient engagement, and self-reported medication adherence and frailty: comparison by level of education.

Questionnaire	Overall N=659	Primary school n=94	Secondary school** n=266	Degree level or above n=280	P value
Quality of Life (EQ-5D-3L score)					
Mobility	1.0 (1.0-2.0)	2.0 (1.0-2.0)$^{+}$	1.0 (1.0-2.0)	1.0 (1.0-2.0)	**0.002**
Self-care	1.0 (1.0-1.0)	1.0 (1.0-2.0)$^{+}$	1.0 (1.0-2.0)	1.0 (1.0-1.0)	**<0.0001**
Usual activities	2.0 (1.0-2.0)	2.0 (1.0-2.0)	2.0 (1.0-2.0)	1.5 (1.0-2.0)	0.189
Pain discomfort	2.0 (1.0-2.0)	2.0 (1.0-2.0)	2.0 (1.0-2.0)	2.0 (1.0-2.0)	0.147
Anxiety/Depression	2.0 (1.0-2.0)	2.0 (1.0-2.0)	2.0 (1.0-2.0)	1.0 (1.0-2.0)	0.50
VAS	70.0 (50.0-80.0)	60.0 (50.0-76.2)	66.5 (50.0-80.0)	70.0 (55.0-80.0)$^{++}$	**0.004**
Perception of quality of care (HCCQ[1])	4.66 (2.84)	5.33 (3.83-6.33)	5.00 (3.50-6.83)	4.33 (3.00-5.83)	**0.004***
Medication Adherence (MARS-5[2])	24.00 (22.00-25.00)	25.0 (23.0-25.0)$^{+++}$	24.0 (22.0-25.0)	24.0 (22.0-25.0)	**0.009**
Frailty (FRAIL)	1.00 (0.0-2.0)	1.0 (1.0-2.0)	1.0 (0.0-2.0)	1.0 (0.0-2.0)	0.505
Patient Engagement (PHE-s®[3])	3.0 (2.0-3.0)	3.0 (2.0-3.0)	3.0 (2.0-3.0)	3.0 (2.0-3.0)	0.053
Patient Engagement (ACE[4])	52.00 (46.67-58.67)	49.33 (42.66-54.66)	52.0 (46.66-58.66)	53.33 (48.00-58.66)$^{++}$	**<0.0001**

[1]The Health Care Climate Questionnaire, [2]Medication Adherence Report Scale (5 items), [3]Patient Health Engagement Scale, [4]Altarum Consumer Engagement Scale.

[+]significant compared to "Secondary" and "Degree level or above" groups.

[++]significant compared to "Primary" group.

[+++]significant compared to "Degree level or above" group.

**Post-hoc pairwise comparisons show no differences between groups*

*** High school and Apprentice/Professional Training/Vocational Training were included in the 'Secondary level' education group*

5.1.4 Correlation analysis

A partial correlation analysis (controlling for sex and age) showed that there was a weak, positive significant correlation in patient engagement between the ACE and PHE-s® scores ($r_s(655) = .265$, $p < 0.0001$). There was no correlation between patient engagement and frailty (PHE-s and FRAIL score ($r_s(655) = -0.004$, $p = 0.915$) or ACE and FRAIL score($r_s(655) = 0.006$, $p = 0.970$). Full analyses are provided in Annex A.

5.1.5 Impact of comorbidities on the engagement level

Patient engagement in healthcare was significantly different depending on the number of co-morbidities, when assessed with both the PHE-s scale (χ^2=11.893, p=0.003), and the ACE scale (χ^2=15.473, p=<0.0001) (Table 7). Those with three or more co-morbidities reported less engagement in the management of their healthcare than patients with two or less comorbidities (Table 7).

Table 7. Engagement level by number of co-morbidities reported.

Questionnaire Median (IQR)	1-2 comorbidities N=275	3-5 comorbidities N=297	>5 co-morbidities N=66	P- value (Kruskal-Wallis)
Patient Engagement (PHE-s®[1])	3.0 (2.0-3.0)	3.0⁺ (2.0-3.0)	3.0⁺ (2.0-3.0)	**0.001**
Patient Engagement (ACE[2])	53.3 (49.3-60.0)	52.0 (46.6-57.3)⁺	49.3 (44.0-57.3)⁺	**0.001**

[1]Patient Health Engagement Scale, [2]Altarum Consumer Engagement Scale

⁺significantly different compared to those with 1-2 comorbidities

5.2 Caregivers

5.2.1 Differences in quality of life, impact on life and engagement in the care process by sex and age group.

The only difference in quality of life between male and female caregivers was in the pain/discomfort domain, with female caregivers reporting significantly greater pain/discomfort impacting their quality of life compared to male caregivers (Table 8). Men reported less negative impact on their life (assessed by the BCOS scale) than women.

There were no significant differences in caregiver engagement level neither between men and women, nor between age groups.

Age significantly affected quality of life, with caregivers under 65 years reporting poorer mobility and ability to conduct their usual activities. Caregivers aged ≥75 years reported greater self-care compared with other groups. Caregivers aged <50 years reported greater anxiety and depression compared with other groups. Overall quality of life was better in caregivers aged <65 years (Table 8). No differences in the pain/discomfort score was found between age groups. Caregivers <75 years old reported greater negative life changes, with caregivers in the age group 50-64 years being the most affected.

