Deliverable 2.1
Album of European Good Practices
Sara Santini*, Francesco Barbabella*, Giovanni Lamura*

*INRCA, Ancona, Italy

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Contact:

Sara Santini
Istituto Nazionale di ricerca e Cura degli Anziani (INRCA)
Via Santa Margherita 5
60124 Ancona
Italy
Tel 071 800 4798
E-mail: s.santini2@inrca.it
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Associated Partners

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UNCCAS
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Special thanks also to the experts who have contributed to the reports of good practices, providing the information needed: Robin Miller, Tessa Overmars-Marx, George Ruppe, Zsuzsa Szeman, Synneve Dahlin-Ivanoff, Areti Efthymiou, Judy Triantafillou and Francisco J. Ródenas Rigla.
1. **Introduction**

1.1. **The AIDA project**

The AIDA project aims at strengthening the integration between health and social care services for frail older people, in order to improve the quality of care provided. Once completed, the project will exploit the Information System for Dependent People (SINA) developed in Italy, which has made available at a national level individual information on long-term care services and on other benefits provided.

The project is financed by the EU PROGRESS Programme, which aims to make national and European social policies more efficient through the exploitation of social innovations, partnerships and information sharing. The AIDA consortium includes the Liguria Region (local government, Italy) as coordinator, and other five organisations: INRCA (research institute, Italy), Eurocarers (user organisation at a European level), the Veneto Region (local government, Italy), Anziani e Non Solo (user organisation, Italy), and ENEA Aps (user organisation, Italy).

The SINA represents the first attempt to establish a linkage between data on health and social care for the Italian context. A minimum data set has been defined during 2009-2011, leading to a new information system that serves for a better understanding of how health and social care can be integrated at a local level, where usually multiple actors and stakeholders are in charge of these services.

The AIDA project is based on the SINA, and is in line with current Italian and European policies aiming at improving efficiency in the public care sector through a better care coordination. Given the importance of achieving such an integration of services, it is crucial to improve the SINA with lessons learnt at a both national and international level, in order to enhancing its characteristics and adopt further measures for developing a better system. In fact, the quantitative analysis of the SINA database, in addition to the case study analysis of 10 European good practices in LTC service integration and the updated portfolio of innovative projects on LTC managed by Italian Regions, will be used within the AIDA project for developing National Guidelines for Social and Health Integration (GfI) at a national level. This report represents one of the major outputs of AIDA and will serve to implement the final version of the SINA, addressing at the same time the major barriers that could be encountered by Districts and Local Health Authorities in the re-organisation of integrated services.

A first version of the GfI will be tested through its application – together with the SINA – in six Italian Health Districts. Local coordination groups will be activated in each District and will discuss the applicability and pertinence of the GfI, considering their implementation at the local level. The GfI will be experimented at a local level in a sample of Italian Districts characterised by a preliminary low level of integration of social and health services, in order to monitor their implementation and get feedback on their application by professionals and stakeholders.

On the basis of the results emerging from the testing phase, GfI will be integrated and improved. The final version of the GfI, which will include contributions from local coordination groups and interregional meetings, will be included in a National Plan for Social and Health Integration, to be
formally adopted by the Italian Ministry of Labour and Social Policies. The results of testing the GfI and their final version will be discussed at a European level during an international seminar involving representatives of major stakeholders and policy officers from different countries. The main aim of such a seminar will be to evaluate the potential transferability of the GfI in other European contexts. A Transferability Report will be also finalised, in order to address possible benefits and challenges of adopting the GfI in other countries. Furthermore, various dissemination activities are planned. In addition to on-line ad hoc channels, the GfI and Transferability Report will be translated in five languages (English, Italian, French, German, Spanish) and both presented in five countries to national and local policy makers. Moreover, various conferences will take place, aimed at disseminating results among Italian local, regional and national policy officers, as well as among European Commission policy officers and representatives of major stakeholders (e.g. local governments, user organisations, research institutes) at EU level.

1.2. Aims and structure of this deliverable

The present document Album of European good practices constitutes an official deliverable of the AIDA project, produced as a result of the activities carried out in Work Package 2 (Preliminary Investigation: The European Framework). Its goal is to present a collection of good practices identified all over Europe, through a case-by-case descriptive analysis that underlines their success factors and impact on users, service providers and overall health and social care systems. The deliverable is structured as follows. After this introduction, the methodology for selecting the 10 good practices is described (Chapter 2), in order to give details of the selection process. The following section (Chapter 3) constitutes the core of the deliverable, since it includes the individual reports for each selected initiative: the reader can find here descriptive analyses of all cases, structured according to a standard template and outline. Finally, references are provided, as well as other annexes which have been operative tools during the project activities, including the criteria for selecting the good practices (Annex 1), the long list of initiatives considered from different sources (Annex 2), and the standardised template (Inquiry Form) used for reporting information from each initiative (Annex 3).
2. **Methodology for selecting good practices**

2.1 **WP2: Identification of European good practices**

During the first phases of the project, an investigation at the EU level was carried out to gain a better understanding of which innovative initiatives in the field of LTC have been considered as successful and efficient. Indeed, Work Package 2 aimed to identify 10 existing good practices at European level in different countries, i.e. at least two per each welfare regime as identified in the current literature (Simonazzi, 2009): Nordic regime; Anglo-saxon regime; Continental regime; Southern European regime; Eastern European regime.

Initiatives should represent relevant projects and/or services developed at regional or local level (by local health authorities, districts, municipalities or third sector organisations), which allow an efficient integration between health and social care services delivered at home and/or in residential settings. In particular, these initiatives should guarantee continuity and quality of LTC during individuals’ life phases, as well as the appropriateness of care delivered. Selected good practices should aim also to promote rights and wellbeing of older people, to decentralise service provision of care (according to an “ageing in place” approach), and to integrate innovative devices and solutions into the LTC service.

2.2 **Geographical coverage**

The following table provides an overview of the collected initiatives, classified by geographical areas/Welfare Regimes and countries they belong to. The Continental Area is represented by Austria and The Netherlands, the Northern area by Sweden, the Eastern Area by Hungary, the Anglo-Saxon Area by the United Kingdom and the Southern Area by Greece and Spain.

<table>
<thead>
<tr>
<th>Geographical Area/ Welfare Regime</th>
<th>Countries</th>
<th>Number of collected initiatives</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anglo-Saxon</td>
<td>United Kingdom</td>
<td>1</td>
</tr>
<tr>
<td>Continental</td>
<td>Austria</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Netherlands</td>
<td>1</td>
</tr>
<tr>
<td>Eastern</td>
<td>Hungary</td>
<td>1</td>
</tr>
<tr>
<td>Northern</td>
<td>Sweden</td>
<td>1</td>
</tr>
<tr>
<td>Southern</td>
<td>Spain</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Greece</td>
<td>2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td></td>
<td><strong>10</strong></td>
</tr>
</tbody>
</table>

*Tab.1 Initiatives per Geographical Areas/Welfare regimes*
2.3 Selection criteria

In order to assess the quality of an initiative candidate to be included among the good practices, it was necessary to develop a set of specific selection criteria. These criteria have been drafted by the project consortium on the basis of most relevant conceptual frameworks on integrated health and social care for older people (Banks, 2004; Billings & Leichsenring, eds., 2005; Hofmarcher, Oxley & Rusticelli, 2007; Hollander & Prince, 2008; Leichsenring, 2004; Kodner & Spreeuwenberg, 2002; Leutz, 1999; MacAdam, 2008). The so identified criteria have been later on integrated and validated by an Advisory Board (AB) composed by five international experts in the field: Stephanie Carretero (Institute for Prospective Technological Studies), Kai Leichsenring (Associated Senior Researcher of the European Centre for Social Welfare Policy and Research), Jolanta Perek-Bialas (Warsaw School of Economics), Elizabeth Hanson (Swedish Family Care Competence Centre), and Sue Yeandle (University of Leeds).

In Annex 1 the reader can find the validated list of selection criteria used for filtering a long list of good practices that have already been considered and selected in other recent European projects in this field, i.e. Interlinks (http://interlinks.euro.centre.org/), Procare (www.euro.centre.org/procare/), WeDo (www.wedo-partnership.eu/) and CARICT (http://is.jrc.ec.europa.eu/pages/EAP/eInclusion/carers.html). Other potentially good initiatives have been suggested by experts of the AB. A total of 28 initiatives have been pre-selected (see Annex 2).

Each pre-selected initiative has been assessed through the application of the selection criteria, in order to understand whether they matched basic requirements and to check their appropriateness and relevance for the objectives of the AIDA project. Initiatives have been then ranked within the same welfare regime, in order to be able to select the two most relevant ones in each geographical area. 10 initiatives have been finally selected (see Table 2 in next chapter 3).

2.4 Data collection

An Inquiry Form was carried out as a tool for data gathering. This form has been developed within the AIDA project in order to ensure that all relevant and detailed information are presented in each case (see the Inquiry Form in Annex 3). It is made of two macro areas: “Background” and “Initiative” description for qualitative data collection. The first part collects information about social-demographic aspects and the national/local legislative framework. The second one concerns the description of the service in its innovation and target features and sustainability, transferability and future perspectives. For each selected initiative, information has been collected through the direct involvement of their coordinators or contact persons, who have been asked to fill in the inquiry form and submit individual reports. All reports have been validated and are included in this deliverable. In the following chapters of the deliverable, all initiatives are reported case-by-case.
3. **Description of 10 European Good practices**

In this section is proposed an in depth description of the 10 initiatives collected as good practices: table 2 shows an overview.

Single reports of the initiatives are provided in the next pages.

<table>
<thead>
<tr>
<th>Care Regime</th>
<th>Country</th>
<th>Name of the Initiatives</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Anglo-Saxon</td>
<td>United Kingdom</td>
</tr>
<tr>
<td>2</td>
<td>Continental</td>
<td>Austria</td>
</tr>
<tr>
<td>3</td>
<td>Continental</td>
<td>The Netherlands</td>
</tr>
<tr>
<td>4</td>
<td>Eastern</td>
<td>Hungary</td>
</tr>
<tr>
<td>5</td>
<td>Eastern</td>
<td>Hungary</td>
</tr>
<tr>
<td>6</td>
<td>Northern</td>
<td>Sweden</td>
</tr>
<tr>
<td>7</td>
<td>Southern</td>
<td>Spain</td>
</tr>
<tr>
<td>8</td>
<td>Southern</td>
<td>Spain</td>
</tr>
<tr>
<td>9</td>
<td>Southern</td>
<td>Greece</td>
</tr>
<tr>
<td>10</td>
<td>Southern</td>
<td>Greece</td>
</tr>
</tbody>
</table>

Tab.2 Names of the initiative per Care regime
3.1 Anglo-Saxon Care Regime

Care Trusts

Author: Robin Miller
Affiliation: University of Birmingham

Abstract
The option of developing a Care Trust as an integrated health and social care organization in England was announced in 2002 following long-standing concerns regarding the ability of the statutory bodies responsible for health and social care to work together. It was envisaged by central government that Care Trusts would become the norm in relation to the planning and delivery of community services for older people. In fact though there were no more than 10 in operation at any time (out of 150 localities in which they could have been developed), with approximately half of these having responsibility for commissioning all and providing an element of health and social care services for the adult population as whole. The rest focused on delivering services for people with mental health problems and/or a learning disability. Care Trusts were therefore primarily an example of structural integration, but (dependent on the individual Trust) also sought to develop ‘linkage’, coordination’ and ‘networks’ with other local health and social care organizations. No formal research was undertaken of the impact of Care Trusts as such in comparison to other approaches to facilitate joint working between health and social care. Evaluations of Torbay Care Trust did suggest that positive impacts had been achieved, although the extent to which these could be attributed to the development of an integrated organization rather than other factors were not established. Senior Managers in Care Trusts who participated in research reviewing their experiences suggested that using such a structural approach to achieving integration could cause as many problems as it solved. Following recent national policy changes the Commissioning-provider Care Trusts have been disbanded, but the Provider Care Trusts have expanded in size and the range of services provided. Four new social enterprises have recently been created through the ‘spinning out’ of NHS and Local Authority services from the statutory to the third sector, and these provide a new organizational structure through which to deliver community health and social care services.

<table>
<thead>
<tr>
<th>Leader organisation(s)</th>
<th>Health Services Management Centre, University of Birmingham</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other organisations</td>
<td>The Care Trusts that were set up across England</td>
</tr>
<tr>
<td>Contact details</td>
<td>Robin Miller, <a href="mailto:rs.miller@bham.ac.uk">rs.miller@bham.ac.uk</a>, 0121 414 8018</td>
</tr>
<tr>
<td>Website</td>
<td><a href="http://www.hsmc.bham.ac.uk">www.hsmc.bham.ac.uk</a></td>
</tr>
<tr>
<td>Date of data collection</td>
<td>March 2013</td>
</tr>
</tbody>
</table>
BACKGROUND

The socio-demographic context

The population of England was estimated to be 51,809,700 in 2009, with 91% of the population from a ‘white’ ethnic background and the remainder from other ethnic groups (Boyle 2011). In line with most developed nations the demography of England is changing, with predictions that by 2032 the number of people aged over 65 will expected have grown by more than a third from 9 million to 13.5 million and the number of people aged over 85 will double from 1.3 million to 2.6 million (Imison 2012). Whilst life expectancy is increasing for the population as whole, health inequalities also continue through the more educated and well-off being better engaged with promotional advice regarding healthy lifestyles and disease avoidance. The number of people with three or more long-term conditions is predicted to increase by 50% between 2008 and 2018. This is due in part to the ageing population and improvements in treatments, but also due to increasing obesity and inactivity (Department of Health 2012).

The NHS Budget in England in 2011/12 was £105.4 billion and was largely funded through taxation and national insurance contributions. Responsibility for the planning and oversight of healthcare services in England is held by the Secretary of State for Health who in turn is accountable to parliament. The Secretary is supported by civil servants within the Department of Health who set the overall health policy and strategy. The Department of Health has until the recent changes outlined below had regional bases in the form of Strategic Health Authorities. Commissioning (i.e. the planning and purchasing of health services) is currently undertaken by locally based Primary Care Trusts, but this is currently transferring to Clinical Commissioning Groups (CCGs). CCGs are statutory bodies led by General Practitioners who will commission most local healthcare services. Primary care and specialist services will be commissioned by a national NHS Commissioning Board, and this Board will also hold the CCGs to account for their delivery of an agreed set out of health outcomes.

Access to publically funded healthcare is on the basis of clinical need and is largely free (apart from ‘over the counter’ medicines, dental and optician charges) and this has mostly been provided through publically run acute and/or community healthcare trusts. Self-employed General Practitioners act as the gatekeepers to NHS services and with their practice nurses provide much of direct primary care. Since the 1980’s successive governments have sought to introduce market based reforms in an attempt to increase quality and efficiency through the power of competition. These reforms include - greater patient choice over who provides elective care, increased autonomy for NHS providers (through for example the development of the more business like NHS Foundation Trusts), enabling of independent providers to bid for NHS funded work, and new payment processes that are based on activity and (increasingly) outcomes rather than on historical block contracts. Private Medical Insurance contributes only 2.9% of the overall health care expenditure in the UK, with the majority of PMI being purchased by employers as part of employee benefit packages (Boyle 2011). The NHS also purchases treatment from private and voluntary sector healthcare providers and whilst this is still less than 10% of the total budget such purchasing has increased steadily in recent years.

Whilst central government sets the overall legal and policy framework in which social care
operates, it’s planning and co-ordination is the responsibility of Local Authorities and so comes under the leadership of local rather than nationally elected politicians. Thus whilst there is a national eligibility system in place to determine who is able to access publically funded social care services, Local Authorities can determine what level of need will be met in their area and this differs from locality to locality. If older people meet the local criteria then they are subject to financial assessments, which in can result in them meeting the whole costs of their care. This means that approximately half of older people who require care fund this by themselves. Social care services for older people are largely provided by the private and third sectors, with Local Authorities’ direct role generally being limited to providing specialist home care reablement services and undertaking safeguarding and care management roles. There has been increasing emphasis in recent years in the potential of more ‘individualised’ approaches in which the public social care funding available to each older person is made transparent and they are able to direct how this is spent.

Financial payments to those with a disability and carers are made through a separate welfare benefits system overseen by a separate central government department (the Department for Work & Pensions).

The legislative framework

The National Service Framework (NSF) for older people was published in 2001 and set the vision for how health, social care and other public agencies should support older people. The NSF was developed in response to the changing demographics and the corresponding increase in demand on public services, the perception that health and social care services were not always able to provide the quality and flexibility that older people expect and were entitled to, and the inequality of access and treatment experienced by disadvantaged groups such as older people with a learning disability, those from minority communities and those who were detained in prison. The NSF had four key themes under which were set out eight standards with milestones to be achieved –

- **Respecting the Individual:** addressing age discrimination in relation to access to treatment and care and ensuring that health and social care services are co-ordinated around the individual
- **Intermediary Care:** developing services that work at the boundary between hospital and the community, preventing older people from being admitted and/or enabling their safe and timely discharge from hospital
- **Providing Evidence-based Care:** to achieve consistency in the standard of specialist care, in particular within hospital, to prevent falls, and to support people with mental health difficulties and/or who had survived a stroke
- **Promoting an Active, Healthy Life:** to encourage and facilitate older people to remain healthy and independent

Since the NSF was published there have been further guidance and strategies related to conditions that affect older people. Of particular note are the Dementia Strategy (DH 2009) and the Stroke
Strategy (DH 2007). Both of these set out expected improvements across the diagnostic, treatment and care pathway for these conditions, alongside increased public awareness and support for carers.

