

# DELIVERABLE 4.1: REPLICATION GUIDE

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## Introduction

The purpose of the replication guide is to summarize the primary findings of the DIGITALIS project and outline strategies for capitalizing on its outcomes. The guide aims to achieve the following objectives:

- Develop a plan for capitalizing on the activities undertaken in previous project phases.
- Identify potential for replicating project outcomes.
- Provide support for the future expansion of the DIGITALIS approach at the European level.

To accomplish these goals, the document is structured around three main pillars:

1. **Overview of DIGITALIS:** This section provides a concise summary of the project's logical framework and the outcomes achieved. The overview includes the project's goals, methodologies, and key activities. It also highlights the successes and challenges encountered during the implementation phase. By offering a clear and detailed account of the DIGITALIS project, this section ensures that stakeholders understand the foundation upon which the replication strategies are built.
2. **Capitalization Plan:** This section outlines the steps involved in integrating DIGITALIS training into a new social context. It provides a roadmap for organizations and institutions looking to adopt the DIGITALIS approach. The plan includes a detailed analysis of the project's core components, such as training modules, resources, and tools. It also presents strategies for adapting these components to different cultural, social, and economic environments. By following this capitalization plan, stakeholders can effectively transfer the knowledge and practices developed during the DIGITALIS project to new settings, ensuring sustainable and impactful outcomes.
3. **Conclusion & Recommendations:** This section offers guidance and suggestions to promote a caregiver-friendly environment in the EU. It emphasizes the importance of creating supportive policies and frameworks that facilitate the integration of DIGITALIS training into various sectors. The recommendations are based on the insights gained from the project and aim to address the specific needs and challenges faced by caregivers. By implementing these recommendations, policymakers and practitioners can foster a more inclusive and supportive environment for caregivers across Europe.

In addition to these three main pillars, the replication guide also includes practical tools and resources to assist stakeholders in the replication process. These tools encompass templates, checklists, and case studies that provide concrete examples and best practices. Furthermore, the guide highlights the importance of collaboration and networking among stakeholders to enhance the dissemination and uptake of the DIGITALIS approach.

By offering a comprehensive and practical framework, the replication guide ensures that the valuable outcomes of the DIGITALIS project can be effectively leveraged and expanded across Europe. It serves as a vital resource for policymakers, practitioners, and organizations committed to promoting innovation and improving the quality of care in the EU.

## Digitalis at a glance

### PR1- State of the art

The state-of-the-art analysis focused on two primary areas: understanding the needs of family informal caregivers (FICs) and compiling an inventory of the key digital healthcare services and technologies utilized in the pilot regions. The overarching goal was to illustrate and establish connections between the essential needs and capabilities of FICs and the core tools necessary for managing the daily lives and health of those they care for.

In pursuit of this objective, three main goals were pursued:

- Gain insight into the current level of basic digital skills among FICs in the target countries.
- Identify and validate a roster of digital tools commonly utilized by FICs in the pilot countries (Greece, Hungary, and Italy) for caring for older adults under their charge.
- Assess the awareness of FICs regarding the potential of emerging digital technologies.

To conduct the preliminary analysis (PR1-D.1.1,2,3, and 4), a questionnaire (D.1.1 – Digitalis Inclusion Assessment Scheme) was administered to a group of 34 voluntary informal caregivers in Hungary and 22 in Greece. The questionnaire was designed to evaluate the basic digital skills and needs of the participating FICs, and the collected data was subsequently analyzed and reported in D.1.2.

### Sample panel description (D.1.2)

#### GREECE PILOT

All 22 informal family caregivers in the sample are from Greece, with 22.7% being male and 77.3% female. Approximately 45.5% fall within the 46-60 age range. They all reside in urban or suburban areas. The majority (54.5%) reported providing regular care for their parents. Of the Greek caregivers, 59.1% are fully employed while caring for their loved ones, and 63.6% hold a higher education degree. Interestingly, 31.8% have received some form of caregiving training in the past, while 68.2% have not had such an experience.

#### HUNGARY PILOT

In Hungary, 28 women participated in the questionnaire, with 26 aged above 61 and 2 aged between 18-30. A significant portion (73.5%) of the caregivers reported providing care for strangers, while over 10% provided care for neighbors or acquaintances. The majority (73.5%) claimed to be retired, with only 11.8% being fully employed. Nearly all caregivers (94.1%) reside in urban areas across Hungary, and 88.2% hold a higher education degree. Despite their education, 73.5% of respondents have never received any formal caregiving training. Interestingly, most caregivers are proficient in using digital devices, with 28 maintaining in-person contact with recipients and only 3 using communication apps for communication.

### FICs need assessment (D.1.4)

The majority of the informal family caregivers (FICs) involved in the study perceive themselves as possessing adequate skill levels in various digital competencies:

- Utilizing digital tools and online services.
- Articulating information needs, creating, and updating personal search strategies.
- Proficiency with computers, the internet, and computing technologies.
- Sharing information on websites or blogs and understanding copyright rules.
- Creating digital content and accessing free content.
- Developing digital skills.

Specifically, according to the DigComp 2.2 framework, most FICs are independently or at an advanced level, capable of solving non-routine problems, assessing information needs, adapting search strategies, accessing data, and sharing information using various methods.

Interestingly, while caregivers primarily use smartphones, most do not use technology to stay in touch with the person they care for. Instead, they prefer personal visits, despite many caregivers living with the care recipient.

Survey results also indicated that there is a lack of intermediate skill levels: 40.9% of participants rated their digital skills as advanced, while 4.6% reported having no skills at all.

