



## RESEARCH ARTICLE

# The CAREPATH Study for Personalized Management of Multimorbidity in Elderly with Mild Cognitive Impairment and Mild Dementia

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## ABSTRACT

**Introduction:** Multimorbidity is prevalent among older adults and is associated with cognitive impairment and dementia, increasing the need for innovative care solutions. The CAREPATH project, funded by the European Commission Horizon 2020 program, has developed an integrated care platform tailored to older adults with multimorbidity, particularly those with mild cognitive impairment or mild dementia. This platform aims to enhance screening, optimize personalized treatment, and support multidisciplinary care, aligning with the European Society of Medicine's policy framework for managing neurodegenerative diseases.

**Methods:** This paper describes the methodology for implementing an integrated care platform focused on managing mild cognitive impairment and mild dementia. CAREPATH architecture supports multidisciplinary care teams in creating personalized treatment plans based on evidence-based guidelines, involving patients and their caregivers. The platform for healthcare professionals features modular disease pages for comprehensive care, including dedicated sections for screening complications and delivering non-pharmacological interventions such as nutrition, lifestyle, and physical exercise recommendations.

**Results:** The CAREPATH platform has been fully implemented from a technical perspective, with the next step being the clinical investigation to evaluate its efficacy in improving health-related quality-of-life for older adults with mild cognitive impairment or mild dementia and its cost-effectiveness. This study will be conducted in two phases: a technical validation and usability study, followed by a clinical investigation (randomized clinical trial) across four European centers in Spain, Germany, the United Kingdom and Romania. Preliminary tests, including functional, integration, and laboratory system testing, have been conducted to ensure the platform's readiness, with most technical issues resolved. The TVU phase is scheduled to begin in September 2024.

**Keywords:** integrated care, personalized care, multimorbidity, mild dementia, mild cognitive impairment.

## 1 Introduction

Multimorbidity, the coexistence of two or more chronic conditions, is highly prevalent among older adults<sup>1</sup>. There is growing evidence that multimorbidity is also associated with cognitive impairment and dementia<sup>2,3,4</sup>. In older adults, having multiple chronic conditions is associated with an increased risk of mild cognitive impairment (MCI), an important precursor for Alzheimer's disease and other dementias<sup>5</sup>.

Dementia introduces a high burden on the well-being and healthcare needs of older patients and their families<sup>6</sup>. Quality-of-Life (QoL) for patients and their families is significantly affected, with caregivers facing immense challenges in providing daily care and support<sup>7</sup>. Patients with dementia may require hospitalization for conditions that could otherwise be managed if their cognitive functions were intact<sup>8</sup>. Cognitive impairment also hampers the patients' ability in effective self-management of health conditions that are generally managed by patients without cognitive problems. Hence, the management of older adults with dementia requires innovative approaches to address these challenging demands effectively. Integrated care solutions are needed to manage these complex patients at home<sup>9,10</sup>, especially in the initial stages like MCI<sup>11</sup>.

With the increasing prevalence and incidence of neurodegenerative diseases, including dementia, in Europe, the European Society of Medicine emphasizes the urgent need to address the increasing burden of these diseases to healthcare systems and economies. It has recently published a comprehensive policy framework providing a roadmap for tackling these complex conditions through a multifaceted approach<sup>7</sup>. The following important actions are highlighted in this policy framework:

- **Enhanced screening via digital health applications:** Early diagnosis of neurodegenerative diseases, including dementia, is presented as a crucial activity for effective management and improving patient outcomes. It is advised to integrate digital health applications into national health systems for enhanced screening and diagnosis.
- **Digital health solutions for optimized personalized treatment and monitoring:** The integration of advanced technologies, including AI and digital health tools, is presented as a potential method to optimize treatment plans and monitor patient progress more effectively, facilitating personalized care.
- **Strengthening integrated care delivery:** It is highlighted that due to the fragmented nature of current care services, a shift towards integrated care delivery is necessary for long-term care to bridge existing divides in care services.
- **Investing in non-pharmacological interventions:** Non-pharmacological treatments, such as physical therapy and lifestyle modifications including diet and exercise changes, are highlighted as important interventions to improve overall health and potentially slow disease progression.