Improved integrated working between health and social care, and increased levels of support being provided in the community rather than in acute settings have been embedded within these and other policy and care guidelines. There are indications of positive changes subsequently being achieved in the care system, for example in relation to improved hospital discharge (delayed transfers of care fell from 3,600 a week in 2003/4 to 2,200 a week in 2008/9) and corresponding increases in older people being supported in the community. However emergency hospital admissions of older people still rose by over 12% between 2004/5 and 2009/10, and overall use of hospitals has steadily increased, highlighting that community based support is still not able to respond to the increasing demands (Humphries 2011, Thorlby & Maybin 2010). Integrated care is also still to be consistently achieved, with a recent government review concluding that ‘too many people fall through gaps between services as they traverse journeys of care which are often too difficult for them to navigate themselves. This lack of integration results daily in delays and duplication, wasted opportunities and patient harm. It is time to “mind the gaps” and improve the experience and outcomes of care for people using our services.’ (Future Forum 2012, p3).

**INITIATIVE**

**Rationale**

The Labour government elected in the 1997 identified partnership working across different sectors and bodies within the public sector as being a priority, and singled out collaboration between health and social care as needing particular improvement. The strength of their commitment is captured in the following quote by the then Secretary of State to a Select Committee hearing - ‘There cannot be any question of anyone in the NHS at any level in any part of the country not cooperating with their local social services...or local authority. Anyone who wishes to further their career in the NHS, I think, should demonstrate that they are in favour of cooperating with partners who are necessary to the proper discharge of their duties’ (Greig & Poxton 2001). In 1999 the Health Act introduced new legal powers that statutory bodies could use to promote better integration, including ‘lead commissioning’ (in which one body can be delegated responsibility to plan and purchase services on the other’s behalf), ‘pooled budgets’ (into which health and social bodies make contributions and which is then used to purchase a joint area of service) and ‘integrated provision’ (in which a public sector body is able to deliver both health and social care services). The option of Care Trusts as an organizational form through to which to deliver these ‘Health Act Flexibilities’ were set out the following year in the NHS Plan. Whilst it was envisaged that these would generally be created on the basis of local agreement that such an organization would be the best option to deliver integrated services there was also a threat that they could be imposed by central government if it was deemed that an area had ‘failed to establish effective joint partnerships’ (Secretary of State 2000, p73).

The aim of Care Trusts were to achieve ‘tailored and integrated care, greater accessibility, and one
stop shops for services that used to entail repeated conversations and a procession of different faces at times of illness, stress and vulnerability’ (Department of Health 2002: p 1). Care Trusts would also offer better benefits for staff (in the form of enhanced career opportunities and simplified management structures), engage clinicians and practitioners meaningfully in the development and implementation of integrated care pathways and be vehicles to facilitate single IT systems to improve joint patient information and performance management systems (Miller et al 2011a,b).

Specificities and innovation
Localities had flexibility to decide what populations (if any) could be best served by a Care Trust and could choose to focus on a particular service user / patient group or the needs of a range of service user / patients within a single locality. The initial guidance did though envisage that Care Trusts would be most relevant for services to support older people and people with mental health problems rather than those supporting people with a learning disability and / or with a physical disability. This was on the basis that the latter group’s needs were primarily in relation to social inclusion rather than addressing underlying health conditions, and would therefore be better served through Local Authorities leading on the planning and delivery of their care rather than an NHS body. In terms of area of coverage, Care Trust could be co-terminus with the geographic boundaries of a single local authority or work across a number of Local Authorities in relation to a specialist area of provision.

The government initially predicted that they would be the predominant model for the delivery of services for older people within five years. In fact though there has only been limited take up over the past decade, with no more than ten in existence at any one time (see Table 1 below).

Table 1: Number of Care Trusts launched each year (note that a number were subsequently disbanded) (Miller at al 2011b)
Service model and integration patterns

<table>
<thead>
<tr>
<th>Level of organisational integration of care</th>
<th>Linkage: users are appropriately cared for within systems that serve the whole population (not for specific target groups), e.g. older people are cared for by services addressing all people with long-term care needs (and not by special services for older people only).</th>
<th>Coordination: explicit structures and individual managers are installed to coordinate benefits and care across different providers; structures are still separate, e.g. sharing clinical information in a planned manner, managing transitions between settings, assigning primary responsibility for coordinating care</th>
<th>Networking: different care providers establish detailed protocols and intervention models, as part of a joint programme</th>
<th>Full integration: creation of new structures or units dedicated to the specific user needs where resources from multiple providers/systems are pooled, e.g. organisation of multidisciplinary teams managing all care, control or direct provision in all care settings</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
</tbody>
</table>

There were essentially two models of Care Trusts developed –

1) **Provider Care Trusts**: these delivered direct health and social care services and purchased individual social care packages. These Care Trusts were largely focused on mental health, substance misuse and learning disability services.

2) **Commissioning-provider Care Trusts**: these were responsible for commissioning all health services in their area and adult social care services and for delivering community health services and all/a proportion/no adult care services

Table 2 below provides an overview:

Table 2: The services provided by Care Trusts (Miller et al 2011a)

<table>
<thead>
<tr>
<th>Area</th>
<th>Service provision</th>
<th>Commissioning</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bradford</td>
<td>Mental health Learning disability Substance Misuse</td>
<td>No</td>
</tr>
<tr>
<td>Camden &amp; Islington</td>
<td>Mental health Learning disability Substance misuse</td>
<td>No</td>
</tr>
<tr>
<td>Manchester</td>
<td>Mental health Learning disability Substance misuse</td>
<td>No</td>
</tr>
<tr>
<td>Northumberland</td>
<td>Community health services (not including mental health) and adult social care</td>
<td>Yes</td>
</tr>
<tr>
<td>Witham, Braintree &amp;</td>
<td>Care Trust element focussed on older people’s</td>
<td>Yes</td>
</tr>
<tr>
<td>Area</td>
<td>Services Provided</td>
<td>Social Care Provision</td>
</tr>
<tr>
<td>-------------------</td>
<td>-------------------------------------------------------</td>
<td>-----------------------</td>
</tr>
<tr>
<td>Halstead</td>
<td>Services (including housing support)</td>
<td>Yes</td>
</tr>
<tr>
<td>Bexley</td>
<td>Community Health Services (no social care)</td>
<td>Yes</td>
</tr>
<tr>
<td>Sandwell</td>
<td>Mental health</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>Learning disability</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Substance misuse</td>
<td></td>
</tr>
<tr>
<td>Sheffield</td>
<td>Mental health</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>Learning disability</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Substance misuse</td>
<td></td>
</tr>
<tr>
<td>Torbay Care Trust</td>
<td>Community health services (not including mental health) and adult social care</td>
<td>Yes</td>
</tr>
<tr>
<td>Solihull Care Trust</td>
<td>Community health services (not including mental health) and adult social care</td>
<td>Yes</td>
</tr>
<tr>
<td>North East Lincolnshire</td>
<td>Older people and physical disabilities</td>
<td>Yes</td>
</tr>
<tr>
<td>Blackburn with Derwen</td>
<td>Community health services (no social care)</td>
<td>Yes</td>
</tr>
</tbody>
</table>

In relation to the delivery of services, both Care Trust models were similar in that the staff and connected social care budgets from Local Authorities were delegated to these new NHS bodies who were responsible for employing, deploying and managing these staff. Transferred social care staff generally remained on Local Authority rather than NHS Terms & Conditions, but new social care staff have been employed under NHS Terms & Conditions. This means that staff undertaking the same job could have different pay and leave entitlements. The Care Trusts were responsible for developing access arrangements and care pathways through their services and for agreeing these with relevant partner agencies such as acute hospitals, police and housing.

The direct services within Provider Care Trusts were in-patient and community based mental health and learning disability services, including psychiatry, community psychiatric nursing, psychology and therapy. Direct social care provision included care management, mental health social work, community support and respite. Individual social care packages would be bought in from the private and third sector provision and/or through service recipients employing staff through a direct payment.

The direct provision with Commissioning-provider Care Trusts were community based health professionals and commonly included community nursing, health visiting and occupational, speech and language therapy. There were other community health services included dependent on the historic arrangements with that locality – these could include community paediatricians, dental services and podiatry services amongst others. Social care services included care management and social work teams for the user group concerned (typically older adult, physical disability and learning disability), occupational therapy and reablement services. Dependant on the locality there may have been other direct services such as home care, day care and respite care.

The commissioning responsibilities in relation to health services were to undertake population needs assessments, prioritizing current and future areas of need, and then purchasing primary,
community and acute health care services to meet these needs. This included mental health services and services that they delivered directly. They were not though responsible for specialist health services which were purchased regionally through regional Strategic Health Authorities. In relation to adult social care services Commissioning Care Trusts were also responsible for needs assessment and planning of services and the purchasing of direct packages from the private or voluntary sector (if the budget had not been passed to the service user in the form of a direct payment).

Target population
Whilst there would be variation dependent on the range of services provided by each Care Trust, older people who accessed the services of Provider Care Trusts would largely be –
- Those with severe and enduring mental illnesses such as bipolar disorder and schizophrenia
- Those with dementia and other degenerative mental health conditions
- Those with severe anxiety and depression who require more support than can be provided through general practitioners
- Older people with a learning disability who have additional complex physical and/or mental health conditions

Older people who received direct support from Commissioning-provider Care Trusts would essentially be those who required a service beyond the capacity or capability of general practitioners and who do not require in-patient treatment or residential care. This would include those in generally good health but who had a temporary health condition that could be treated through short-term or a one-off interventions to those who had chronic, complex and multiple conditions that required intensive support for the medium to long term

Commissioning-provider Care Trusts were responsible for planning and procuring health and social care services for the whole of the older people’s population within their locality.

Financial aspects and sustainability strategies
Care Trusts were almost entirely resourced through public funding, with the health care element of this being allocated to them via the Department of Health and the Social Care element being delegated from Local Authorities. Charging would be in line with the financial system outlined above (i.e. health care essentially free and a financial assessment process for social care).

Staff would largely be employed on a permanent basis by Care Trusts and receive a monthly salary. There will also be a small proportion of staff who were employed on a casual basis and receive payment for the hours worked each week.

The Care Trusts had different budgets and approaches to addressing financial pressures and information is not centrally available on these.

Partners involved
Each Care Trust will have had local partners to engage with in the development of the organization and in coordinating the delivery of services in the locality.

Common partners would include:
• Local acute NHS providers and mental health trusts (if a Commissioning-provider Care Trust)
• Local authority housing and leisure services
• Private and third sector providers of health and social care services
• Police and other criminal justice agencies (in respect of safeguarding issues in particular)
• The Care Quality Commission (national regulator and inspector of health and social care services)
• User representative and advocacy groups for older people
• Primary care services, in particular general practitioners

Strengths and weaknesses
Chief Executives of Care Trusts report different impacts from the same organizational forms. This was dependent on a host of local factors, in particular the previous history of partnership working across health and social care, the level of trust between key participants and the development process used. Table 3 provides a summary of these (Miller et al 2011a).

<table>
<thead>
<tr>
<th></th>
<th>Reported Strengths</th>
<th>Reported Weaknesses</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Staffing</strong></td>
<td>Redesigning roles across health and social care workforce.</td>
<td>Complexity of managing staff with different Terms &amp; Conditions.</td>
</tr>
<tr>
<td></td>
<td>Portrayal as ‘innovative’ organisation spanning health &amp; social care can act as recruitment tool.</td>
<td>Harmonisation of Terms &amp; Conditions is time consuming and can lead to additional staff costs (if one staff group receives additional salary as a consequence).</td>
</tr>
<tr>
<td></td>
<td>Additional career opportunities (particularly for social care staff working in mental health).</td>
<td>Tension caused by staff groups feel that other disciplines are given stronger voice and more influence.</td>
</tr>
<tr>
<td><strong>Service development</strong></td>
<td>Power to ‘shape’ the whole of health and social care system through managing commissioning process.</td>
<td>If relationship with Council is not strong then gaining approval for redesign of social care services can be problematic.</td>
</tr>
<tr>
<td></td>
<td>Build on the ‘best’ of social care and health approaches to develop innovative services.</td>
<td>Care trust can be expected to modernise services within existing social care budget (even if this is already under pressure).</td>
</tr>
</tbody>
</table>
Opportunities for development lost as initial focus was on dealing with transactional issues.

<table>
<thead>
<tr>
<th>Co-ordination of care</th>
<th>Easier to develop joint teams with single manager and integrated processes.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Sharing of information between disciplines.</td>
</tr>
<tr>
<td></td>
<td>A ‘culture of integration’ is also required and this can be neglected with time spent addressing process issues.</td>
</tr>
<tr>
<td></td>
<td>Barriers between health &amp; social care IT systems remain</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Wider partnerships</th>
<th>Care trust is an example of what can be achieved with investment in integrated working.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Engagement with local community on health and social care issues as a whole.</td>
</tr>
<tr>
<td></td>
<td>Stronger influence to advocate for health &amp; well-being agenda within local strategic partnerships.</td>
</tr>
<tr>
<td></td>
<td>Social care seen as ‘outside’ of the local authority and so not a priority within other functions such as housing.</td>
</tr>
<tr>
<td></td>
<td>‘Contractual’ rather than ‘partnership’ relationship with local authority.</td>
</tr>
<tr>
<td></td>
<td>Maintaining links with changing inspection and commissioning bodies (and leads) and responding to different (and at times conflicting) demands of central government departments.</td>
</tr>
</tbody>
</table>

**Impact assessment and performance evaluation**

Whilst as a whole Care Trusts have not been subject to formal research to compare with other approaches to achieving integrated care, the Kings Fund produced a series of evaluations focusing on the impact of Torbay Care Trust. This was created in 2005 against a backdrop of previous collaboration between the Local Authority and the Primary Care Trust (highlighting that impacts cannot clearly be ascribed to the Care Trust in isolation).

Headline findings from these evaluations are provided by Thistlewaite (2011) & Curry & Ham (2010):

- The daily average number of occupied beds fell from 750 in 1998/99 to 502 in 2009/10.
- Emergency bed day use in the population aged 65 and over became the lowest in the region at 1920 per 1000 population compared with an average of 2698 per 1000 in 2009/10.
- Emergency bed day use for people aged 75 and over fell by 24 per cent between 2003 and 2008 and by 32 per cent for people aged 85 and over in the same period
- Delayed transfers of care from hospital were reduced to a negligible number and this was sustained over a number of years.
• The use of Direct Payments by adult social care users was one of the best in the region.
• The national care regulator the Care Quality Commission judged Torbay to be ‘performing well’ in relation to adult social care services.
• A survey ranked Torbay highest in the South-west region for the proportion of people reporting confidence with NHS services.

**Reproducibility and transferability**

Assuming there are the legal flexibilities in place for the transfer of duties, staff and budgets then in principle single organizations to commission and/or deliver health and social care services could be created. However the limited research to date suggests that developing integrated organizations on the scale of Care Trusts is not guaranteed to improve integrated care in practice, either in respect of the patients / service users’ experiences or greater efficiencies in the use of available resources. Potential benefits are only likely to be achieved if they are developed as the ‘next step’ in an on-going process through which health and social care have sought to work together, rather than as a means to force integration on services (and their leaders) that did not previously have a positive relationship.

Through the experiences of Care Trusts, the following issues been identified as important within the development and management processes of integrated organisations (Miller et al 2011a,b; Thistlethwaite 2011; Lavendar 2006)—

• Consultation with patients, services users, communities, staff and wider stakeholders as a means to set an overall vision of what should be achieved and as a legitimizing process
• Sensitivity to the importance of setting a positive culture within the new organization that can embrace the values and norms connected to different health and social care professions
• Investment in organizational development programmes that are based on evidence of successful organizational ‘mergers’
• Leadership that can gain the confidence of the different professional groups and is not seen to favour health over social care (or vice versa)
• A willingness to collaborate with other partners within the locality to avoid the risk that the services within the organization become more isolated from those which are not included
• Maintaining the focus of the organization on the needs and aspirations of the people who will access its services and on achieving good practice in care (in particular supporting people in the community rather than in hospital / institutional settings)
• Clarity regarding what is meant by key terms such as ‘integration’ and ‘integrated care’

**Future developments and possible implementations**

Two recent national policies have had a significant impact on the Care Trusts. The first was the requirement under the Transforming Community Services initiative that organizations could no
longer be responsible for the commissioning and providing of healthcare services. This meant that
the Commissioning-provider Care Trusts (along with the more common model of health-only
Primary Care Trusts) had to transfer their direct provision to another NHS organization and/or
create new organizations to take over their running. The second national policy change was the
decision to disband Primary Care Trusts altogether and transfer lead responsibility for the planning
and purchasing of services to CCGs (described above). These changes have meant that the
Commissioning-provider Care Trusts have been disbanded. The direct health services within these
Care Trusts have been largely been transferred to existing NHS Acute Providers and the direct
social care services transferred back to the Local Authorities. However in one area (North East
Lincolnshire) two new social enterprises have been created to directly provide health and social
care services (one focusses on mental health services and the other on general community
services) and in another locality an NHS Acute Provider has taken over the health and social care
provision. The Provider Care Trusts have all continued though, and indeed have expanded through
taking on responsibility for direct services that were previously part of Primary Care Trusts.
Furthermore there have been two social enterprises created in localities that had not previously
adopted Care Trust models which will deliver direct health and social care services on behalf of the
NHS and the Local Authority.

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Home Palliative Care Support Teams

Author: Dr. Georg Ruppe, M.A.
Affiliation: Austrian Interdisciplinary Platform on Ageing, ÖPIA

Abstract
Home Palliative Care Support Teams (HPCST) represent one essential element in the implementation plan for a graded hospice and palliative care system in Austria. Central objective is the provision of multidisciplinary and continuous mobile palliative and social care in order to maintain or improve quality of life and to allow a terminally ill person to stay at home or in a familiar surrounding as long as possible. Since 2000 a total of 40 Home Palliative Care Support Teams (HPCSTs) have been established and implemented in all Austrian provinces. Composed as multi-professional teams MPTs intend to do justice to the individual and often complex needs of patients and relatives and to coordinate their intervention with existing informal and formal networks. In this way a high level of integration can be guaranteed.

Existing evaluations and impact assessments have shown that HPCSTs are cost efficient in particular in the last month of life by reducing hospital related costs. Additionally, HPCSTs represent an interesting role model for integrated geriatric care and may be transferred to and implemented in health care systems of other countries as well.