A significant concern highlighted by the survey is the protection of personal data: only 7% of surveyed FICs feel capable of safeguarding their personal data, indicating a lack of proficiency in utilizing special security measures, despite regular use of desktops, laptops, and smartphones.

The most challenging aspect of their role for informal family caregivers (FICs) is often intertwined with their personal lives. For approximately 50% of the FICs surveyed, striking a balance between their daily work, family responsibilities, and caregiving duties proves to be the most difficult aspect of their informal care work. Juggling these multiple roles presents a significant challenge, requiring caregivers to manage their time and resources effectively while meeting the needs of their loved ones. This struggle highlights the complex and demanding nature of informal caregiving, where caregivers must navigate various responsibilities and commitments to provide care and support to their family members or loved ones in need.

### Inventory of relevant to ICs digital healthcare services and technologies used in the pilot areas (D.1.3)

In order to align with the prevailing ICT tools utilized in diverse local contexts during training implementation, a comprehensive list of digital tools commonly employed by informal family caregivers (FICs) in the pilot countries has been meticulously curated and validated. The overarching goal of this deliverable is to delineate e-health services, thereby facilitating the creation of a tailored mapping and inventory of e-health services and associated technologies. This endeavor aims to equip informal caregivers with the necessary resources to streamline their caregiving responsibilities and enhance outcomes for their patients across all pilot

countries, including Greece, Hungary, and Italy. Through the identification and validation of these digital tools, caregivers can harness technological advancements to bolster their caregiving efforts and optimize the delivery of care to those in need. The deliverable 1.3 is structured as follow:

- Communication, emergency alert: including all the general communication and networking tools (e.g. whatsapp, viber,...), the specific communication tools more specialized for homecare recipients or communication networks developed for caregivers and all the emergency alert devices for homecare recipients.
- Home and Safety security: including all the detectors, sensors, home treatment connected to applications and able to monitor several physiologic parameters, heart problems, sleep monitor...
- Mental Health: which are games or learning apps and online community sites to maintain mental health and to support both the patient and the female informal caregivers.
- National E-health Systems: in this case we decided to include all the electronic health record /system / services useful for the all the citizens in Italy, Hungary and Greece for booking their appointments, receiving their medication or examinations prescription and consulting the entire history of their health care life.

The PR1 added value.

The overall value of the project results can be examined from a dual perspective, each shedding light on distinct facets of the project's impact:

1. The result of the implemented analysis: The data gleaned from the self-perception assessments of the volunteer caregivers provide invaluable insights into a population that has thus far been overlooked and underexplored in terms of digital exclusion. The findings paint a vivid picture of a caregiver community grappling with digital literacy challenges and grappling with their own perceptions of technological proficiency. This nuanced understanding of caregivers' digital experiences serves as a critical foundation for devising targeted interventions and support mechanisms aimed at bridging the digital divide and fostering digital inclusion among this demographic.
2. The methodology (the digital inclusion assessment scheme): The innovative methodology developed as part of the project—the digital inclusion assessment scheme—holds immense potential for broader application beyond the confines of the pilot areas. Serving as a gold standard for assessing digital inclusion, this meticulously crafted framework offers a systematic and comprehensive approach to evaluating individuals' digital literacy levels and perceptions. By standardizing the assessment process, stakeholders across diverse contexts can gain invaluable insights into the digital landscape and tailor interventions to address specific needs and challenges. This scalability and adaptability make the digital inclusion assessment scheme a valuable

tool for advancing digital inclusion efforts on a global scale, ultimately empowering individuals and communities to fully participate in the digital age.

## PR2: defining the contents

### Digitalis curricula

The project results 2 were dedicated to meticulously crafting the content for the five modules of the training curriculum, utilizing a collaborative approach involving informal family caregivers (FICs) in the cocreation process. Drawing insights from the needs analysis conducted in earlier project activities, the consortium formulated the following modules:

- MODULE 1: Basic digital skills and competences for caring for older adults (aligned with the DigComp framework)
- MODULE 2: Assistive technologies and health-related information services
- MODULE 3: Self-monitoring and disease management using ICT
- MODULE 4: Digital adherence technologies (e.g., smartphone-based tools, digital pillboxes)
- MODULE 5: Social networks and online communities for active and healthy aging

Given the project's innovative approach to online adult education, the consortium collaborated closely with female informal caregivers to develop collaborative lesson plans for each module. Through focused discussions and refinement in specific focus groups across the pilot countries, the consortium not only fine-tuned the module content but also crafted the initial draft of the overall training syllabus.

The curriculum/syllabus encompasses various elements, including learning goals, participant motivations, teaching methodologies, assessment strategies, duration, workload estimates, prior knowledge requirements, and learning guides. Each module description outlines specific learning outcomes, skills, competences (aligned with the European Qualifications Framework and DigComp), topics, and assignments.

The curriculum/syllabus serves as a comprehensive framework to guide local training implementation, providing a roadmap for trainers and caregivers alike. Through co-creation workshops, stakeholders collaborated to refine the training approach and content, ensuring alignment with local community needs.

The culmination of these efforts resulted in the finalization of the DIGITALIS curricula/syllabuses, uniquely tailored to address the specific challenges and opportunities present within each local community. This iterative process underscores the project's commitment to empowering informal caregivers with the knowledge and skills needed to navigate the digital landscape and enhance the quality of care provided to older adults.

