

# Supporting carers through the web: the road towards a new European web platform

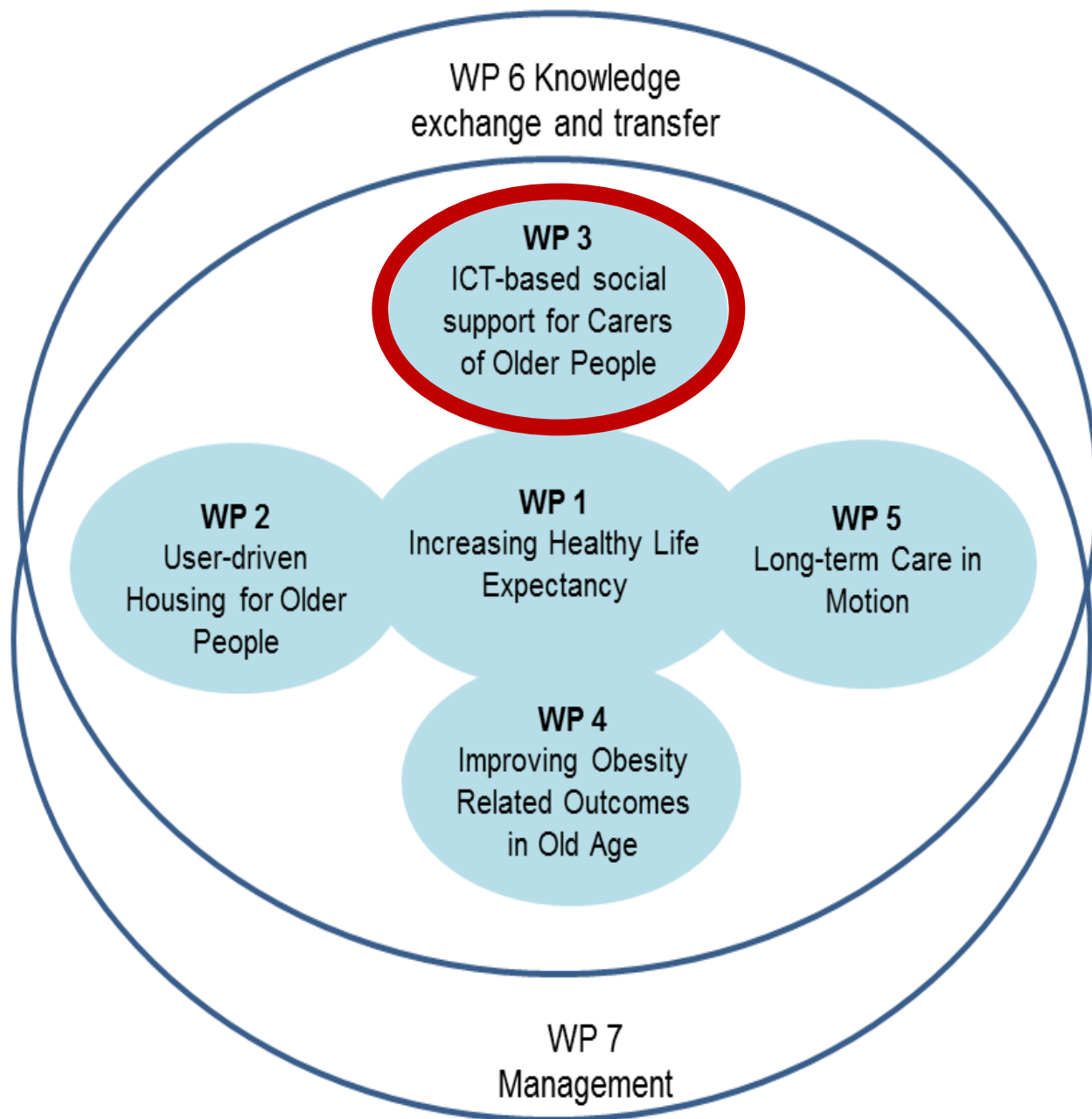
Areti Efthymiou  
*Eurocarers*

On behalf of the research team composed by:

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## Project Partners

1. University of Sheffield, UK (Coordinator)
2. Lund University, SE
3. Heidelberg University, DE
4. Newcastle University, UK
5. Italian National Institute of Health and Science on Ageing (INRCA), IT
6. Age Platform Europe, BE
7. Eurocarers, LU
8. Sheffield Hallam University, UK
9. Latvian Council of Science, LT



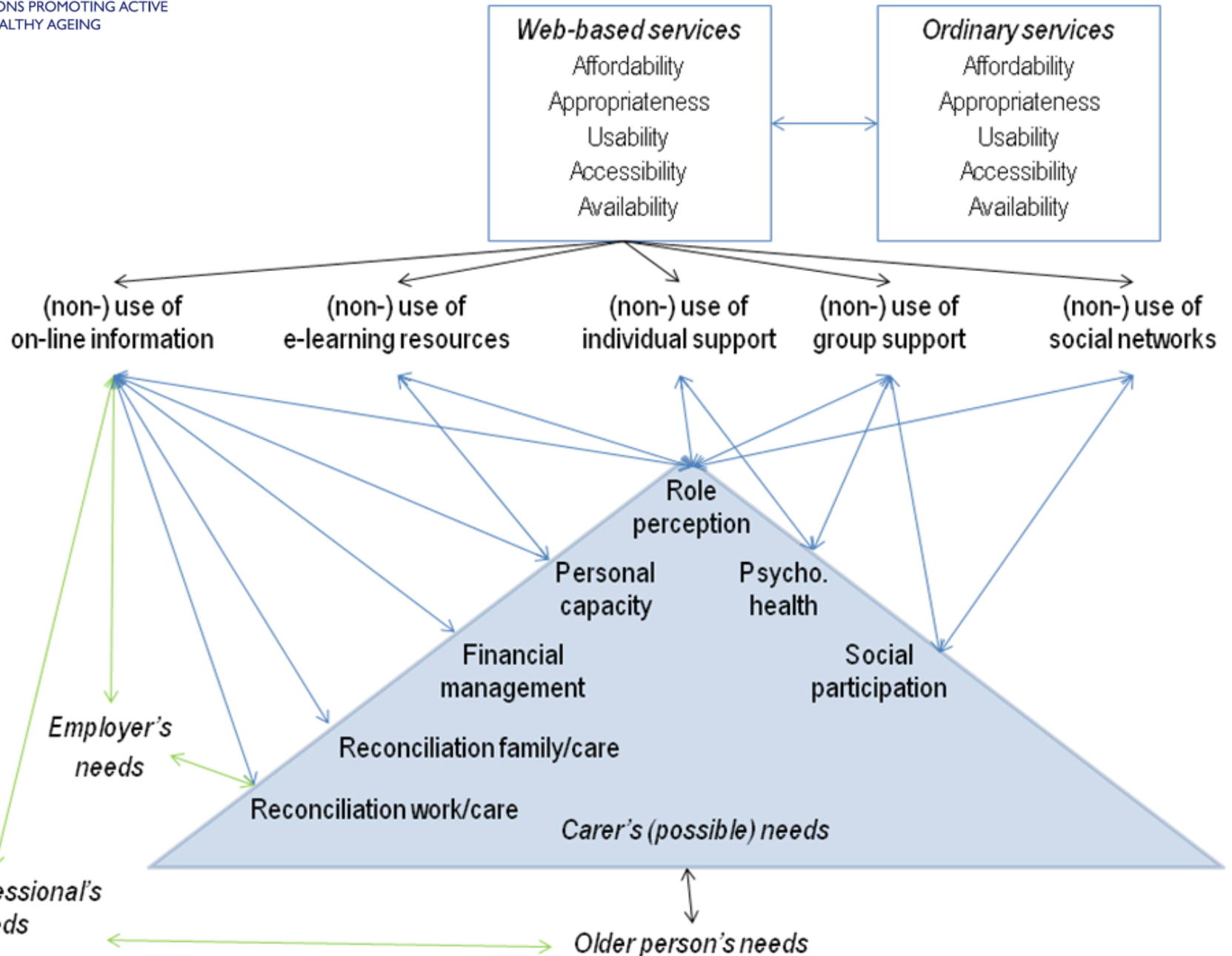
# A multilingual platform for informal carers

**INRCA** and **EUROCARERS** are contributing as INNOVAGE partners by developing a web platform addressing *informal carers'* needs, which will be implemented in 27 EU member states with both common and national-specific services.