<table>
<thead>
<tr>
<th>Leader organisation(s)</th>
<th>Dachverband Hospiz Österreich</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other organisations</td>
<td>Organisation of Author: ÖPIA: <a href="http://www.oepia.at">www.oepia.at</a></td>
</tr>
</tbody>
</table>
| Contact details         | HOSPICE AUSTRIA: Mag.a Leena Pelttari, +43 1 803 98 68, dachverband@hospiz.at
                          | ÖPIA: Dr. Georg Ruppe, +43 699 81699239, ruppe@oepia.at |
| Website                 | www.hospiz.at |
| Date of data collection | March 2013 |
The socio-demographic context in Austria

The country of Austria has a dimension of 83,853 square metres and currently around 8.3 million inhabitants (Statistik Austria 2012). Austria is subdivided into nine provinces (B, K, N, O, S, St, T, V, W) with corresponding provincial governments and subordinated administrative districts in form of municipalities. Vienna as the capital of Austria represents in unison a municipality as well as a province. During the past 15 years, the Austrian population has aged to a consistently higher degree than the EU27 average, as the share of those aged 65 and older in the total population increased. As a consequence, Austria has a relatively aged population even for EU27 standards and according to projections from Eurostat this ageing process is not likely to stop in the next decades. Statistik Austria (2012) projects that the Austrian population aged 65 and over will increase between 2006 and 2030 by about 56%, while the younger population (0-19 years) might decrease by 7%.

Table 1 Main demographic information – trends and projections

<table>
<thead>
<tr>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td>Total population</td>
<td>7,644,818</td>
<td>7,943,489</td>
<td>8,002,186</td>
<td>8,265,925</td>
<td>8,723,363</td>
<td>8,988,139</td>
</tr>
<tr>
<td>65+</td>
<td>1,139,841</td>
<td>1,196,874</td>
<td>1,233,667</td>
<td>1,361,804</td>
<td>1,688,465</td>
<td>2,129,450</td>
</tr>
<tr>
<td>80+</td>
<td>270,370</td>
<td>308,437</td>
<td>272,111</td>
<td>361,100</td>
<td>453,201</td>
<td>601,501</td>
</tr>
</tbody>
</table>

**Share of total population**

<table>
<thead>
<tr>
<th></th>
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<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>65+</td>
<td>14.9%</td>
<td>15.1%</td>
<td>15.4%</td>
<td>16.5%</td>
<td>19.4%</td>
<td>23.7%</td>
</tr>
<tr>
<td>EU-27 average</td>
<td>12.9%</td>
<td>13.9%</td>
<td>14.7%</td>
<td>15.7%</td>
<td>19.2%</td>
<td>22.6%</td>
</tr>
<tr>
<td>80+</td>
<td>3.5%</td>
<td>3.9%</td>
<td>3.4%</td>
<td>4.4%</td>
<td>5.2%</td>
<td>6.7%</td>
</tr>
<tr>
<td>EU-27 average</td>
<td>2.8%</td>
<td>3.1%</td>
<td>3.0%</td>
<td>3.7%</td>
<td>5.0%</td>
<td>6.4%</td>
</tr>
</tbody>
</table>

Source: Eurostat.

The health status of older people is an important determinant in shaping the demand for long-term care. While health conditions deteriorate with age, the age group of 75-80 seems to mark the point from which prevalence of dementia and severe activity restrictions increases sharply, making the age group of the 80+ the most likely to have long-term care needs (Huber et al., 2009, forthcoming).

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1 B=Burgenland, K=Kärnten, N=Niederösterreich, O=Oberösterreich, S=Salzburg, St=Steiermark, T=Tirol, V=Vorarlberg, W=Wien
According to existing studies on prevalence of dementia in Europe (Alzheimer Europe, 2006; Ferri et al., 2005), the share of the population affected by dementia in Austria has increased but it is in line with the EU average, totalling an estimated 94,000 to 104,000 people with Dementia in 2005. As for activity restrictions, the older age groups are also those with an increased share of people reporting severe activity restrictions, although these problems are much more likely to respond to adequate prevention and rehabilitation in earlier stages of life. In any case, women seem to have lower health conditions than men in their later stages of life.

Projections taking into account different assumptions concerning the development of the health status predict in any case a further increase of people with needs of help and care so that, in 2030, between 645,000 (Scenario “Better Health”) and 811,000 people (Scenario “Status Quo”) in Austria will need one or the other kind of support (Badelt et al, 1995). The number of beneficiaries of LTC allowances, almost 400,000 in 2007, is estimated to rise about 65 percent until 2030 (Hammer/Österle, 2006).

The legislative framework in Austria

The Austrian government describes the social welfare sector in Austria as comprising three main ways of organising and funding social expenditure: social insurance, social assistance and “other support” such as the LTC allowance, support for people with disabilities, support for victims of war and crime (BMSK, 2009). Social insurance provides sickness, pension and accident insurance to defined population groups in return for mandatory contributions. Social assistance provides a means-tested safety-net for individual social risks. “Other support” is provided as coverage for special groups for which the Federal State takes direct responsibility.

The most important in-cash entitlement for persons in need of care is the Austrian LTC allowance. Introduced in 1993 for all Austrian citizens as a non-means tested cash allowance it is generally administered at the level of the federal state and funded from general taxation. Additionally, publicly supported in-kind services for people in need of care are provided at the provincial/municipal level and require separate assessments as well as a means test for the client.

Services in cash

With the Federal Long-Term Care Allowance Act (“Bundes-Pflegegeldgesetz”) the Austrian long-term care allowance was introduced in 1993 for all Austrian citizens as a non-means tested cash allowance. Thus the formerly scattered and unequal cash benefit schemes for persons in need of care were comprehensively regulated. Austrian residents of all ages (and Austrians living in another EU country) are since then eligible for the LTC allowance if they are assessed as needing permanent (expected to last at least six months) care for more than 50 hours per month.

The Austrian LTC allowance has 7 levels depending on the hours of care needed due to physical and mental restrictions a person suffers from. The level of allowances (Table 2) depends on a medical assessment in which a specialised physician of the responsible administrative body (e.g. pension insurance agency or the social welfare agency) assesses the applicant’s monthly care needs during a home visit. Applications can be made at the responsible social insurance institutions, which also arrange the assessment procedures.
Table 2 The Austrian LTC allowance

<table>
<thead>
<tr>
<th>Level</th>
<th>Care needs per month</th>
<th>Amount in € per month</th>
<th>Beneficiaries in % per level</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>&gt; 60 hours</td>
<td>€ 154.20</td>
<td>22.32%</td>
</tr>
<tr>
<td>II</td>
<td>&gt; 85 hours</td>
<td>€ 284.30</td>
<td>30.85%</td>
</tr>
<tr>
<td>III</td>
<td>&gt; 120 hours</td>
<td>€ 442.90</td>
<td>17.17%</td>
</tr>
<tr>
<td>IV</td>
<td>&gt; 160 hours</td>
<td>€ 664.30</td>
<td>14.06%</td>
</tr>
<tr>
<td>V</td>
<td>&gt; 180 hours of heavy care</td>
<td>€ 902.30</td>
<td>9.53%</td>
</tr>
<tr>
<td>VI</td>
<td>&gt; 180 hours of constant attendance</td>
<td>€ 1,260.00</td>
<td>4.03%</td>
</tr>
<tr>
<td>VII</td>
<td>&gt; 180 hours of care in combination with complete immobility</td>
<td>€ 1,655.80</td>
<td>2.04%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Total number of beneficiaries: 435.517</td>
</tr>
</tbody>
</table>

Source: BMASK, 2012 (www.bmask.gv.at)

Table 3 shows the numbers of male and female beneficiaries of the LTC allowance in Austria.

Table 3 Number of beneficiaries of the federal LTC allowance by sex

<table>
<thead>
<tr>
<th>Level</th>
<th>Men</th>
<th>Women</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>30.081</td>
<td>67.117</td>
<td>97.198</td>
</tr>
<tr>
<td>II</td>
<td>46.493</td>
<td>87.868</td>
<td>134.361</td>
</tr>
<tr>
<td>III</td>
<td>26.200</td>
<td>48.593</td>
<td>74.793</td>
</tr>
<tr>
<td>IV</td>
<td>21.500</td>
<td>39.714</td>
<td>61.214</td>
</tr>
<tr>
<td>V</td>
<td>13.415</td>
<td>28.097</td>
<td>41.512</td>
</tr>
<tr>
<td>VI</td>
<td>6.746</td>
<td>10.791</td>
<td>17.537</td>
</tr>
<tr>
<td>VII</td>
<td>3.025</td>
<td>5.877</td>
<td>8.902</td>
</tr>
<tr>
<td>Total</td>
<td>147.460</td>
<td>288.057</td>
<td>435.517</td>
</tr>
</tbody>
</table>

Source: BMASK, 2012

**Services in kind**

In principle, each citizen has the right to call social services if s/he is in need of care. Though their organisation, coverage, regulation and financing differ with each of the nine regions, it can be stated that their take-up rate depends much more on local availability, personal information and costs for out-of-pocket contributions than on individual needs.

In Austria, health and social care services for people living at home are almost entirely provided by third sector organisations, mainly associations affiliated to the churches or to political parties. In residential care, about 55% of the facilities are publicly provided; about 21% are managed by commercial providers and the remaining 24% by private non-profit organisations (Schneider et al, 2006).
The availability and accessibility of services, semi-residential and residential care facilities have increased significantly over the past ten years: in some regions supply of home care has more than doubled, though from a very low level. Notwithstanding this positive development, there are still considerable regional differences so that community care services – home help, home nursing, geriatric aides – remain inadequate to meeting needs in some of the nine regions (Österle, 2001). A particular challenge for home care services remain alpine and border regions with difficult accessibility and long distances between the agencies’ headquarters.

Table 4 shows the kind of services used by carers of persons entitled to LTC allowance. Only about a quarter of all carers are using community care services and only 5.1% report the use of day care or short-term care facilities. Lack of information, lack of local availability and mainly lack of financial means to (co-)pay these services are the main motives given by carers for not considering these respite services.

Table 4 Types of services used by beneficiaries of LTC allowance

<table>
<thead>
<tr>
<th>Kind of service</th>
<th>LTC beneficiaries and their carers using the service</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community care services</td>
<td>24.9%</td>
</tr>
<tr>
<td>• of which:</td>
<td></td>
</tr>
<tr>
<td>Home nursing</td>
<td>46.0%</td>
</tr>
<tr>
<td>Home help</td>
<td>38.0%</td>
</tr>
<tr>
<td>Meals-on-wheels</td>
<td>29.6%</td>
</tr>
<tr>
<td>Day care</td>
<td>3.4%</td>
</tr>
<tr>
<td>Short-term care (respite care)</td>
<td>5.1%</td>
</tr>
</tbody>
</table>


A nurse from a regional or municipal care agency which is responsible for the distribution and control of publicly available and co-financed in-kind services in a certain region of Austria will assess the physical and mental state of a person and his/her respective care needs as well as the family and social situation. Based on this assessment, the nurse will determine what public services the client is entitled to and – for instance in Vienna – which sub-contracted care organisation will provide the services. As already mentioned, home help, home care and other social services needed for long-term care are subject to co-financing by the users (see below). The care agency calculates the cost-contribution the client is obliged to pay for the different kind of services. The calculation of personal cost-contributions usually takes into account the income/pension, the amount of LTC allowance scheme and personal property in the form of savings, deposits etc. For all different kinds of services a maximum contribution fee per hour is defined. In general, users pay about 1% of a calculation base (own income including LTC allowance) per hour of service, with exemptions for persons entitled to a minimum pension only.

For residential care there are currently about 68,000 places in about 800 old-age and nursing homes available in Austria. As in most other European countries, the average age of residents in most institutions is above 80 and residential homes are increasingly being transformed into nursing
homes. However, reforming large institutions into smaller units that are more adequate for hosting the increasing number of residents with dementia will still take several years. Apart from physical restructuring, first steps have been taken to improve the organisational framework of residential care: today, most regional governments have implemented specific legal regulations concerning institutional care, e.g. specifying education and training for managers of nursing homes, contracts with residents defining rights and duties, and some structural requirements concerning space, staffing or the maximum number of places. Once more, regulations differ remarkably from region to region (see also Leichsenring, Ruppe, Rodrigues, Huber 2009).

In some regions of Austria a precondition for the admission into an assisted-living facility is the entitlement to at least a level 2, for a nursing home to at least a level 3 of the Austrian LTC allowance. Unfortunately, a thorough geriatric assessment for example in hospitals is often missing before the decision for permanent admission into institutional care is taken. In general, permanent residents of nursing homes have to contribute 80% of their pension, their LTC allowance and all of their convertible property (incl. an owned house or apartment). 20% of the pension plus 10% of the level 3 public LTC allowance (i.e. currently €44.29) remains as a private allowance (more or less “pocket money”). In any case, a minimum asset of €3000 is allowed for private use on the bank account of the resident.

Concerning in-kind services it is important at this point to add that in the Austrian health sector a professional specialisation in geriatrics has only been established recently. The lack of implantation of gerontology and geriatrics at Austria’s three large public Medical Universities was partly responsible for the negative attitude of many of the responsible political and professional representatives towards the creation of a specialisation and postgraduate curriculum in geriatrics. A few years ago, the Ministry of Health has established a working group with the goal of conceptualising geriatrics as a sub-specialisation within internal medicine, neurology, psychiatry, physical medicine/rehabilitation and general medicine. (http://www.geriatrie-online.at). In 2012 an institute and chair for geriatric medicine at the Medical University in Vienna has been established.

**INITIATIVE**

**Rationale**

In 2000 palliative medicine was mentioned and introduced for the first time in the Austrian Krankenanstalten und Großgeräteplan ÖKAP/GGP (see ÖBIG 2004), which means a plan that determines the general structural requirements of hospitals and the national acquisition and distribution of large and very expensive health care related machines, such as computer tomographers or other special machines. Since then there has been systematic planning and development of structures and respective quality criteria necessary for Hospice and Palliative Care in Austria.

Caritas (1989) and Caritas Socialis (1992) provided the first hospice and palliative care services in Vienna. In 1993 Hospice Austria was founded as the umbrella organization for hospice and
palliative care services in Austria. Following the “Declaration of the Austrian Government 2003 to 2006” aiming for a fair access to hospice and palliative care services for all those who need it in 2003, Hospice Austria and the Austrian Federal Health Institute (Österreichisches Bundesinstitut für Gesundheitswesen) developed a master plan for a graded hospice and palliative care network, which suggested structures and defined quality of care. The plan was published and its integration into the healthcare system and National Health Care Plan (Österreichischer Strukturplan Gesundheit) was started in 2004 (see table below).

The scheduled implementation of a graded Hospice and Palliative Care system containing different forms of inpatient and outpatient services has been compiled in the respective national plan Abgestufte Hospiz- und Palliativversorgung in Österreich (ÖBIG 2004). Home Palliative Care Support Teams (HPCSTs) represent one essential component of this implementation plan. The underlying intention and general objective of HPCSTs is the provision of multi-professional and continuous mobile palliative and social care in order to maintain or improve quality of life and to allow a terminally ill person to stay at home and/or in familiar surroundings as long as possible and to avoid (unnecessary) hospitalisation. Another important objective is to bridge common gaps and facilitate transition processes between hospital and (nursing-) home care, which can be exhausting and sometimes even traumatising for a terminally ill person.

Table: Plan for a graded hospice and palliative care provision in Austria

<table>
<thead>
<tr>
<th>Hospice and Palliative Care services in Austria</th>
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</thead>
<tbody>
<tr>
<td><strong>Primary Care</strong></td>
</tr>
<tr>
<td>Providers of General Care</td>
</tr>
<tr>
<td>Acute inpatient care</td>
</tr>
<tr>
<td>Long term care</td>
</tr>
<tr>
<td>Outpatient Care</td>
</tr>
<tr>
<td>Routine Situations 80 – 90% cases of death</td>
</tr>
</tbody>
</table>

Source: HOSPIZ ÖSTERREICH, ÖBIG 2004

**Specificities and innovation**

Services delivered by HPCSTs can be taken up by clients with chronic and terminal illnesses living at home. The provided services are generally free of charge for the user and access to services is not dependent on any means testing. Also professionals, who work in mobile or residential LTC services and need support with issues of palliative care or treatment can make use of HPCSTs services. Since 2000 a total of 40 Home Palliative Care Support Teams (HPCSTs) have been established and implemented in all Austrian provinces according to the national plan for graded hospice and
palliative care. This already innovative national policy was combined with the intention to reduce unnecessary hospitalisation and to cope with a growing number of potential clients. These were the main drivers for the development and continuous expansion of HPCSTs in Austria. In 2011 these 40 HPCSTs cared for 8142 patients, 54% of which were female. The average age of the female patients was 71.5, the average age of the male patients was 69.9. 80% were oncological patients (Source: Data Survey 2011, Hospice Austria).

Concerning geographical coverage it can be stated that the availability and expansion of MPT services differs between the regions in the following way: Burgenland 1 HPCST, Carinthia 3, Lower Austria 10, Upper Austria 4, Salzburg 4, Styria 8, Tyrol 3, Vorarlberg 1, Vienna 3 (Source: Data Survey 2011, Hospice Austria).

The plan for a graded hospice and palliative care network published in 2004 suggested one HPCST for every 140,000 inhabitants in Austria, one team consisting of 4.5 full time equivalents (FTE) of different professions (doctors, nurses, social workers etc). A new assessment of these figures is due in 2013. With regards to FTE’s of HPCSTs Austria had a coverage of 63% by the end of 2011 (Source: Data Survey 2011, Hospice Austria). The national umbrella organisation Hospice Austria monitors the development and current expansion of all related services.

Important characteristics and innovative aspects of HPCSTs are the composition as multi-professional teams and the thorough coordination with the formal and informal health and care network of each client. The multi-professional composition of HPCSTs as well as the individuality and flexibility of provided services allow to meet individual needs and context and to overcome gaps in collaboration and transition processes between large and often rigid social, health and care structures. HPCSTs do not replace but complement the existing medical and home care services with regards to palliative care.