The CAREPATH project is an international research and development project, funded as a part of European

Commission Horizon 2020 programme, under the research topic 'Healthcare interventions for the management of the elderly multimorbid patient', addressing these actions. It has developed a patient-centered integrated care platform tailored to older adults with multimorbidity, specifically addressing the needs of those with MCI or mild dementia (MD)<sup>12</sup>. This integrated care platform enables the screening of older adults with MCI/MD, guiding advanced assessments for the identification of pre-clinical dementia or high risk of developing dementia in light of evidence-based guidelines. The CAREPATH platform provides a holistic environment for creating personalized treatment plans for several multimorbidities of older adults, including frailty, sarcopenia, malnutrition, diabetes, heart failure, chronic obstructive pulmonary disease (COPD), asthma, chronic kidney disease (CKD), stroke, coronary artery disease (CAD), and hypertension, based on evidence-based guidelines<sup>13</sup>. Based on the recommendations provided by these guidelines, a personalized treatment plan is created, including non-pharmacological interventions. Finally, the integrated care platform enables cooperation among multidisciplinary care team members, as well as with the patient and the informal care giver, enabling them to be active participants in their care.

This paper introduces the methodology followed to implement this integrated care platform, specifically focusing on the needs of MCI/MD. We present in detail how we are addressing the recommended actions of the European Society of Medicine's policy framework for effective management of these complex conditions burdening older adults.

## 2 Methodology

The CAREPATH project has followed a user-centered requirements analysis and design approach to ensure we address the needs of patients with MCI/MD and their care teams. We aimed to make sure that the platforms to be developed would be beneficial in the eyes of the target end users of CAREPATH systems, which includes patients, patients' informal caregivers, and clinicians.

First of all, we conducted interviews with patients and informal caregivers to gather information about the opinions and attitudes of target end users towards IT-based environments such as CAREPATH, as well as the necessary preconditions for user acceptance. At the four pilot sites of the CAREPATH project, health professionals conducted interviews with four patients and four informal caregivers they were familiar with at each site. The results of the interviews<sup>14</sup> have been utilized in the later phases of the architectural design to reflect the preferences and needs of patients and informal caregivers in the system design.

Following this, key scenarios were captured from the clinicians involved in the pilot sites. These were designed as use scenarios that describe key application use cases of the CAREPATH system<sup>15</sup>. These detailed key scenarios were later used to extract detailed technical requirements for the system and also for the architectural design of the system. They were also used in the usability test phase by clinical sites, after the system was completed.

Once the detailed user requirements were documented, we took an engineering approach to design and implement a set of integrated ICT components to realize the key usage scenarios. This includes the Adaptive Integrated Care Platform (AICP) as a clinician-facing platform and the Patient Empowerment Platform (PEP) as a patient-facing platform, as well as several other enabling components such as the Technical and Semantic Interoperability Suite (TIS/SIS) and the Home and Health Monitoring Platform (H/HMP). Integration among the core components of the system was achieved via standard-based interfaces conforming to HL7 FHIR specifications. More details about these platform features are presented in the following sections.

During the implementation phase of these components, the co-creation approach was continued, involving end-users as much as possible. Mockups and early prototypes of the platforms were presented to end-users to collect feedback at an early phase.

## 2.1 CAREPATH ARCHITECTURE ENABLING INTEGRATED CARE

The CAREPATH project aims to deliver integrated care solutions to multidisciplinary care teams, enabling them to follow evidence-based guidelines to create personalized treatment plans for older adults. As part of the integrated care approach, this personalized care plan is also shared with the patient and their informal caregivers to actively involve them in their care. This is achieved via a set of interlinked tools:

- **The Adaptive Integrated Care Platform (AICP)** is a web-based application designed for healthcare professionals (HCPs), enabling them to review a patient's medical summary retrieved from underlying Electronic Health Record (EHR) systems. AICP enables the creation of personalized treatment plans with the support of clinical decision support (CDS) services, which automate evidence-based guidelines<sup>13</sup>. Suggestions for personalized treatment plan are provided through CDS services, encompassing setting personalized treatment goals (e.g., systolic/diastolic blood pressure goals), adding or updating treatment activities (e.g., medications), ordering additional investigations (e.g., lab tests), consultations and referrals, as well as non-pharmacological patient interventions such as self-monitoring activities, dietary adjustments, and exercise regimens. The AICP is accessible to multidisciplinary care team members, including general practitioners (GPs) and specialists, facilitating the creation of a comprehensive consensus care plan addressing the patient's various multimorbidities. Team members can collaboratively edit the care plan, add comments to treatment activities, and discuss open issues through the communication platform supported by AICP.
- **The Technical and Semantic Interoperability Suite (TIS/SIS)** enables integration with EHR systems, allowing retrieval of the most recent patient medical summary from underlying medical information systems<sup>16</sup>. This data can then be processed by the AICP and CDSs. This is essential for customization of CDS suggestions to create personalized treatment plans.

- In the CAREPATH integrated care approach, patients and informal care givers are also part of the care team. A dedicated platform, **the Patient Empowerment Platform (PEP)**, shares the personalized treatment plan with the patient and their informal care giver<sup>17</sup>. PEP is designed to offer personalized assistance and guidance to patients, considering the cognitive challenges faced by those with MCI/MD. It delivers reminders about care plan activities including medications to enhance treatment adherence, provides a daily calendar with clear guidance, and collects patient symptoms.
- Another platform supporting patients is **the Home and Health Monitoring Platform (H/HMP)**. It provides sensors and services to continuously collect real-time data for early detection of onset and changes in functioning, autonomy, and underlying cognitive and physiological functions of patients. H/HMP includes a home automation sensor network with various domestic and environmental sensors (such as temperature and light sensors, movement sensors, smart plugs, etc.), as well as a health/medical sensor network consisting of wearable health and activity devices (such as blood pressure monitors, pulse oximeters, weight scales, glucose meters, and fitness smartwatches). The data collected via H/HMP becomes available to AICP for clinical assessment and to CDS services for personalized suggestions. Additionally, it incorporates a **Smart Rule Engine** to automatically assess sensor readings and notify HCPs of detected events, e.g., 'Patient is at risk of arrhythmia (heart rate < 50 bpm OR heart rate > 110 bpm)', via notifications through AICP.

## 2.2 PERSONALIZED CARE PLANNING IN THE CAREPATH ARCHITECTURE

As briefly explained in section 2.1, the AICP enables HCPs to create a care plan for each patient based on evidence-based guidelines. The AICP is designed as a web-based portal with modular disease pages that activate based on the patient's multimorbidities. According to the eligibility criteria of CAREPATH clinical studies, each patient has at least MCI or MD. Therefore, as one of the core modules, AICP includes a dedicated page to review the cognitive status, conducting necessary risk assessment to incorporate required interventions into the care plan. The AICP is designed as an easy-to-follow, dynamic tool to edit the patient's care plan, encompassing all other multimorbidities of the patient. A Clinical Reference Group (CRG) has been formed by CAREPATH project clinical partners based in Germany, Spain, Romania, and the UK. The CRG has identified hypertension, heart failure, diabetes, CKD, COPD, asthma, CAD, stroke, malnutrition, sarcopenia, and frailty as common multimorbidities that should be assessed in older adults with MCI/MD. Therefore, a dedicated page is also designed for each condition to review and update the holistic care plan, addressing the needs of these conditions.

To guide the implementation of the CDS services that assist HCPs in creating personalized care plans, the CRG has designed a consensus clinical guideline for addressing the needs of selected comorbidities<sup>18</sup>. Following a literature review to identify suitable clinical guidelines.

52 guidelines addressing selected chronic conditions and multimorbidity were evaluated for quality using the AGREE II methodology<sup>19</sup>. Consequently, 25 final guidelines were chosen for review, approval, or disapproval, and were grouped and consolidated by the project CRG using a modified Delphi process. The finalized guidance and actions were compiled into the master narrative consensus guideline. The CAREPATH consensus clinical guideline provides advice, information, and actions in the following areas: overarching principles of management, MCI and dementia, physical exercise, nutrition and hydration, common use of drugs, CAD, heart failure, hypertension, diabetes, CKD, COPD, stroke, sarcopenia, frailty, and caregiver support.

