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

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on behalf of the research team composed by:
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1. **Background**
   How web services can address informal care

2. **INNOVAGE WP3: InformCare platform**
   Development of a web prototype

3. **Evaluation**
   Pilot test in three countries

4. **Steps forward**
   Implementation and dissemination phases
1. BACKGROUND
The importance of informal care in complementing (and sometimes substituting) formal care services addressed to dependent older people is widely recognised.

It is known that family carers of dependent older people often have to face many difficulties: burden, depression, anxiety, decreasing of work productivity (or even job loss), difficulties in reconciling with family activities, financial problems, and social isolation, among the others.

Additional problem: many countries experience a small (or even none) cultural and social recognition of carers’ role.
Evidence from current practice allows identifying some specific types of effective interactive web-based services:

- **individual support** by health professionals to carers (via e-mail, audio or video communication);
- **structured group support** (via video-conferencing group sessions with a moderator);
- **unstructured group support** (via on-line groups or fora);
- **social participation tools** for interacting with other carers and significant others (via social networks and other tools).
2. INNOVAGE WP3: INFORMCARE PLATFORM
The overall goal of INNOVAGE WP3 is to contribute to improving the quality of life of informal carers of dependent older people in Europe, by developing an integrated set of web-based, multilingual support services, to address main carers’ needs in an adequate and effective manner.

The specific objectives of WP3 are (1) to develop, (2) test (3) implement and (4) disseminate in the EU-27 the web platform with an integrated package of basic services.

Services: information resources and interactive services

Funded by the European Commission's Seventh Framework Programme
FP7-HEALTH-2012-INNOVATION-1/No 306058
• The overall process of designing the platform was aimed to accomplish requirements of a **user-centred approach** in order to develop an appropriate, useful and effective package of services.

• Overall, the project involved **almost 200 among end-users and experts**, and **32 stakeholders** (user organisations, research centres or individuals).
• **Advisory Board** with 15 external experts

• **Series of surveys** for 58 experts, users and stakeholders, in order to get the most useful feedback from all parties involved

• **Review** of most successful web-based services tested and implemented in Europe and elsewhere (around 100 services analysed)

• **User tests** for getting immediate feedback by end users on prototypes of the platform

• **Pilot test** with 122 users in three countries with intermediate feedback and evaluation
Where will it be available? Eurocarers.org!

EUROCARERS is the European network representing informal carers and their organisations, irrespective of the particular age or health need of the person they are caring for.

Our aim is to advance the issue of informal care at both national and European levels by:

- Raising awareness of the significant contribution made by carers to families, care systems and the economy as a whole, and of the need to safeguard effective contributions;
- Ensuring that EU and national policies take account of carers, i.e. provide for inclusion of carers, the development of support services for carers, and for carers to remain active in paid employment and maintain a social life.
Coping with caregiving

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

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

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 also a devoted carer generates stress, not always easy to manage. A
InformCare: Home page / Main menu

Caring for older people
Your own needs
Support by the state
Get help
Interactive services

Making life easier
Different types of equipment or changes to your home could help...
More

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InformCare: Support by the state

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Caring for older people

In Caring for Older People section you will find useful information on Older age related conditions and Care management, available Care and Support services, Mobility services in your country and safety at home advice.

A detailed presentation of older age related conditions offers information on symptomatology, progression and therapeutic interventions, while another part is devoted to providing information on coping with conditions.
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Care and Support Services include a wide range of support available to yourself as a carer, and the person you care for. This section includes information about care services available within the home as well as residential care and independent living options for older persons.

Community support such as the services available for people with ADL limitations, counselling support and activities available for carers are also detailed. The type of support available to carers varies from one local authority to the next therefore the information contained in this section is designed as a guide and a starting point of finding out what is available in your local area.
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**Home Care**

Homecare services can include assistance with shopping, cleaning, etc.

**Residential Care**

There are a number of options available when considering residential care for older people.

