WP3 Social innovation

ICT-based social support for carers of older people: The InformCare platform

[Website Link]

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1. THE INFORMCARE PLATFORM
Web-based support services for carers

• Previous evidence showed how web-based support services can contribute to address informal carers’ needs via on-line resources and individual or group support.

• However, many initiatives in Europe are small-scale projects and low-funded services (Schmidt et al., 2011; Carretero et al. 2012).

• Furthermore, many countries in Europe experience (a) a low penetration of low-cost broadband internet connection and/or (b) a small (or even no) cultural and social recognition of carers’ role (like in some Mediterranean and Eastern European areas).
INNOVAGE WP3 goal

to contribute to improving informal carers’ quality of life and health status, with a consequent increasing in the long-term of HLE
The specific objectives were (1) to **develop**, (2) **test** (3) **implement** and (4) **disseminate** in the EU-27 a new multilingual web platform – **InformCare** – with an integrated package of basic support services for informal carers.

**Services offered:**
- **information resources**
- **interactive services**
InformCare

Home page

Coping with caregiving

Being a carer sometimes makes it difficult to take care of yourself. Priorities are changing, disease condition progresses and looking after yourself takes usually last place on a long list of heavy duties. Caring for a loved one isn’t an easy task, but it is important to understand the value of being a carer and living well.

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.

More >

Work reconciliation

Working while caring isn’t an easy task. Employers and fellow employees might just not get it. Trying to be on time with work tasks and to be a devoted carer generates stress, not always easy to manage. A key factor to reconcile work and care is to raise awareness among your colleagues and employers.

More >

About the platform

Innovage Project

INNOVAGE is a three-year project dedicated to social innovations which support active and healthy ageing. The project will develop and test, as well as survey and catalogue, social innovations that will have a solid impact on improving the quality of life and well-being of older people.

More >

Video

Watch our promotional video...

Help! Technical support

We made our best for making your navigation experience the easiest and most comfortable as possible. However, you could have to face some situations where a page cannot be reached, content is not displayed correctly, or you cannot find a specific area.

More >

Privacy & Cookies Policy
Dementia

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

Information on a number of conditions is provided.

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

What is Dementia and Alzheimer’s Condition?

Symptoms of Alzheimer’s
Risk factors of Alzheimer’s
Behavioural and Psychological symptoms (BPSD)
Is there a cure for Dementia?
Prevention of Dementia
Caring at a distance

Dementia in numbers

Dementia affects 8% of people over 65 years, a percentage that increases significantly with age, as highlighted by a significant number of surveys. It is estimated that if people lived until the age of 95, then one out of two would suffer from some type of Dementia.

It is estimated that 44 million cases are suffering from dementia worldwide and 10 million in Europe. It is estimated that this percentage will rise to 104 million worldwide, while the proportion of people over 65 years old in Europe accounts for 35% of the general population.

What is Dementia?

The term “Dementia” refers to a group of symptoms that appears to people with conditions which destroy brain cells and cause a gradual deterioration of cognitive abilities. People suffering from types of dementia, actually means that memory, attention, judgment, speech, behaviour are affected.

In order for Dementia to be officially diagnosed, cognitive symptoms should represent a significant loss of previous level of functioning in everyday life.
Ciao Francesco Barbarella!

Cosa c’è di nuovo

Pubblica Qualcosa...

Ecco un articolo su Porte Aperte all’INRCA!

Una folta di visitatori per conoscere l’Inrca
ANCONA - La piovuta notturna non ha fermato l’iniziativa ‘Porte aperte all’inrca’ - oggi entra nel vivo - tesa a far conoscere e visitare le tre sedi di Ancona della storica...

mar alle 11.21 - Mi piace - Commenta - Rimuovi - Condividi

Buongiorno a tutti! :)

mar alle 11.00 - Mi piace - Commenta - Rimuovi

Jag fick ett tips om en dokumentärserie som startar på svt kanal 1 ikläv till 21.00 om medboringe. Verkar mycket intressant. Ni kan gå in och läsa om den på länken nedan.