Table 8. Differences in quality of life, caregivers' engagement, and life changes: comparison by sex and age group

Questionnaire (median-IQR)	**Sex**				**Age groups**				
	Overall N= 201	**Men N=54**	**Women N=147**	**P value**	**<50 years N= 57**	**50-64 years N= 81**	**65-74 years N= 29**	**75+ years N=34**	**P value**
Caregiver Engagement (CHE-s®^{1})	3.0 (2.0-3.0)	3.0 (2.0-3.0)	3.0 (2.0-3.0)	0.644	3.0 (2.0-3.0)	3.0 (2.0-3.0)	3.0 (2.5-4.0)	3.0 (2.0-3.0)	0.143
Quality of Life (EQ-5D-3L score)									
Mobility	1.0 (1.0-1.0)	1.0 (1.0-2.0)	1.0 (0.0-1.0)	0.249	1.0 (1.0-1.0)	1.0 (1.0-1.0)	1.0 (1.0-2.0)$^{+}$	2.0 (1.0-2.0)$^{++}$	**<0.0001**
Self-care	1.0 (1.0-1.0)	1.0 (1.0-1.0)	1.0 (1.0-1.0)	0.199	1.0 (0.0)	1.0 (0.0)	1.0 (0.0)	1.0 (1.0)$^{++}$	**<0.0001**
Usual activities	1.0 (1.0-1.0)	1.0 (1.0-1.0)	1.0 (1.0-1.0)	0.583	1.0 (1.0-1.0)	1.0 (1.0-1.0)	1.0 (1.0-2.0)	2.0 (1.0-2.0)$^{++}$	**<0.0001**
Pain/discomfort	1.0 (1.0-2.0)	1.0 (1.0-2.0)	1.0 (1.0-2.0)*	0.40	1.0 (1.0-2.0)	1.0 (1.0-2.0)	2.0 (2.0-2.0)	1.0 (1.0-2.0)	0.104
Anxiety/Depression	1.0 (1.0-2.0)	1.0 (1.0-2.0)	1.0 (1.0-2.0)	0.148	1.0 (1.0-2.0)$^{+}$	2.0 (1.0-2.0)	2.0 (1.0-2.0)	2.0 (1.0-2.0)	**0.001**
VAS	80.0 (56.0-90.0)	77.50 (59.25-90.00)	80.00 (50.00-90.00)	0.842	80.00 (70.00-90.00)$^{+++}$	80.00 (52.50-90.00)	70.00 (50.00-80.00)$^{+}$	69.00 (50.00-92.50)$^{+}$	**0.002**
Life changes (BCOS^{2})	62.00 (52.75-73.00)	63.5 (57.5-85.0)**	61.0 (50.0-70.0)	0.24	60.0 (52.00-81.00)	59.0 (50.00-65.00)	66.0 (60.00-78.00)	70.0 (57.50-88.50)$^{++++}$	**0.006**

^{1}*Caregivers Health Engagement Scale,* ^{2}*Bakas Caregiving Outcomes Scale* _*significantly different compared to men_

**significantly different compared to women

$^{+}$_significantly different compared to <50 years age group_

$^{++}$_significantly different compared to <50 years age group and to 65-74 years age groups_

$^{+++}$_significantly different compared to 65-74 years age group and to +75 years age group_

$^{++++}$_significantly different compared to 65-74 years age group_

5.2.2 Differences in quality of life, life changes and engagement in the care process between countries.

Caregivers from Romania reported better self-care compared to caregivers from Spain, and lower anxiety/depression compared to caregivers from Italy (Table 9). Overall quality of life was significantly higher in caregivers from Romania compared to those from Spain and Italy (Table 9). There was no significant difference in mobility, usual activities, and pain/discomfort scores for caregivers between countries.

Caregivers from Spain reported lesser negative life changes (BCOS scale) compared to caregivers from Italy and Romania.

Preliminary analyses showed an overall difference in caregivers' engagement between countries, however after pairwise comparisons adjusted by the Bonferroni correction, no significant differences between groups were identified.

Table 9. Differences in quality of life, caregivers’ engagement, and life changes: comparison by country.

Questionnaire	Overall N=195[a]	Italy n=49	Spain n=66	Romania n=80	P value
Caregiver Engagement (CHE-s®[1])	3.0 (2.0-3.0)	3.0 (2.0-3.0)	3.0 (2.0-3.2)	3.0 (2.0-3.0)	**0.037***
Quality of Life (EQ-5D-3L score)					
Mobility	1.0 (1.0-1.0)	1.0 (1.0-1.5)	1.0 (1.0-1.0)	1.0 (1.0-1.0)	0.104
Self-care	1.0 (1.0-1.0)	1.0 (1.0-1.0)	1.0 (1.0-1.0)	1.0 (1.0-1.0)$^{+}$	**0.011**
Usual activities	1.0 (1.0-1.0)	1.0 (1.0-2.0)	1.0 (1.0-1.2)	1.0 (1.0-1.0)	0.340
Pain/discomfort	1.0 (1.0-2.0)	2.0 (1.0-2.0)	1.0 (1.0-2.0)	1.0 (1.0-2.0)	0.109
Anxiety/Depression	1.0 (1.0-2.0)	2.0 (1.0-2.0)	1.0 (1.0-2.0)	1.0 (1.0-2.0)$^{++}$	**0.018**
VAS	80.0 (57.0-90.0)	75.00 (50.00-82.50)	70.00 (50.00-81.75)	80.00 (70.00-90.00)$^{+}$	**0.001**
Life changes (BCOS[2])	62.00 (53.00-73.00)	60.0 (52.50-64.00)	66.0 (61.75-88.00)$^{+++}$	58.0 (49.25-76.75)	**<0.0001**

[a] Caregivers from the UK was removed from the analysis as the sample size was too small (n=6), no caregivers from Denmark were recruited.