Two additional sections of the platform will be prepared for a certain number of countries for other target groups:

- *Employers of working carers*
- *Care professionals*

# A conceptual framework



# Static information

- Information on illnesses and care management
  - Available care and support services
  - Psychological support- consultation
  - Information on taking care of yourself
  - Work and care reconciliation
  - Family and care reconciliation
  - Legal aspects
  - Financial aspects
  - Good Practices
  - Emergency services
- Caring for the elderly*
- Your own needs*
- Support by the state*
- Get Help*
- 
- ```
graph LR; subgraph Caring_for_the_elderly; direction TB; C1[Information on illnesses and care management]; C2[Available care and support services]; end; subgraph Your_own_needs; direction TB; C3[Psychological support- consultation]; C4[Information on taking care of yourself]; C5[Work and care reconciliation]; C6[Family and care reconciliation]; end; subgraph Support_by_the_state; direction TB; C7[Legal aspects]; C8[Financial aspects]; end; subgraph Get_Help; direction TB; C9[Good Practices]; C10[Emergency services]; end;
```

# Static information

## Common information

Common contents have been retrieved from other reliable websites and organisations that have a longstanding expertise in the field:

**Parkinson's Association of Ireland**  
**Anziani e non solo – ASPASIA project**  
**Athens Association of Alzheimer's Disease –**  
**SET CARE project**  
**Stroke UK Association**  
**Arthritis Ireland**  
**CARERS UK**  
**Caregiving.com**  
**Alzheimer Scotland**  
**NHS health Scotland**  
**The Scottish dementia working group**  
**Dementia challengers website**

Default

Large

Largest

English

Search ...

Exit



[Caring for the elderly](#)

[Your own needs](#)

[Support by the state](#)

[Get help](#)

[Interactive services](#)



Care and support services

Lorem ipsum dolor sit amet, consectetur adipiscing elit. Fusce euismod commodo ante....

[More...](#)



[GO TO INTERACTIVE SERVICES](#)

### Latest posts from the social network



Areti Efthymiou has just signed up.

Say hello!

September 5, 2013 - [Like](#) - [Comment](#) - [Delete](#)



### Coping with caregiving

Lorem ipsum dolor sit amet, consectetur adipiscing elit. Fusce euismod commodo ante. Suspendisse potenti. Nunc pellentesque quam vel pede. Ut a lorem non urna molestie euismod.

[More >](#)



### Family reconciliation

When you are a carer, sometimes you find yourself in a position where you try to combine different family roles: as a parent, as a spouse, as a child and as carer. Reconciliation between family relationships and caregiving is a difficult task.



### Test Yourself

Lorem ipsum dolor sit amet, consectetur adipiscing elit. Fusce euismod commodo ante. Suspendisse potenti. Nunc pellentesque quam vel pede. Ut a lorem non urna molestie euismod.

[More >](#)

## Impairments and care management

Carers / Caring for the elderly / Impairments and care management

### Impairments and care management >

Dementia

Parkinson's disease

Stroke

Arthritis

Osteoporosis

Eves Diseases

Deafness

Diabetes

Hypertension

Bedsore

Urinary Incontinence

Care and support services >

Mobility services >

Home environment >

This section is devoted to Pathologies of older people and care management.

Information on a number of diseases are provided.

You may visit each page by clicking on boxes below or by clicking on your left side list.



Dementia

The term "dementia" refers to a group of symptoms that appears to people with diseases which destroy brain cells and cause a gradual deterioration of cognitive abilities.

[More >](#)



Parkinson Disease

It is a progressive neurological disorder, which so far cannot be cured.

[More >](#)



Stroke

A stroke is a brain attack. For your brain to function, it needs a constant blood supply, which provides vital nutrients and oxygen to the brain cells.

