Setting standards in the provision of web-based support services for carers of older people in Europe: Eurocarers’ new multilingual InformCare platform

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1: INRCA; 2: NKA; 3: EUROCARERS; 4: WirPflegen

Funded by the European Commission's Seventh Framework Programme FP7-HEALTH-2012-INNOVATION-1/No 306058
1. Introduction: why InformCare?

2. How the InformCare platform was built

3. What is in InformCare: resources and services

4. Evaluation by users in three countries

5. Final remarks
1. Introduction: why InformCare?
Support needs of informal carers in ageing societies

- Population ageing, a positive phenomenon in itself, leads often also to an increase in long-term care (LTC) needs.
- As formal/professional care services are not able to meet (fully, but often not at all) this LTC demand, informal/family carers remain crucial in addressing (elder) care needs, thus relieving the pressure on public resources.
- By doing this, however, carers often have to face many difficulties, e.g. health problems (depression, anxiety), lower work productivity (or even job loss), financial problems, family conflicts and social isolation.
- To tackle such difficulties, in some countries different forms of support services for carers have been implemented.
An increasing number of support services for carers are being delivered via internet, in a static or interactive way, to provide the following:

- **Information** on different care-related aspects (static sites)
- **individual counselling** by health professionals to carers (via e-mail, audio or video communication)
- **group support** *(structured: via video-conferencing group sessions with a moderator; unstructured: via on-line fora)*
- **social participation tools** for interaction with other carers & significant others (via social networks etc.)
Many web-based services for carers existing in the EU present substantial limitations (Schmidt et al 2011) as:

- many initiatives are **small-scale** and **low-funded**, with limited geographical coverage, so web-based services are available & accessible to few people only

- 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 (e.g. in Southern and Eastern Europe)
2. How the InformCare platform was built
WP 3 ICT-based social support for Carers of Older People

WP 1 Increasing Healthy Life Expectancy

WP 2 User-driven Housing for Older People

WP 4 Improving Obesity Related Outcomes in Old Age

WP 5 Long-term Care in Motion

WP 6 Knowledge exchange and transfer

WP 7 Management

The INNOVAGE project (WP3)

Project Partners
1. University of Sheffield, UK (Coordinator)
2. Lund University, SE
3. Heidelberg University, DE
4. Newcastle University, UK
5. 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
Goals of INNOVAGE-WP3: a multilingual platform for carers in the EU

• **Overall goal:** contribute to improving quality of life of informal carers of frail older people in Europe, by developing an integrated set of web-based, multilingual support services, to more effectively address carers’ needs.

• **Specific objectives:** (1) to **develop**, (2) **test** (3) **implement** and (4) **disseminate** in the EU-27 the web platform with an integrated package of basic services.

• **Two main types of services:** information resources and interactive services
Three target groups

• Primary target group: Informal carers (all countries)
• Secondary target groups:

Care professionals (10 countries): Health care workers, psychologists, psychotherapists, social workers, adult educators etc., who directly interact with informal carers (e.g. to promote integration of formal and informal care, provide direct support etc)

Employers (10 countries): Owners, CEOs & HRMs of organisations interested in addressing the potential difficulties (also on the workplace) experienced by the (growing number of) employees who provide informal care
Three target groups

- **Common contents for informal carers**: All 27 EU Member States
- **National contents for informal carers**: All 27 EU Member States
- **National contents for care professionals**: 10 countries: Austria, Belgium, Czech Rep., Finland, Germany, Luxembourg, Malta, Slovakia, Sweden, UK
- **National contents for employers**: 10 countries: Bulgaria, Germany, Estonia, France, Lithuania, Latvia, Netherlands, Portugal, Sweden, UK
A user-centred approach was adopted to design the platform and develop the services offered through it, based on:

- **a wide mix of user representatives**: almost **200 end-users/experts** and **32 stakeholders** (mainly user organisations & research centres), including an **Advisory Board** of 15 experts

- **a series of user-centred development activities**:
  - **review** of most successful web-based services tested and implemented in Europe & beyond (≈ 100 services reviewed)
  - **surveys** involving 58 selected experts, users and stakeholders, to get feedback on platform’s main features
  - **preliminary round of user tests** to receive immediate feedback on prototypes of the platform
  - **pilot test** with 118 users in three countries (Germany, Italy & Sweden) for a more in-depth feedback and evaluation
1. Contents for Informal Carers:
   a. revision of translations of common contents
   b. development and uploading of national contents

2. Contents for Care Professionals and Employers:
   a. translation of common contents
   b. development of national contents
## Implementation and dissemination: a EU-wide joint effort