**Independent living for older people**

Equipment and technology can provide independence for older people living
Homecare services can include assistance with shopping, cleaning, cooking as well as visits from paid care workers who can assist with bathing, getting out of bed and many other activities. These services can be provided through the local authority, the voluntary sector or by private providers.

Home visits by health professionals such as community nurses are provided by the National Health Service and are free at the point of delivery.

Age UK has published a comprehensive guide for home care – Care at Home: Getting help to live independently in your own home. It includes information about getting help at home, telecare, payment for services, information about help for carers and local health services.

Where these services are provided through the local authority eligibility criteria are used to determine who may be provided the service, these are largely based around needs testing. Eligibility criteria differ across local authorities, and will be determined following a Social Care Assessment of the person being cared for.

How much someone pays for a service depends upon how much income and assets the person has, what the charging policy is of the local authority and how much the service costs. There are rules which govern what services the local authority is able to charge for and the level of disposable income a person must be left with. The local authority can also choose which services it makes free, with many choosing to make carers' services free of charge.

All care providers in England are regulated by the Care Quality Commission who provide a review of each provider on their website. Information about care providers and reviews to help you select home care in England, Wales and Scotland is also

Impairments and care management

Care and support services

Home care

Residential care

Independent living for older people

Care services for people with ADL limitations

Volunteer support services

Counselling services

Community activities for carers
Level 3: ‘Home care’

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Home care
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- Independent living for older people
- Care services for people with ADL limitations
- Volunteer support services
- Counselling services
- Community activities for carers

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Go to interactive services...

own needs | Support by the state | Get help | Interactive services

Latest posts from the social network

Frida Andreasson Trevlig
valborgsmåsoafton!
April 30 - Like - Comment - Delete

Frida Andreasson Det kommer många appar nu.

Den här appen hjälper personer
med demens att minnas. JDS så
Social network

Interactive Services

Hi Francesco Barbabella!

What's New

Post Something...

Frida Andreasson: Travig valborgsmansson!

Frida Andreasson: Det kommer många appar nu.

Network Stats

259 members
469 friendships
3,300 posts
1,588 comments
43 uploads

Newest Members

Roberto Antonicelli
April 6

Friends Online (2)

Cinzia
Cristina
Andrea
Benjamin
Arianna
Friends Online (2)
Forum (IT)

Servizi Interattivi

Forum

1. Di positivo oggi c’è che...
   - 13 risposte
   - 85 visite
   - Ultimo Post di Arianna Poli
     1 aprile

2. Al fianco di una persona con Demenza...
   - 21 risposte
   - 236 visite
   - Ultimo Post di
     1 aprile

3. Spazio di scrittura - Le vostre storie
   - 26 risposte
   - 188 visite
   - Ultimo Post di
     11 marzo

4. quando l’assistenza del malato diventa troppo stressante...
   - 0 risposte
   - 10 visite
   - Ultimo Post di Cinzia Giuli
     25 Luglio 2014

5. Assistenti familiari - Badanti
   - 9 risposte
   - 95 visite
   - Ultimo Post di Arianna Poli
     30 giugno 2014

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Cinzia, Cristina, Andrea, Benjamin, Arianna, Amici Online (2)
Servizi Interattivi

I Miei Messaggi

0 nuovi messaggi ricevuti su un totale di 5

- 11 novembre 2014
- Arianna Poli
- 11 novembre 2014
- 10 settembre 2014

(Nessun Oggetto)

10 people

(Nessun Oggetto)
Videochat

Interactive Services

Video Chat

Benvenuto in AVChat 3.0 (http://www.avchat.net). Manda un messaggio agli altri utenti digitando il tuo messaggio nella casella di testo in basso e premendo INVIO.
3. EVALUATION
• **Research design**: one-group pretest-posttest study

• **Intervention duration**: 12-17 weeks (Apr-Jul 2014)