### Training methodology & platform

In PR 2, the Consortium, spurred by Prompt's initiative and with Prolepsis's agreement, opted for a **blended learning approach** for the developed training course. Blended learning, also called hybrid learning, seamlessly integrates traditional face-to-face teaching with online learning experiences, as outlined by Garrison and Kanuka (2004). This method offers numerous

advantages, including flexibility, effectiveness, personalization, wider accessibility, and cost-effectiveness. The course will utilize an e-learning platform for online modules, complemented by in-person practical sessions. This decision was informed by the characteristics of the target audience, informal caregivers (FICs), who are primarily adult women juggling work and caregiving responsibilities. Online delivery allows them to learn at their own pace, accommodating their busy schedules. Furthermore, the preference for hands-on learning over theoretical instruction, revealed in the PR1 survey, will be addressed through practical workshops alongside the online component.

After thorough deliberation, the Consortium selected **Moodle** as the most suitable Virtual Learning Environment (VLE) for delivering the course to Greek and Hungarian informal caregivers. Moodle stands out for several reasons:

- It's freely available as a cloud service or for download.
- It's extensively tested and widely used, including adoption by institutions like the UK's Open University.
- It seamlessly integrates common authentication services like LDAP and Active Directory.
- It's well-maintained with regular security updates and long-term release points.
- It boasts a rich array of features and customization options. Moodle benefits from a large community of users and developers, ensuring continuous improvement and support. It offers extensive customization options, allowing for integration of diverse external content types such as videos, audios, and photos to enhance learner engagement and motivation. Its forum functionality facilitates ongoing discussion among participants, mentors, and peers, supporting collaborative learning and group work. Additionally, Prompt's expertise in developing multilingual Moodle courses and its extensive testing with adult learners further underscore Moodle's suitability for the project.

### Co-creation process.

In the "DIGITALIS" project, co-creation sessions were conducted in Greece and Hungary to develop training modules on promoting female caregivers' digital health literacy. These sessions, lasting 1-4 hours each, involved engaging participants through group interaction. Participants, recruited via the project partners' network, included female informal caregivers involved in healthcare delivery.

A total of 10 sessions, one for each educational module, were conducted in each partner country. Discussion guides were developed to focus on participants' views on module content, information transmission, and overall opinions. Participants freely shared personal experiences and opinions during the sessions. Moderators refrained from directing or reacting to responses. Following the sessions, transcripts were transcribed verbatim in local languages, with identifiers removed for anonymity.

Thematic analysis was conducted independently by two researchers in each country.

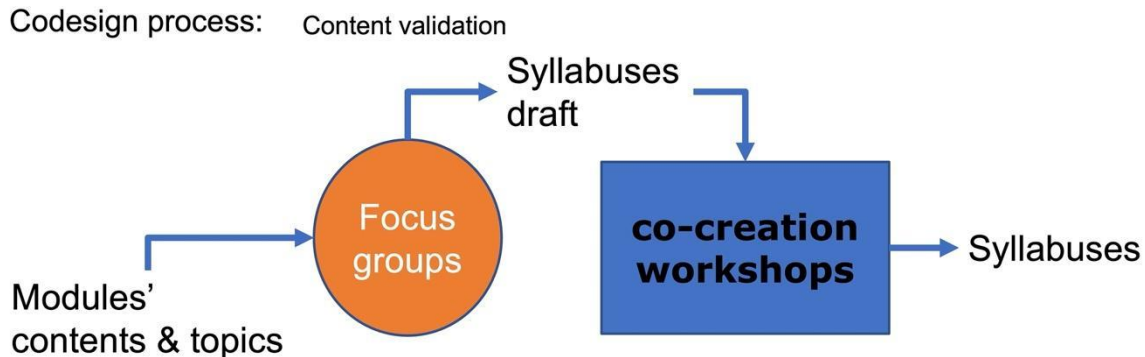
Nine female informal caregivers participated, with a mean age of  $61 \pm 8$  years. Educational levels varied, with participants holding upper secondary education, tertiary education, master's



degrees, and doctoral diplomas. Employment status varied, with some participants working full or part-time and others having household responsibilities or being retired. Most participants were involved in regular caregiving activities, including caring for parents, partners, neighbors, or acquaintances.

The co-creation sessions provided valuable insights into participants' perspectives on digital health literacy. Themes that emerged included the need for accessible and user-friendly digital tools, the importance of tailored content to individual needs, and the desire for practical, hands-on learning experiences. Participants expressed interest in learning about digital health resources, such as telemedicine and health apps, to better support their caregiving roles.

The project partners recognized the importance of incorporating these insights into the development of the training modules. Feedback from the co-creation sessions informed the content and delivery methods of the modules, ensuring that they were relevant, engaging, and accessible to the target audience. By actively involving participants in the development process, the project aimed to create training materials that would effectively meet the needs of female informal caregivers and empower them to navigate the digital health landscape with confidence. Overall, the co-creation sessions were a valuable opportunity to engage directly with the target audience and gain a deeper understanding of their perspectives, preferences, and needs. The insights gained from these sessions played a crucial role in shaping the development of the training modules and ensuring their relevance and effectiveness in addressing the digital health literacy needs of female informal caregivers in Greece and Hungary.