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<thead>
<tr>
<th>COUNTRY</th>
<th>ORGANISATION</th>
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<tbody>
<tr>
<td>Austria</td>
<td>European Centre for Social Welfare Policy and Research</td>
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<td>Belgium</td>
<td>Thomas More Kempen vzw</td>
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<td>Bulgaria</td>
<td>Alzheimer Association in Bulgaria</td>
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<td>Cyprus</td>
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<tr>
<td>Czech Republic</td>
<td>Centre of Expertise in Longevity and Long-term Care / DIACONIA?/ 50plus?</td>
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<tr>
<td>France</td>
<td>Association Francaise des Aidants</td>
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<td>Germany</td>
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<td>Magyar Máltai Szeretetszolgálat Egyesület - Hungarian Maltese Charity Service (MMSZ)</td>
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<td>INRCA - Italian National Institute on Health and Science of Ageing</td>
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<td>Poland</td>
<td>European Care Foundation (EFO)</td>
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<td>Portugal</td>
<td>Jose Alves</td>
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<td>Romania</td>
<td>Ana Aslan National Institute of Gerontology and Geriatrics</td>
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<td>Slovakia</td>
<td>Civic Association for Sustainable development of Regions in Slovakia (CASDRDS)</td>
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<td>Slovenia</td>
<td>Slovenian Federation of pensioners’organisations (ZDUS)</td>
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<td>Spain</td>
<td>FUNDACIÓ JOAN COSTA ROCA (Group Consorci Sanitari de Terrassa)</td>
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<td>Sweden</td>
<td>National Family Care Competence Centre (NKA)</td>
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<td>UK</td>
<td>CARERS UK</td>
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<td>UK - Scotland</td>
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3. What is in InformCare: information resources & interactive services
### Where is the InformCare platform?

To access the information and services available in your country, please see the related links below:

<table>
<thead>
<tr>
<th>COUNTRY</th>
<th>LANGUAGES</th>
<th>CARE PROFESSIONALS</th>
<th>EMPLOYERS</th>
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...
InformCare: section for carers

Making life easier
Different types of equipment or changes to your home could help...
More
As a carer you may experience the psychosocial, physical and financial burden of caregiving. Help yourself section presents 4 main topics to help you cope with caring:

- Coping with caring
- Family and Care Reconciliation
- Work and Care Reconciliation
- Physical Exercise – Staying Active

3stress, depression, family relationships, balancing between care and work and tips to stay active are discussed in above sections.

Remember, looking after yourself improves your quality of life and care!
Example of Level 2 information

Coping with Caregiving

The Caregiving years: An introduction

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

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.

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 >
Stage 1: The Expectant Carer

In the near future, I may help a family member or friend.

Who are you?

You have a growing concern that, within the near future, your family member or friend will...
Summary of static information for carers

- 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 an older person

Your own needs as a carer

Support by the state

How to get practical help
The Caregiving years: an introduction

When you expect a child, the community (your family, friends, co-workers) rally around you and your spouse. When you expect your first child, you receive gifts, well wishes and the encouragement that you are entering a wonderful, albeit challenging, chapter in your life. As you prepare to welcome your child, you feel pride at the thought of your role as parent: How you will shape the mind of a youngster, impacting him or her with your wisdom, insights and knowledge.

Now think about a similar life experience, just one on the other end of the spectrum. An aging relative, a spouse, a parent, a grandparent, needs your help. And, you want to help—you believe in making the most of the years you have left together. But, when you tell your friends, your colleagues, even other family members, the comments you may hear are a far cry from well-wishes. “I could never do that! Why do you?” Or, the more common response: “Why don’t you just put your mother (or your wife, or your grandfather) in a nursing home? That way you won’t...
Ciao Giovanni Lamural

Cosa c’è di nuovo

Pubblica Qualcosa...

Arianna Poli PROSSIMO EVENTO...
Assistenza ai pazienti con demenza, conferenza Auser - Inca
L’evento Assistenza ai pazienti con demenza, conferenza Auser - Inca inizia il 05.06.2015 !

29 maggio - Mi piace - Commenta - Condividi

Arianna Poli Buongiorno a tutti! :)
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<th>Ultimo Post</th>
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<td>Al fianco di una persona con Demenza...</td>
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<td>236</td>
<td>Arianna Poi 1 aprile</td>
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<td>Spazio di scrittura - Le vostre storie</td>
<td>26</td>
<td>188</td>
<td>Antonio Marina 11 marzo</td>
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<td>10</td>
<td>Cinzia Giuli 25 Luglio 2014</td>
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<td>Assistenti familiari - Badanti</td>
<td>9</td>
<td>95</td>
<td>Arianna Poi 30 giugno 2014</td>
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</table>
I Miei Messaggi

0 nuovi messaggi ricevuti su un totale di 6
Check All

- **Messaggi Ricevuti**
  - **Pierpaolo D'Antonio**
    - 11 novembre 2014
      - Il testo del messaggio è stato rimossato.
  