This consensus guideline has been methodologically examined to implement CDS services aimed at automating suggestions from the selected clinical guidelines<sup>13</sup>. Each page of the AICP has been designed to review the input parameters of these CDS services and present suggestions such as ‘lab orders, medication updates, referral recommendations, non-pharmacological interventions like diet and physical exercise’ for editing the personalized care plan. The AICP page created for MCI/MD management is presented in the next section as an example.

### 2.3 CAREPATH APPROACH FOR SCREENING COMPLICATIONS OF MILD COGNITIVE IMPAIRMENT AND MILD DEMENTIA

In light of CAREPATH consensus guideline, a dedicated page for screening complications of MCI/MD is designed. Main functionalities of this page can be summarized as follows:

- The platform enables four important assessments – namely, the Clinical Dementia Rating<sup>20</sup>, Neuropsychiatric Inventory<sup>21</sup>, Mild Behavioral Impairment Checklist (MBI-C)<sup>22</sup>, and Patient Health Questionnaire 9 (PHQ-9)<sup>23</sup> – are presented, as shown in Figure 1. HCPs can review previous assessments and initiate a new assessment.
- The platform presents existing diagnoses of the patient for MCI, mild dementia, and Alzheimer’s disease are presented, retrieved from the underlying EHR system, and allows the clinician to re-assess the patient’s MCI and mild dementia status.
- Personalized recommendations are presented based on evidence-based guidelines. For example, when the patient does not have confirmed MCI or MD, the HCP is reminded that ‘Cognitive screening tools exist specifically for the early identification of MCI, like the Montreal Cognitive Assessment (MoCA),’ and suggested to ‘Consider using these tools for early identification of MCI,’ as shown in Figure 1.