[1] Caregiver Health Engagement Scale, [2] BAKAS Caregiving Outcomes Scale, $^{+}$significant compared to Spain, $^{++}$significant compared to Italy,

*$^{+++}$significant compared to Italy and Romania, *post-hoc pairwise comparison shows no significant differences between groups*

5.2.3 Differences in quality of life, life changes and engagement in the care process between levels of education

Caregivers with only primary school level education reported greater impairment in usual activities and mobility, compared to those with greater educational attainment (Table 10). Overall quality of life was rated significantly higher by caregivers with degree level education or above (Table 10). No statistically significant differences were reported between groups in the pain/discomfort score. Preliminary analysis showed an overall difference in the anxiety/depression domain by education level, however after pairwise comparisons adjusted by the Bonferroni correction, no significant differences between groups were evident.

Caregivers with primary education reported less negative life changes compared to the other groups (Table 10). There were no significant differences in caregiver engagement by level of education.

Table 10. Differences in quality of life, caregivers' engagement, and life changes: comparison by level of education.

Questionnaire	Overall N=201	Primary n=25	Secondary** n=77	Degree level or above n=77	Other/ prefer not to say n= 22	P value
Caregiver Engagement (CHE-s®[1])	3.0 (2.0-3.0)	3.0 (2.0-3.0)	3.0 (2.0-3.0)	3.0 (2.0-3.0)	3.0 (1.0)	0.902
Quality of Life (EQ-5D-3L score)						
Mobility	1.0 (1.0-1.0)	2.0 (1.0-2.0)$^{+}$	1.0 (1.0-1.5)	1.0 (1.0-1.0)	1.0 (1.0-1.0)	**<0.0001**
Self-care	1.0 (1.0-1.0)	1.0 (1.0-2.0)$^{+}$	1.0 (1.0-1.0)	1.0 (1.0-1.0)	1.0 (1.0-1.0)	**<0.0001**
Usual activities	1.0 (1.0-1.0)	2.0 (1.0-2.0)$^{++}$	1.0 (1.0-1.5)	1.0 (1.0-1.0)	1.0 (1.0-1.0)	**0.002**
Pain/discomfort	1.0 (1.0-2.0)	2.0 (1.0-1.5)	2.0 (1.0-2.0)	1.0 (1.0-2.0)	1.0 (1.0-2.0)	0.064
Anxiety/Depression	1.0 (1.0-2.0)	2.0 (1.0-2.0)	2.0 (1.0-2.0)	1.0 (1.0-2.0)	1.0 (1.0-1.25)	**0.047***
VAS	80.0 (56.0-90.0)	65.0 (50.0-70.0)	70.0 (50.0-86.0)	80.0 (70.0-90.0)$^{+++}$	82.5 (60.0-90.0)$^{++++}$	**<0.0001**
Life changes (BCOS[2])	62.00 (52.75-73.00)	84.0 (63.5-92.5)$^{+}$	61.0 (52.5-70.0)	59.0 (50.0-71.5)	61.0 (54.0-64.5)	**0.001**

[1]*Caregiver Health Engagement Scale,* [2]*Bakas Caregiving Outcomes Scale*

$^{+}$*significant compared to all the other groups*

$^{++}$*significant compared to "Degree level or above" group and to the "Other/prefer not to say" group*

[+++] *significant compared to “Primary” and “Secondary” group*

[++++] *significant compared to “Primary”*

**Post-hoc pairwise comparison shows no differences between groups*

*** High school and Apprentice/Professional Training/Vocational Training were included in the ‘Secondary level’ education group*

5.3 *Engagement Personas*

Utilising data from the ACE and PHE-s®, characteristics of the patient engagement personas were identified (Figure 4). Based on the PHE-s®, 428 (65%) and 231 (35%) were defined as 'high' and 'low' engagement, respectively. Patients in the high engagement group were more likely to be male (χ^2=15.425, *p=<0.0001*), be <75 years of age (X^2=6.457, *p=0.04*), have less than three co-morbidities (χ^2=11.893, *p=0.003*), and have secondary level education or above (χ^2=9.028, *p=0.29*), compared to those in the low engagement group (Table 11). No differences in high vs. low engagement were found by country of recruitment (Table 11). Based on the ACE, 369 (56%) and 290 (44%) people were defined a 'high' (median score ≥52) and 'low' engagement. Patients in the high engagement group were more likely to be <65 years old (χ^2=10.680, *p=0.005*), living in Northern Europe (χ^2=6.773, *p=0.034*), have degree level or above education (χ^2=17.975, *p<0.0001*), and less than three co-morbidities (χ^2=15.473, *p=<0.0001*) compared to those in the low engagement group (Table 11). There were no significant differences in sex frequency between patients in the high and low engagement groups (Table 11).

Based on the CHE-s®, 138 (69%) and 63 (31%) were classified as 'high' and 'low' engagers, however, there were no significant differences between sex, age group, country of recruitment, or level of education (Table 12).

