



CARERSUPPORT - AN INNOVATIVE SOLUTION FOR ADDRESSING THE UNMET NEEDS OF INFORMAL CARERS

GOOD PRACTICE - PROJECT



European Union
European Regional
Development Fund

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Introduction to the Good Practice:

Development of an innovative support platform for informal carers (notably family members) who are nowadays the backbone of long-term care systems in Europe and who are themselves at risk for developing neurodegenerative diseases on long-term if not supported properly to cope with chronic stress related to caring activities.

The AAL – JP projects provides the platform content development, a pilot testing, support for cooperation between business and academia. Good practice for cooperation among academia, clinics, SMEs, large business entities and other relevant stakeholders.

Problem:

1. Nowadays informal carers receive learning, orientation and psychological support according to a variety of ad-hoc models, which usually involve the active participation of a care services provider (such as hospital, care centre or patients advocacy group).
2. It was necessary to support informal carers to avoid neurodegenerative diseases on long-term due to the chronic stress generated by caring activities.

Solution:

- CarerSupport aimed at reducing the fragmentation of existing service models, based on the introduction of a centralized ICT platform, which serves as a single entry point to a wide range of services for secondary users (i.e. informal carers) including training services, psychological support services, as well as a range of tele-consultation and collaboration services (with the involvement of formal carers and health professionals).

Impact:

- The main innovation of the project lies in the creation and operation of a sustainable pan-European ICT-based ecosystem for the training, orientation and support of informal carers.
- The platform impacts the ecosystem made by the formal carers and informal carers, along with other stakeholders such as organizations providing training services, ICT solution providers for an active ageing and social inclusion, as well as policy makers emphasizing on LTC (Long Term Care) policies that affect informal carers.
- The pilot platform addresses combined services of informal careers: education&training, psychological support, collaboration and teleconsulting in Romania, Italy, Norway and Switzerland.

1. Relevancy of the Good Practice (GP) project

The “Relevancy of the GP project” section provides quick check and definition of its relevancy in regards to HoCare project objectives.

Good practice of quadruple-helix cooperation in R&I?	Yes, this GP project includes good practices of quadruple-helix cooperation in R&I
Good practice of delivery of Home Care R&I?	Yes, this GP project includes good practices of delivery of Home Care R&I.
If not in Home Care R&I, description and proof of its potential for transferability to delivery of Home Care R&I	
Generation of innovation in home care through answering unmet needs identified by formal or informal healthcare providers?	Yes, this GP project includes good practices of innovation through answering unmet needs.
Generation of innovation in home care through public driven innovation?	Yes, this GP project includes good practices of public driven innovation.
Generation of innovation in home care via quadruple-helix cooperation for quicker delivery to the market?	Yes, this GP project includes good practices of innovation via cooperation for quicker delivery to the market.

2. Quick overview of the GP project

The “Quick overview of the GP project” section provides initial overview of the good practice project (GP project) and enables readers to see if this GP project idea is relevant for possible transfer to their organization potential innovation activities.

Name of the GP project	CarerSupport
Region of origin of GP project	Italy
5 keywords that best describe the content of the GP project	Integrated support for informal carers Tele-consultations Forums Psychological tools for decreasing carer's burden
Relevant Programme name through which the GP project has been	National Plan for Research, Development and Innovation II 2007-2013 (“Planul National de Cercetare, Dezvoltare si Inovare - PNCDI II 2007-2013”) – from the Executive Unit for Funding Higher Education, Research, Development and Innovation (UEFISCDI) of the Ministry of Education;