Novità

Process towards implementation

- Design and development
- User tests
- Finalisation of the prototype
- Pilot tests
- Evaluation & Finalisation of the platform
- Implementation & Dissemination

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2. PILOT TEST IN THREE COUNTRIES
Study design

• **Research design**: one-group pretest-posttest study

• **Duration**: 3 months (Apr-Jul 2014)

• **Country settings**: Italy, Germany, Sweden

• **Intervention**: information resources + interactive services (moderated by professionals)

• **Sampling design**: convenience sample approach

• **Overall sample size**: 118 informal carers

• **Users of the platform**: 94 informal carers (79% of sample)

• **Dimensions assessed**: effectiveness, usability, usefulness, appropriateness

• **Measures**: structured questionnaires and focus groups (6-7 per country)

• **Validation workshop** with 6 external experts
Characteristics of the carers

- Sub-samples in each country differed according to some socio-demographic variables.
- In Italy, the common carer profile was a middle-aged woman employed, child/child-in-law of the older person, responsible of both childcare and eldercare, with medium-low educational level.
- In Sweden, most carers involved were older spouses, retired and with high educational level.
- In Germany, the majority of carers were middle-aged women not employed, child/child-in-law of the older person, with medium-high educational level.
Carers’ confidence with internet

<table>
<thead>
<tr>
<th>Country</th>
<th>No/Low</th>
<th>Medium</th>
<th>High</th>
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<tbody>
<tr>
<td>Total</td>
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<td>Italy</td>
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<td>Germany</td>
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Italy has the highest confidence with the internet, while Germany has the lowest.
Usage and usability

- Information resources usage:
  - The Swedish sample spent on average 7 hours, whereas German and Italian ones much less.
  - The Italian sample spent over 24 minutes per page on average, 50% more than the Swedish and German ones.

- Among interactive services:
  - Most success was obtained by social network, forum and private messages.
  - Chat and videochat were used less for peer interactions.
  - Most users adopted a passive use of services (e.g., reading posts, discussions and messages).

- Overall, over 80% of carers thought the platform is quite or totally useful for addressing their needs at present or in the future.
- Generally speaking, scores of global usability were everywhere satisfactory.
- Some technical problems occurred during the intervention, mainly due to low digital skills of many carers or to compatibility issues with certain mobile devices.
Effectiveness

• Data analysis found that, at the end of the intervention, users had a different perception about values of caring (COPE positive scale, p-value 0.017) and social support received (COPE quality of support, p-value 0.020; MSPSS family and social support scales, respective p-values 0.043 and 0.035).

• We can interpret this result considering that the platform contributed to increasing self-awareness of carers, stimulating reflection on their actual needs and lack of support (previously unrecognised), thus fostering better self-empowerment, coping strategies and access to support services.

• Relevant quotes from users (from focus groups):
  
  ▪ *I feel happier and calmer* when I can share the positive and negative things that happen in my situation as a carer – Swedish user
  
  ▪ *Reading stories from other carers helps to feel not lonely.* You can also realize how the future will be – Italian user
  
  ▪ *I feel less stressed* and that can be a result of other people post that I allow myself to have negative feeling and thoughts – Swedish user
  
  ▪ You got the impression that *you are understood*, able to talk openly and got to reflect your own situation. This motivates to take on new steps to improve the personal situation – German user
  
  ▪ Also just knowing that there are this kind of support services and *trustworthy people* working behind them is really important and helpful for family carers – Italian user
Main benefits and challenges emerged

- Possibility to receive **reliable information, advice** and **counselling** through interpersonal and/or group communication channels
- **Company, social** and **emotional** support by peers, as well as **solidarity** and **mutual learning**
- The platform felt as a **safe virtual environment** and a **flexible tool**
- **Self-empowerment** and **awareness** concerning carers’ role and needs, presumably leading in the long-term to better **health, quality of life** and **HLE**

- **Low digital level of many carers**: need for training and continuous support
- **Reconciliation issues**: low-educated, middle-aged women in labour market and engaged in both childcare and eldercare have many difficulties in accessing also web-based support services
- **Passive behaviour**: the stimulation of active request for support is necessary
- **Technical problems**: constant technical support should be guaranteed
- **Limitations of research**: further in-depth research should be carried out
2. IMPLEMENTATION IN EU-27
The role of Eurocarers in implementation

Eurocarers is a European non-profit organisation, representing informal carers, officially established in 2006, consisting of over 65 organisations.