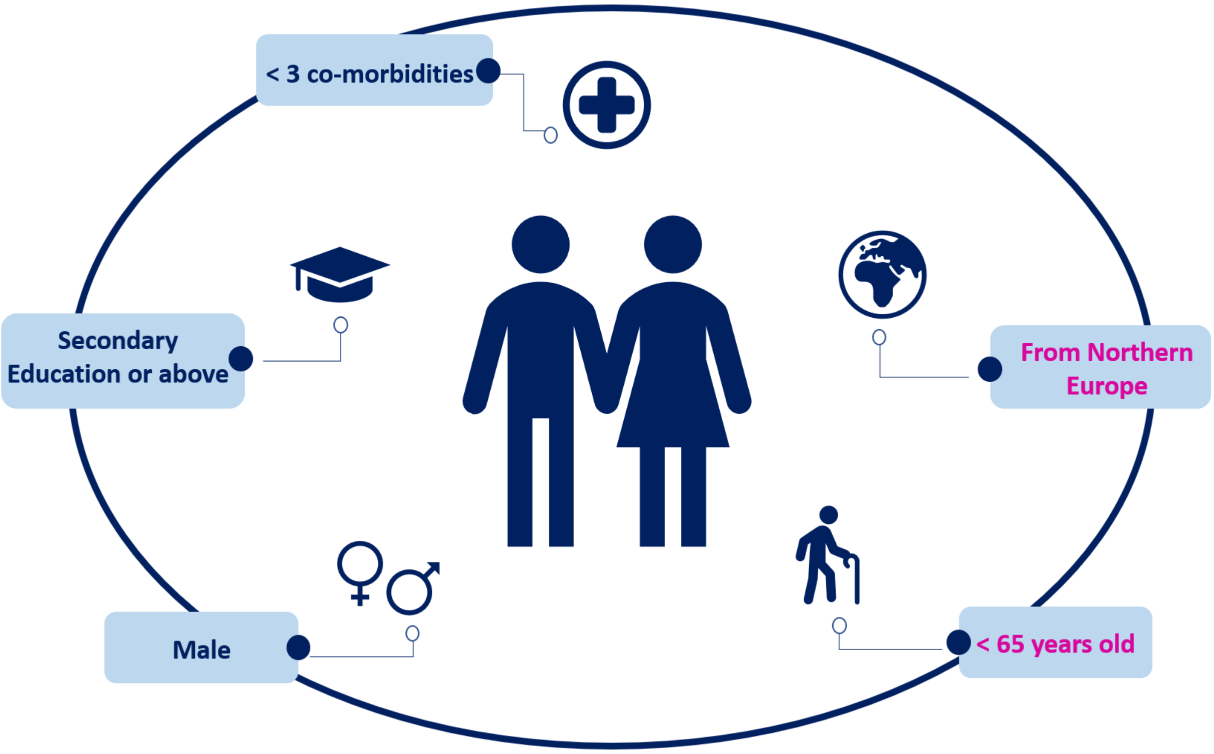


Figure 4: Characteristics of patients with a high engagement persona.
Pink text indicates results from the ACE score and **Blue** from the PHE-s.

Table 11. Participants grouped by high and low level of engagement, by PHE-s® and ACE scores.

	PHE-s®[1]			**ACE[2]**		
	High engagement n=428 (65%*)	**Low engagement n=231 (35%*)**	**p-value**	**High engagement n=369 (56%*)**	**Low engagement n=290 (44%*)**	**p-value**
Age, mean (SD)	71.3 (10.1)	70.0 (10.6)	0.071	69.9 (10.1)	72.0 (10.5)	**0.004**
Age groups						
<65	96 (14.6)	60 (9.1)		105 (15.9)†	51 (7.7)	
65-74	144 (21.9)	93 (14.1)	**0.04**	122 (19.1)	111 (17.4)	**0.005**
75+	188 (28.5)	78 (11.8)††		123 (17.3)	114 (18.7)	
Sex						0.151
Male	226 (34.3)†	85 (12.9)	**<0.0001**	165 (25.0)	146 (22.2)	
Female	202 (30.7)	146 (34.3)		204 (31.0)	144 (21.9)	
Level of education						
Primary	62 (9.4)	32 (4.9)		38 (5.8)	56 (8.5)††	
Secondary**	156 (23.7)†	110 (16.7)	**0.029**	141 (21.4)	125 (19.0)	**<.0001**
Degree level or above	195 (29.6)†	85 (12.9)		176 (26.7)†	104 (15.8)	

Other/prefer not to say	15 (2.3)	4 (0.6)		14 (2.1)	5 (0.8)	
No. of comorbidities (n=638)						
1-2	198 (31.0)[+]	77 (12.1)		173 (26.3)[+]	102 (15.5)	
3-5	182 (28.5)	115 (18.0)	**0.003**	156 (24.5)	141 (21.1)	**<.0001**
>5	35 (5.5)	31 (4.9)		25 (3.9)	41 (6.4)[+]	
Country						
Eastern Europe	58 (8.8)	34 (5.2)		54 (8.2)	38 (5.8)	
Northern Europe	230 (34.9)	131 (19.9)	0.546	215 (32.6)[+]	146 (22.2)	**0.034**
Southern Europe	140 (21.2)	66 (10.0)		100 (15.2)	106 (16.1)[++]	

* % of the total

[1] *Patient Health Engagement Scale,* [2] *Altarum Consumer Engagement Scale*

[+] *significant compared to low engagement group*

[++] *significant compared to high engagement group*

*** High school and Apprentice/Professional Training/Vocational Training were included in the 'Secondary level' education group*

Table 12. Caregivers engagement grouped by higher and lower level of engagement using the CHE-s®

	CHE-s®[1]		
	High engagement **N=138 (69%*)**	**Low engagement** **N=63 (31%*)**	**p-value**
Age, mean (SD)	58.4 (15.2)	57.5 (15.7)	0.914
Age groups			
<50	41 (20.4)	16 (8.0)	
50-64	51 (25.4)	30 (14.9)	0.384
65-74	23 (11.4)	6 (3.0)	
75+	23 (11.4)	11 (5.5)	
Sex			
Male	40 (19.9)	14 (7.0)	0.316
Female	98 (48.8)	49 (24.4)	
Level of education**			
Primary	18 (9.0)	7 (3.5)	0.832
Secondary	50 (24.9)	27 (13.4)	

Degree level or above	54 (26.9)	23 (11.4)	
Other/prefer not to say	16 (8.0)	6 (3.0)	
Country			
Italy	30 (15.4)	19 (9.7)	
Romania	54 (27.7)	26 (13.3)	0.240
Spain	50 (25.6)	16 (8.2)	

** % of the total*

[1] *Caregiver Health Engagement scale*

*** High school and Apprentice/Professional Training/Vocational Training were included in the ‘Secondary level’ education group*

6 List of identified needs, quality performance indicators and outcomes

A list of 53 items were identified from the online survey related to needs, quality performance indicators and outcomes which patients and caregivers identified as important to them (Table 13). This list formed the basis for the Delphi process (T4.5). The results of the Delphi process have been reported in Deliverable report 4.4.