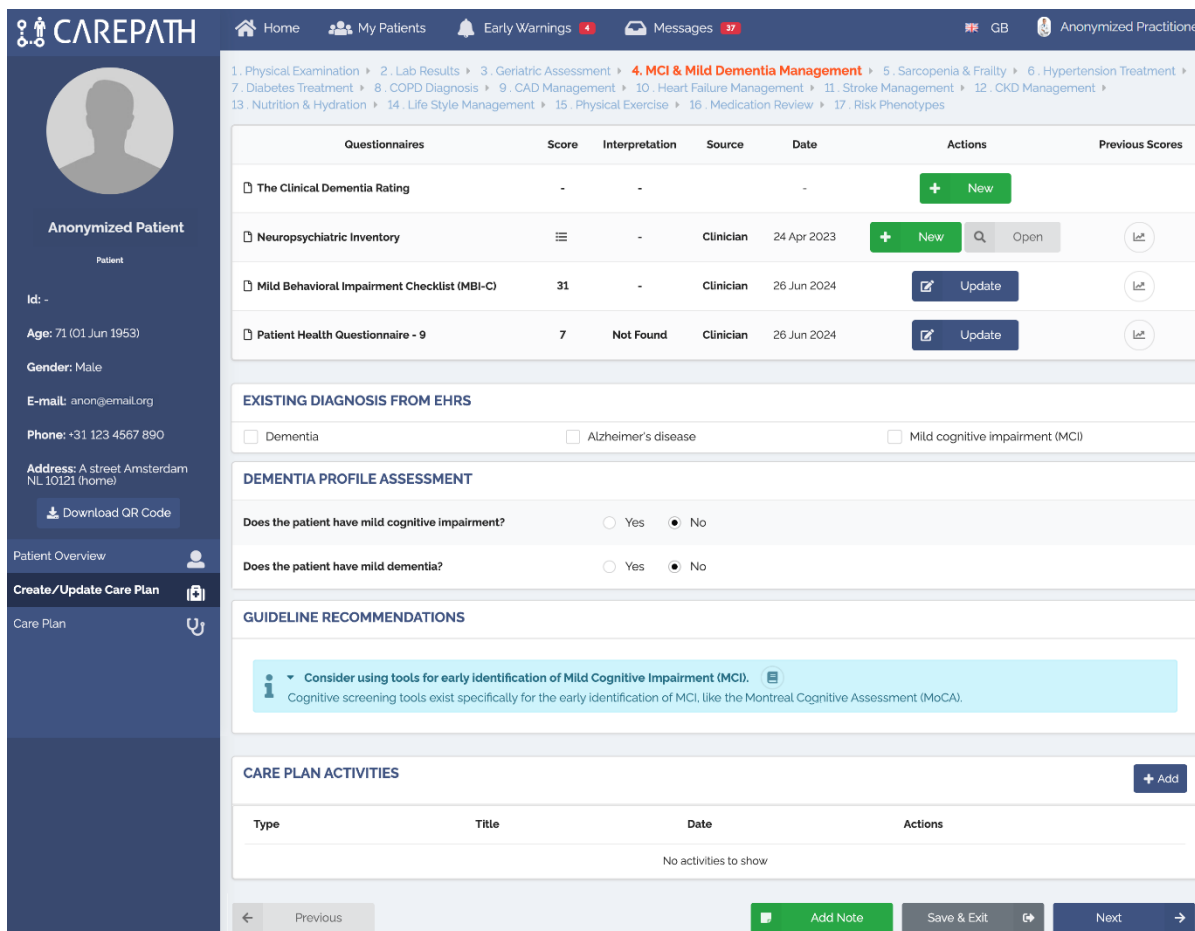


Figure 1 - MCI & MD Management Page

- The platform enables carrying out functional impairment and gait speed assessment. In line with consensus guideline recommendations, sleep monitoring parameters from H/HMP are presented to enable sleep history assessment that may facilitate identification of pre-clinical dementia. For patients

- with MCI or MD, an additional set of questions about behavioural and neuropsychiatric symptoms are presented.
- Based on these assessments, the platform dynamically presents additional recommendations according to consensus guidelines. For example, if a



mood change has been recorded, it reminds the HCP that 'the Patient Health Questionnaire-9 should be performed'<sup>24</sup>.

- The MCI/MD Management page also enables the HCP to review the patient's existing medications and presents recommendations based on the CAREPATH consensus guideline. For example, for older adults (over 65 years old) with MCI or mild dementia exhibiting behavioral and neuropsychiatric symptoms, antipsychotics are offered only when the HCP indicates 'there is a risk of harming themselves or others' or 'the patient is experiencing agitation, hallucinations, or delusions' via the panels in the AICP.
- Finally, based on the CAREPATH consensus guideline, the AICP provides recommendations for the next follow-up visit in 6 months to monitor changes in cognitive status<sup>24</sup> as an appointment activity, and referrals to specialists for occupational therapy when consultation is needed<sup>25</sup>.

#### 2.4 CAREPATH APPROACH FOR DELIVERING NON-PHARMACOLOGICAL INTERVENTIONS

The CAREPATH consensus guidelines provide several recommendations for non-pharmacological interventions for the selected patient group. These recommendations are grouped under three main pages in the AICP as follows:

- **Nutrition and Hydration Recommendations:** It enables the HCP to first review the patient's related comorbidities and body parameters, including total body water, body muscle mass, body fat and body fat percentage in charts (Figure 2). It enables carrying out scored assessments, particularly the Mini Nutritional Assessment -Short Form® (MNA-SF®)<sup>26</sup> and MUST (Malnutrition Universal Screening Tool). Based on the body mass index (BMI), MNA-SF® and MUST profile, and existing comorbidities, the page provides personalized diet recommendations and allows for setting goals for weight and water

consumption based on consensus guideline recommendations, supported by CDS services.