- **Messaggi Inviali**
  - **Arianna Poli**
    - 11 novembre 2014
      - Il testo del messaggio è rimasto intatto.

- **Componi Messaggio**

**Messaggi Inviali**

**Arriva dai collaboratori di Valentina**

NON FAR TROPPO CASO AL FIDO TESTO, VOLEVA ESISTERE QUANTO PIÙ STIMOLANTE E PROVOCATORIO. PARE ABBIAMO SINCEREMENTE QUALCOSA. AD OGNI CASO, TROVATE I RISPETTI. SCITTE... Ciao a tutti! Come state? Spero tutte bene... Volevo chiedervi della vostra disponibilità ad incontrare la mia nonna, Valentina. Come vi è stata trovata nel ruolo delle interviste? E andato tutto bene? Spero di sì... Il ruolo del Caregiver sembra sia quanto da guardare piano piano più spazio e considerazione. Che ne pensate? Sono rimasti da un meeting per il progetto INNOVAGE dove alcuni colleghi stranieri ci hanno chiesto del loro interesse in Italia non ci sia un nome italiano specifico per il ruolo del caregiver, che noi usiamo. E preso il presto dell'inglese... Sarebbe stato un bello se fosse stato il ruolo non è riconosciuto nel mondo e considerato come dovrebbe essere la professione di un caregiver. Sono di sentirti presto, buona sera e grazie ancora... Arianna Serenella Sarconi 9 novembre Ciao Arianna, Carnissima Valentina, mi hai fatto molto piacere trovare giovani che sono interessati e sensibili a certe problematiche sociali, mi fa sperare in un futuro migliore. Ciao a tutti, un abbraccio Roberto Marcelli il 9 novembre Ciao Arianna, grazie Serenella Valentina, così carina e sensibile, fa proprio bene sperare. Il sogno di essere stato realizzato. Per quanto riguarda il termine "caregiver", che in italiano non esiste, forse il suo equivalente è stato "in da sempre". Di volta in volta "figlia", "higia", "serena", o "moglie" (senza nulla togliere agli amori oggi se occupano di un bambino) Forse proprio la nostra cultura che ha fatto inglobare il ruolo di "caregiver" nel dover scontare di una "dora di casa", senza che nessuno si sia mai reso conto, almeno fino ad ora. "di quanto sia passato" integrativo e per nulla facil, ma sono sicura che, prima o poi, anche Italia troverà il suo "nome proprio". A presto e un saluto a tutti...)

**10 people**

- **Nessun Oggetto**
  - 10 settembre 2014
    - Il testo del messaggio è rimasto intatto.

- **2 people**

- **Nessun Oggetto**
  - Il testo del messaggio è rimasto intatto.
Chat

Interactive Services

Introduce Yourself

Browse Chatrooms

Francesco Barbabella
Hi everybody!

Frida Andreasson

Friends Online (2)
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.
The Caregiving years: an Introduction

Stage 1: The Expectant Carer

I May Help

Stage 1

Who are you?

In the near future, I may help a family member or friend.

You have a growing concern that, within the near future, your family member or friend will...
The Caregiving years: an Introduction

Stage 1: The Expectant Carer

In the near future, I may help a family member or friend.
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Betydelsen av anhörigomsorg


Juridiska aspekter för professionella som möter anhöriga i sitt arbete

Den rättsliga ställningen för den som är i behov av vård och omsorg regleras genom lagstiftning. För personal som arbetar inom vård och omsorg och socialt arbete finns det flera olika lagar som styr och påverkar arbetet. För personal som möter både enskilda och anhöriga är det naturligtvis viktigt att vara känslig för patienternas behov och villkor.

Att hantera vård- och omsorgspersonals belastning i arbetet

"Jag har arbetat som socialarbetare på en dagverksamhet för personer med demens i fem år nu. Förra året vaknade jag en morgon och kände mig på väldigt dåligt humör och ville inte gå till jobbet. Så fort jag kom till jobbet kände jag mig utmattad och energilös, som om jag redan hade arbetat i flera timmar. Under en tid var jag trött och matt.

Att hantera vård- och omsorgspersonals belastning i arbetet är enligt de flesta professionella ett stort problem. Det kräver både personlig styrka och professionell kompetens.
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<tr>
<th>COUNTRY</th>
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</table>
Employers

Your business and informal care

If not currently caring for someone ourselves, we probably all know somebody (a relative, a friend, a colleague) who is responsible for looking after a dependent person, such as an older parent. The experience of providing informal care to our loved ones can be satisfying but it is also a challenging

Legal framework

Carers' legal rights have changed over recent years and it is important for employers to ensure that they are complying with the law. This section highlights the key legislation affecting carers in employment and the issues of which employers should be aware...