funded	in close cooperation with EUprogramme, AAL (Ambient Assisted Living) Joint Programme (Call 5) No operational program support was involved
Relevant support programme / intervention area name of the GP project through which it was funded	Programme 4 – Partnerships in priority domains (“Programul 4 – Parteneriate in domenii prioritare”)
Single or multiple recipients?	Multiple recipients
Type of lead recipient and its role (SME, LME, research centre, innovation centre, network/association, university/school, municipality, other public body, other (specify))	Large Industry player
Types of participating partners and their roles (list all participating partner types. E.g.: hospital, social house, senior house, patient association, networks, SMEs, LMEs, research actors, business supporting organizations, public institutions/regulators, other (specify))	Large Industry player, SME (Industry and Consultancy), Research organizations, Academic organizations End-User organizations
Summary of the good practice	<p>The success of active ageing and social inclusion policies has always been highly dependent on the ever important human care factor, notably on the support provided by formal and informal carers to vulnerable individuals, i.e. individuals who cannot function without the practical help of others.</p> <p>The proliferation of the various care services in most developed countries has led to a pressing demand for formal carers (such as paid workers, nurses and health professionals), but mainly for informal carers (notably family members) who are nowadays the backbone of long-term care systems in European and beyond. The informal carers role is very challenging, given that they have to deal with a variety of symptoms, treatments and care services, which span a wide range of illnesses, diseases, chronic conditions and health problems. Specifically, informal carers need to be able to understand the various conditions, while also possessing the knowledge and skills required to provide support to elderly, patients and vulnerable individuals. At the same time carers are in need of psychological support in order to be able to cope with the psychological challenges of their role (i.e. the so called emotional labour) and to perform their tasks in a sustainable way.</p> <p>EU and national policies for long-term care acknowledge the role of informal carers and in several cases provide them with incentives and financial benefits. However, there is still no adequate support to informal carers in terms of their training towards improving their skills, as well as in terms of alleviating their psychological stress. Towards these directions informal carers could benefit from:</p>

	<p>(A) Structured and targeted training/orientation programmes (including programmes that focus on the carers' digital skills), (B) Communication, collaboration and experience sharing with formal carers, who have typically more experience and skills than informal carers and (C) Programmes for their continuous social, psychological and emotional support. In response to these challenges, CarerSupport will integrate, deploy and test an integrated ICT platform enabling the participation and collaboration of informal carers, psychologists and health professionals towards facilitating the training, learning, orientation, tele-consulting and psychological support of the carers.</p> <p>Based on this platform the project deployed and offers a wide range of services to informal carers including:</p> <p>A) Training, learning and orientation programmes, including general-purpose training programmes and programmes that emphasize on the carers' digital skills. The former will include introductory blended-learning programmes emphasizing on the needs of elderly, and on how to plan and perform the most common care-related activities. On the other hand digital skills training programmes will enable carers to use and fully leverage ICT based solutions for active ageing and social inclusion.</p> <p>B) Psychological support services, aiming at alleviating the stress of informal carers, while at the same time providing them with emotional support. The scope of the support to be provided will include social support services, services facilitating carers to discharge their role, services alleviating stress and boosting mental health, as well as services that could minimize or eliminate smoking and drinking. The support to be provided will facilitate carers to deal with their own sorrow and sense of impending loss. Psychological services will be supported by the ICT platform of the CarerSupport project, through appropriate on-line gaming activities, on-line tips and advice, quizzes, as well as educational activities assisting them in better planning and carrying out their tasks.</p> <p>C) Collaboration and tele-consulting services, which will emphasize communication and experience sharing between formal and informal carers. The main goal of these services will be to achieve knowledge transfer from experienced formal carers to the (usually) less experienced informal carers. As part of those services synchronous services for advise and handling/dealing with emergencies will be provided (e.g., in the form of a web-based 112 service for informal carers).</p>
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3. Transferability

The "Transferability" section provides more detailed review of strengths and weaknesses of this GP project including description of necessary basic conditions for region and leading organization to potentially transfer it. At the end of the section, the key threats in the successful transfer open up possibility to focus on specific relevant issues important for the successful transfer.

Strengths and weaknesses of the project

What are the GP project strengths? Why it was funded?	The innovative idea of creating an ICT-based ecosystem that integrates in one place the training, orientation and support provided for the informal carers of the patients with neurodegenerative diseases. This ecosystem will bring together formal carers and informal carers, along with other stakeholders such as organizations providing training services, ICT solution providers for active ageing and social inclusion, as well as policy makers emphasizing on LTC (Long Term Care) policies that affect informal carers.
What are the key	The project has been finalized recently and its business model is under tests and

weaknesses of the GP project?	validation in real-life setting.
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Basic conditions for successful transfer