- **Lifestyle Recommendations:** On this page, the HCP is reminded of the patient's weight, height, and BMI measurements. The HCP can review weight and BMI goals and update them as necessary. During follow-up meetings, the HCP can also assess whether the patient has achieved these goals by viewing related observations in a chart view. The patient's smoking status is also reminded and assessed in this page. Based on this information, personalized recommendations from various guidelines included in the CAREPATH consensus guideline regarding lifestyle changes, such as setting goals for weight loss or smoking cessation, are presented.
- **Physical Exercise Recommendations:** The CAREPATH project utilizes findings from the VIVIFRIL project to provide personalized physical exercise recommendations for older adults. The VIVIFRIL exercise training program is recognized as an effective and safe therapy for improving functional capacity in community-dwelling frail/prefrail older patients with mild cognitive impairment or mild dementia<sup>27</sup>. Currently, it is utilized by over 5,000 health professionals, impacting a population of more than 15,000 individuals. To recommend exercises from VIVIFRIL, the HCP must first complete the Short Physical Performance Battery (SPPB)<sup>28</sup> and Risk of Fall questionnaires. These assessments are shared with the VIVIFRIL service, which then generates a personalized physical exercise plan. The AICP allows the HCP to select the days on which the patient is expected to do exercises. Once the days are chosen, HCPs can specify which exercises should be excluded from the patient's exercise plan. The final exercise plan becomes part of the patient's care plan, which are then shared with the patient via the PEP interfaces, as explained in the next section.