Action run by employers

Apart from the legal framework, employers can implement different measures for supporting working carers, thereby both benefitting and getting benefit from them...
4. EVALUATION BY USERS IN 3 COUNTRIES
• **Design:** one-group pre-test/post-test study (pilot)

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

• **Countries involved:** Italy, Germany, Sweden

• **Sampling:** convenience sample approach (exception in Italy: all patients approaching an Alzheimer Assessment Unit)

• **Sample size:** 118 carers

• **Measures:** structured questionnaire (with validated scales & ad-hoc items) & focus groups in each country
<table>
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<tr>
<th>Carer</th>
<th>Total</th>
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<td>70.8%</td>
<td>69.6%</td>
<td>60.0%</td>
<td>77.3%</td>
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<tr>
<td>Age</td>
<td>58.5 (11.5)</td>
<td>53.1 (10.2)</td>
<td><strong>60.6 (9.0)</strong></td>
<td><strong>64.7 (10.8)</strong></td>
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<td>Relationship with elderly:</td>
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<tr>
<td>Spouse/Partner</td>
<td>30.6%</td>
<td>3.5%</td>
<td>26.3%</td>
<td><strong>66.7%</strong></td>
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<tr>
<td><em>Children/Children-in-law</em></td>
<td>61.2%</td>
<td><strong>84.2%</strong></td>
<td>57.9%</td>
<td>33.3%</td>
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<tr>
<td>Other</td>
<td>8.3%</td>
<td>12.3%</td>
<td>15.8%</td>
<td>0.0%</td>
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<td>Children: yes</td>
<td><strong>77.5%</strong></td>
<td>78.6%</td>
<td>65.0%</td>
<td>81.8%</td>
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<tr>
<td>Grandchildren: yes</td>
<td>35.5%</td>
<td>22.8%</td>
<td>20.0%</td>
<td>59.1%</td>
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<tr>
<td>Education</td>
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<tr>
<td><em>Low (up to lower secondary school)</em></td>
<td>18.3%</td>
<td>28.1%</td>
<td>15.8%</td>
<td>6.8%</td>
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<tr>
<td><em>Medium (upper secondary school)</em></td>
<td>37.5%</td>
<td>56.1%</td>
<td>26.3%</td>
<td>18.2%</td>
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<tr>
<td><em>High (post-secondary, tertiary education)</em></td>
<td>44.2%</td>
<td>15.8%</td>
<td><strong>57.9%</strong></td>
<td><strong>75.0%</strong></td>
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<tr>
<td>Employment: yes</td>
<td>52.1%</td>
<td><strong>62.5%</strong></td>
<td>31.6%</td>
<td>47.7%</td>
</tr>
</tbody>
</table>
Carers’ confidence with internet

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>Little</th>
<th>Somewhat</th>
<th>Much</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Italy</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Germany</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sweden</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

[Diagram showing confidence levels across countries]
Usage of the platform

- Average **days of visits** varied from 5 in Italy to 23 in Germany, and average **time spent** surfing in the platform from 3 hours in Italy to over 7 hours in Germany and Sweden
- Most users preferred a **passive use** of services
- Among interactive services, the most successful was the **social network**, followed by the **forum**
- **Private messages** were a major communication channel in Sweden (over 70% of users sent/replied to messages) and used also in Italy and Germany
- **Chat** and **videochat** were the least used
Adequateness, usability and barriers

• Carers in all three countries appreciated the adequateness and usefulness of information provided from project staff through the platform.

• Some passive users reported that even simply to know they could get any time support via the interactive services of the platform was a positive, reassuring feeling.

• Overall scores of global usability were satisfactorily, albeit some Swedish carers were concerned about helpfulness and efficiency of the platform.

• This was to a large extent related to technical problems during the pilot phase, affecting especially Swedish and Italian users (25% and 20% of cases, respectively).
5. Final remarks
Main achievements of 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

• Contents’ quality and user-centeredness has been ensured via a systematic involvement of final users and stakeholders through countless contacts (e-mails, skype and phone calls) over 2 years, and a 3-month field phase

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

• For some countries, this kind of web-based support is available in local/national language for the first time!
InformCare’s potential for the future

• **Additional versions**, countries and languages can be added at any time via Eurocarers.

• **Adaptation** and **update** of contents in each version can occur according to national/local needs.

• Wide choice of what **interactive services** to provide.

• Possibility to become a **national information hub** for carers, employers and care professionals.

• Potential for strengthening a **Europe-wide network of stakeholders** active and interested in supporting, lobbying and advocating for carers.

• **A powerful tool** to promote the adoption of **EU-wide policy measures to better support carers**!
Thank you!