**Focus group:** composed by experts, will provide the modules contents

**Co-creation workshop:** composed by stakeholders, will validate the provided contents and draft the modules syllabi.

## PR3: training fine tuning

### Trainings assessment

The assessment methodology for the training program comprises three main goals:

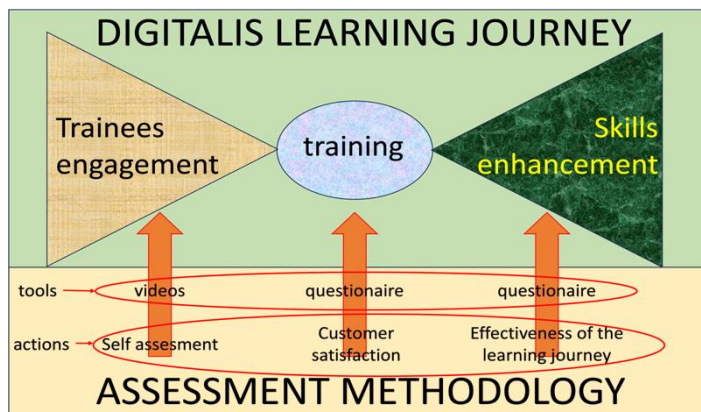
1. Assessing the trainees' awareness: Simple questions in interactive videos gauge the FICs' competencies and highlight the importance of training module contents, determining their entry skill level.
2. Evaluating the effectiveness of the training: At the end of each module, trainees' competencies are assessed based on their understanding of the module's contents.
3. Measuring customer satisfaction: Feedback questions assess the effectiveness, ease of use, and utility of the training for users.

Assessment tools include online questionnaires or quizzes for prompt, automated analysis of responses. These tools are shared with learners through customized videos and Moodle e-learning platforms. Questions types vary, including yes/no, multiple-choice, and short free-text responses.

Self-assessment is integrated into personalized module videos, prompting learners to reflect on their existing knowledge and experience related to the module topics. Modules 1 and 5, being optional, lack motivating videos and preliminary self-assessment questions, allowing learners to choose their delivery independently.

### The Digitalis training course

The "Digitalis" online course marks a significant leap forward in the project's mission to empower informal caregivers with the necessary digital skills and knowledge. For the first time,



project partners collaborated to develop the course content in English and structured within a clearly defined module template. Recognizing the caregivers' preference for succinct and visually appealing content, the course was meticulously curated to provide concise yet comprehensive learning materials.

Taking into account the feedback received from caregivers during the cocreation process, the course content is enriched with an array of multimedia elements, including links to supplementary resources, embedded video tutorials, captivating images, and informative presentations. This approach not only enhances the learning experience but also caters to diverse learning preferences, ensuring that caregivers can engage with the material in a manner that suits their individual needs.

Hosted on the Moodle platform by PROMPT, the course is easily accessible to registered users, allowing caregivers to access the materials at their convenience. Furthermore, the course is available in three languages—English, Greek, and Hungarian—reflecting the project's commitment to inclusivity and accessibility across diverse linguistic communities.

In response to the evolving digital landscape, the course was meticulously designed to be responsive and mobile-friendly, ensuring seamless access across various devices, including PCs, laptops, and smartphones. This adaptability underscores the project's dedication to reaching caregivers wherever they are, empowering them to acquire essential digital skills regardless of their technological proficiency or device preference.

As depicted in the accompanying image, the course interface is thoughtfully optimized for mobile devices, providing caregivers with an intuitive and user-friendly learning environment. Through the "Digitalis" online course, caregivers gain invaluable insights and practical knowledge to enhance their caregiving practices, ultimately improving outcomes for older adults in their care and fostering a more inclusive and supportive caregiving community.

## Capitalization plan: how to replicate Digitalis

Replicating the Digitalis training in a new local society requires a thoughtful and systematic approach to ensure its effectiveness and relevance. This can be achieved through a comprehensive three-step procedure that addresses the unique needs and circumstances of caregivers in the target community:

1. Assess the needs of local caregivers
2. Engage FICs in adapting the training contents
3. Personalize the training modules and upload the Moodle platform

By adhering to these three crucial steps, stakeholders can adeptly replicate the Digitalis training in a new local context, thereby equipping caregivers with the essential knowledge and skills required to offer proficient care in the digital era. Through active engagement, customization, and harnessing the power of technology, the Digitalis training stands poised to deliver a profound impact on caregivers and the older adults they support in communities worldwide.

Active engagement serves as the cornerstone of this approach, fostering a collaborative environment where caregivers actively participate in shaping the training to suit their unique needs and circumstances. By involving caregivers in the development and refinement of training materials, stakeholders ensure that the content resonates deeply with their experiences and challenges, thus enhancing its relevance and effectiveness.

Customization is equally vital in tailoring the Digitalis training to the specific requirements of the local community. Through a comprehensive needs analysis and co-creation methodology, stakeholders can identify and address the distinct needs, preferences, and cultural nuances of caregivers in the target area. This personalized approach ensures that the training aligns closely with caregivers' realities, thereby maximizing its impact and empowering them to deliver high-quality care.

Leveraging technology further amplifies the reach and efficacy of the Digitalis training. By utilizing user-friendly platforms like Moodle and incorporating interactive elements, stakeholders can deliver engaging and accessible training experiences to caregivers. This seamless integration of technology facilitates learning and knowledge transfer, enabling caregivers to acquire essential digital skills and stay abreast of advancements in care practices. Ultimately, by following these strategic steps, stakeholders can unlock the full potential of the Digitalis training, empowering caregivers to navigate the complexities of caregiving in the digital age with confidence and proficiency. This concerted effort promises to foster positive outcomes for caregivers and the older adults they serve, enhancing the quality of care and support in communities across the globe.

### Assess the needs of local caregivers.

To effectively tailor the Digitalis training to the specific needs of the local community, conducting a thorough needs analysis is essential. This involves engaging directly with informal

family caregivers (FICs) to gain insights into their challenges, preferences, and priorities. Surveys, interviews, and focus groups are valuable tools for gathering this information and understanding caregivers' digital literacy levels, caregiving responsibilities, and areas where additional support is needed. By conducting a comprehensive needs analysis, stakeholders can ensure that the training addresses the most pressing concerns and resonates with caregivers on a personal level.