[More >](#)



Arthritis

Arthritis is an inflammation of the joints that causes pain and immobility, ranging from mild to severe.

[More >](#)



Osteoporosis

Osteoporosis is a disease of the bones which provokes calcium and mineral reduction. Bones are becoming weak and may break easily.

[More >](#)



Visual impairment

We see now pathologies that affect sight and hearing, provoking sensory deficits.

[More >](#)



## Coping with Caregiving

Carers / Your own needs / Coping with Caregiving

### Coping with Caregiving >

The Caregiving years: an Introduction

Carers' Stories

Looking after yourself

Coping with stress and depression

Relaxation techniques

Coping with dementia

Family reconciliation >

Work reconciliation >

Physical exercise - Staying Active

Test yourself



### The Caregiving years: An introduction

When you expect a child, the community (your family, friends, co-workers) rally around you and your spouse.

[More >](#)



### Carers' stories

I am exhausted and extremely tired but I have not had a good night's sleep since we moved. Everyone tells me to stop worrying, things will work out, etc, etc.

[More >](#)



### Looking after yourself

Being a carer sometimes makes it difficult to take care of yourself. Priorities are changing as the disease progresses and looking after yourself takes usually last place on a long list of heavy duties.

[More >](#)



### Coping with stress and depression

Stress is part of everyday life and, for many carers, stress can be a major factor affecting their health. Stress is caused by the many demands made on our time and energy and the



### Relaxation technique

When we are thinking of relaxation, we usually think of doing activities that we enjoy as sleeping, watching TV, going out with friends.

[More >](#)



### Coping with dementia

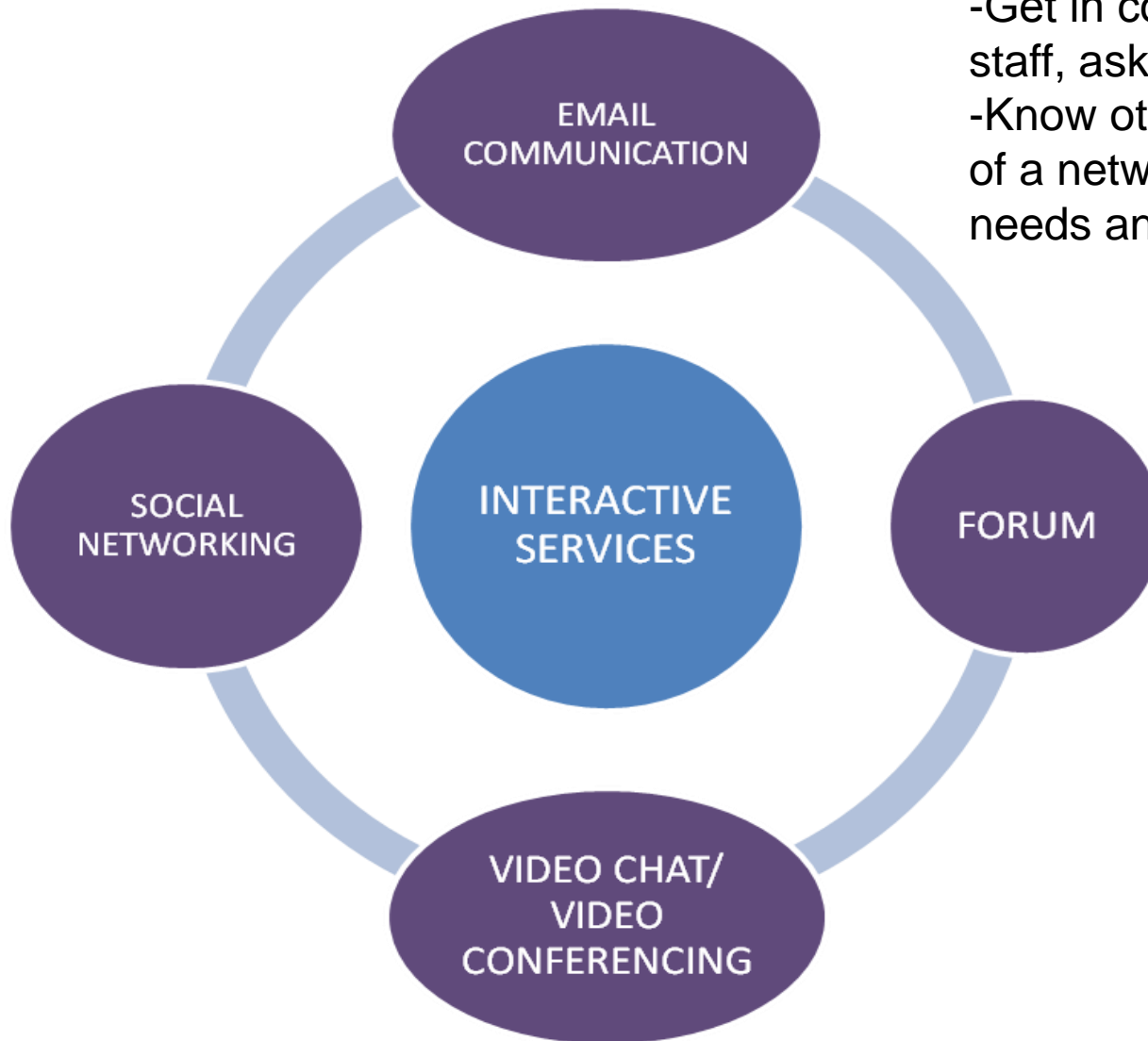
The Coping with Dementia DVD is made up originally of 7 chapters and is addressed to people caring for someone in the middle to late stages of dementia.