Why is this GP project transferable? – innovation, impact, financial, legal, and timeframe aspects	Because it has been designed as such – a sustainable pan-European ICT-based ecosystem with the possibility to localize its content towards the individual markets, in local languages.
What are the basic conditions the region needs to have to be successful in transferring this good practise?	To acknowledge the benefits of the integrated support this platform provides to the exposed group of informal carers, who face similar challenges across Europe, beyond the some of cultural peculiarities of each country/smaller region of Europe.
What are the basic conditions the leading recipient from the region needs to have to be successful in transferring this good practice?	To assure the organizational capacity and the adequate network required to effectively disseminate and transfer this good practice OR to identify the most suitable business or public partners able and willing to do this. To come with a clear and valid business proposal for securing the long-term sustainability of the GP.

Key threats in GP project transfer

What are the key potential threats for the GP project transfer?	Not identifying and validating the most adequate business model in order to provide the long-term sustainability. Not being able to disseminate / market effectively the solution towards its potential beneficiaries.
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4. Description of the GP project

The “Description of the GP project” section provides more detailed information on the Good Practice project (GP project) and enables readers to get further detailed inspiration and easy ready-to-use information for possible innovation transfer to other project applications. This includes: tackled problem, time length of the GP project, objectives, phases, activities and deliverables of the GP project, its main innovation and target group.

Description of the tackled problem

What was the problem / challenge tackled by the project?	Although EU and national policies for long-term care acknowledge the role of informal carers and in several cases provide them with incentives and financial benefits, there is still no adequate support to informal carers in terms of their training towards improving their skills, as well as in terms of alleviating their psychological stress.
What were the reasons for the problem?	<ul style="list-style-type: none"> • Lack of easy-to-access educational resources for informal carers – many countries (especially in East Europe) do not have any kind national programs/strategies for the patients with AD and other dementia, and even those countries having these national policies, they focus mainly on the patient’s case management and not too much on the impact it has on their family members (the informal carers); • Furthermore, beside lacking educational resources they are also not receiving psychological support; • Nor do they know how to find and discuss with people facing similar challenges and exchanging information in a structured way

Time length of the GP project

What was the time length of the GP project in months?	30 months
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Objectives of the GP project

Describe the overall and specific objectives of the GP project	<p>The project aimed to successfully develop, integrate and test the CarerSupport platform and services.</p> <p>CarerSupport aimed at reducing the fragmentation of existing service models, based on the introduction of a centralized ICT platform, which will serve as a single entry point to a wide range of services for secondary users (i.e. informal carers) including training services, psychological support services, as well as a range of tele-consultation and collaboration services (with the involvement of formal carers and health professionals). In the scope of this integrated service model, the main exploitable products and services of the project were: (i) Training materials and courses, (ii) Training programmes, (iii) Tele-consulting services including synchronous interactions in case of emergency, (iv) Psychological support services and programmes. These products and services will be exploited in the scope of a value chain that involves both organizations offering these services (i.e. training organizations, care services providers, ICT experts, subject matter experts), and organizations that use these services (notably carers organizations, individual informal carers and care service providers). Overall, CarerSupport will invert the loop of current support services for informal carers on the basis of a technology-driven and more integrated approach that eases the participation of all stakeholders.</p> <p>At the same time the partners are working out an exploitation agreement, which will regulate rights and obligations in the scope of joint exploitation. From a technical viewpoint these services could be rolled out within a timeframe of 6-12 months following the end of the project, targeting secondary users from the consortium organizations, the business networks of the partners, as well as the project's external stakeholders' group.</p> <p>From a marketing and business perspective the full roll-out of the services may need a rather longer period (i.e. 18-24 months), which will allow the consortium to ensure a critical mass of participants, along with a critical mass of content (training materials, courses, training programmes, tele-consulting programmes, psychological support programmes), which will boost the commercial success of the services to be offered to secondary users and other stakeholders.</p>
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Phases, activities and deliverables