Registered clients of HPCSTs and their caregivers benefit from individually adapted plans for home visits including all kinds of specific services provided by the multi-professional teams. Telephone counselling and acute (medical) care are available over a 24 hour period. Additionally, support to coordinate admission to or discharge from hospitals as well as transfer to hospices is offered by HPCSTs.

HPCSTs represent a promising role model for mobile community care services for frail older people in general.

In Lower Austria a project for integrating hospice and palliative care in nursing homes revealed a huge need of and gap in palliative and geriatric medical services. Lower Austria now tries to solve this problem by linking existing HPCSTs with nursing homes to provide sufficient palliative care. A challenge is to finance larger teams and to combine palliative expertise with knowledge in geriatrics. At the moment palliative care is still oncology focused.

Styria is just doing a test run in establishing a geriatric support service for nursing homes consisting of regular visits by a doctor schooled in palliative care and geriatrics. The first results show a considerable decline of transfers to hospitals (Source: W. Schippinger et al., Mobiler geriatrischer Konsiliarer Dienst für Pflegeheime. Untersuchung der Effektivität eines internistisch-fachärztlichen Konsiliardienstes zur medizinischen Versorgung von Pflegeheimbewohnern, in: Z Gerontol Geriat 2012, 45:735–741).
### Service model and integration patterns

<table>
<thead>
<tr>
<th>Level of organisational integration of care</th>
<th>Linkage: users are appropriately cared for within systems that serve the whole population (not for specific target groups), e.g. older people are cared for by services addressing all people with long-term care needs (and not by special services for older people only).</th>
<th>Coordination: explicit structures and individual managers are installed to coordinate benefits and care across different providers; structures are still separate, e.g. sharing clinical information in a planned manner, managing transitions between settings, assigning primary responsibility for coordinating care</th>
<th>Networking: different care providers establish detailed protocols and intervention models, as part of a joint programme</th>
<th>Full integration: creation of new structures or units dedicated to the specific user needs where resources from multiple providers/systems are pooled, e.g. organisation of multidisciplinary teams managing all care, control or direct provision in all care settings</th>
</tr>
</thead>
</table>
| Clients or their carers, who directly want to take up services by HPCSTs, have to register in advance with a respective regional provider organisation. They often do so on their own initiative or after having received preliminary information about such services, e.g. by their general practitioner. After an initial home visit, where specific needs and circumstances of the client are assessed, an individual care and support plan is set up in coordination with the user, carer and with other professional staff already attending the client, such as general practitioners or home care providers. There are a number of things that will be determined in the care plan; these include the frequency of home visits, the appropriate kind of palliative care and treatment as well as relevant additional services, such as psychosocial support, occupational therapy or assistance by volunteers. Over the course of time the individual care plan will be continuously adapted to meet predominant and current needs of the client. Mobile medical services and telephone counselling are available 24 hours a day.

Services by HPCSTs may also be provided as support service to medical or nursing staff in LTC institutions.

The Austrian Federal Institute of Health has determined criteria for the establishment of HCSTs (ÖBIG 2004). Apart from 24-hour availability for telephone counselling and for acute (medical) interventions, the service provision by a multi-professional team is a basic requirement. Medical and nursing staff, at least one social worker and administrative staff, have to be present in a HPCST. Additionally, physio-, psycho-, speech- and occupational therapists as well as dieticians, spiritual carers from different confessions and volunteer workers have to be available to each team. Most providers of HPCSTs collaborate with teams of hospice volunteers, who have to pass a basic course in palliative care according to the standards of Hospice Austria and engage mainly in home visits and supportive activities. In 2011, more than 3,200 volunteers – 88.5% of them female – cared for approximately 10,000 patients in hospitals, palliative care units, nursing homes and at people’s homes across Austria (Source: Data Survey 2011, Hospice Austria). These volunteers work in teams and are co-ordinated by a part-time professional. Volunteers are experts in the art of...
being present and are someone to talk to.

Recommendations for the quality for all services of the graded hospice and palliative care have been developed covering quality of structure and quality of processes. A manual for all services with the key-processes (start of care, care, end of care) has been published in November 2012. It was developed in a joint effort by Hospice Austria and the Austrian Federal Health Institute (GÖG/ÖBIG).

**Target population**
The main target group of Home Palliative Care Support Teams are people with chronic and terminal illnesses living at home (not in particular frail older people). HPCST services can also be taken up by professionals (family doctors, medical and nursing staff in the LTC sector) in need of support with issues of palliative care and treatment. Services by HPCSTs are also accessible for socially disadvantaged people.

In 2011 the 40 HPCSTs cared for 8142 patients, 54% of which were female. The average age of the female patients was 71.5, the average age of the male patients was 69.9. 80% were oncological patients (Source: Data Survey 2011, Hospice Austria). When reaching out for frail people and inhabitants of nursing homes as a new target group the challenge will be how to finance the bigger HPCSTs needed and how to combine palliative expertise with knowledge in geriatrics. At the moment palliative care is still very much focused on oncology.

**Financial aspects and sustainability strategies**
Home palliative care constitutes a regular and widely accessible service in Austria and is generally free of charge for the client. Services are mainly financed by sponsoring, private donations, and public funding. Funding differs a lot from region to region in Austria and is generally a complicated mix of public funding (incl. contributions from welfare organisations, hospital providers, regional governments etc.) complemented by private donations accounting for between 0 - 30%.

Apart from a basic salary, providers (mainly non-profit organisations) usually pay their staff according to their time on duty (e.g. time spent for a home visit) and not according to specific kinds of interventions performed (e.g. to administer an injection). This has an obviously significant positive influence on the general quality of services. Staff members of HPCSTs can be solely employed by the respective provider or work part time with the HPCST and have an alternative work (e.g. in a hospital or in individual practice).

Annual costs for running a HPCST roughly amount to 250.000 - 300.000 €. (see statistics under 2.2)

**Partners involved**
HPCSTs are usually affiliated to large welfare organisations, such as Caritas, Red Cross, or to hospitals as well as to regional hospice societies and have their own respective management structure.
HPCSTs are composed of a multi-professional group, always consisting of medical doctors, nurses, physio-, psycho-, speech- and occupational therapists as well as dieticians and pastors. In this way a HPCST represents an autonomous, multi-professional entity that integrates different professional groups and services but collaborates and coordinates interventions with the client’s existing formal and informal network.

The informal side includes first of all caring family members, who might be in need of psychological or social support themselves but at the same time represent important partners when setting up and continuously adjusting a care plan for the client. Other partners in the informal network are caring friends and neighbours as well as already existing volunteer services.

The formal network includes partners in the health system – such as family doctors, other attending specialised physicians, hospitals, palliative care units or hospices – and in the care sector – such as home nurses or 24-hour care workers.

Most HPCSTs have – depending on region and affiliation - developed their own professional culture to coordinate their interventions with other professional services and to communicate and exchange all kinds of necessary information. Professional medical and care services provided by HPCSTs are not intended to substitute existing services – e.g. by GPs or home nursing services – but rather to complement these services.

**Strengths and weaknesses**

**Strengths**
- Due to the multi-professional composition, flexibility, and cooperation with other professional sectors, carers and users of HPCSTs have the potential to bridge crucial gaps in LTC systems.
- Patients and their personal preferences are intensely integrated and respected when setting up an individual care and support plan.
- A political commitment for the national implementation and future expansion of services by HPCSTs exists in Austria.
- Additionally, hospice and palliative services have a quite strong representation in their national umbrella organisation Hospiz Österreich.

**Weaknesses**
- Current HPCST services are mainly limited to the group of terminally ill people, although they represent a promising role model of care for frail older people in general.
- In some regions/organisations limited possibilities and resources (staffing, financial resources) exist in relation to the demand of services.
- Palliative Care expertise is still focused on oncology. Geriatric knowledge needs to be integrated.

**Potential improvements**
- Cooperation with the professional and institutional sector of care provision could still be improved.
- HPCSTs provide a role model for mobile and multi-professional care teams for frail older people in general.
Impact assessment and performance evaluation

HPCSTs facilitate the transition process between hospital and home care and seek to coordinate their activities with existing professional and private networks (family doctor and medical specialists, mobile-/24-hours care staff, family members etc). In this way valuable links to family members as well as to health and care professionals already involved in care are usually established. To support a person in their desire to stay at home and/or in a familiar surrounding as long as possible can positively influence clients’ subjective feelings concerning independency, autonomy, and health.

Additionally, having multi-professional support and advice available 24 hours a day is of great relief for a carer. Psychosocial support is usually offered to caring family members by HPCSTs. However, the physical burden and amount of necessary care work at home cannot be reduced significantly by HPCSTs alone.

Costs for the user and in particular for the public health care sector can be assumed to be generally lower compared to care in hospitals or other institutions. A cost analysis and evaluation report from 2008 on Home Palliative Care Support Teams in the city of Graz (region of Styria) shows that in particular hospital related costs for terminally ill patients in the last month of life could be reduced significantly by interventions of HPCSTs. While services by HPCSTs accounted for average costs of € 729 per client in the last month of life, average hospital related costs could be reduced from € 5,855 to € 3,523 for this same period (Joanneum Research, 2008). A recent study from the US widely confirms these results.

Styria is just doing a test run in establishing a geriatric support service for nursing homes consisting of regular visits by a doctor trained in palliative care and geriatrics. The first results show a considerable decline of transfers to hospitals (Source: W. Schippinger et al., Mobiler geriatrischer Konsiliardienst für Pflegeheime. Untersuchung der Effektivität eines internistisch-fachärztlichen Konsiliardienstes zur medizinischen Versorgung von Pflegeheimbewohnern, in: Z Gerontol Geriat 2012, 45:735–741)

Reproducibility and transferability

In general HPCSTs have been established to support and take care of terminally ill people (mostly oncologic patients) in their private environment. However, this type of multi-professional care and treatment also seems to be a very attractive idea for providing palliative care to frail older people, who want to die at home. In this way HPCSTs do not only foster multi-professional cooperation within their specific domain, but might also impact on future LTC concepts for frail older people living at home or in nursing homes.

The concept of HPCSTs can easily be and has been implemented in other countries as well. However and as always, this is depending on political will, financial resources, and organisation of the existing health and social sector.

Future developments and possible implementations

Currently HPCSTs exist in all Austrian provinces in slightly varying prevalence and organisational
forms and further expansion is to be expected. An annual survey monitoring the development and delivery of hospice and palliative care services in Austria according to the guidelines of the plan Abgestufte Hospiz- und Palliativversorgung in Österreich (ÖBIG 2004) is undertaken by Hospiz Österreich.

A new assessment of the need of HPCSTs and all other services as defined in Abgestufte Hospiz- und Palliativversorgung in Österreich (ÖBIG 2004) is due in 2013. As a medium and long-term strategy it is planned to extend the services of HPCSTs also to frail people at home and in nursing homes and to children and adolescents with life limiting illnesses and their families. The realisation will mainly be a matter of financial support and combining current palliative care expertise with geriatrics at the one hand and palliative paediatrics on the other.

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Living comfortable in Menterwolde

**Author:** Drs. Tessa Overmars-Marx  
**Affiliation:** Vilans, centre of expertise for Long-term Care

**Abstract**

The number of people who need care but wish to live as independent as possible is increasing. To encourage this independent living for people who need long-term care, the government in the Netherlands developed several financial regulations like the “Woonzorgstimuleringsregeling” in 2000 and the "Beleidsregel zorginfrastructuur" in 2006. Also European grants are used for developing innovations, for example technology services which enable independent living. The project ‘Comfortabel Wonen Menterwolde’ (Living comfortable in Menterwolde) aims to provide enough opportunities for contact and support to vulnerable local citizens. The strength of the project is the cooperation between health and social services which not only focus on care facilities but especially try to find solutions for living independent in a nice way. These solutions are found in several health and social services like activities to meet, a restaurant, day care for people with disabilities, 24 hours care, technology services etc. All these services and facilities are provided in or from the multifunctional (meeting) center ‘De Gilde’ and support people in the apartments of the Gilde and people in the neighbourhood in their own houses.

The building ‘De Gilde’ contains 18 apartments for older people from which 70% have a need for care. There are also 26 studios for people with an intellectual disability. In the meeting centre several organisations provide their services like home care, a playground for children, activities for older people and people with an intellectual disability. But also a restaurant and activities for the citizens in the neighbourhood is available. Examples of these activities are computer courses and cooking. The activities focus especially on social interaction. The health and social services which are provided in ‘De Gilde’ support people who live in the apartments but also vulnerable people in the neighbourhood who live in their own houses.

Several care and welfare organisations cooperate to provide the health and social services. The organisations involved are the housing corporation, welfare organisation, care organisation for older people and two services for people with an intellectual disability. In the meetings endusers are also involved.

Another part of the project are the technology services which are offered in the apartments for older people and people with an intellectual disability.

In Menterwolde there are most people who are self reliant. The project leader (from the health care organisation) initiated different services but especially asks users to be involved in arranging activities.

Supporting empowerment of vulnerable local citizens is another purpose of the project. People who are in need of care become more independent, empowered and integrated into the
The project is funded through different financial European and national regulations. With the help of these regulations the building can be financed. To get the costs of the services covered, organisations cooperate efficiently (eg night shifts) and a lot of volunteers are involved.

The last two years a transition is initiated with the main goal to support the empowerment of citizens and to crystallize the cooperation between the organisations for care, welfare and housing. The basic principle is that people who are or become dependent of care can stay comfortable in their own home, even in the countryside.

<table>
<thead>
<tr>
<th>Leader organisation(s)</th>
<th>Gemeente Menterwolde – Municipality of Menterwolde (local government)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Zorggroep Meander - care organisation Meander</td>
</tr>
<tr>
<td></td>
<td>De Zijlen – care organisation for people with intellectual disabilities</td>
</tr>
<tr>
<td></td>
<td>NOVO - care organisation for people with intellectual disabilities</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Other organisations</th>
<th>Welzijn Menterwolde – welfare organisation Menterwolde</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Stichting Groninger huis – housing corporation</td>
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<table>
<thead>
<tr>
<th>Contact details</th>
<th>Tessa Overmars-Marx</th>
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<tr>
<td></td>
<td><a href="mailto:T.Overmars-Marx@vilans.nl">T.Overmars-Marx@vilans.nl</a> / <a href="mailto:tessamarx@hotmail.com">tessamarx@hotmail.com</a></td>
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<th>Website</th>
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| Date of data collection | November 2011 and January 2013                                      |
BACKGROUND

The socio-demographic context in Menterwolde, region Oost-Groningen, the Netherlands

In the municipality of Menterwolde live 12,385 inhabitants (2011). Nearly 15% is older than 65 years. Menterwolde is part of the region Oost-Groningen in the Netherlands. In Oost-Groningen 42 percent of the inhabitants has a lower education compared with the average of 31 percent in the Netherlands, this is a high percentage. The average income is also lower in Oost-Groningen compared to the average in the Netherlands. This means people in Oost Groningen are in a less favourable economic position than the average Dutch.

The future of Oost-Groningen also shows a significant change in the demographic composition. This means less inhabitants, more older people and less younger people. The proportion of older people will increase from 19% in 2010 to 29% in 2013. More older people means more demand for senior housing facilities and more need for care. It is important for the region to anticipate on these changes and to provide the needed housing and care.

Zorggroep Meander provides care and services for older people. These health and social services will be provided as much as possible at home or nearby in the neighbourhood. About 3,750 clients receive care and support from Zorggroep Meander.

NOVO and De Zijlen are two care organisations which provide care and support for people with an intellectual disability. NOVO organises customized care from care units in neighbourhoods, close to the clients. They are connected to the network of the client and cooperate with local institutions and volunteers. NOVO provides care and support in different types of housing depending on the need and the level independence of the client. Empowerment of the people with an intellectual disability is a central concept in their vision and mission. Also care organisation De Zijlen provides care and support in the neighbourhoods of Menterwolde. Being part of the (local) community and being able to participate are key principles in the care and support they provide.

The legislative framework in the Netherlands, region Groningen and Menterwolde

Long term care in the Netherlands includes nursing and care for older people, people with disabilities and people with mental health problems. In 2010 there were approximately 600,000 people in the Netherlands who rely on long-term care. These are people who are vulnerable and have limitations who hinder their daily living. They get care and support at home (380,000) or in an institution (220,000) who is funded by the AWBZ, but often also from the Health Insurance Act, the SSA (municipality) and the Youth Care Act (province).

The Netherlands, as well as other countries, faces the challenge of providing high quality health and long-term care services to an ageing population in a cost-efficient manner. The main challenges are to complete the transition to regulated competition in health care provision, to strengthen the role of health insurers as purchasing agents and to secure cost containment in an increasingly demand-driven health care sector. Home care should be further encouraged at the expense of institutional care, while screening and targeting should be improved. (OECD, 2012)

The future shows major changes in the long term care for clients, health care workers, care organisations and local and governmental policies. These changes are necessary to anticipate on...
the future cuts, staff shortages and the ageing population. Policies focus on the empowerment and freedom of choice for citizens. Also the role of their own social network becomes more important and professionals are expected to cooperate with this social network and with other professionals. Care organisation provide their care and support in neighbourhoods so people can stay in their own homes. Despite the goal of policies, it is also the wish of people to stay independently as long as possible in their own familiar neighbourhood.

The municipality of Menterwolde initiated (together with the other organisations) this project. But the current cuts on a local level are threat for the sustainability of the project, especially when it comes to the welfare part. The welfare organisation is cut so deeply that there is no longer budget to participate any longer in the project. The current situation shows only the participation of the care organisation. They try to maintain the care and support which is needed by their clients but it is difficult to maintain the welfare support when the welfare organisation and municipality have drawn back their involvement.

**INITIATIVE**

**Rationale**

With the help of different financing regulations many good initiatives started in the local community, where health and social services are brought together. The example of Menterwolde was started in 2003 when a location of one of the organisations became vacant. Citizens and organisations wanted a new destination for this location. The first project phase was focussed on the ‘hardware’: financing the location and dividing the different rooms. The project was funded through European and national regulations. Different healthcare and welfare organisations were involved and also the housing corporation. In 2008 a project leader was assigned for organising the care and welfare services. The project leader brought the organisations together at the practical level and they started making plans.