| <b>COUNTRY</b>        | <b>ORGANISATION (SHORT NAME)</b>                                                     |
|-----------------------|--------------------------------------------------------------------------------------|
| <b>Austria</b>        | European Centre for Social Welfare Policy and Research (European Centre)             |
| <b>Belgium</b>        | Thomas More Kempen vzw (Thomas More)                                                 |
| <b>Bulgaria</b>       | Alzheimer Association in Bulgaria                                                    |
| <b>Cyprus</b>         | Cyprus Alzheimer Association                                                         |
| <b>Czech Republic</b> | Gerontologické centrum                                                               |
| <b>Denmark</b>        | Carers Association Denmark                                                           |
| <b>Estonia</b>        | Estonian Carers                                                                      |
| <b>Finland</b>        | The Central Association of Carers in Finland                                         |
| <b>France</b>         | Association Francaise des Aidants                                                    |
| <b>Germany</b>        | Wir pflegen                                                                          |
| <b>Greece</b>         | Athens Association of Alzheimer's Disease and Related Disorders                      |
| <b>Hungary</b>        | Magyar Máltai Szeretetszolgálat Egyesület - Hungarian Maltese Charity Service (MMSZ) |
| <b>Ireland</b>        | Care Alliance Ireland                                                                |
| <b>Italy</b>          | Italian National Institute on Health and Science of Ageing                           |

|                          |                                                                                                          |
|--------------------------|----------------------------------------------------------------------------------------------------------|
| <b>Italy</b>             | Anziani e non solo                                                                                       |
| <b>Latvia</b>            | Apvienība „Apeirons”                                                                                     |
| <b>Lithuania</b>         | Lithuanian Multiple Sclerosis Union                                                                      |
| <b>Luxembourg</b>        | RBS-Center fir Altersfroen (RBS)                                                                         |
| <b>Malta</b>             | SoS Malta                                                                                                |
| <b>Netherlands</b>       | VILANS                                                                                                   |
| <b>Poland</b>            | European Care Foundation (EFO)                                                                           |
| <b>Portugal</b>          | Jose Alves (will collaborate with Santa Casa da Misericordia)                                            |
| <b>Romania</b>           | Ana Aslan International Foundation (AAIF)                                                                |
| <b>Slovakia</b>          | Civic Association for Sustainable development of Regions in Slovakia (CASDRDS)                           |
| <b>Slovenia</b>          | Slovenian Federation of pensioners’organisations (ZDUS)                                                  |
| <b>Spain</b>             | Confederación Española de Asociaciones de Familiares de Personas con Alzheimer y otras demencias (CEAFA) |
| <b>Sweden</b>            | National Family Care Competence Centre                                                                   |
| <b>UK</b>                | CARERS UK                                                                                                |
| <b>UK -<br/>Scotland</b> | VOCAL                                                                                                    |

# Interactive services

- Get in contact with organisations' staff, asking for support;
- Know other carers and being part of a network of persons with same needs and experiences.



