ICT-based social support for carers of older people

Developing and implementing a new multilingual web platform in the EU-27

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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 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.
• More and more investments – in North America but also in Europe – are provided for testing innovative support services delivered through information and communication technologies (ICTs).

• In this respect, services delivered through the internet seem to constitute the first step for reaching and making available essential services to carers in Europe.

• In fact, web-based services can offer on-line resources (texts and/or multimedia) and/or a set of interactive services.
Among interactive services, evidence from current practice allows to identify some specific types:

- **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** with other carers and significant others (via social networks and other tools).
Gaps in EU context

However:

- many initiatives in Europe are **small-scale projects** and **low-funded services** with a short geographical coverage (Schmidt et al., 2011): availability of and accessibility to web-based services are guaranteed only to few people;

- many countries in Europe experience (a) a **low penetration of broadband internet connection** and/or (b) a **small** (or even none) **cultural and social recognition** of carers’ role (like in Mediterranean and Eastern European areas).
A NEW WEB PLATFORM FOR CARERS IN EUROPE
The overall goal of WP3 is to improve the quality of life of informal carers of dependent older people through the development of an integrated package of web-based support services, which can address major users’ needs in an adequate and effective manner.

The concrete objectives of WP3 are (1) to develop, (2) test and (3) implement in the EU-27 an integrated package of basic web-based services.
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WP3 output

• The main output of WP3 will be the **on-line set up of a web platform** which will include different web-based services for carers, to be achieved via an adequate development, refinement and evaluation process that will guarantee quality of services provided and their usability.

• The final platform will be **accessible in 24 EU official languages** and will include both standardised contents and national-specific ones for each country of EU-27.

• The platform will be **integrated into the website of Eurocarers** (www.eurocarers.org): this will help disseminating and promoting the platform to all the relevant stakeholders both at European and national level.
DEVELOPMENT

February-October 2013
Preliminary steps included:

- **Identification of users’ needs**: major needs and types of possible support were defined through previous experience of relevant European research projects (EUROFAMCARE, Carers@Work, CARICT);

- **Review of good practices**: an analysis of current available web services for carers was carried out by exploiting different sources (survey with stakeholders, literature review, sets of initiatives collected by the CARICT and CARICT-PUBL projects);
Consultation process with external experts, users and stakeholders: the aim was to gain valuable opinions on seven core dimensions: relevance of users’ needs; implementability of services; digital competences of users; appropriateness of web tools; user-friendliness; sustainability; feasibility
Web-based support services

- Technical development (during project)
- Technical updating (after project lifetime)

Feasibility

Users’ needs

Relevance

Sustainability

Implementability

Appropriateness

User-friendliness

Digital competences of users

Users

Human, technical and financial resources for updating contents

Human, technical and financial resources for digital implementation
• **Selection of web services to be developed in the platform**: the selection was done on the basis of results from consultation process and further considerations over project constraints and sustainability of the intervention after project lifetime;

• **Web and graphic design**: a set of core accessibility, usability and design principles were adopted from current practice and literature.
Set of selected web services

- **information and self-assessment**: static web-pages and multimedia materials in the platform, as well as tools for a self-assessment of specific dimensions of carers’ quality of life (e.g. burden, social isolation);
- **e-learning resources**: a separated area where carers can access to training materials concerning both caregiving activity and coping strategies;
- **individual support via e-mail**: the possibility for the user to ask further information, advice, counselling, psychological or emotional support by the counsellor through e-mail correspondence;
- **group support via video conferencing sessions**: periodical video-communication sessions among a group of carers (around 6 per group) and a moderator/facilitator. It is thought as a virtual self-help group with the purpose of sharing experiences and advices among peers, as well as a psychological support by peers living analogous situations;
- **forum**: the possibility for carers to post questions, information and other materials in a dedicated forum, including opening threads and topics, replying and commenting to other users, sharing external useful sources (e.g. links);
- **social network**: the possibility for carers to participate and contribute to build an on-line community of carers, with the supervision of a moderator/facilitator.
A specific objective of the pilot test is to collect a first evidence of the **usability** and, to some extent, of the **effectiveness** of the developed web-based services.

The pilot will be a **one-group pretest-posttest study**, aiming to make assessments both at baseline (T0) and at end of intervention (T1). Services will be piloted in Italy, Germany and Sweden. Each country will test a different mix of services for a period of 4 months.

In each country, **60 informal carers** will be recruited (180 users in total).
Different dimensions related to the carer will be assessed:

- Demographic, socio-economic status and background characteristics;
- Health status;
- Quality of life;
- Self-perception of carer’s role;
- Perceived social support;
- Usability of the web services;
- Perceived usefulness and appropriateness of the services;
- Navigation patterns of the carer through the platform.

An expert meeting with external researchers and stakeholders will be organised at the end of the assessment in order to discuss and validate results from the pilot test.
Main activities of the implementation phase:

- **translation and implementation of the common contents for informal carers** in all 27 countries: a subcontractor will translate common contents (in English, Italian, German, Swedish) in the other 19 official languages of EU-27;

- **development of national contents for informal carers** (in all 27 countries), **for care professionals** (in 10 countries) and **for employers of working carers** (in 10 countries).
Which contents in which countries...

| German Dutch French German Bulgarian Greek Czech German Danish Estonian Greek Spanish Finnish Swedish French Hungarian Irish English Italian Lithuanian Dutch French German Latvian Maltese English Dutch Polish Portuguese Romanian Slovakian Slovenian Swedish English |
| Common contents for informal carers | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X |
| National contents for informal carers | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X |
| National contents for employer | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X |
| National contents for care prof. | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X |
Which contents in which countries...

**NATIONAL CONTENT FOR INFORMAL CARERS**

- 27 EU-MEMBER STATES

**NATIONAL CONTENT FOR CARE PROFESSIONALS**

- Austria
- Belgium
- Germany
- Czech Republic
- Finland
- Luxemburg
- Malta
- Slovakia
- Sweden
- United Kingdom

**NATIONAL CONTENT FOR EMPLOYERS**

- Bulgaria
- Germany
- Estonia
- France
- Lithuania
- Latvia
- Netherlands
- Portugal
- Sweden
- United Kingdom
Presentation and training events will be organised at international, national and eventually at regional/local levels for informal carers and relevant stakeholders.

- 1 EU-event with user organisations
- 27 National events carried out by representatives of national organisations
- N Local events carried out by representatives of national organisations
FINAL REMARKS
Empowerment of informal carers’ voice in Europe

Development for the first time of a common web platform for informal carers for all EU Member states!

Carers organisations involvement will increase the possibility to consider and address national organisation’s needs

Development of an active network of user organisations sharing experience on interventions delivered through ICTs
Key questions for the discussion group

- Is the platform design based on plausible and adequate conceptual principles?

- Do you see any significant gaps in the selected set of web-based support services? Which ones are the most relevant in your opinion?

- What problems and issues might arise in implementing such a platform in all EU countries and to ensure its sustainability in the long-term?
Thank you for your attention!

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