Living comfortable in Menterwolde was implemented to meet the wishes of people with care needs to stay in their own neighbourhood as long as possible and another goal of the project was for people with a disability to participate in the community, for example in voluntary work. The tenants of the apartments of ‘De Gilde’ became an active community and feel ownership. Clients of the de Zijlen have expanded their social network and became part of the neighbourhood and the clients of NOVO experience that things began to happen. This was realized because of the users, visitors and need for catering.

Also the cooperation between the different organisations was a valuable experience, an important result were the short lines of communication between the organisations.

The housing corporation hoped for a good working facility in the field of home technology, that has not happened. Also the ratio of 70/30 for clients with a need for care and without a need for care who live in the apartments of De Gilde is not realized. It seems that older people are moving to De Gilde preventively.
Specificities and innovation
Since 2009 health and social services are provided at the multi functional (meeting) center ‘De Gilde’. These services are open for all citizens at the municipality of Menterwolde. Different partners in health and welfare offer these services. The strength of the initiative is the cooperation between the different partners. This good cooperation makes De Gilde the central meeting place for residents and neighbours who are welcome to ask all their questions about housing, welfare and care and who can participation numerous activities. This cooperation leads to innovation at the intersection of housing, welfare and care.
De Gilde is visited by clients of the participating organisations and also by local citizens. Also volunteers and informal carers become more important. De Gilde is part of the neighbourhood and important for the future plans of different neighbourhoods because of the neighbourhood function.

Service model and integration patterns

| Level of organisational integration of care | Linkage: users are appropriately cared for within systems that serve the whole population (not for specific target groups), e.g. older people are cared for by services addressing all people with long-term care needs (and not by special services for older people only). |  
| | Coordination: explicit structures and individual managers are installed to coordinate benefits and care across different providers; structures are still separate, e.g. sharing clinical information in a planned manner, managing transitions between settings, assigning primary responsibility for coordinating care | X |
| | Networking: different care providers establish detailed protocols and intervention models, as part of a joint programme |  
| | Full integration: creation of new structures or units dedicated to the specific user needs where resources from multiple providers/systems are pooled, e.g. organisation of multidisciplinary teams managing all care, control or direct provision in all care settings |  

**Linkage:** all citizens of Menterwolde are welcome at De Gilde. Questions in the area of housing, welfare and care will be anwered and different health and social services are offered: something for everyone! Examples of these services are day and night care, a playground for children, activities for older people and people with an intellectual disability. But also a restaurant and activities for the citizens in the neighbourhood are organised, like bridge, computer courses and cooking. The activities focus especially on social interaction.

**Coordination:** different healthcare and welfare organisations are involved and also the housing corporation. In 2008 a project leader was assigned for organising the care and welfare services. The project leader brought the organisations together at the practical level and they started making plans.

**Networking/full integration:** The project phase is ended. This means the coming period will be the
period of sustainability and pursue with the cooperation in the neighbourhood, close to the citizens. The structure will be less intense. There will be meeting on the level of the administrative platform, the project group and the integral user consultation.

**Target population**

The project Living comfortable in Menterwolde focuses on two target groups:

- Vulnerable older people who live independently. The involved project partners provide health and social services which anticipates on the question what do older people need to stay in their own home as long as possible and also to enjoy this independent living.
- People with intellectual disabilities who live in regular neighbourhoods. For the people with intellectual disabilities the focus is more on participating and feeling at home in their own neighbourhood. Through different initiatives people with intellectual disabilities become part of their local community.

The main benefits of the project ‘Comfortabel Wonen Menterwolde’ is that older people and people with disabilities who have a need for care can stay independent in their own neighbourhood in a meaningful way. Empowerment of vulnerable people is an important part of the project. The other benefit is the integration of people with disabilities in their community. People experience care close to their homes, they have opportunities to meet each other. Also feelings of safety play an important role. When someone is in need of care, the carer is able to respond at short notice because the care organisation is nearby.

**Financial aspects and sustainability strategies**

The project is funded through different financial European and national regulations. With the help of these regulations the building can be financed. To get the costs of the services covered, organisations cooperate efficiently (eg night shifts) and a lot of volunteers are involved.

Because the municipality of Menterwolde is no longer involved and the welfare organisation has no budget, only the care organisation are still able to participate. These organisation have seen the effects of the intervention over the last years and are very willing to maintain the health and social services which are provided at De Gilde but there are no longer project funding’s which can fund for example a project leader.

**Partners involved**

- Gemeente Menterwolde – Municipality of Menterwolde (local government):
- Zorggroep Meander - care organisation Zorggroep Meander: provides care at home (for older people) and has an office at ‘De Gilde’
- De Zijlen – care organisation for people with intellectual disabilities: rents 26 apartments for people with an intellectual disability at ‘De Gilde’.
- NOVO - care organisation for people with intellectual disabilities: provides support for people with an intellectual disability through daytime activities at ‘De Gilde’.
- Welzijn Menterwolde – welfare organisation Menterwolde: provides services for the
municipality of Menterwolde and has an office at ‘De Gilde’.

- Stichting Groninger huis – housing corporation: rents the apartments at ‘De Gilde’.

**Strengths and weaknesses**

- The strengths of this project are especially focused on the cooperation between the different organisations. In the beginning, the project leader had to invest a considerable amount in this cooperation but it created, good communication and a lot of enthusiasm.

- Another strength of the project is the support within all the cooperating organisations. On every level in the organisation there was a lot of enthusiasm for the project and so every organisation involved was willing to invest time and energy.

- The project leader divided different portfolios (like technology or welfare services) to the organisations so they became portfolio managers, responsible for their portfolios. This was a strength of the project. Organisations became more involved and felt obliged to make their portfolio a success.

- The weaknesses and threats of the project were also evident within the cooperation between the different organisations. When organisations have internal challenges there is limited time and energy to invest in the project. Another threat for the project is a lot of staff movements. The involvement of staff is crucial.

- Political interests are also a threat. After four years the political climate may change which means different interests and investments from the local authorities.

**Impact assessment and performance evaluation**

There are several project effects:

- People in need of care can stay independently in their own neighbourhood for longer because of the apartments and services. Without these facilities they would have to move to another village.

- People with disabilities are able to participate in activities or as a volunteer. Participation gives them self esteem and they integrate in their own neighbourhood.

- There is also a positive effect for the neighbourhood. A lot of services are provided nearby which has a positive dynamic; people feel more involved in their neigbourhood which improves social cohesion. For example the Christmas market is visited by 500 people from the area. This development can be a a tool to prevent decreasing rural populations; citizens see more reason to stay in Menterwolde.

- Research has shown that the quality of life from the older people in the apartments improved significantly. The services and activities also prevent people from becoming isolated.

- Professional carers feel the additional value of cooperating with different organisations. They are trained in this cooperation as a T-shaped professional: the vertical bar on the T represents the depth of related skills as expertise in his/her own field, whereas the horizontal bar is the ability to cooperate across disciplines with experts in other areas, and to apply knowledge in areas of expertise other than the own.

- The integration of health and social services has a positive effect on the way professionals
reflect on their work

Reproducibility and transferability
In the Netherlands more initiatives are developed in cooperation between housing, welfare and care organisations. These initiatives are necessary to anticipate on the future care and welfare questions. People wish to stay longer independently and staff shortages are becoming a future problem.
The experiences of the initiative at Menterwolde is shared in different Dutch meetings and is also described. The project is not yet reproduced. The strength of this project is that it brings together two target groups. This results in more possibilities for clients and also increases efficiency.

Future developments and possible implementations
The future is still unclear, without the involvement of the municipality and the welfare organisation. The success of the project depends on the participation of the different organisations and the enthusiasm of the involved persons. The care organisations are still very willing to maintain. Hopefully De Gilde can stay an important meeting point in Menterwolde also for the future.

References
http://www.degildementerwolde.nl/home
3.3 Eastern Care Regime

Emergency Alarm

Author: Zsuzsa Szeman
Affiliation: Institute for Sociology

Abstract
In 1994 the Emergency Alarm Service was a device resembling a wristwatch used by the elderly to summon help in case of a crisis, especially in case of falls at home. The device sends signals to the 24-hour control centre of a care centre. The significance of the system is that it linked a technological element to care. After continuous development of the model and its successful integration into different conditions the system was incorporated into the Hungarian social eldercare. Persons covered by the system receive some form of social care provided within the frame of home care as a mandatory local government service. The technical solution made it possible for elderly persons to continue living at home with a high degree of safety and so replaces the more costly institutional care (nursing home, hospitals) or postpones the time of admission to such care and the knowledge they are able to remain at home in safety improves the quality of life of the elderly person. The estimation and calculation of the Methodological Centre of the Hungarian Maltese Charity Service found that the Emergency Alarm largely replaced admission to a residential home or hospital, or shortened the period of rehabilitation there. The calculation based on the comparison of the per capita normative for home care and for residential institutions showed that if an elderly person was able to continue living at home for only one year longer on average, the cost of the ICT-based service is returned to the state at least seven-fold.

Although the elderly are the main target group for the device, the linking of home care and the emergency alarm system element also has a positive effect on family carers. Because home care can be provided for only a maximum of 4 hours a day, in many cases family carers also have to be involved in care of the elderly. Based on a representative survey (2011) among family carers it was found that it eased or eliminated the physical or mental burden of care for them (e.g. they no longer suffered constant anxiety). Reconciliation of work and care was also resolved for many family carers because the alarm system meant that the centre took over the responsibility of taking prompt action. All these factors improve the health of family carers, eliminate stress, somatic problems of caused by caring for older people disappear, fewer family carers need medication.

The system is technically easily transferable and can be adapted to the regulatory structure of any given country, enabling it to be integrated into the eldercare system; it prevents the social exclusion of frail elderly persons as well as of the family members caring for them.
**BACKGROUND**

The socio-demographic context in Hungary

The emergency alarm system that was elaborated by the researcher of the Institute of Sociology of the Hungarian Academy of Sciences was set up as an innovative 1 year model program by the Budapest Centre of the Hungarian Maltese Charity Service in 1993. It included 30 persons all receiving home care and was carried out by the home care service of the Budapest Centre on the basis of a contract with the local government. The original target group, as the Maltese focused on the groups at social risk, was older people at social (low income) and health risk (need of care). For a long while the innovation started as model program, it was the only technical device used in eldercare. The model programme originally planned with the involvement of the public sphere was to have been launched in one of the most aged districts of Budapest. Despite the availability of foreign funding (COST financing), the programme regarded as good by the home carers foundered on the rigidity of the public sector actor, the local government. The researcher who designed the programme then contacted the Maltese Service known to be open to innovation with an experimental programme that aimed to solve a care problem considered to be insuperable under Hungarian conditions of the early 1990s: combining technology and formal home care for the first time (alarm signals sent from a device worn by the elderly were received in a 24-hour control centre). Because of the poor health status of persons over 60 in Hungary also younger older persons were included in the programme. Besides formal care, many of them needed additional help from family members. In 1994 the public sphere still showed no interest in the positive results of the model programme and would not provide funds for development or adaptation to other regions. The positive feedback eventually helped to persuade the macro level and in the late nineties funding obtained through a successful tender made it possible to extend the system and the organisation was authorised to lead a methodological centre. The organisation’s basic aim was to incorporate the emergency alarm system into the system of home care that was mandatory for all local governments from 1993. On the basis of the principle of equal opportunities that the organisation regarded as a fundamental consideration, it focused on the disadvantaged regions of Eastern Hungary. The Methodological Centre developed a uniform system that made possible the training and continuous monitoring of home carers. The emergency alarm system was continuously developed and adapted to the given conditions, always keeping in sight the principle of equal opportunities. It developed a technology that did not require connection to the electricity grid so that the system could be extended to elderly persons with low income living on isolated
farms without electricity. By the year 2000 the alarm system was operating in all counties. In 2004 it was incorporated into the care system through an amendment to the Social Welfare Act (that first came into force in 1993). The incorporation of the alarm system into the care system can be regarded as an important step in view of the ageing trend of the Hungarian population. Persons over 60 represented 20.1% of the population in 2000, 21% in 2004, 21.8% in 2008, and this figure is expected to reach 34.6% by 2050. At the same time, together with the steady increase in life expectancy, healthy life expectancy at birth was low: 62 years for men and 67 for women (WHO 2003). As a result younger age groups of the elderly also appeared in care, also influencing the age limit for entitlement in the case of the emergency alarm system.

The legislative framework
The Social Welfare Act of 1993 made it possible to involve nonprofits (NGO associations) and the market sector in the provision of social services besides the public sector. It basically divided eldercare activities into two types, basic services: home help, social meals, and specialised services: clubs for pensioners (day care), residential institutions providing nursing and care. The basic services were listed among the mandatory tasks of local governments for which they received a normative support, but local governments were also allowed to contract out these tasks to non-profit organisations or market actors. (The village caretaker service also became entitled to the normative. From January 2007 it was made compulsory to provide care centres for persons in need in settlements or micro-regions grouped together with a population exceeding 10,000.)

This regulation made it possible for one of the districts of Budapest to contract out to the Budapest Centre of the Hungarian Maltese Charity Service, to which the Maltese Service added in 1994 the alarm system it operated in its centre. The continuous development of the model and its successful integration into the district’s home care encouraged the macro sphere, the ministry to announce a tender by invitation, making it possible to involve regions. On the basis of the positive results there, an important regulatory measure by the macro sphere was to authorise the organisation to set up a methodological centre (2001). The national coverage achieved as a result encouraged the macro actor to introduce new regulation: in 2004 the alarm system was included in the Social Welfare Act as a supplementary service to home care. Entitlement to the service was granted to the following persons in need because of their health status and social situation: a.) persons over 65 living alone, b) two-person households over 65 years, c.) persons living alone with serious disability or mental illness. (Under a separate regulation, evidence had to be provided of the need in case of serious disability, mental illness and health status.) Because of the worse financial situation of the elderly among the oldest age group, the fee charged has been set at a maximum of 2% of the regular monthly income. The local government can set a lower rate within its own competence, or can entirely exempt the socially needy from payment at the discretion of the head of the care centre and taking into account all the circumstances. In this way most of the elderly received this service free of charge or for a very small sum.

The normative received by the local governments also made it possible for them to contract out the service to market. Large numbers of small and large market firms appeared in the public sector to provide the service; the more units they operated, the more profit they were able to make. In
some areas, especially micro regions, this led to abuses. This was the justification the public sphere gave when it abolished the normative payment in 2009 (Government regulation No. 191/2008. (VII. 30.) Kormányrendelet), transforming it into a source from which funding could be provided for old and new operators on the basis of applications. As a result, even those who had been operating the system for years did not automatically receive the required funding. The previous sum of 3,448,276 EUR (1 billion HUF) was available in the following year too, but providers had to apply for it. Subsequently the sum was reduced. At the same time, various professional requirements were set for applicants who also had to maintain an annual average of at least 40 units. The normative system resulted in the steady increase in the number of units. Because of the growing number of persons over 65 and their proportion within the population (15.1% in 2001, 16.1% in 2008) and their poor health status there was a steady increase in the demand for the alarm units. In 2010 close to 30,000 units were operated in the country but the change made in the funding and the deterioration in the financial situation of the local governments obliged many of them to raise the fee or end the free provision.

**INITIATIVE**

**Rationale**

In 1993 there were many gaps in Hungarian eldercare. Although under the Social Welfare Act it was mandatory for local governments to provide home help, the system contained many gaps. Only 4% of persons over 60 received home care but the demand was many times greater. Home help was maximised at 4 hours per day, and although it was compulsory for local governments to provide the basic services there was no home help in the smaller settlements (the normative was not sufficient to cover the cost), there were no provisions for care at the weekend or in response to crisis situations. There were many falls, especially among those over 75, resulting in several thousand cases of hip fracture a year. In the absence of an alarm system some of the elderly who suffered accidents were found (by chance by their child, neighbour or home carer) only after a long delay. The delayed hospitalisation imposed an additional burden on the family and the health and social systems. It aggravated the elderly person’s health problem and in many cases led to death. Those who recovered lost their relative independence and became dependent. They needed greater daily care and supervision that the home care service was unable to provide. The solution would have been a residential or nursing home but applicants typically had to wait several years for a place. In 1992 slightly less than 3% of persons over 60 received care in a residential institution. As a result such elderly people lacked security and had no way to seek help in an emergency, a situation that caused constant stress for the family carer or family member (in the majority of cases a family carer was needed to supplement the formal care). This was especially the case in certain types of homes such as family houses with gardens where mobility outdoors was very dangerous in winter (e.g. if the outdoor toilet could only be reached by negotiating steps). The many long hospital stays for treatment imposed a substantial financial burden on the health system. In addition to the gaps in the care structure there was a gap in the infrastructure inconceivable in Western countries. Moreover, many old people living alone did not have the possibility of phoning. Hungary was characterised by backwardness of the ICT network in the early
nineties; because of the ideological control, a home telephone was an exceptional privilege during the socialist period (the absence of a telephone, like that of a copier or fax made control easier). There was a need to introduce the emergency alarm solutions already widespread in the Western countries but it was not technically possible to apply this solution because it was linked to the telephone. The 1 year model programme was basically launched to solve these problems. The author of the study (senior researcher of the Institute of Sociology of the Hungarian Academy of Sciences) received funding within the frame of the COST programme for a model programme linking technology and care that she had elaborated. Because the public sphere was not prepared to implement it she sought a new actor in the non-profit sphere and the programme was launched together with the Hungarian Maltese Charity Service, an innovative actor open to anything new. This organisation linked the alarm system to the home care service that it operated on the basis of a contract with the local government and developed a technical solution to overcome the infrastructure problems (an alarm system based on radio waves).