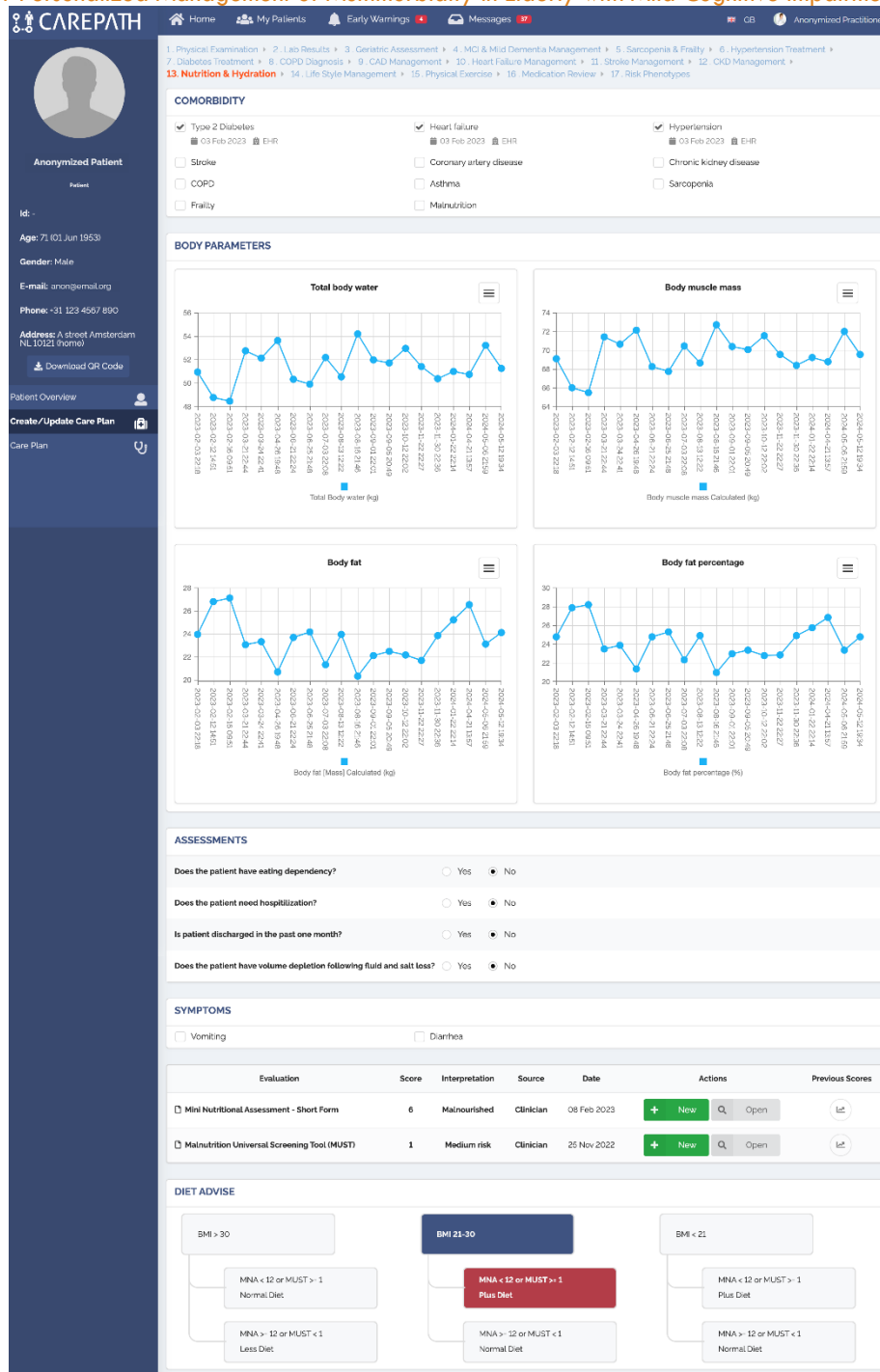


Figure 2 - Nutrition & Hydration Page

## 2.5 CAREPATH APPROACH FOR SUPPORTING PATIENTS WITH MILD COGNITIVE IMPAIRMENT OR MILD DEMENTIA

The CAREPATH PEP has been implemented as a tablet application to provide personalized assistance and guidance to patients, reinforcing treatment adherence. PEP presents care plan activities, including medication intake, measurements at home, appointments, diet, and exercises, as daily tasks. It also collects feedback from patients to monitor their adherence to the care plan and to carry out geriatric assessments, as illustrated in Figure 3. Additionally, it sends notifications about care plan goals and activities, reminding patients to perform their daily tasks.

To ensure the provision of an effective personalized assistance to older multimorbid patients with MCI/MD,

PEP has been designed as a simple tablet application, taking several principles into account:

- The application has been designed exclusively for tablets because previous studies<sup>29,30,31</sup> have shown that tablets are easier for older patients with MCI/MD to use than computers. Tablets eliminate the need for an external keyboard or mouse, reducing cognitive load, and they provide larger texts on larger screens compared to mobile phones.
- A consistent design format has been followed on each page to ensure uniformity across the application, which benefits patients' cognitive function in daily use<sup>32</sup>.
- The amount of information shown on each page has been minimized as much as possible to avoid overwhelming patients with dementia, thereby reducing disorientation and anxiety<sup>33</sup>.

- Clear and concise language has been used on all screens, avoiding complex expressions and abbreviations to prevent confusion for patients.