Table 13. Full list of items identified from the survey that were formed the basis for the Delphi process.

Key Needs (n=27)		Quality Performance Indicators (n=9)	Key outcomes (n=17)
• Assessment of frailty • Avoid hospitalisation • Balance benefit/risk ratio due to anticoagulant treatment • Caregiver involvement in treatment decisions • Co-morbidity management • Control AF symptoms • control heart failure symptoms • Control possible interactions between anticoagulant and other ongoing treatments • Improved communication between GP and other specialists • Individual care plan • Management of frailty • Managing the impact on dementia • Materials to explain conditions and treatment options • Patient education • Patient involvement in treatment decisions	• Reduce number of medications • Reducing anxiety • Reducing cardiovascular events (e.g., stroke, heart attack) • Reducing medication side effects • Reducing number of medical appointments • Reduction of major bleeding • Social network/support • Social/leisure activities • Stroke prevention • Sufficient information on management plan • Support for caregivers • Symptoms control (all symptoms)	• Appropriate prescription review to reduce drug interaction and medication side effects • Appropriate prescription review to reduce the number of medications • Appropriate resources (e.g., booklets, websites) to provide information on the management of the conditions and on medical recommendation to patients and their caregivers • Appropriate strategy in place to reduce the number of medical appointments • Appropriate stroke prevention/treatment • Appropriate treatment to reduce the occurrence of cardiovascular events • Appropriate treatment to reduce the risk of major bleeding • Appropriate treatment to reduce/avoid hospitalization • Reduction/alleviation of symptoms	• Ability to work • Cognitive functioning • Emotional functioning/wellbeing • Exercise tolerance • Longevity/reducing mortality • Maintaining independence • Pain control/relief • Physical functioning • Preventing heart failure • Preventing major bleeding • Preventing/reducing adverse treatment effects • Preventing/reducing hospitalisation • Quality of Life • Reducing medication side effects • Social/leisure functioning • Stroke prevention • Symptoms reduction/alleviation

7 Conclusions

The online survey recruited a total of 1,305 participants and identified 53 items, including 27 key needs, nine quality performance indicators, and 17 key outcomes. This list formed the basis for the Delphi process (T4.5).

In the patients' group, there were significant sex differences related to quality of life, with women reporting better mobility and less pain/discomfort compared to men. However, men reported a higher overall QoL rating. Sex differences impacted patient's engagement with healthcare: men were more engaged with the care process and reported greater satisfaction with their quality of care. Patients aged >65 years reported greater impairment in the quality of life. Patients aged <65 years reported greater engagement in the care process when assessed by the ACE scale. Patients with higher education (degree level or above) reported significantly better overall quality of life and greater engagement in healthcare. The presence of three or more co-morbidities negatively affected patient's engagement level. Younger groups were more affected in terms of anxiety/depression. Patients in Eastern Europe reported greater frailty compared to those from Northern and Southern Europe. Number of comorbidities affected self-reported patient engagement in their healthcare; patients with three or more co-morbidities were less engaged.

In the caregiver group, women reported less pain/discomfort but greater negative life changes. Caregivers aged <65 years reported greater impairment in mobility and usual activities, than those aged <50 years, and also reported more anxiety/depression. Negative life changes were greater in caregivers aged <75 years. Caregivers from Romania reported higher overall quality of life compared with Spain and Italy, with less impairment in self-care and lower anxiety/depression. Caregivers from Spain were less affected by negative life changes. Higher education level (degree level or above) was associated with better overall quality of life.

Patients and caregivers' characteristics and empowerment level were used to define the engagement personas. Based on the PHE-s® scale, highly engaged personas were defined as being male, aged <75 years, having secondary education or higher, and having <3 co-morbidities. Country of recruitment was not relevant to the engagement personas. For the ACE scale, highly engaged personas were defined as <65 years, educated at degree level or above, from Northern Europe, and having <3 co-morbidities. Sex was not relevant to the engagement personas assessed by the ACE. For the caregivers' group, no differences were found in engagement in healthcare when comparing sex, age, country of recruitment, or level of education. The difference in the patient engagement findings results from differences in the aspects of the engagement process assessed by each scale. The PHE-s® measures engagement as the level of psychological readiness, while the ACE measures three domains of engagement (commitment to everyday health behaviours, informed choice, and navigation).

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9 Annex A – Partial Correlation Analysis

Supplementary Table 1: Partial correlation analysis between patient engagement, frailty, age and sex.

	PHE-s		**ACE**		**FRAIL**		**Age**		**Sex**	
	r	**P-value**	**r**	**P-value**	**r**	**P-value**	**r**	**P-value**	**r**	**P-value**
PHE-s[1]	-	-	.251	<0.0001	-.001	0.984	.012	0.750	.147	<0.0001
ACE[2]	.251	<0.0001	-	-	-.001	0.970	-.145	<0.0001	-.024	0.530
FRAIL	-.001	0.984	-.001	0.970	-	-	.049	0.211	.013	0.746

[1]*Patient Health Engagement Scale,* [2]*Altarum Consumer Engagement Scale*

10 Annex B– Copy of the English version of the online Survey

Validated questionnaires included in the surveys are provided in a separate PDF.

10.1 PATIENTS

Introduction

We are asking the following questions to find out about your health conditions, how they affect your daily activities a quality of life. At the end of the questionnaire, there are a few questions about your age, sex, and marital status etc. T information will help us to describe the people who have taken part in this survey to show that it represents a range people who suffer from long-term health conditions.