<< Back to main site

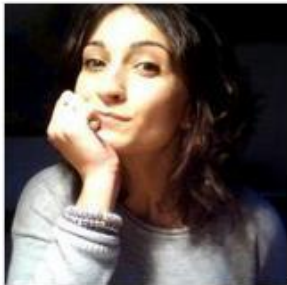
Social Network

Messages

Chat

Video Chat

Hi Arianna Poli!



 View Recent Updates  View My Profile  Edit My Profile  Browse Members

Requests

 2 friend requests

What's New

Post Something...



**Arianna Poli** Cosa causa la malattia di Alzheimer? Proviamo a saperne di più...



Cosa causa la malattia di Alzheimer?

Le cause della malattia spiegate dal dott. Giovanni Frisoni, neurologo e riconosciuto esperto internazionale.

1 hour ago · Like · Comment · Delete · Share



**D. M.** shared **Arianna Poli's** link. Anche a mia madre nel 2007 venne diagnosticata l'alzheimer e inizio' a prendere i farmaci per il rallentamento dell'avanzare della malattia. Ora la malattia è andata avanti, oggi ancora cammina delle passeggiate al mattino e al pomeriggio, si alimenta ... [more](#)

"Familiari, salvaguardate voi stessi solo così potrete aiutare il malato" - Repubblica.it  
Storia numero 1 Mia madre, una bambina. Parafrasando un libro che ho letto, è questa la situazione che ha inizio 14 anni fa a mia madre che ha oggi 87 anni. Sono un medico di 53 anni, figlio unico, e speravo che tale lavoro mi servisse ad apprezzare meg

May 31 · Unlike · Comment · Delete

Newest Members



**sct**  
May 26



**Cinzia Giuli**  
May 23



**UK**

A. [unreadable]

In questo modo dovresti poter ricominciare a rispondere dall'ultima domanda incompleta

**Arianna Poli**  
ottimo!

**Arianna Poli**  
fammi pure sapere se c'è qualche problema

**Arianna Poli**  
😊

5 Members Online



Network Stats

239 members

250 friends

# Implementation in 27 countries

**Information and services for INFORMAL CARERS will be  
available in**

**27 EU MEMBER STATES**

## **Information for Care Professionals in:**

**Bulgaria  
Czech Republic  
Germany  
Lithuania  
Luxembourg  
Malta  
Portugal  
Slovakia  
Spain  
Sweden**

## **Information for Employers in:**

**Bulgaria  
Czech Republic  
Germany  
Lithuania  
Malta  
Poland  
Portugal  
Slovakia  
Sweden  
United Kingdom**

## **Test sites – Italy, Germany, Sweden**

In **Italy**, around 55 carers of older people affected by Alzheimer's Disease could access the following services:

- information resources;
- e-learning resources;
- group support via social network and forum;
- individual support via e-mail, private messages, chat and video-chat;

In **Germany**, around 20 carers of dependent older people could access:

- information resources;
- individual support via e-mail and private messages;
- group support via social network
- two sub-groups of 3 people attended weekly sessions of group support via video-conferencing.

In **Sweden**, around 40 carers of dependent older people could access the following services:

- information resources;
- individual support via e-mail and private messages;
- group support via social network and forum.