To facilitate this process, the **Digitalis need analysis methodology and questionnaire scheme (D.1.1 - Digital Inclusion Assessment Scheme)** can be applied. This structured approach provides a framework for assessing caregivers' digital skills, understanding their caregiving roles, and identifying specific areas where they may require assistance. By utilizing this methodology, stakeholders can gather robust data that informs the development of targeted training programs and resources tailored to the needs of the local community.

By applying the Digitalis need analysis methodology and questionnaire scheme, stakeholders can gain a comprehensive understanding of caregivers' needs and preferences, ensuring that the Digitalis training effectively addresses their unique challenges and empowers them with the knowledge and skills needed to provide high-quality care in the digital age.

### Engage FICs in adapting the training contents.

The success of the Digitalis training hinges on active participation and input from informal family caregivers (FICs) within the target community. To achieve this, a co-creation methodology can be employed, facilitating the involvement of caregivers in adapting training contents to suit local contexts. This collaborative approach ensures that the training reflects the unique needs and cultural nuances of the community, enhancing its relevance and effectiveness. By leveraging the Co-creation & Stakeholders Engagement Methodology outlined in the toolkit (D.2.3 - Co-creation Content Development Frame), stakeholders can support a smooth and effective engagement process with FICs. This methodology provides a structured framework for involving caregivers in the development and refinement of training materials, ensuring that their voices are heard and their perspectives are integrated into the content.

Through this collaborative process, FICs have the opportunity to contribute feedback, ideas, and insights based on their lived experiences as caregivers. Modules can be tailored to incorporate relevant examples, case studies, and practical tips that resonate with the realities of caregiving in the local community. By actively involving FICs in the co-creation process, the training not only becomes more relevant and impactful but also fosters a sense of ownership and empowerment among participants.

Ultimately, the application of the Co-creation & Stakeholders Engagement Methodology (D.2.3 - CO-CREATION CONTENT DEVELOPMENT FRAME) enables stakeholders to effectively engage FICs in shaping the Digitalis training to meet their needs, ensuring that it is both responsive to local contexts and reflective of caregivers' experiences and preferences.

## Personalize the training modules and upload the Moodle platform

The user-friendly Moodle platform stands out as an ideal tool for hosting the Digitalis training, offering a seamless experience for both trainers and participants. With its intuitive interface and robust features, Moodle is well-equipped to accommodate the adjusted contents developed through the co-creation process.

Moodle serves as a valuable tool for delivering the Digitalis training to caregivers in the target community. To maximize its effectiveness, it's crucial to provide guidance on navigating the platform and accessing training materials. This may involve offering training sessions or resources to familiarize local trainers and caregivers with the platform's features and functionalities. Emphasizing user-friendly navigation, interactive elements, and ongoing support is essential to ensuring a seamless learning experience for participants.

Flexibility and customization are paramount when replicating the Digitalis training in a new local society. While the training modules provide a foundational guideline, they should be adapted to reflect the specific needs and preferences of caregivers in the target community. This involves several key steps:

**Translation:** Translating content into the local language ensures accessibility for all participants. By providing materials in a familiar language, stakeholders can enhance comprehension and engagement.

**Cultural relevance:** Incorporating culturally relevant examples and scenarios helps the training resonate with participants' lived experiences. Drawing on familiar cultural contexts facilitates deeper connections and understanding.

**Pace and structure:** Adjusting the pace and structure of the training accommodates diverse learning styles and preferences. Offering flexibility in content presentation allows participants to engage at their own pace, enhancing retention and comprehension.

By personalizing the training modules in these ways, stakeholders can effectively address the needs and preferences of caregivers in the target community. This enhances the relevance and effectiveness of the training, fostering a supportive and inclusive learning environment where all participants feel valued and empowered. Through the user-friendly Moodle platform, stakeholders can seamlessly deliver personalized training modules, empowering caregivers with the knowledge and skills needed to provide effective care in their local context.

## Lessons learned, recommendation beyond Digitalis.

### European care strategy

#### Caregivers

The Commission Staff Working Document accompanying the Commission Communication on the European care strategy of the 2022, provides a detailed overview of the development of the European care strategy, which is aimed at comprehensively addressing the needs of caregivers and care receivers across the European Union. This strategy represents a significant step towards enacting policy reforms that are essential for ensuring sustainable long-term care, improving access to high-quality services, narrowing gender employment disparities, and enhancing working conditions within the care sector. By synthesizing insights gathered from extensive consultations with stakeholders, including various public consultations on crucial aspects such as the European Pillar of Social Rights action plan, the Green Paper on ageing, and the Gender equality strategy, the European care strategy aims to address the multifaceted challenges inherent in the caregiving landscape. Stakeholders have emphasized the critical need for holistic EU action on long-term care, advocating for the establishment of minimum standards, quality guidelines, and robust monitoring mechanisms. Additionally, there have been calls for fostering enhanced mutual learning, facilitating exchanges of best practices, and implementing a comprehensive Care Package. This Care Package would include a revision of the Barcelona targets, which are instrumental in ensuring the provision of accessible and affordable quality long-term care and childcare services. Furthermore, stakeholders have underscored the importance of adopting an integrated approach to long-term care, one that prioritizes the individual needs of care recipients and upholds their right to live in dignity.