List all main phases of the GP project including their time length	<ul style="list-style-type: none"> - User Requirements & Platform Specifications: 8 months - Platform Development (including 3 iterations): 22 Months - Services / Content creation (in 2 iterations): 10 months - Pilot Testing / Evaluation: 6 Months
List and describe all main activities that were implemented by the GP project	<ul style="list-style-type: none"> - Project Management - User & Other Stakeholders Requirement / Platform Specifications - Platform Development, Integration & Implementation - Pilot Testing, Evaluation & Validation - Dissemination activities & Exploitation Plan
List all main deliverables of the GP project	<ul style="list-style-type: none"> - User requirements (informal carers and other stakeholders) - Quality Assurance & Risk Assessment Handbook - Platform specifications - Services specifications - ICT based Training and Psychological Support Programmes - Blended Learning Services - Tele-consultation Services

	<ul style="list-style-type: none"> - Psychological Support Services - Digital Literacy Services - Pilot Testing, Evaluation and Validation - Disseminating activities – scientific events (scientific papers in development) - Exploitation and Business planning
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Main innovation of the GP project

What was the main innovation of the GP project?	The main innovation of the project lies in the creation and operation of a sustainable pan-European ICT-based ecosystem for the training, orientation and support of informal carers.
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Target group of the project

Who was the main target group of the GP project? (SME, LME, research organization, university, public institution, healthcare provider, business supporting organization, other (specify))	<ul style="list-style-type: none"> - Informal Carers and their Associations - Formal care service providers (public and / or private) - Providers of support services (training organizations, experts in psychology) - Local public authorities (e.g. the social service dept from local city halls)
Describe the main target group	The stakeholders described above, with the main focus on the needs of the informal carers.

5. Impact

The “Impact” section provides more detailed information on the effect of the GP project implementation and dissemination of major outputs.

Impact

What was the level of geographical impact of the GP project? (village, city, county, country, international, other (specify))	National and European (Italy Norway and Switzerland)
What were the final impact indicators including their quantification?	Too early to assess (project has just successfully finished).
Describe the changes resulted from the project activities	Not applicable

Dissemination of outputs

Describe dissemination activities of the project outputs carried out during the GP project	<p>During the project its concept and development has been disseminated through scientific events (medical and ICT related) relevant to the stakeholders; and through the project website.</p> <p>Scientific publications are planned for the next coming period.</p>
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6. Risks

The “Risks” section provides more detailed review of potential risks of this GP project implementation including their defined mitigation strategies to eliminate them.

Describe risks involved in implementing this GP project including their mitigation strategies	The Romanian variant could be not quickly updated in terms of content and legal context. The continuity in further updates should be obtained via a multiannual programme for sustaining the project results customized in Romania under OP Competitiveness (OPC) or Administrative Capacities (OPAC) or other programmes.
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7. Budget

The “Budget” section provides more detailed review of costs regarding the project implementation as well as operational sustainability after its end. In addition, if relevant, public tenders within the project and additional generated incomes by the project are showed and explained.

Budget

What was the overall budget of the project in EUR?	€ 2.301.379,90
List relevant budget lines of the project including their % share from total budget	Staff costs – 60% Administration – 3% External expertise – 6% Travel and accommodation – 10% Meetings and events – 15% Promotion costs – 1% Equipment – 1% Other – 4%

Additional income generated by the project

Did the project create any additional income?	no, the GP project did not generate additional income
If yes, specify which type of income and what amount in EUR?	

Public tender

Did the project include any public tender?	no, the project did not include a public tender
If yes, specify what kind of contract (specific contract, general contract, other)	N/A
If yes, specify in what amount in EUR	N/A
Describe the public tender subject	N/A

Financial sustainability after GP project end

Was there an operational financial sustainability plan in the project after its end?	no, the GP project did not include an operational financial sustainability plan
If yes, specify where the operational funds after project end came from?	N/A
If yes, specify the amount of operational funds in EUR	N/A

8. Other information

In this section, specific additional information about the GP project could be revealed.

Please describe any other relevant information about this GP project (if relevant)	-Project basic information: http://www.carersupport.eu/
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9. Information gathered by ...

The information about this good practise (GP) project has been gathered for the purpose of the HoCare project (Interreg Europe Programme) by the following organization:

Region	Romania
Organization name(s)	National Institute for Research and Development in Informatics (Institutul National de Cercetare Dezvoltare in Informatica)
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National Institute for Research and Development in Informatics – www.ici.ro