**Specificities and innovation**

The model programme was launched in 1993 in the 3rd district of Budapest and ran for one year. The Maltese Service then used its own funds to involve more elderly people among those it was providing care for. During the 90s they worked on the continuous of the model. The organisation then targeted the disadvantaged counties in the east of Hungary. From 2001 it was appointed to act as a national methodological centre for the “Preventing through play” and the “Home care with emergency alarm system” model experimental programmes. After the system was included in the Social Welfare Act in 2004 the ministry appointed the organisation to carry out national methodological tasks for a further 5 years from 1st January 2006 in the “Home help with emergency alarm system” service. These tasks basically comprised the following: professional consulting on the alarm system for social service providers; assistance in the applications for permits; expert opinion on professional programmes; passing on technical difficulties that arose to the technical service provider; producing an electronic newsletter for the centres, liaising between the service providers and the ministry; developing the service; cooperation with other professional organisations; training; producing publications and workshop studies. To achieve all this the organisation held national conferences with large numbers of participants and workshop discussions (in 2002 in the disadvantaged region in the east of Hungary; in 2005 in Western Hungary) including both practical matters and research reports (authorisation procedures, the question of micro-regional groups, presentations on technical service providers, the role of the emergency alarm system in home help and its effectiveness, its impact on other services, research findings). The experiences were evaluated together with the participants.

At the request of the Ministry of Welfare and Family Affairs in 2002 the organisation began to develop a new programme for emergency alarm system with home care and within the frame of the already operating systems they monitored successful applicants in a total of 27 institutions (monitoring protocols, interviews with the heads and carers of the institutions and with the recipients of care, evaluation of the institutions’ basic statistics: type of model used, material and personnel conditions for the work, criteria for the selection of recipients of care, satisfaction of
recipients). They launched a three-year social development plan for a micro-regional group in Eastern Hungary (Upper Tisza Region Multi-purpose Micro-regional Group) in 2006 within the frame of the programmes for the catching up of micro-regions, with funding from the ministry and counties. Analyses of the situation and proposals for development in the area of basic services for the elderly formed an important part of the development plan.

For the number of users per year, accessibility, e.g. universal, means-tested, etc. see other sections.

Service model and integration patterns

<table>
<thead>
<tr>
<th>Level of organisational integration of care</th>
<th>Linkage: users are appropriately cared for within systems that serve the whole population (not for specific target groups), e.g. older people are cared for by services addressing all people with long-term care needs (and not by special services for older people only).</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>Coordination: explicit structures and individual managers are installed to coordinate benefits and care across different providers; structures are still separate, e.g. sharing clinical information in a planned manner, managing transitions between settings, assigning primary responsibility for coordinating care</td>
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<tr>
<td></td>
<td>Networking: different care providers establish detailed protocols and intervention models, as part of a joint programme</td>
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<tr>
<td></td>
<td>Full integration: creation of new structures or units dedicated to the specific user needs where resources from multiple providers/systems are pooled, e.g. organisation of multidisciplinary teams managing all care, control or direct provision in all care settings</td>
</tr>
</tbody>
</table>

The emergency alarm system was integrated into basic social services as a supplement. The home nursing financed by health insurance and present in eldercare is available for only 14 days. With its full integration the emergency alarm system also included appropriate quality assurance in the form of control by the methodological centre. An interesting pattern can be observed in the emergency alarm system introduced by the Maltese Charity Service. A model programme elaborated by an NGO reshaped the public care system, filled a gap in care, linked technology and human resources, targeted disadvantaged groups, it changed the quality of life of the primary target group (elderly people) and as a secondary effect also eased the care burden of family carers. This shows that a well-elaborated innovation focused on the right target group can have an impact in multiple directions.

Care tasks within the social home care system are carried out exclusively by social carers. However, there is an example of their link to health care. Since 1992 the Hungarian Maltese Charity Service has operated a two-year training course combining social and health care knowledge giving a qualification as nursing assistant. Graduates can work in home care and are also qualified to perform certain basic health tasks (e.g. giving injections).

The health care qualification also appears elsewhere. The persons on night duty in the centre receiving the emergency alarm calls are often retired nurses who are paid a token fee as volunteers. The small sum they receive is not subject to taxation but nevertheless is a welcome
income supplement for the pensioners. Token fee volunteers are also present in small numbers in the public sphere. Provided that there is no change in the regulation in this area, this kind of volunteering helps to ensure the sustainability of the system. The Hungarian Maltese Charity Service also makes regular use of volunteers to care for its own recipients of care, generally for mental care and conversation. This is of importance because it can prevent institutionalisation, especially in the case of health problems arising from depression.

If the alarm system and care are operated on a purely market basis, the service can be purely technical or it can be of a social and health nature, or a combination of the two, but because of the market prices only a narrow stratum can afford such services.

**Target population**

The target group is older people at social and health risk. Because of the change in the regulations (service no longer provided free of charge or for a very low fee), many elderly persons cancelled the service although they still needed it, and the number of persons covered by the system in the country fell from the earlier 30,000 to around 20,000, but this figure then began to rise slightly with the appearance of new elderly recipients of home care. The change in the regulations also affected the market actors. Many of the small firms were forced to withdraw as they were unable to sell the service at market prices because of the characteristics of the target group (persons in poor social circumstances). The bigger, stronger market actors relying on several pillars have been able to remain in the public eldercare sphere. Growth gave way to decline in 2010 then to renewed growth. In 2012 approx. 1.4% of the population over 65 years old (over 20,000 persons) received home care with emergency alarm system.

**Financial aspects and sustainability strategies**

Normative financing in 2008 and in 2009 amounted to 3,448,276 EUR (1 billion HUF), in 2010 it was 3,214,286 (900.000.000 HUF), then somewhat less in the following years. Priority was given to the following applicants for funding: who wish to cover an area where there are no services; who meet a real demand; who provide the service primarily for socially needy elderly persons, persons with disabilities, persons receiving psychiatric care; provide the service in at least 20% of cases to persons with a certified care need who request care for more than 2 hours a day or who are waiting for a place in a home for the aged; who have signed a cooperation agreement with the local authority in the place where they are based, have premises that are open, or where the professional centre is located. There is a co-payment by users, the fee was set at a maximum of 2% of the regular monthly income, but many local governments covered the fee themselves in view of the poor financial situation of the oldest of the older age group. The reduction in local government funds has been a big factor in the decline in the number of operating alarm units (as they are no longer able to cover the difference).

**Partners involved**

Role of researcher: Elaboration of the idea, ensuring found for the model programme through research fund, joint work with the Budapest Centre of the Ungarian Maltese Charity Service.
Role of the Hungarian Maltese Charity Service: carrying out the model, for a long time ensuring technical development, their adaptation, new experimental, innovative models, co-operation with local governments and macro level (ministry), impact on care policy, the full integration of a new service in the eldercare system, altering the legislation, developing methodological means to control, evaluate and train of home carers, evaluation of proposals, elaboration impact assessment means.

**Strengths and weaknesses**

**Strengths:**
Technology easy to use,
Linked to social eldercare,
Creates equal opportunities by targeting group at health and social risk,
Incorporated into care system and regulated by law,
Improves the security, quality of life of the target group,
Indirectly improves the quality of life of family members.

**Weaknesses:**
The partial financing of the market segment is a danger – erosion of the financing leads (can lead) to withdrawal of the market actor.
The constantly changing regulations slow down or prevent development.
With the partial withdrawal of the state some of the target group falls out of the system. The efficiency of the system can quite clearly be reduced by the restriction of available funding and by the fact that, due to lack of development funds, the service providers are unable to keep pace with the steadily improving technical background.
Another problem is that because all areas are not covered and capacity is limited, not all those in need have access to the service.

This negative trend could be reversed with a return to the original normative-based structure of eldercare, setting an even lower payment fee for the elderly; persuading them of the importance of the emergency alarm system in their own interest.

**Impact assessment and performance evaluation**
The Methodological Centre of the Hungarian Maltese Charity Service has conducted several impact assessment research projects as well as representative surveys in 2006 and 2010 among the service providers, examining among others the regional distribution, data on users of the service, the nature of the service providers, the forms of employment, whether carers are volunteers or professionals, the technical background, the method of communication, how carers reach the site, the reasons for calls for assistance, their characteristics, the crisis situations, the personnel conditions of the service, the reasons for leaving the service. In 2011 the service providers supplied data on elderly family members. The results of this representative survey showed the positive impact of the Emergency Alarm System on the families. (In 45% of cases at least one family member mentioned that it eased their burdens: the decrease or disappearance of stress, or/and
somatic health problems, reconciliation of care and work and/or more leisure time). It is considering an impact assessment follow-up among service-providers in the near future (2013-2014). The known major impact is the full integration in the eldercare system with a positive impact on the quality of life of older people, their family carers, as well as the cost saving for the health and social systems.

**Reproducibility and transferability**

Already in the nineties interest in the system was shown by East European countries with less developed infrastructure and the system was introduced in the mid-nineties in a district of St Petersburg. The continuous technical development is resulting in solutions giving ever greater security making it possible for elderly persons to continue living at home and also provides protection against violence.

**Future developments and possible implementations**

A future development depends on decisions made in policy on the elderly, and on the available state funding. Although the system gives priority to new applicants in areas not covered by the service and this represents development, the restriction of available funding and the operation of the system of applications are slowing down development. Another problem is that service providers entering the system earlier cannot count on receiving the necessary funding through the application system. This situation could, however, be reversed with a return to the original normative-based structure of eldercare, setting an even lower payment fee for the elderly and persuading them of the importance of the emergency alarm system in their own interest.

**References**


Skype in Elder Care

Author: Zsuzsa Szeman
Affiliation: Institute for Sociology

Abstract
The hypothesis of a one-year action research (2011) was that if use of Skype and internet were to be incorporated into the life of digitally illiterate lonely very old persons requiring long-term care, their activity and customs would change and their daily time schedule would be different and at the same time this would have a positive indirect impact on families, family carers decreasing their stress and caring tasks. The innovation model proved the hypothesis. Older people could be involved in the pilot program as they had a very strong motivation to see and talk to family, especially to grandchildren. After their first success they had a strong desire to learn despite illness, and a new goal (worth living). A very strong motivation appeared: keeping contact with family, friends, searching for new contacts by learning to operate Skype. This motivation helped to overcome difficulties (e.g. to switch the computer on and off, overcome the fear of the mouse imagining it would eat their food, or of virus thinking it would cause flu). By the 4th month even the most unskilled acquired new knowledge from internet use. Spending 3-5 hours daily on the internet (chat, email, Google search, Skype, etc.) their depression ended, they gained a new daily activity, new goal in their life and had the desire to learn something new. In some cases medication needed earlier for psychosomatic symptoms, emergency service calls, visits to the general practitioner were reduced and many health problems also disappeared, and the burden on social carers and on families were eased as well. Older people no longer needed mental care, suicide attempts ended (there were two in the sample). They could be reintegrated into society. This positive mental change could be observed by 4th month. Social work students involved found the formerly mentally ill people to be open-minded and cheerful persons; home carers also mentioned a basic change in the mental health. By the end of the program older people had an increasing not a decreasing personal network. The most important measure of the positive outcome of the innovation was shown by the older care recipients themselves. At the end of the program all of them wanted to pay the monthly internet fee they received free of charge for the 1 year period of the model program saying that use of Skype and internet has fundamentally altered their life as they now have a goal, want to live and be a socially integrated member of the society.

However, all these positive outcomes could not have been achieved without including the approach of volunteering with a special feature, that is, the involvement of the volunteer activity of teenagers from a secondary school. Permanent help was ensured by the regular weekly visit made by 16-year-olds. Soon a very close intergenerational relationship was formed. Both the elderly and the young showed empathy to each other. The old persons accepted them as teachers and the young people were happy to teach them. Through their regular presence older people received permanent help and a continuous learning was ensured. By improving intergenerational relations they also helped to end the strong prejudice against older people existing in the society,
in families and among market actors. The volunteering of young people played an important role in social inclusion of the elderly and could be considered therefore as a kind of care resource.

<table>
<thead>
<tr>
<th>Leader organisation(s)</th>
<th>Hungarian Maltese Charity Service, Institute for Sociology, Centre for Social Sciences of the Hungarian Academy of Sciences</th>
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<tr>
<td>Other organisations</td>
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</tr>
<tr>
<td>Contact details</td>
<td>Zsuzsa Szeman, Institute for Sociology, CSS, HAS, 1014 Budapest Országház u. 30. <a href="mailto:szemanzs@hu.inter.net">szemanzs@hu.inter.net</a></td>
</tr>
<tr>
<td>Website</td>
<td>No</td>
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<tr>
<td>Date of data collection</td>
<td>January 2013</td>
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</tbody>
</table>

**BACKGROUND**

**The socio-demographic context in Hungary**

The pilot program was conducted in two settlements the capital (Budapest) and a county seat (Székesfehérvár) in two home care centers where 3% of the older persons above 60 years received this service. A proportion corresponding to national average. To carry the program it was necessary: 1. A sponsor to provide the technology, someone who thought that even the very old receiving LTC can be taught to use Skype. The start of the pilot program was delayed considerably by the prejudice found among market actors approached as potential sponsors (who thought that the very old receiving LTC were incapable of such learning). 2. Open-minded home care centre managers willing to take up the program. 3. Care recipients who met the criteria for the target group (see 2.4) and were prepared to participate in the program. The program was finally launched thanks to the attitude of the Hungarian Maltese Charity Service that was able to accept the idea, is open to anything new and has a record of developing successful, innovative models. It provided the infrastructure (10 PCs, 15 internet connections), and involved its own home care service (in the capital) in the program. A small businessman also contributed to the launching of the program (5 PCs). A care centre in the public sphere also participated in the program.

**The legislative framework**

The Social Welfare Act introduced in 1993 makes home care a mandatory basic service to be provided by local governments. This means a maxim of 4 hours per day of help that can be performed in the social sphere (bathing, helping with lunch, obtaining medicines, accompanying to hospital, etc., as well as mental care, conversation) and if necessary the provision of meals. Care is basically lacking at the weekend although in many places the carers visit the recipients of care then too, out of empathy or for a small payment. Despite the fact that the provision of home help is mandatory, due to financial problems or the widely dispersed homes it is not available in some smaller settlements. National geographical coverage of the service is around 60%. As a proportion of the elderly, for years home help has been extended to around 3% of persons over 60 (home help 2%, home help and meal 1%). One of the shortcomings of the system is that there is little time for
mental care and conversation; it is not able to meet the needs in this direction of frail elderly people or to resolve their loneliness. In 2004 the alarm bell system was incorporated into the system as a form of social care. It is regulated together with home help by laws and regulations: on social services (Act No. III of 1993; Government Regulation No. 191/2008. (VII. 30. Korm. Rendelet); Ministerial Regulation No. 1/2000. (I. 7. SzCsM rendelet); Government Regulation No. 29/1993. II.17. Korm. Rendelet); Ministerial Regulation No. 1999. (XI.24.) SzCsM rendelet); Government Regulation No. 321/2009. XII.29 Korm. Rendelet); detailed rules on the examination and certification of care need, health status and social neediness (Ministerial Regulation No. 36/2007. XII.22. SZMM rendelet). In principle the home nursing available for 14 days within the health care system and funded by health insurance is part of LTC, but it cannot be regarded as a solution because many of the elderly are in need of health care for much longer periods due to chronic diseases. The local doctor and district nurse do not perform tasks specifically for the elderly. Market actors developed various health care or complex social, health care and/or technical solutions in response to fill the gaps in the social and health care system of the public sphere. However it was only elderly persons or their family members in the upper middle class or highest stratum who could afford them. The same was the case for the undeclared migrant carers who came from the regions of Romania or Ukraine (Transylvania; Subcarpathia) inhabited by the Hungarian minority to work as live-in carers providing 24-hour care and so substituting for the care that could be provided in residential/nursing homes. In most cases that was regarded as only the last solution by the elderly themselves and the family members who cared for them alone or with the help of others. The absence or inadequacy of care elements enabling the elderly to continue living at home are forcing them to consider institutional care. Despite this, only 2% of the population over 60 live in institutions; there is often a long waiting list both for private homes (around 2% of the total), and homes run by foundations or churches (around 13%). The changes made in 2012 to regulations governing the public sphere also affect the social sphere, but the directions these changes will take are still taking shape. It is to be feared that the alarm system that greatly improved the quality of life of recipients when it was incorporated into the system, will be excluded from the system. At the same time definite efforts are being made to incorporate technology into care.

**Rationale**

In Hungary the rate of successful suicide per 100,000 persons is: men 60-64 years old: 51.7, women: 14.9; 80-84 years old: men 127.6, women 27.5; over 85 years old: men 160.6, women 28.5.² There are no reliable figures on suicide attempts; the two attempts in the sample (see 2.4) have not appeared in the statistics either. However, presumably carers are aware of such attempts and also know their causes. To provide suitable mental care that is missing in long-term care. The aim of the innovation was to fill this gap, to ease loneliness, depression, isolation and social exclusion by teaching older care recipients how to use Skype to maintain and strengthen family relationships and widen their social network.

The initiative was elaborated by the author of this case study and supported, financed and carried out with the help of the Hungarian Maltese Charity Service.