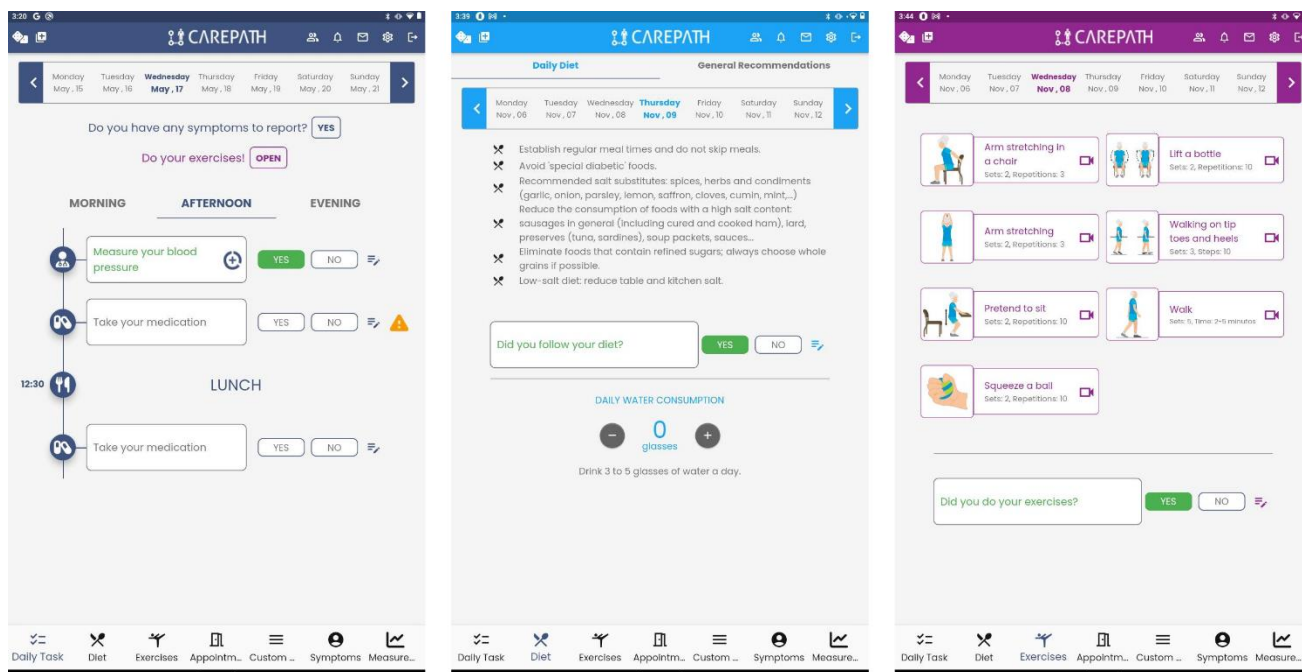


Figure 3 – CAREPATH Patient Empowerment Platform pages for daily task, diet and exercises

### 3 Results

The technical implementation of the CAREPATH platform has been completed. Our next objective is to conduct a clinical investigation study to assess the efficacy of the CAREPATH system in improving the QoL of participants compared to usual care. Additionally, we aim to analyze the cost-effectiveness of the platform, possible reductions in unplanned care, inappropriate drug prescriptions, and the number of participants with advanced directives. Moreover, we will evaluate the potential reduction or cost-neutrality associated with the intervention from a societal perspective. This study will be conducted in two phases: a Technical Validation and Usability (TVU) study, followed by a clinical investigation (randomized clinical trial) across four European centers in Spain, Germany, the United Kingdom and Romania. Preliminary tests, including functional, integration, and laboratory system testing, have been conducted to ensure the platform's readiness, with most technical issues resolved. The TVU phase is scheduled to begin in September 2024.

### 4 Discussion

The CAREPATH Integrated Care approach aims to significantly enhance the quality of life for patients, carers, and relatives by demonstrating how digital services for integrated adaptive care can improve care and reduce healthcare costs for long-term chronic patients, especially those with MCI/MD. It achieves this by equipping healthcare managers and professionals with the necessary tools and data to optimize resource allocation and care delivery. The platform and CDS services facilitate collaborative creation, execution, and monitoring of personalized care plans by a multidisciplinary team through clinical guideline reconciliation. CDS modules also assist in risk stratification, poly-pharmacy management, and goal setting. Patient and informal caregiver involvement are supported by the mobile Patient Empowerment Platform.

Interoperability Middleware enables seamless integration with various patient data sources and national EHR systems, aiding informed decision-making.

The CAREPATH project focuses on improving the lives of elderly patients with multimorbidities and MCI/MD, addressing the needs of a growing elderly population in Europe, which increased from 16.2% to 21.3% between 2003 and 2023<sup>34</sup>. Traditional care settings for these patients are complex and costly, particularly regarding hospitalization and medication expenses. By reducing hospitalization rates by 20%, CAREPATH can substantially lower healthcare costs and support the sustainability of health systems by optimizing available resources. However, it should be noted that the target user group of the CAREPATH solution is limited to older multimorbid patients with MCI or MD, because managing multiple chronic conditions in people with moderate or severe dementia has more challenging specific needs than the ones for people with mild dementia, hence it is out of scope of this study.

### 5 Conclusions

This paper presents the CAREPATH approach for delivering personalized care to manage multimorbidities in older patients with MCI/MD. We have specifically focused on our methodology for addressing the needs of these individuals. The CAREPATH project enables the screening of older adults, facilitating the identification of pre-clinical dementia or high risk of developing dementia based on evidence-based guidelines. We have demonstrated how CDS services can deliver personalized treatment and monitoring. Lastly, we have shown how personalized non-pharmacological interventions are suggested via digital health solutions to support older patients with MCI/MD and multimorbidity. Thus, we illustrate how the recommended actions of the European

Society of Medicine policy framework can be implemented as a digital health solution.

## 6 Conflict of Interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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