In response to feedback, stakeholders have identified several key priorities, including making childcare and dependents' care more readily available, accessible, and affordable. Supporting informal carers to bolster women's labor force participation has emerged as a crucial focus area, alongside efforts to promote equal sharing of caring responsibilities between parents and enhance conditions for part-time work and family leaves. Additionally, there is a strong emphasis on improving childcare provision for under-served groups to ensure inclusivity and equity. The document also highlights common challenges and structural weaknesses prevalent in care systems across the EU, such as issues related to availability, access, affordability, and workforce shortages. Stakeholders advocate for a rights-based approach to care, emphasizing principles of human rights, dignity, inclusiveness, and solidarity. They stress the importance of fostering a resilient ecosystem for care services and unlocking the job creation potential within the care sector. Transformative care policies are seen as essential for ensuring decent work for care workers and delivering quality care for recipients.

Overall, the European care strategy outlined in the Commission Staff Working Document represents a comprehensive and inclusive framework aimed at addressing the complex and evolving needs of caregivers and care receivers across the European Union. By incorporating stakeholder feedback and prioritizing key areas of action, the strategy seeks to pave the way for a more equitable, accessible, and sustainable caregiving landscape in Europe.

Concerning the social value of informal carers' work is often overlooked, but the European care strategy has the potential to address this issue.

Here are some key points on how to recognize and support informal carers:

1. **Access to Information and Services:** Informal carers should have access to information, training, counseling, and complementary care services to support them in their caregiving role. Providing these resources can improve care quality, safety, and sustainability.
2. **Legal Recognition and Rights:** It's important to define a legal status for informal carers and facilitate their access to rights such as employment rights, social protection, respite care, financial support, pension credits, and flexible working arrangements. Recognizing their status and improving their situation is crucial for their well-being.
3. **Support Measures:** Relief for informal carers should be prioritized, including targeted relief services like respite care and holiday care, as well as extending existing services such as day centers with longer opening hours and mobile services. Flexibility in exercising carers' rights in cross-border situations and specific support for informal carers of migrant origin are also important.
4. **Work-Life Balance:** Informal carers should be able to enjoy a proper work-life balance and have flexibility to spend quality time with their children. Increasing the non-taxable income threshold for carers, introducing care credits, and providing targeted labor market integration measures can help support their financial stability.
5. **Recognition and Validation:** The skills acquired while providing unpaid family care work should be recognized and validated. Incorporating targeted health prevention measures, such as mental health support and better communication channels with formal carers, is also essential for their well-being.

A better recognition and support for informal carers are essential for ensuring the sustainability of care provision and improving the quality of life for both carers and care recipients.

### Digitalization and innovation for the care sector

Digitalization holds immense potential for transforming the delivery of long-term care, benefiting both care recipients and carers. Here's a summary of key points:

- **Improved Information Systems:** Investing in effective information systems can simplify administrative procedures and enhance communication between service providers and recipients, leading to more efficient care delivery.
- **Telemedicine Advancements:** Telemedicine is increasingly becoming the standard of care for certain visits, check-ups, and consultations, particularly for chronic conditions and long-term diseases. This can improve access to care services, especially in remote and rural areas.
- **Enhanced Accessibility:** Digitalisation can enhance the accessibility of care services, potentially benefiting home care as a long-term care option. However, it's important to maintain a balance between digital and physical provision of care.



- **Improved Working Conditions for Carers:** Digitalisation can improve working conditions for carers by employing assistive technology and applications to increase care recipient's independence and reduce the intensity or time of care needed. It can also make care jobs more flexible, allowing for remote working opportunities.
- **Addressing Digital Inequalities:** Efforts should be made to address digital inequalities and the digital divide to ensure that all individuals, including those in need of care, can access and benefit from digital tools.
- **Building on EU-funded Projects:** Solutions can build on EU-funded social innovation projects in long-term care and guidelines on integrated care by organizations like the WHO. However, current legislation and regulations may hinder the development of innovative care concepts.
- **Promoting Innovation:** Innovation in care should be promoted through targeted calls within EU programmes like Horizon Europe and the European Competence Centres for Social Innovation. Financial instruments and investment should be utilized to boost investment in the social sector.

Overall, digitalisation offers significant opportunities for improving long-term care delivery, but efforts are needed to address digital inequalities, regulatory challenges, and promote innovation in the sector.

## Caregiver Situation in Hungary, Greece, and Italy

### Hungary

- **Availability and Accessibility:** In Hungary, care services are often insufficient and inaccessible. Long waiting lists and administrative hurdles exacerbate the issue.
- **Affordability:** High costs of care services make them unaffordable for many households. Around a third of households with long-term care needs do not use home care services due to financial constraints.
- **Impact on Women:** The inadequacy of care services disproportionately affects women, who often bear the brunt of informal care responsibilities. This impacts their participation in the labor market and career advancement.

### Greece

- **Availability and Accessibility:** Greece faces similar challenges with care services being unavailable or not aligned with the needs of the population. Rural areas are particularly affected due to long distances and limited public transport options.
- **Affordability:** Many households in Greece also struggle with the high costs of care services, leading to significant out-of-pocket expenses and financial hardship.
- **Impact on Women:** Women in Greece are heavily impacted by the inadequacy of care services, leading to reduced work participation and career progression. The high prevalence of informal care provided by women results in economic and personal burdens.

## Italy

- **Availability and Accessibility:** In Italy, there is a notable shortage of both early childhood education and long-term care services. The availability of care options is particularly limited in rural and remote areas.
- **Affordability:** The high cost of care services in Italy poses a significant barrier to access. Many families face high out-of-pocket costs, making care unaffordable and leading to income poverty.
- **Impact on Women:** The care responsibilities predominantly fall on women, affecting their labor market participation and contributing to gender inequalities in pay and pensions. Women often take long absences from work or withdraw from the labor market to provide care.