The steps were the following:

- finding sponsors (see the difficulties mentioned),
- searching for suitable care centres, leaders,
- selection of sample with their help,
- observation of old persons, talk to them before starting installation of computers,
- during installation, observe and talk to older people.
- the 3rd month, choice of 16-year-old volunteers (task: twice weekly visit), a conscious choice – they had no prejudice against other actors,
  - such as families (“I hadn’t thought of that, but if it could be done it would be good.” daughter)
  - 26-30-year-old young man setting up the computers (“I’d like to see what these old people are going to do with these computers: probably put a lace doyley on them, and a vase on that and then look at them.”).
- Involvement of social worker students in the 4th month (with the task of making interviews without knowing the former mental state and personality of the old persons).
- A continuous feedback from every actor to the researcher during the whole period and based on these to make interventions where needed.
- Elaboration of permanent intervention plan by the researcher

Results:

by the 4th month

- all of the participants could use Skype without difficulties.
- depression, loneliness disappeared. No more suicide attempts (e.g. the one who tried it several times found a virtual partner, searched on the internet, visited check box, etc.). Social workers found only positive open-minded older people with intensive family relations, widened social relations. Role of grandchildren is important, they act as teacher (even the very young)
- desire to learn how to use the internet aroused.

by 6th-8th months

- already good internet skill and a strong intergenerational relationship between the young volunteers and the older people.

by 9th-10th months

- the number of volunteers doubled. The reason: they like to teach the old persons, they transfer their up-to-date internet knowledge to the oldest ones. Changed role

by 12th month

- complete ICT knowledge transfer
- old people have the same internet skill as the young
- common interest
- very strong intergenerational relationship without any prejudice between the oldest and the youngest ones (89-90-year-olds and 8-16-year-olds)
- all participants want to use the computer and internet and are ready to pay for it.
**Specificities and innovation**
The initiative as mentioned above ended with very positive result, and filled the gap of providing suitable mental care in the form of conversation, however the highly effective program also raised new questions. How can this positive process be launched for people with disadvantages, even multiple disadvantages? What phase lag must be anticipated for elderly persons of different age, social background, level of schooling, gender, type of settlement and region? Could the attempt be unsuccessful and if so, to what extent and in what cases? What other type of problems could arise and what intervention would be needed to solve them? These questions could only be answered with a new action research building on the results obtained so far. This resulted in a second, more advanced pilot innovative model that started at the end of 2012.

**Service model and integration patterns**
The initiative is in the pilot phase. This point cannot be filled therefore. About the role of volunteers see other sections.

**Target population**
The target group of the innovative model program should include all of the criteria mentioned below:

- chronic physical or cognitive disorders with moderate to serious health problems (such as severe asthma, persons with multiple illnesses – e.g. cardiovascular disorders, and/or
- limited mobility
- lonely and/or depressed (2 of them were serious cases as they had made several suicide attempts)
- receiving home help
- receiving mental and/or physical home care
- restricted network of interpersonal contacts (even if they had family members)
- no experience of computer or internet use (even the most basic)
- family carers with PC and internet connection.
- Sample size: 15 persons of which
  - ~10 in the capital (Budapest, 3rd district),
  - 5 in a county seat (Székesfehérvár in West-Hungary)
  - Average age 80 + years,
  - Majority women
  - Majority white collar

**Financial aspects and sustainability strategies**
A small businessman provided 5 PCs, the Hungarian Maltese Charity Service provided a further 10 PCs as well as mobile internet connections for the 15 persons in the sample for the duration of the 1-year model program. On completion of the program, seeing the positive impact it had had, both small businessman and the Maltese Charity Service donated the PCs to the care centres. Should
one of the elderly persons die or for some reason no longer be able to use the PC it will be returned to the care centre to be redistributed. At the end of the 1-year period the elderly participants undertook to pay the internet subscription (15-21 EUR/month). The Maltese Charity Service is providing 50 PCs and internet or mobile internet connections for 1 year, for the current, second pilot program. In view of its low cost, the initiative is expected to spread rapidly with the involvement of the following actors: reutilisation, redistribution (the use of old computers from institutions, firms, etc.), sponsors, family members (who buy the PC, pay for the internet connection), or the elderly persons themselves cover the cost in full (purchase of PC, internet connection) or in part (internet connection), in the frame of research projects seeking answers to further questions. An essential part of the fund-raising strategy is dissemination at multiple levels: making the good example known through the media, and the internet, presenting papers at conferences, publishing studies, meetings with decision-makers, students, elderly persons, presenting reports for them, involving pensioners’ interest protection organisations, drawing the attention of market and potential market actors to the opportunity to sponsor a possible new target group by offering free internet connections for a certain period in the interest of later profit (the elderly persons will become buyers within 1 year at the most, once the internet has become part of their lives).

**Partners involved**
The project was an initiative of the researcher of this paper at the Institute for Sociology, CSS, HAS. It was elaborated by her. The sample was ensured by the Home Care Centre of the Hungarian Maltese Charity Service in the 3rd district in Budapest (capital) and the Care Centre of Szekesfehervar (a county seat). In both cases the field work was carried out here and there was a continuous interaction between the researcher and the leaders of the care centres and technical staff who reported on the state of the project. These results were carefully analysed and discussed with the leaders. Based on these regular reports, the feedback of volunteers and social work students involved in the project and the carers who reported weekly on any change in the behaviour, mental state and social network of the older people, the researcher elaborated an implementation plan if necessary. This was carried out by different actors, carers, technical staff, etc. The researcher gave feedback to the small businessman and the Maltese organisation about the state of the project. The small businessman declared already at the beginning of the pilot phase that the older people could keep the computer if they found it useful. The same decision was made by the Maltese organisation. At the end of the program the researcher made a final analysis and reported it to the head of the Hungarian Maltese Charity Service; in view of the positive results the organisation was ready to start the new pilot program mentioned already to explore how the initiative can be spread widely in a short time. The regions were chosen together with the Maltese organisation.
**Strengths and weaknesses**

**Strengths**

− Less burden on family carers: time and cost saving (e.g. no travel to check, less stress for family)
− transfer of up-to-date ICT knowledge by younger generation resulting in disappearance of knowledge gap between the younger and oldest generations
− consequence: stronger intergenerational relationship
− possibility of involving younger generations into eldercare
− cost saving for the social and health institutions (illnesses caused by loneliness disappear, less medication, medical treatment)
− new stratum of consumers for market (internet connections, computers)
− greater empathy of younger generations towards problems of older people
− strengthens volunteering
− ensures a “new life” for older people that:
  o Maintains or strengthens family relationship
  o Keeps old relationships alive
  o Widens social network
  o New intragenerational relationship (e.g. among care recipients)
  o New habits (listening to music, reading the paper, shopping etc. online
  o Learning new ICT language (chat, email, surf, etc.)
  o Resuming old habits given up because of illness
  o Learning, interest, new hobbies
    − Useful daily activity (3-5 hours)
    − Social integration
    − Increased well-being,
    − Better quality of life,
  − Easily transferable
  − Less educated people and aged settlements can be involved
  − Redistribution by society (distribution of old, still working computers)

**Weaknesses**

The innovation has no weaknesses, however there are matters which could slow down its spread

− prejudice of families/society (often the old persons who were willing to participate in the program withdrew their permission at the last minute because the family had talked with them or simply not allowed them to participate)
− finding sponsors (partly because of prejudice) to cover internet fee until the old person feels its usefulness (max. 1 year) and until the society, social and health institutions and decision-makers on macro level become aware of its positive effects
− poor ICT/environment infrastructure (e.g. lack of 3G mobile internet)
Impact assessment and performance evaluation

Use of qualitative method during the whole model program (interviews, reports, observations) ended with very positive results, some examples mentioned by different actors:

Heads of the care centres
4th month. Person who did not dare even switch on the computer:
“... she was the timid one, now she keeps in touch with five people on Skype, reads email messages and uses the Google browser like an expert”.

Depressed old man:
“Uncle A. has opened up like a rose.”

2nd month. 89-year-old man with suicide attempt:
“He wanted to commit suicide because he was overwhelmed by loneliness and depression, we found him by chance.” .... “Since then (Skype, computer and internet) his mood is well balanced and good.”

Young volunteers
3rd-6th months.
“Aunt J. can switch on the PC, she can use Skype and search in the Google browser, her control of the mouse is uncertain but she is enthusiastic and uses it.”

“We taught Aunt K. to use the internet. She learnt to switch the PC on and off and to use the mouse, to visit port.hu, create an email account. I have a lot of other plans for her, which is why I would like to continue intensive voluntary work with Aunt K.”

Social work students
4th month. Old person received mental care because of depression.
“Uncle A. seemed to be a well-balanced, confident, communicative, optimistic person with good empathy.” (social work student did not know about mental care, depression)

“That day when my student partner and I visited Uncle A. in the morning, the meeting had a positive influence on our whole day because it was a very good feeling to talk with him; that conversation gave us a lot of energy.”

Older people
-2nd-4th months.
“We are on Skype every day with our grandchildren too, sometimes I practically fall asleep at the PC because they could go on talking forever while I am tired, but I don’t mind.”

“I looked up an old fishing friend, and I found him.”

-at the end of the program.
“......It has opened up the way to acquiring knowledge! The computer has brought great help and constant curiosity into my home. ...I am doing research on my family roots on the internet, tracing all the complicated paths from 1311 right up to the present. I will have something to pass on to my grandchildren. I conduct a lively correspondence with my family members and friends.”

Reproducibility and transferability
With suitable infrastructure, the involvement of young volunteers and a mediator, preliminary training of the persons responsible for the care of the elderly person and the family (if they show prejudice), and persuasion of decision-makers at local and macro levels, and potential sponsors. Reproducibility requires adaptation to the given circumstances, fine-tuning of the methods accordingly and intervention if necessary. Dissemination is essential for transferability. The case histories portraying various life situations that will be available after completion of the second phase planned for 1 year will hopefully be sufficient to shake the prejudices in society in this direction and so make possible the rapid spread of the initiative. International transferability of the initiative can also begin, especially in countries of Eastern and Southern Europe where frail elderly people have a very low level of internet skills. A guide could be drawn up for use by those interested in the initiative, or its methodology could be adapted to local circumstances.

Future developments and possible implementations
A second phase of the innovation financed by the Hungarian Maltese Charity Service is under way to find answers to questions raised in the “Specificities and Innovation” section. In the second phase 50 old persons in 14 settlements in backward regions, in a rural area (North-East, including small, aged settlements) and in an industrial region (North) will be involved. The majority of old people cared for have a low level of education. Based on the outcome of the first phase, a more elaborated method is being used. The innovation has shown the very important role of young volunteers. Therefore already at the beginning (and not only from the the 3rd month) young volunteers from secondary schools have been involved. Secondary schools were asked to provide students for the program. This wish met with their own as from 2012 a new subject was built into their curriculum, teaching students how to volunteer. Classes of 14-15-year-old students were chosen for the model program. Another new element is a mediator (researcher) with “teaching” tasks: to explain to the young people how to act, what to do with a frail old person and at the same time dispel the fear of the elderly. At the beginning of 2013 already 10 computers were installed and the results so far have justified the fine-tuning of the methodology and are having clearly positive effects. In the earlier innovative model learning to use the internet started in most cases only after the involvement of the volunteers. In the second pilot initiative however learning of Skype and the internet goes parallel.
Other regions are interested in introducing the innovation and are in the process of fund raising.
References

Continuum of care for frail older people: from emergency ward to living at home

(in Swedish: Vårdkedja: från akutmottagning till eget boende)

Authors: Synneve Dahlin-Ivanoff, Kajsa Eklund, Katarina Wilhelmson, Anne-Charlotte Larsson, Ann-Marie Predan, Helena Gustafsson, Sten Landahl

Affiliation: Vårdalinstitutet, The Sahlgrenska Academy at University of Gothenburg, Sweden, Department of Medicine, Sahlgrenska University Hospital/Mölndal, Sweden

Abstract

This initiative has been carried out in Mölndal, a municipality situated on the west coast of Sweden, close to the city of Gothenburg. The education- and income level of the population is slightly higher than in Sweden as a whole. The proportion 65 years and older in Mölndal is 15% compared with 18% in Sweden and 80 years and older constitute 4% vs 5%. In Sweden, integration and collaboration between all care providers involved in rehabilitation, health and social care for older people is stated in legislation.

The origin of the creation of the coordinated health care chain for frail older people was the shortcomings in the care of the elderly patients that the Swedish National Board of Health found in a supervision of emergency departments in 2006. As a result, the Sahlgrenska University Hospital/Mölndal started collaboration between the emergency department, and medicine and geriatric wards in order to improve the management of frail older people. The University of Gothenburg, Vårdalinstitutet was contacted for a scientific evaluation of such a project. A Steering group was developed representing the hospital, primary care, municipal home health services and researchers from the University. All agreed on the need to create an integrated chain of care for frail elderly people from the emergency department, through the hospital ward and back to their own homes. This collaboration lead to the development of an integrated intervention. In 2008 the RCT study “Continuum of care for frail older people: from emergency ward to living at home” started. The hypothesis of the project was that an intervention program for frail older people can reduce the number of visits to the emergency department, increase satisfaction with health and social care, and maintain functional ability.

The intervention involves collaboration between a nurse with geriatric competence at the emergency department, the hospital wards and a multi-professional team for care and rehabilitation of the older people in the municipality with a case manager as the hub. The multi-professional team includes professionals in nursing, occupational therapy, physiotherapy and social work. Together they create a continuum of care for the frail older person from the emergency
department, through the hospital ward to their own homes. Information is immediately transferred from emergency department to the wards and the municipality. Discharge planning starts the same day as the older frail person is admitted to the hospital and all planning is coordinated by the case manager. The intervention has a person-centred approach with shared decision-making throughout the care chain.

The goal for the target population is to focus on ageing in place and therefore addresses community-dwelling frail older persons. All persons 75 years of age or older who are screened for frailty within the continuum of care process are target users. So far results from the randomized control study has revealed positive results for the users. The participants in the integrated care program are significantly more satisfied with the care planning and their own possibility of participating in the care planning compared to the control group. Yet unpublished material shows promising effects on the participant’s independence in activities of daily living up to 12 months and indications that the municipality saves money. Today the initiative is included as a permanent activity in the city of Mölndal as well as in the hospital.

<table>
<thead>
<tr>
<th>Leader organisation(s)</th>
<th>University of Gothenburg, Vårdalinstiitutet (the Swedish institute for health sciences), Sahlgrenska University Hospital/Mölndal, Mölndal Stad municipality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other organisations</td>
<td>Primary health care</td>
</tr>
<tr>
<td>Contact details</td>
<td><a href="mailto:Synneve.dahlin-ivanoff@gu.se">Synneve.dahlin-ivanoff@gu.se</a></td>
</tr>
<tr>
<td>Website</td>
<td><a href="http://www.sahlgrenska.se/sv/Ovriga-sidor/TAGE/m">http://www.sahlgrenska.se/sv/Ovriga-sidor/TAGE/m</a> (under development).</td>
</tr>
<tr>
<td>Date of data collection</td>
<td>January 2013</td>
</tr>
</tbody>
</table>

**BACKGROUND**

**The socio-demographic context**

Mölndal is a municipality situated on the west coast of Sweden, close to the city of Gothenburg. It had nearly 61,000 inhabitants at the beginning of 2013. The municipality of Mölndal comprises both urban and rural areas. In Mölndal, you find modern living areas bordering to wide areas of nature and idyllic countryside. Mölndal is an expanding city. A totally new city centre will emerge during the next few years. Older people’s well-being in focus in 2013 is investing for the elderly in the city of Mölndal in a quality program which focuses on protecting older people’s right to live in dignity and well-being. All staff working in elderly care will learn more about the national value system - a set of values which are now included in the Social Services Act.

The education- and income level of the population is slightly higher than in Sweden as a whole with an 11.5 % higher mean income and 8 % higher level with university education compared to Sweden as a whole. The proportion stating their health as poor is, 5% among women and 6% among men vs. 6 and 7 per cent in the rest of Sweden. No information has been found about older persons’ specific health problems in Mölndal compared with Sweden as a whole. The proportion 65 years and older in Mölndal is 15% compared with 18% in Sweden and 80 years
and older constitute 4% vs 5%. The population aged 65-74 years was 5092 persons, the population aged 75-84 was 3055 persons and 85 years and older were 1347 at the beginning of 2011. In 2032 the persons aged 65-74 are expected to increase to approx. 6300, aged 75-84 to 4200 persons and aged 85 years and older to 2010 persons.

When an elderly person in Sweden is no longer able to manage independently, she or he can apply for assistance from the municipal home-help services. The extent of such support is subject to an assessment of needs. The support includes meals on wheels, help with cleaning and shopping, assistance with personal care, safety alarms as well as transportation service. The elderly are also offered health care, provided either by the municipal home-help services or by the home medical care service. In June 2008, 11.6% of those aged 65 or older received some kind of help or care from the municipality.

**The legislative framework**

Integration and collaboration between all care providers involved in rehabilitation, health and social care for older people is stated in both the Social Services Act of 2001 (SFS 2001:453) and the Health and Medical Services Act of 1982 (SFS 1982:763).

Social Services Act 2001:453 Social services in each municipality have the main responsibility for providing care for the elderly. This is their duty under the Social Services Act. Municipalities are entitled to design health and social care services that are adapted to local conditions. This means that the support offered to elderly people may vary. For further information see [http://www.government.se/sb/d/15568/a/182986](http://www.government.se/sb/d/15568/a/182986).

The Health and Medical Services Act of 1982 (SFS 1982:763) regulates the general conditions for health care and the competences of both county councils and municipalities. defines health and medical services as medical measures to prevent, investigate and treat diseases and injuries. This also includes medical transport as well as taking care of diseased. Dental care is regulated in another law. The goal for healthcare is according to the Health and Medical Care Field Act good health and equal conditions for everybody. The Health and Medical Services Act does not mention a duty for the patient but rather an obligation for the health professional to perform the treatment and care in cooperation with the patient as far as possible. They have right to quality care and high quality care entails care in accordance with the prevailing standards as determined by the current state of science. For further information see [http://ec.europa.eu/information_society/activities/health/docs/studies/legal-fw-interop/ehealth-legal-country-profile_sweden.pdf](http://ec.europa.eu/information_society/activities/health/docs/studies/legal-fw-interop/ehealth-legal-country-profile_sweden.pdf)

**Rationale**

The origin of the creation of the coordinated health care chain for frail older people were the shortcomings in the care of the elderly patients that the Swedish National Board of Health found in a supervision of emergency departments in the country 2006. The identified weaknesses included the lack of age as a risk factor, of prioritization, monitoring and surveillance of elderly patients, as well as poor documentation and information. As a result, the Sahlgrenska University
Hospital/Mölndal started collaboration between the emergency department, and medicine and geriatric wards in order to improve the management of frail older people. Contact was taken with Professor Sten Landahl Vårdalinstitutet for a scientific evaluation of such a project. Together with Professor Synneve Dahlin-Ivanoff, University of Gothenburg, a project were also the municipal social services and the primary care also should participate was initiated. The creation of an integrated care chain for frail older involving all the organizations became the result. This resulted in a clinical intervention study combining a randomized controlled trial (RCT) with of the implementation process. As the intervention was complex, both quantitative and qualitative methods were used to capture the multidimensionality of the provision and the different effects of the study. The combination of methods provided a unique opportunity to investigate and analyse what was in the "black box".