Core aims:

- to **raise awareness** of the significant contribution made by carers to health and social care systems and to the economy in every country of the EU
- to **advocate and lobby** at national and EU levels for supporting policies addressing carers’ needs

*Eurocarers is responsible for implementation and sustainability of InformCare, by coordinating a network of 29 national organisations!*
Eurocarers’ InformCare network
Profile of national organisations

29 national organisations
of which 20 Eurocarers members

- Carers associations: 41%
- Disease specific associations: 14%
- Research Institutions: 14%
- Associations working with older people, people with disabilities and carers: 24%
- University college: 4%
- Individual member: 3%
The role of national organisations

1. **To write national contents** for informal carers (and in some cases for care professionals and employers of working carers)

2. **To translate and adapt common contents** for informal carers (and in some cases for care professionals and employers of working carers)
Crucial aspects for implementation

Concerning development of contents...
• To provide specific guidelines on the development and the uploading of contents
• To have regular contacts between project staff and national organisations

Concerning InformCare as a tool...
• To being able to gather national information for carers in one place
• To exchange of information, communication and support through the interactive services
• For some countries, this kind of web-based support is available in local/national language for the first time!
InformCare in numbers

www.eurocarers.org/informcare

• A set of both common and country-specific support services for carers, available for free via internet in 32 versions, 27 EU countries and 23 languages

• More than 2,500 web pages of contents specifically produced to address informal carers’ needs & over 300 web pages for care professionals and employers

• Design, development and implementation process involved almost 200 among end-users and experts, and 32 stakeholders
4. DISSEMINATION IN EU-27
Dissemination levels: EU and national

EU level:
• INNOVAGE website, events, newsletter and social media
• Eurocarers website, events, newsletter and social media, website information (as part of the INNOVAGE project)
• EU dissemination conference (May 2015)
• International scientific and networking events

National level in the 27 EU MS:
• Web platform naming: InformCare, the EU Information Hub for Informal Care
• Brochure and leaflets in almost all languages and countries
• Participation and networking in national workshops and conferences
• National organisations’ websites
• National events of dissemination (July-October 2015) and press release
• Animated video subtitled for the EU-27
EU dissemination conference

EU Conference
On 6th - 7th of May 2015
Radisson Blu, Brussels

innovAge
SOCIAL INNOVATIONS PROMOTING ACTIVE AND HEALTHY AGEING
Providing online support services to informal carers, care professionals and employers across Europe

80 Participants
48 Representatives registered from the involved organisations

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www.eurocarers.org/informcare

InformCare
The EU Information Hub on Informal Care
2013 - 2015

• По проект финансиран от Програмата за подкрепа на НПО в България по Финансовия механизъм на ЕИП
• 6 кръгли маси - Берковица, Добрич, Габрово, Пловдив, София и Стара Загора
Доклад върху националните политики и практики
Challenges for sustainability

A sustainability plan is under discussion for continuing the implementation of InformCare after INNOVAGE project lifetime. Three core challenges have been identified by an open discussion with national organisations:

1. How to manage possible drop outs of organisations due to various reasons
2. How to address eventual organisations’ lack of human and financial resources to sustain the web platform
3. How to manage “competition” with eventual other available online web services
The potential of InformCare at EU level

- Empowerment of informal carers’ voices in Europe
- Development for the first time of a common web platform for end users in 27 EU Member states!
- Additional versions could be added in the future
- The possibility for national organisation to adapt contents and services according to their own and country needs
- Development of an active network of stakeholders working together for informal carers
Animated promotional video available on-line
Choose your language!

www.youtube.com/playlist?list=PLr50Bh2p_bxd8yvIAKYStius7_rKsjJYf
Thank you for your attention!

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