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

• **Sampling design**: convenience sample approach (partly exception: Italy, all patients with Alzheimer’s disease)

• **Sample size**: 122 carers

• **Measures**: structured questionnaire (including validated scales and ad hoc items), focus groups (6-7 users in each country)
Carers’ confidence with internet

- 33% Not at all
- 10% Little
- 20% Somewhat
- 40% Much

Total: [Bar Chart]
Italy: [Bar Chart]
Germany: [Bar Chart]
Sweden: [Bar Chart]
Usage

• 76% of the initial sample accessed at least once

• The average days of visits varied across countries (5 in Italy - 23 in Germany) and also the average time spent in the platform (3 hours in Italy, more than 7.5 hours in Germany and Sweden)

• Among interactive services, most success was obtained by the social network, and to a less extent by forum.

• Private messages were a major communication channel in Sweden (over 70% of users sent or replied to messages) and used also in Italy and Germany

• Chat and videochat were the least used services

• Most users preferred a passive use of services
Main benefits

- **Self-empowerment** and **awareness** concerning carers’ role
- Possibility to receive **reliable information, advice** and **counselling**
- Access to a **flexible tool** available whenever they need
- Sense of **solidarity** and **mutual learning** from each other experiences
- Platform felt as a **safe virtual environment**
- Acceptable level of **usability**

Funded by the European Commission’s Seventh Framework Programme
FP7-HEALTH-2012-INNOVATION-1/No 306058
4. STEPS FORWARD
Outputs: Huge work...

• A web platform available in 32 versions, for 27 EU countries, in 23 languages

• More than 2,500 web pages produced for carers (less than 50 currently under refinement process)

• Over 300 web pages for care professionals and employers

• Uncountable number of contacts through e-mails, Skype and phone calls with all stakeholders involved

Funded by the European Commission’s Seventh Framework Programme FP7-HEALTH-2012-INNOVATION-1/No 306058
Potential

• Additional versions, countries and languages could be added at any time
• Adaptation and update of contents in each version according to national context and needs
• Choosing what interactive services can be provided
• Possibility to become a national information hub for carers
• Establishment of a European wide network of stakeholders active and interested in supporting, lobbying and advocating for carers
Main challenges

- **Low digital level of many carers**: need for training and continuous support
- **Passive behaviour in the platform**: need for carrying on adequate stimulation strategies
- **Low (or none) cultural and social recognition of their role**: need to improve self-awareness of what means being a carer and let their needs emerge
- **Technical support**: need for technical staff for guaranteeing correct implementation and fixing raising issues
- **Limitations of research**: need for further in-depth research beyond a pilot intervention
- **Involvement of organisations**: avoiving drop out after the development phase
- **Lack of human resources and sustainability**: how to sustain the web platform after project lifetime
- **Available online web services**: in some countries other similar services exist
Support needed by organisations

• Specific **guidelines** on the development and the uploading
• Regular **communication** and support by the research assistants
• **Gathering** of national carers information in one place
• **Exchange** of information, communication and support through the interactive services
Profile of the organisations

...of which, 20 are 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%

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Examples of dissemination activities

- Project website and logo as part of the wider INNOVAGE project
- Newsletter, Social media, website information as part of the wider INNOVAGE project
- Web platform identification: Official Name
- Publications and other forms of printed material
- Participation and networking in workshops and conferences of relevant projects and conferences of the target audience
- Project information on core partners’ websites: EUROCARERS, INRCA, ORGANISATIONS involved in implementation and dissemination
- Animated video subtitled in 27 EU Member States
- ...
Dissemination: EU conference

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

innovAge
SOCIAL INNOVATIONS PROMOTING ACTIVE AND HEALTHY AGING

Providing online support services to informal carers, care professionals and employers across Europe

80 Participants,
48 Representatives registered from involved organisations

Funded by the European Commission's
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FP7-HEALTH-2012-INNOVATION-1/No 306058
Thank you for your attention!
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