## Common Challenges

1. **High Costs:** Across all three countries, the high cost of care services is a major barrier, leading to financial strain for many families.
2. **Gender Inequality:** The care burden disproportionately affects women, limiting their career opportunities and perpetuating gender inequalities.
3. **Rural Disparities:** Rural areas in these countries face greater challenges in accessing care services due to geographic and logistical barriers.

## Recommendations

- **Increase Investment:** Investing in care services to improve availability, affordability, and quality.
- **Support for Caregivers:** Enhancing support systems for informal caregivers, predominantly women, to balance care responsibilities and work.
- **Policy Reforms:** Implementing policies to ensure equitable access to care services and improve working conditions for care workers.

These measures are essential to address the care needs in Hungary, Greece, and Italy, promoting gender equality and improving overall societal well-being

## Hinds and tips from the Digitalis battlefield

The need analysis conducted in Greece and Hungary, the intense cocreation and validation process offer valuable insights into the complex landscape of informal caregiving in these countries. In Greece, where the majority of caregivers are women, often caring for their parents, there is a notable absence of formal training programs in caregiving. Despite this lack of formal education, caregivers exhibit a commendable level of proficiency in digital skills, indicating a potential for leveraging technology to support their caregiving responsibilities. It is noteworthy that while caregivers frequently use smartphones and other digital devices in their daily lives,

they rely more on personal interactions than technology to maintain contact with care recipients. This preference for face-to-face communication underscores the deeply personal and intimate nature of caregiving relationships.

Meanwhile, in Hungary, informal caregivers are predominantly older women with higher education who have transitioned into retirement. Many of these caregivers provide care for individuals they are not closely related to, reflecting the broader societal need for informal caregiving support. Despite their advanced age, caregivers in Hungary demonstrate a varying degree of digital literacy, with some feeling confident in their skills while others struggle with certain aspects of digital technology. Interestingly, while they use digital devices regularly, their usage patterns indicate a reluctance to incorporate technology into their caregiving routines. This discrepancy highlights the need for targeted interventions to bridge the gap between digital literacy and its practical application in caregiving contexts.

|                                      |
|--------------------------------------|
| <i>Leverage<br/>Digital Literacy</i> |
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Across both pilot areas, there **is a common desire among caregivers to connect with peers and share experiences**. This desire for social connection underscores the importance of fostering a sense of community and support among caregivers, who often face challenges and stresses in their caregiving roles. By harnessing the power of digital technology, there is an opportunity to create online platforms and support networks tailored to the unique needs of informal caregivers. These platforms could facilitate knowledge sharing, provide emotional support, and offer practical resources to caregivers, ultimately enhancing their well-being and efficacy in their caregiving endeavors.

In conclusion, the pilot projects in Greece and Hungary shed light on the diverse needs and experiences of informal caregivers in different cultural contexts. By recognizing the strengths and challenges faced by caregivers and leveraging digital technology to augment their support networks, stakeholders can work towards creating a more inclusive and sustainable caregiving ecosystem. Through collaborative efforts and innovative solutions, we can empower caregivers to fulfill their vital roles with confidence and compassion.

### 3 tips

#### To enhance the FICs daily routine

##### 1. Leverage Digital Literacy

Caregivers demonstrate a commendable level of digital skills, indicating an opportunity to leverage technology to support their caregiving responsibilities effectively.

## 2. Foster Peer Support

There is a common desire among caregivers to connect with peers and share experiences. Creating online platforms and support networks tailored to caregivers' needs can provide valuable emotional and practical support.

## 3. Bridge the Gap

Despite their digital literacy, caregivers show reluctance to incorporate technology into their caregiving routines. Targeted interventions are needed to bridge this gap and help caregivers harness the full potential of digital tools in their caregiving roles.

*Foster Peer  
Support*

## ...and 5 recommendations

To **support family informal caregivers in Europe and foster a smooth and effective policies implementation** here are four key recommendations:

### 1. Financial Support and Incentives

*Bridge the Gap*

- **Caregiver Allowances:** Provide direct financial support to informal caregivers through allowances or stipends. This can help alleviate the economic burden and recognize the value of unpaid care work.
- **Tax Benefits:** Offer tax deductions or credits to caregivers for care-related expenses, reducing their financial strain and incentivizing caregiving roles.

### 2. Access to Respite Care and Flexible Services

- **Respite Care Services:** Develop and expand access to respite care services, allowing caregivers to take breaks and reduce stress. This can include temporary residential care or in-home support.
- **Flexible Care Options:** Provide flexible and customizable care services, such as part-time or on-demand care, to better meet the varying needs of caregivers and their families.

### 3. Training and Psychological Support

- **Caregiver Training Programs:** Implement training programs to equip caregivers with the necessary skills and knowledge to provide high-quality care. This includes medical, emotional, and practical aspects of caregiving.
- **Psychological and Emotional Support:** Offer counseling services, support groups, and helplines to address the mental health and emotional well-being of caregivers, reducing feelings of isolation and burnout.

#### 4. Work-Life Balance and Employment Protection

- **Flexible Work Arrangements:** Promote policies that allow flexible working hours, remote work, and part-time options for employed caregivers. This helps balance their caregiving responsibilities with professional commitments.
- **Employment Protection:** Ensure job security for caregivers through legislation that protects their employment rights, such as the right to return to work after a caregiving period, anti-discrimination laws, and leave entitlements specifically for caregiving.

#### 5. Implementation and Policy Integration

- **Policy Integration:** Integrate these recommendations into national and EU-level policies to ensure consistent and comprehensive support across Europe.
- **Monitoring and Evaluation:** Establish mechanisms to monitor the effectiveness of these support measures and make necessary adjustments based on feedback from caregivers and stakeholders.