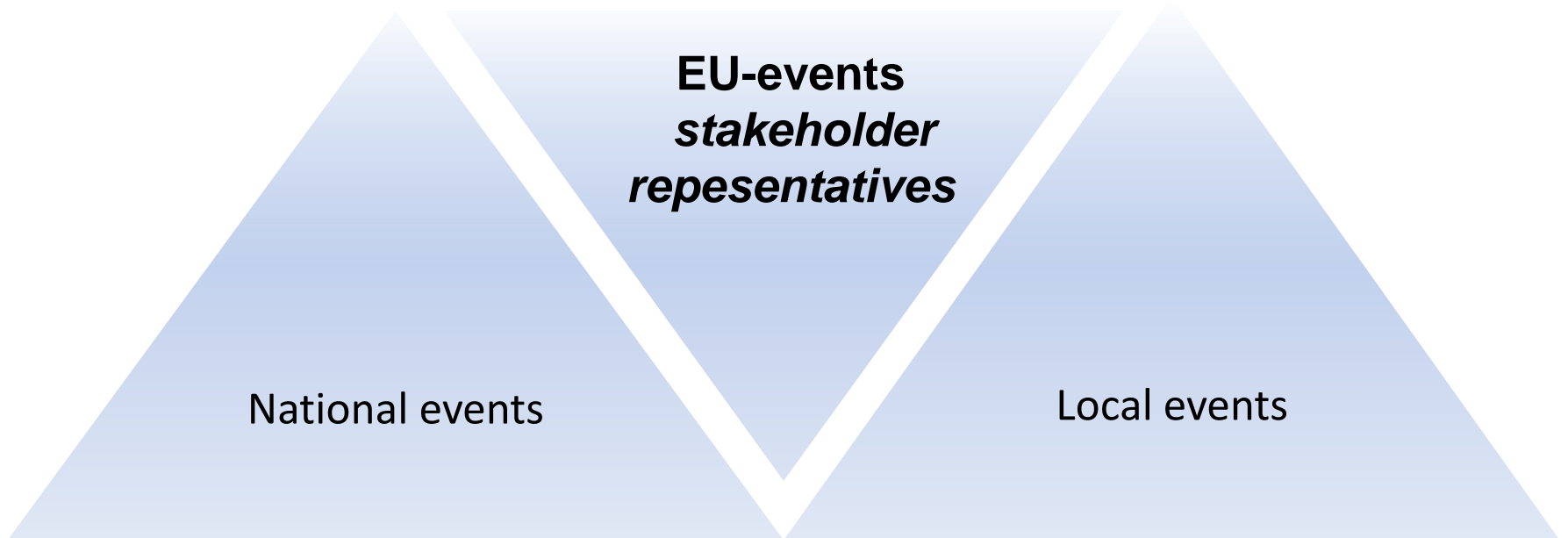
Questionnaires administered before the intervention:

- Changes in health status
- Quality of life (WHOQOL-BREF)
- Social support (MSPSS)
- Self perception of carer's role (COPE Index)

Questionnaires administered after the intervention:

- Changes in health status
- Quality of life (WHOQOL-BREF)
- Social support (MSPSS)
- Self perception of carer's role (COPE Index)
- Ad-hoc questions on usability, usefulness and appropriateness
- Usability assessment: WAMMI scale
- Navigation patterns were tracked with Google analytics

# Dissemination activities



# Why this project is important for carers in EU

- Empowerment of Informal carers' voices in Europe
- Development for the first time of a common web platform for informal carers in all EU Member states!
- Carers organisations involvement increases the possibility for the development of a web platform expressing organisation's needs
- Activation of Eurocarers network of carers organisations in EU



*innovAge*

SOCIAL INNOVATIONS PROMOTING ACTIVE  
AND HEALTHY AGEING

## The INNOVAGE WP3 team

*For additional information, please write to*

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*Or visit the project website: [www.innovage.group.shef.ac.uk](http://www.innovage.group.shef.ac.uk)*

# Introducing EUROCARERS



A European non-profit organisation, representing **informal carers**, officially established in 2006, consisting of:

- 
- Carers Organisations
  - Organisations related to carers
  - Research Institutions
  - Individual members

# Our Activities

- **Encouraging and supporting** the development of carers organisations
- Supporting carers and their organisations through **exchange** of information, good practice and expertise, as well as innovations
- **Advocating** the interests of carers with a focus on health, pensions and social security, social inclusion and employment
- Developing an informed **research agenda**
- Carrying out and supporting research on issues that concern carers, to help build the **evidence** for sound policy, advocacy and development
- Contributing, as partners, to transnational projects