Do you have any of the following conditions? Tick **ALL** that apply:

☐ High blood pressure
☐ Heart disease
☐ Diabetes
☐ Thyroid problems
☐ Chronic obstructive pulmonary disease (COPD)
☐ Gastrointestinal diseases *(e.g. gastritis, gastroesophageal reflux disease, diverticular disease*)
☐ Chronic liver disease
☐ Kidney disease
☐ Previous stroke
☐ Parkinson's disease
☐ Multiple sclerosis
☐ Dementia
☐ Cognitive decline (*e.g. memory problems not impacting daily activities*)
☐ Osteoarthritis
☐ Osteoporosis/previous hip fracture
☐ Rheumatoid arthritis
☐ Chronic pain
☐ Vision problems
☐ Hearing problems
☐ Cancer
☐ Other: ___________________________

Which condition affects your health the most from the list above?__________________________

How many times have you been hospitalised in the last year? ____

Overall, what outcomes from the healthcare you receive are most important to you (max. 3 answers allowe

- ☐ improvement of my quality of life
- ☐ maintenance of my independence in daily life
- ☐ live longer
- ☐ pain reduction/relief
- ☐ have less need for health care
- ☐ maintenance of social and leisure activities
- ☐ improvement of mental/emotional health
- ☐ be able to work
- ☐ other (please specify): ___________________________________

What are the main problems with managing your health (max. 3 answers allowed)?

- ☐ high number of medical appointments
- ☐ difficulties in contacting/seeing a medical doctor
- ☐ too many medications to take
- ☐ having lots of health problems
- ☐ not having enough financial resources
- ☐ travel to medical appointments
- ☐ mobility problems
- ☐ anxiety/worry about my health
- ☐ not having anyone to help
- ☐ not understanding the medical recommendations clearly
- ☐ Having Problems getting in contact with the doctor/healthcare team
- ☐ Not having the opportunity to talk freely with the doctor about doubts and fears about the health conditions and treatment
- ☐ other (please specify): ___________________________________

next page

****Here the list of questionnaires included in the online survey following this order.**

Full versions of the validated questionnaires are included in the attached PDF:

EQ-5D-3L

next page

FRAIL questionnaire

next page

PHE-s

next page

HCCQ – short version

next page

(*Set of Brief Screening Questions*)

When answering the questions below, please select the answers that best represent your response.

How often do you have problems learning about your medical condition because of difficulty understanding written informatio

Never	Occasionally	Sometimes	Often	Always

How often do you have someone help you read hospital materials?

Never	Occasionally	Sometimes	Often	Always

How confident are you filling out medical forms by yourself?

Not confident at all	Not so confident	Neutral	Somewhat confident	Very confident

MARS-5

next page

ACE Measure

next page

Age _____ years

Sex

- ☐ Female
- ☐ Male

Living arrangements

- ☐ Living at home alone with no assistance
- ☐ Living at home with family with no assistance
- ☐ Living at home with part-time assistance
- ☐ Living at home with full-time assistance
- ☐ Living in long-term care facilities

If assistance is needed, is the caregiver

- ☐ Informal (e.g. family member; not paid)
- ☐ Formal (paid)

Marital status

- ☐ Single/never married
- ☐ Married/partnered
- ☐ Widowed
- ☐ Separated/divorced

Ethnicity

- ☐ White British
- ☐ White Irish
- ☐ Gypsy or Irish Traveller
- ☐ Any other White background
- ☐ White and Black Caribbean
- ☐ White and Black African
- ☐ White and Asian
- ☐ Any other mixed/multiple ethnic background
- ☐ Indian

☐ Pakistani
☐ Bangladeshi
☐ Chinese
☐ Any other Asian background
☐ Black African
☐ Black Caribbean
☐ Any other Black background
☐ Arab
☐ Other (please specify)

What is the highest degree or level of education you have completed?

☐ Degree level or above (Bachelor’s degree, Master’s degree, NVQ level 4, Professional Qualifications, etc)
☐ AS, A level or equivalent
☐ GCSEs, O levels or Equivalent,
☐ NVQ or equivalent
☐ Apprenticeship
☐ No qualifications (no academic or professional qualifications)
☐ Other (please specify)

Current employment status:

☐ Employed
☐ Unemployed
☐ Retired
☐ Disability allowance

Smoking habit

☐ Current smoker
☐ Former smoker (for at least one year)
☐ Never smoker

10.2 CAREGIVERS

We are asking the following questions to find out about the person you provide care for, and how being a caregiver affects you. At the end of the questionnaire, there are a few questions about your age, sex, ethnicity, and caregiving arrangements. This information will help us to describe the people who provide care.

Which of the following health conditions does the person you care for have? Tick ALL that apply:

- ☐ High blood pressure
- ☐ Heart disease
- ☐ Diabetes
- ☐ Thyroid problems
- ☐ Chronic obstructive pulmonary disease/COPD
- ☐ Gastrointestinal diseases *(e.g. gastritis, gastroesophageal reflux disease, diverticular disease*)
- ☐ Chronic liver disease
- ☐ Kidney disease
- ☐ Previous stroke
- ☐ Parkinson’s disease
- ☐ Multiple sclerosis
- ☐ Dementia
- ☐ Cognitive decline (*e.g. memory problems not impacting daily activities*)
- ☐ Osteoarthritis
- ☐ Osteoporosis/previous hip fracture
- ☐ Rheumatoid arthritis
- ☐ Chronic pain
- ☐ Vision problems
- ☐ Hearing problems
- ☐ Cancer
- ☐ Other: ___________________________

In your view, which condition affects the health of the person you assist the most from the list above?

Which health condition of the person you assist causes you the most difficulty in providing care?

How many different medications does the assisted person take?