By implementing these recommendations, Europe can better support family informal caregivers, enhancing their well-being and enabling them to provide care without sacrificing their own financial, physical, or emotional health.

### Digitalis: Contribution to the Debate

On November 29, 2024, Modena hosted the Digitalis project multiplier event, where the five key recommendations to support informal family caregivers were presented and discussed. The event, structured as a round table, featured Elisabetta Gualmini, Ilenia Malavasi, and Annalisa Righi, representing the European Parliament, the Italian Parliament, and the local administration, respectively. The primary aim of the meeting was to create a dialogue across three institutional levels—European, national, and local—to reflect on the crucial role of informal caregivers and the policies needed to support them in a concrete and effective manner.

#### The Speakers

##### Elisabetta Gualmini

A Modena-born politician and political scientist, Elisabetta Gualmini is a Full Professor of Political Science at the University of Bologna. With extensive experience in welfare policies, she served as Vice President and Regional Councillor for Welfare in Emilia-Romagna from 2014 to 2019. In 2019, she was elected to the European Parliament, where she serves on the Committee for Industry, Research, and Energy. Her expertise in social policy and her commitment to European initiatives significantly contributed to the discussion.

##### Ilenia Malavasi

An Italian Parliament Member, Ilenia Malavasi is a prominent figure in the political landscape of welfare and healthcare. She holds a degree in Classical Literature with a specialization in Archaeology and began her political career locally in Correggio, where she served as mayor for two consecutive terms. In 2022, she was elected to the Chamber of Deputies and has been a

leading advocate for the formal recognition of family caregivers, becoming the first signatory of the proposed legislation on this issue.

### Annalisa Righi

As the Head of the Social, Health, and Integration Services Department in the Municipality of Modena, Annalisa Righi took office in 2022. With substantial experience in managing both direct and indirect social services, her work focuses on integrating local services and supporting vulnerable populations. Her contribution to the discussion emphasized the need for integrated territorial policies to support informal caregivers.

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## How to Proceed

**At the European level**, the strategy must address two major challenges: territorial disparities and gender inequality. **Territorial disparities** highlight how access to and quality of caregiving services vary significantly between urban and marginal areas. In major cities, caregivers benefit from a broader and more structured network of services, while rural or peripheral areas face a severe lack of infrastructure, transportation, and social connections, making it difficult to support caregivers and chronic patients. These inequalities must be addressed through targeted European strategies, such as enhancing territorial networks in marginalized areas.

**Gender inequality**, on the other hand, underlines how caregiving responsibilities disproportionately fall on women, who account for over 70% of informal caregivers. This imbalance not only perpetuates gender inequality but also limits women's employment opportunities and personal development, creating a vicious cycle of economic and social exclusion. European strategies must include policies that promote a fairer distribution of caregiving responsibilities, such as incentives for male participation and measures to help women balance work and private life.

*Territorial  
disparities*

**At the national level**, it is essential to overcome the familistic model that places the responsibility for managing chronic patients solely on families. This outdated approach overlooks the critical role of the public healthcare system in managing chronic illnesses. Instead, caregivers should be recognized as the final point in the chain of territorial services, integrated into a healthcare system that assumes primary responsibility for managing chronic patients. In this vision, caregivers are no longer left alone but become part of a structured support network with access to resources, training, and financial assistance.

*Gender  
inequality*

The implementation of the five recommendations is therefore crucial:

- Economic incentives to alleviate caregivers' financial burdens.
- Access to flexible and respite services to allow restorative breaks.
- Training programs to equip caregivers with appropriate skills.
- Policies promoting work-life balance.
- Integration of national policies within a unified European vision.

**At the local level**, administrations play a critical role in creating a comprehensive network that reflects the specific needs of the territory. Only a participatory approach, involving caregivers directly in service planning, can ensure adequate and targeted solutions. Administrations must

foster dialogue with caregivers to understand their real needs and facilitate access to resources and support.

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## Conclusions

The Modena event highlighted the importance of addressing the challenges of informal caregiving through a multi-level, integrated approach.

**At the European level**, two key aspects demand attention: territorial disparities and gender inequality. Territorial disparities show how urban and rural areas differ in service accessibility and quality. Urban caregivers often benefit from a better-organized service network, while rural caregivers face infrastructure gaps that hinder effective support. Bridging this gap requires targeted strategies to strengthen local networks in underserved areas.

Gender inequality places an overwhelming caregiving burden on women, often at the expense of their career opportunities and personal growth. Tackling this imbalance requires policies encouraging male involvement in caregiving and supporting women in balancing their dual roles at home and work.

**At the national level**, the focus must shift away from the familistic approach that entirely places chronic patient care on families. Instead, caregivers should be seen as an integral part of the territorial healthcare system, with the public health sector taking responsibility for chronic disease management. Caregivers should be supported with resources, training, and financial aid to enable their effective integration into the care network.

**At the local level**, administrations must establish strong support networks that resonate with the unique needs of their communities. Direct caregiver involvement in service design ensures that solutions are both practical and effective.

In summary, the Digitalis project offers a tangible roadmap for addressing the challenges of caregiving in the modern era. Bridging territorial and gender gaps, integrating caregivers as essential healthcare stakeholders, and moving beyond the familistic model are critical steps towards a more inclusive, equitable, and sustainable caregiving system. Only through coordinated efforts at the European, national, and local levels can we ensure better quality of life for caregivers and those they care for, promoting a truly integrated and supportive welfare system.

***FICs: an integral part  
of the territorial  
healthcare system***