- ☐ 0

- ☐ 1-2
- ☐ 3-4
- ☐ 5 or more

How many times was the assisted person hospitalised in the past year? ____

Which is the mobility level of the person you provide care for?

- ☐ Can walk independently
- ☐ Walks with a cane/walking stick
- ☐ Walks with a walker/Zimmer-frame
- ☐ Moves around with a wheelchair
- ☐ Confined at home, mostly lying on the bed

Does the person you provide care for need help in any of the following activities?

- ☐ Eating
- ☐ Bathing
- ☐ Dressing
- ☐ Toileting
- ☐ Transferring

In your opinion, what health outcomes are the most important for the person you provide care for (max. 3 answers allowed)?

- ☐ improvement of quality of life
- ☐ maintenance of independence in daily life
- ☐ live longer
- ☐ pain reduction/relief
- ☐ have less need for health care
- ☐ maintenance of social and leisure activities
- ☐ improvement of mental/emotional health
- ☐ be able to work
- ☐ other (please specify): ________________________________

What are the main problems with managing the health of the person you provide care for (max. 3 answers allowed)?

- ☐ high number of medical appointments
- ☐ difficulties in contacting/seeing a medical doctor
- ☐ too many medications to manage
- ☐ too many health problems to manage
- ☐ not having enough financial resources
- ☐ travel to medical appointments
- ☐ anxiety/worry of my health

- ☐ anxiety/worry for the health of the assisted person
- ☐ not having anyone else to help
- ☐ the responsibility of caring for someone else
- ☐ mobility problems
- ☐ do not understand medical recommendations clearly
- ☐ having my own health problems
- ☐ Having Problems getting in contact with the doctor/healthcare team
- ☐ Not having the opportunity to talk freely with the doctor about doubts and fears about the health conditions and treatment
- ☐ other (specify): ________________________________

next page

****Here the list of questionnaires included in the online survey following this order.**

Full versions of the questionnaires are included in the attached PDF:

Bakas Caregiving Outcomes Scale

next page

CHE-s

next page

EQ-5D-3L

next page

(*Further Questions*)

In the questions below, please select the answers that better represent your response.

How often do you have problems learning about your medical conditions, or the medical conditions of the person you care for because of difficulty understanding written information?

Never	Occasionally	Sometimes	Often	Always

How often do you have someone help you read hospital materials?

Never	Occasionally	Sometimes	Often	Always

How confident are you filling out medical forms by yourself?

Never	Occasionally	Sometimes	Often	Always

Overall, how would you rate the healthcare services received for the management of the long-term health conditions of the assisted person? Please rate this on the scale below 0 (poor) to 10 (excellent) by circling a number

0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**

Please explain why you gave this score? ________________________________

Who is the main healthcare provider that coordinates care for the person you assist?

- ☐ General Practitioner/Family doctor
- ☐ Geriatrician
- ☐ District/community nurse
- ☐ Other (please specify) ____________

next page

Age ____ years

Sex

- ☐ Female
- ☐ Male

Which type of caregiver are you?

- ☐ Informal (e.g. family member; not paid)

☐ Formal (paid)

If you are an informal caregiver, please specify if the assisted person is:

☐ your spouse/partner
☐ your father
☐ your mother
☐ a relative other than your mother or father
☐ a friend

Do you live with the person you provide care for:

☐ Yes
☐ No

How much time do you spend in caregiving:

☐ I am a full-time caregiver (I have no other occupation than caregiving)
☐ Less than 6 h/day, every day of the week
☐ Less than 6 h/day, NOT every day of the week

How many years have you been a caregiver:

☐ 1 year or less
☐ 2-4 years
☐ ≥5 years

Ethnicity

☐ White British
☐ White Irish
☐ Gypsy or Irish Traveller
☐ Any other White background
☐ White and Black Caribbean
☐ White and Black African
☐ White and Asian
☐ Any other mixed/multiple ethnic background
☐ Indian
☐ Pakistani
☐ Bangladeshi
☐ Chinese
☐ Any other Asian background
☐ Black African
☐ Black Caribbean
☐ Any other Black background
☐ Arab
☐ Other (please specify)

What is the highest degree or level of education you have completed?

- ☐ Degree level or above (Bachelor’s degree, Master’s degree, NVQ level 4, Professional Qualifications, etc)
- ☐ AS, A level or equivalent
- ☐ GCSEs, O levels or Equivalent,
- ☐ NVQ or equivalent
- ☐ Apprenticeship
- ☐ No qualifications (no academic or professional qualifications)
- ☐ Other (please specify)

10.3 HEALTHCARE PROFESSIONALS

Age _____ years

Sex

- ☐ Female
- ☐ Male

Ethnicity

- ☐ White British
- ☐ White Irish
- ☐ Gypsy or Irish Traveller
- ☐ Any other White background
- ☐ White and Black Caribbean
- ☐ White and Black African
- ☐ White and Asian
- ☐ Any other mixed/multiple ethnic background
- ☐ Indian
- ☐ Pakistani
- ☐ Bangladeshi
- ☐ Chinese
- ☐ Any other Asian background
- ☐ Black African
- ☐ Black Caribbean
- ☐ Any other Black background
- ☐ Arab
- ☐ Other (please specify)

Country

- ☐ UK
- ☐ Spain
- ☐ Denmark
- ☐ Italy
- ☐ Romania

What is your occupation?

- ☐ Medical Doctor
- ☐ Nurse
- ☐ Pharmacist

☐ Occupational Therapist
☐ Other (please specify)_____________________

Which of the following best describes your working position? (only for MD)

☐ Self-employed
☐ General Practitioner
☐ Medical resident
☐ Consultant
☐ Hospital doctor working in inpatient clinic
☐ Hospital doctor working in outpatient clinic
☐ Chief of department
☐ Other _____________________________

Specialty:

☐ Cardiology
☐ Internal medicine
☐ Geriatrics/Elderly Care
☐ Haematology
☐ General Practitioner
☐ Other (please specify) __________

How many years have you been in practice since completing your degree?

☐ 0-5 years
☐ 6-10 years
☐ 11-20 years
☐ 21-30 years
☐ >30 years

In which setting, are you currently providing care:

☐ Primary care centre
☐ Secondary care centre
☐ Tertiary care centre

If working in a hospital, is it a University hospital:

☐ Yes
☐ No

Do you work with patients with chronic conditions regularly (1-2 times per week)?

☐ Yes
☐ No
☐ Sometimes

Which are the chronic conditions that you manage most frequently? Please, select all that apply (up to 3):

- ☐ Cardiovascular diseases
- ☐ Diabetes
- ☐ Endocrinologic diseases (other than diabetes)
- ☐ Respiratory diseases
- ☐ Chronic liver diseases
- ☐ Gastrointestinal diseases
- ☐ Kidney diseases
- ☐ Cerebrovascular diseases
- ☐ Neurologic diseases (other than cognitive disorders)
- ☐ Minor/major cognitive disorders
- ☐ Osteoarticular diseases
- ☐ Rheumatologic diseases
- ☐ Chronic pain
- ☐ Vision problems
- ☐ Hearing problems
- ☐ Cancer
- ☐ Other (please specify): ___________________________

On average, how many patients with atrial fibrillation do you manage per week?

- ☐ 0-1
- ☐ 2-5
- ☐ 6-10
- ☐ >10

On average, which age group is most represented by the patients with atrial fibrillation that you usually manage?

- ☐ <60 years
- ☐ 60-70 years
- ☐ 71-80 years
- ☐ >80 years

On average, in your daily practice, what proportion of patients with atrial fibrillation that you see also have at leas one other chronic disease?

- ☐ 0-10%
- ☐ 11-30%
- ☐ 31-50%
- ☐ 51-80%
- ☐ >80%

For those patients with atrial fibrillation who have at least one other chronic health condition, can you identify th main healthcare provider for them?

- ☐ Yes
- ☐ No

In consultation with patients with AF and other chronic long-term conditions (multi-morbidity) do you usuall communicate directly with (please, select all that apply):

- ☐ the patient
- ☐ their family
- ☐ non-family caregiver

Clinicians have different training, orientations and views about a patient's role in their care which results in different approaches when working with people with long term conditions. This survey has been developed by th AFFIRMO team to understand these views and approaches, and the support needs of clinicians.

How do you grade your confidence in…	**Not at all confident**	**Not very confident**	**Neutral**	**Confident**	**Very confide**
Assessing the level of patient's engagement					
Generally supporting patient engagement					
Motivating patients in following medical prescriptions					
Informing patients about disease and treatments					
Assessing patient's health literacy					
Empathising with patients					
Assessing and managing patients' emotions					
Effectively communicating with patients and their families					
Effectively relating to patients and their families					

As a healthcare professional, how important is it to you that your patients with chronic conditions:	**Extremely important**	**Important**	**Somewhat important**	**Not important**	**Not applica le**
Are able to take actions that will help prevent or minimise symptoms associated with their health condition					
Are able to maintain lifestyle changes needed to manage their long-term condition					
Understand which of their behaviours make their condition better and which ones make it worse					
Can follow through on medical treatments they need to do at home					
Know what each prescribed medication does					
Bring a list of questions when they come to the clinic					
Are able to determine when they need to go to see a medical professional for care versus when they can manage the problem on their own					
Are able to work out solutions when new situations or problems arise with their health condition					
Want to be involved as a full partner with you in making decisions about their care					
Tell you concerns they have about their health even when you do not ask					
Want to know what procedures or treatments they will receive and why before the treatments are performed					
Understand the different medical treatment options available for their long-term condition					
Look for trustworthy sources of information about their health and health choices such as on the web, news, or books					

Overall, in your opinion, what are the main needs of patients with AF and other chronic health conditions
Please, select all that apply (up to 3):

- ☐ avoid stroke
- ☐ control AF symptoms

- ☐ balance the benefit/risk ratio due to anticoagulant treatment
- ☐ managing the other comorbidities
- ☐ control possible interactions between anticoagulation and other ongoing treatments
- ☐ avoid hospitalizations
- ☐ Other (please specify) ______________________

What health-related outcomes do you think are most important for patients with AF and other chroni conditions? Please, select all that apply (up to 3):

- ☐ improvement of quality of life
- ☐ maintenance of independence in daily life
- ☐ increase longevity
- ☐ pain control/relief
- ☐ have the least need for health care
- ☐ maintenance of social and leisure activities
- ☐ improvement of mental/emotional health
- ☐ be able to work
- ☐ avoid/prevent adverse events (e.g. accidental falls)
- ☐ other: ________________________________

What are the main difficulties with managing the health of patients with AF and other chronic conditions? Please select all that apply (up to 3):

- ☐ Managing multiple health conditions
- ☐ Dealing with polypharmacy
- ☐ Dealing with possible drug-drug or drug-food interactions
- ☐ Evaluating the benefit-risk ratio of each treatment
- ☐ Managing patients with poor social support or no caregiver
- ☐ Explaining the medical recommendations to patients and/or caregivers
- ☐ Uncertainty regarding patient and/or caregiver understanding of the medical recommendations given
- ☐ Convincing the patient/caregiver of the importance of following the medical recommendations
- ☐ Reaching a satisfactory adherence with medical recommendations by the patient
- ☐ Communication with the patient’s family doctor or with other specialists
- ☐ Conflicting opinions of medical colleagues regarding ‘best’ management due to multi-morbidity
- ☐ Other (please specify): ________________________________