A task force was developed (later the Steering group) representing the hospital (emergency department, geriatrics and internal medicine), primary care, municipal home health services and researchers from the University. All agreed on the need to create an integrated chain of care for frail elderly people from the emergency department, through the hospital ward and back to their own homes. Since January 2007, regular meetings with the Steering group (once a month) have been held to discuss joint issues concerning the the intervention "Continuum of Care for Frail Elderly People" To establish the project regular meetings were held with the senior management of the Mölndal’s hospital, Community of Mölndal, the elderly, and leading politicians.

Today the initiative is included in the permanent activities in the city of Mölndal as well as in the hospital.

**Specificities and innovation**

One of the reasons that the RCT study "Continuum of care for frail older people: from emergency ward to living at home" started in October 2008, was the need for further studies on how to create better care both at the emergency ward and municipal/primary health care. The aim was to create a continuum of care from the hospital through to the older person's own home. The hypothesis of the project was that an intervention program for frail older people can reduce the number of visits to the emergency department, increase satisfaction with health and social care, and maintain functional ability. One of the major strengths of the study is that the implementation process is studied and analyzed along with the intervention study. The study included 161 older people who attended the emergency department at Mölndal Hospital during the period October 2008 to June 2010, and were discharged to their own homes in the municipality of Mölndal. The intention was that the study group should comprise a representative sample of frail older people at a high risk of future health care consumption. The evidence that the study has generated has been used to develop a care process program, now in the process of being implemented in full-scale in “Mölndal stad” a population of 61 000 habitants.
Service model and integration patterns

<table>
<thead>
<tr>
<th>Level of organisational integration of care</th>
<th>Linkage: users are appropriately cared for within systems that serve the whole population (not for specific target groups), e.g. older people are cared for by services addressing all people with long-term care needs (and not by special services for older people only).</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>Coordination: explicit structures and individual managers are installed to coordinate benefits and care across different providers; structures are still separate, e.g. sharing clinical information in a planned manner, managing transitions between settings, assigning primary responsibility for coordinating care</td>
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<tr>
<td></td>
<td>Networking: different care providers establish detailed protocols and intervention models, as part of a joint programme</td>
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<tr>
<td></td>
<td>Full integration: creation of new structures or units dedicated to the specific user needs where resources from multiple providers/systems are pooled, e.g. organisation of multidisciplinary teams managing all care, control or direct provision in all care settings</td>
</tr>
</tbody>
</table>

The level of organizational integration of care is coordination. The intervention involves collaboration between a nurse with geriatric competence at the emergency department, the hospital wards and a multi-professional team for care and rehabilitation of the older people in the municipality with a case manager as the hub. Together they create a continuum of care for the elderly person from the emergency department, through the hospital ward to their own homes. The intervention has a person-centred approach with shared decision-making throughout the care chain. The multi-professional team includes professionals in nursing, occupational therapy, physiotherapy and social work.

At the emergency department, a nurse with geriatric competence makes a frailty screening. When the screening indicates > 2 frailty indicators the nurse with geriatric competence also completes a geriatric assessment of the elderly patient need of rehabilitation, nursing, geriatric and social care. Depending on whether they require hospital care or not; the patients then follow one of the two tracks in the continuum of care: 1) When admitted, the screening information is immediately transferred to the ward and to the case manager in the municipality. The case manager is responsible for contacting the ward and the patient in order to prepare the municipality for the discharge in time. Patient care planning takes place within a couple of days of discharge. 2) When the patient goes directly home from the emergency department the screening information is transferred to the case manager and care planning is offered within a couple of days. In both tracks the care planning takes place in the elderly person's home and the multi-professional team is responsible. The care planning is based on both the screening information and a comprehensive geriatric assessment made during care planning. The care planning is followed up within a week by the case manager, and then at least every month. The elderly person is included in the intervention for at least one year.

The case manager contacts the relatives/informal caregivers, if this is approved by the elderly person, to give information/involve them in the planning and to offer them support and advice. This is initiated as soon as possible, often as early as when the elderly person is still in hospital.
Practice guidelines have been developed at the emergency department eg. treating the identified frail older person as a very important (VIP) person. The implementation of the integration of care has made the personnel greatly aware of the above mentioned weaknesses; knowledge of age as a risk factor, prioritization, monitoring and surveillance of elderly patients. The identified frail older person is prioritized, gets surveillance, nutritional drink and a bed with anti decubitus matress.

The IT system has been elaborated and improved to support information transfer between the levels of care. Malmö hospital, the health care in the municipality and social care has different IT systems that at the start of the integration of care made it time-consuming to transfer patient information. The new IT system makes it possible to transfer the information within seconds and is also safer but still there is problem to solve.

**Target population**

The goal for the target population is to focus on ageing in place and therefore addresses community-dwelling frail older persons. Frail older persons are at high risk of developing chronic diseases, multi-morbidity and functional impairments and also at risk of health and social care consumption. All persons 75 years of age or older how are screened for frailty within the continuum of care process are target users. The frailty screening includes five questions concerning endurance, tiredness, falls, needing support shopping and > 3 visits at the emergency department recent 12 months. When the screening indicates > 2 frailty indicators they are screened for frailty and part of the program. In preliminary data we have seen that of person seeking care at the emergency department approx. 20% are 75 years and older and of those 70 % are classified frail. The numbers of persons will probably be higher when it is implemented in real life.

**Financial aspects and sustainability strategies**

The project is mostly fund financed but the idea is that it will become self-running. We have been funded by the Vårdalinstitutet - The Swedish Institute for Health Sciences and Vinnvård. The National Board of Health and Welfare has also been one of the funding sources. We have other funding for the next phase, which is the evaluation of the implementation of the program. However the government provide 3.75 billion SEK over the next four years to fund projects on a regular basis that provide permanent and long-term improvements for older people like our program. This would be an alternative way to become self-running. Then the program is finally implemented and becoming a regular service and part of the regular health and social care it will substitute other programs.
**Partners involved**

The initiative involves the Sahlgrenska University hospital/ Mölndal (emergency department, geriatric, internal medicine and orthopedic wards), the primary care in the region and the municipal home health services of Mölndal. Sahlgrenska University Hospital (SU) provides emergency and basic care for the region around Gothenburg, and its 700,000 inhabitants. Primary healthcare is responsible for all healthcare and medical treatment that does not require the hospitals’ special resources. Primary healthcare is mainly provided through the healthcare centers. The municipalities are responsible for the financing, content and most of the actual delivery of care services for the elderly.

The hospital reorganized so that a nurse with geriatric competence is placed at the emergency department to screen and make the geriatric assessment. The hospital wards use the information transferred from the nurse with the geriatric competence to get a head start with assessed needs. The municipal home health service reorganized so that a CM and a multi-professional team for care and rehabilitation (care manager, nurse, occupational therapist and physiotherapist) is placed physically together to enhance their teamwork. The CM makes all the first contacts with the older frail person, the wards and the relatives/informal caregivers. The CM constantly keeps the multi-professional team informed of all steps in the care process so that the team is ready with all preparations in time for the discharge from hospital. The assistive devices that have been identified as needed by the rehabilitation personnel at the hospital are also in place when the frail older person comes home. The primary healthcare is available for consultations and advice when needed. The CM has the possibility to contact the healthcare center where the frail older person has her/his GP.

**Strengths and weaknesses**

The emergency department recognizes and treats the frail older person as a VIP information is immediately transferred from emergency department to the wards and the municipality discharge planning starts the same day as the older frail person is admitted to the hospital. All planning is coordinated by the case manager. A case manager is available for the frail older person and her/his relatives during daytime in weekdays. A rehabilitation team is placed in the direct vicinity with the case manager care planning at home which emphasizes the older persons participation. Those persons that are identified as frail older persons but not admitted to the hospital ward are also offered care planning at home continuous follow-ups by the case manager.

**Impact assessment and performance evaluation**

So far results from the randomized control study has revealed positive results for the users. The participants in the integrated care program are significantly more satisfied with the care planning and their own possibility of participating in the care planning compared to the control group. They also, to a higher degree compared to the control group, think that the decisions made about home care, home health care and rehabilitation services fitted their needs well. In addition, the integrated care program has had effect on the participant’s independence in activities of daily living up to 12 months (unpublished material).
The results of the study from the implementation indicate the importance of paying attention to different cultures and traditions of the involved organisations, and to clearly define the roles of the actors involved. Grasping the general aims of the implemented intervention positively affected the response. However, not only the staffs working directly with the intervention needs to be informed. In order for the intervention to have an impact, the staffs in units that are indirectly involved, such as home help services in the municipality, geriatric and internal medicine wards at the hospital, are just as important. Results concerning fidelity of the implementation of the intervention show that it generally was high. Furthermore, there are indications that the municipality has made savings. In Sweden it is regulated that if the municipality is not able to arrange a safe homecoming of a patient from the hospital in stipulated time, the municipality has to pay a fee for each delayed day. This fee has decreased considerably during the implementation of the integrated care program. Due to the immediate transfer of information from the emergency department to the municipality, the municipality has the information to start preparing the home coming process already when the frail older person is admitted to the hospital ward.

Reproducibility and transferability

A key question has to do with the transferability of the intervention but it is in progress. The evidence that the study “continuum of care for frail older people” has generated has been used to develop a care process program for the care of older frail people with complex needs (a combination of social, medical and functional needs). The next step, which is ongoing, is a full-scale implementation of the program continuum of care for older frail people in Mölndal. The overall aim of that study is to evaluate the implementation of the program “Continuum of care for frail older people, with complex needs” focusing on: 1) how successful the program is in identifying and targeting frail older people with complex needs, 2) how sustainable the benefits are for older people when the program is implemented in real life context, 3) how the program is implemented in the involved organizations and 4) how the implementation process can be understood in terms of obstructing and facilitating conditions on operative as well as strategic levels in the organizations internal context as well as in the wider external context. The result will guide us in how the program can be reproduced and transferred to other contexts.

Future developments and possible implementations

The evidence that the study “Continuum of care for frail older people” has generated has been used to develop a care process program, now implemented in full-scale. The evaluation of the implementation of the care process program is ongoing. The research has thus far been successful but the knowledge that has emerged from the studies has also raised new research questions. These will be further elaborated in relation to the different research task in the future. Collaboration has recently started with one of the two other emergency departments in Gothenburg in order to implement our results and to add new research areas within the continuum of care chain for frail older persons.
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The RAI System in Spain

Author: Dr. Francisco J. Ródenas Rigla
Affiliation: University of Valencia (Spain), Polibienestar Research Institute

Abstract

The demographic and epidemiological changes that Spain is facing have sharply increased the expansion in chronic and degenerative illnesses that require long-term care (LTC). The intervention can only be efficient if it is based on inter-disciplinary co-ordination and protocols between health and social systems. It is therefore essential to research, draw up and implement systems that can provide social and health information that can classify it well, using the new information technologies (ICT) that optimize decisions related to timing and hospital discharges or new pathways. Researchers at Polibienestar Institute of the University of Valencia, with the support of national and regional governments, have developed the initiative, “the RAI system”. The main target groups are older people who need institutional health and social care as well as informal caregivers, and professionals in need of support in their management tasks to improve the operation and provision of care.

The main aim of the initiative is the improvement of care continuity between ‘Hospitals for the chronically ill’, ‘nursing homes’ and ‘home hospitalization units’, using the Resident Assessment Instrument (RAI) protocol. This initiative seeks to address the lack of integrated care plans and pathways. This gap means that people who need LTC have different assessments, both medical and social. The initiative takes into account jointly social care and health needs of each patient through a standardized assessment tool (RAI). An innovative aspect in 2009 was the use of ICT in the LTC sector, which lacks global information systems that enable the classification of dependent people and their referral between health and social resources.

The agreements with the regional government and the initial tests were conducted between 2004 and 2008, and the initiative was activated in 2009. The geographical scope is the region of Valencia, with 835,426 people over 65 in 2009. The initiative introduced does not create new coordination structures, so it could be placed in the category ‘linkage’. The evaluation of the experience in hospitals and nursing homes, where it was implemented, allows to establish some impacts such as changes in relationships between professionals within centers, changing the way of conducting assessments or changes in the management agreements for hospitals for the chronically ill (to define goals).

Other international studies show many similarities with the Spanish initiative, supporting the idea that it would be easily replicable and transferred to other contexts. Also, the RAI system can be used for other target groups requiring long-term care, using the appropriate version of the tool (for example, could use the 'Palliative-care' or 'mental health').
The socio-demographic context in Spain

In Spain, health care is an individual right and free of charge for all citizens, whereas access to social care requires a specific needs assessment and is based on a means-tested payment. As a consequence almost 68 per cent of people requiring long-term care (LTC) in Spain are cared for by health services. The usual scenario for people with LTC needs, that is, people requiring assistance for the activities of daily life (ADL), is treatment through health care services, especially hospitals, which are particularly costly and, when occupied unnecessarily, incur an opportunity cost for patients on waiting lists (Garces, Ródenas & Teija, 2012).

Changes in the demographic structure.

In recent decades the Spanish population has experienced considerable growth of over 65 years. According to the Spanish National Statistics Institute (INE) in 2012 the elderly accounts for 17.4% of the total population (more than 8.2 million people), and people of 80 and over is 5.3% (about 2.5 million people) (INE, 2012a). In Valencia, the region where the initiative is applied, the population
over 65 reaches 17.5% of the total (896,472 people) and people over 80 is 4.8% (246,302 people). This situation is linked to the increase in life expectancy (in 2010 life expectancy at birth in Spain was 84.9 years for women and 78.9 years for men) (INE, 2012b) and decreased fertility rates. The aging population and the associated risk of chronic diseases (neurodegenerative diseases such as Alzheimer's, or heart disease), has meant that there is a large number of older people who need help from others to function in their daily lives. Thus, one of the most worrying aspects of the aging in the coming decades is the impact it may have on the future evolution of the number of dependent elderly because age is a decisive factor by its occurrence. In Spain, approximately 23.1% of the population over 65 requires LTC, associated with dependence for the Activities of Daily Living (ADL) (Allen, et al. 2011). According to the Survey of Disability and Independence (INE, 2009), in Spain there are 2,227,100 people over 65 with a disability, 8.5% of the population and 30.3% of those over 65. According to this survey, 756,700 of them are men and 1,470,700 are women. The disabilities that are most relevant for their relationship with dependency are affecting the basic activities of daily living (BADL) (those most basic activities that allow a minimum of autonomy and independence, such as eating or getting out of bed). In Spain there are 2,110,800 people over 65 with severe disabilities / total for BADL (this represents a 28.02% of people over 65 and 4.67% of the total population). In the Valencian Community people over age 65 with a severe disability / total for any of the BADL amounts to 278,500, ie 35.07% of people over 65 and 5.70% of the total population.

Changes in family structure.
In recent years there have been major changes in the composition and structure of Spanish society. Influencing this are, among others, economic factors and cultural changes. This situation has affected families, as seen in the data on Spanish households (INE, 2012c). These have reduced the size, from an average of 3.36 people per household in 1991 to 2.67 in 2010 (the Valencian Community is below average with an average size of 2.59 people in 2010 per household), increasing at the same time their total number (from 11,536,300 in 1991 to 17,173,900 households in 2010). It consolidates the nuclear family model compared to its predecessor in that older people depended on their sons. In 1991 there were 712,800 households with one person over 65, in 2010 the figure was 1,511,800 households, 23.1% have great difficulties to make it to the end of the month with their income (INE, 2012d). This loneliness is also a very feminized reality (approximately 77% are women) and contributes to the emergence of diseases and dependency situations. In addition, households with people 75 and over have raised, according to the 2001 census these households represented a 12% (1,684,927), projections for 2013 put the figure at 14.2% (2,556,380 households) (Rodriguez, Fellinger and Dominguez, 2008).
All these data show changes in family structure that has consequences for the protection of older people, particularly those living alone and requiring LTC, and in the distribution of care responsibilities between professional and non-professional caregivers, or protection systems, public and private.

In summary, the increase in the elderly population will mean more government spending on health care and pensions, in particular the costs associated with long-term care. And there will be a decrease in the Informal models support provided by family. However in Spain care is provided
mainly within the family. This is evident when considering the proportion of people over 65 living in institutions, only 4.1%, with no significant differences in number given on the proportion of people over 65 receiving formal care at home (4.2%) (Allen, et al. 2011). Now, governments have to decide if they want to cope with these challenges carrying out the necessary reforms of social and care policies, or to cope with them as threats if they hinder this change. The current economic crisis affects the funding of social security systems, so it is necessary to restructure the welfare state, especially, in the domain of pension and healthcare systems.

The legislative framework

In this section we analyze the main legislative framework related to health and social services in the Valencian Region, in some cases reference is made to the national level.

The health system attends, through primary care services and hospitals, the elderly and chronic patients requiring long-term care. In 1978 the Spanish Constitution establishes the right of all citizens to health protection (Article 43) and the powers of the regional governments in the field of health (Article 148). Following the decentralization planned by the Spanish Constitution, each region has received adequate transfers to provide the health services. In the case of Valencian Region powers were transferred in 1987 (Law 1612/1987), the Valencian Health Agency currently manages the system.

The General Health Law (Law 14/1986) recognizes the right to medical benefits under the health system for all citizens and foreigners residing in Spain. The administrative tool proposed by this law is the establishment of a National Health System (NHS), as the regions are responsible for health in their respective territories. The state funded the system through general tax revenues (and cofinancing of patients for some services such as pharmaceuticals), but this budget is distributed among the different regions based on several criteria for allocation. The regions within the scope of their powers may adopt their respective portfolios of services, which include at least the service portfolio of the National Health System. In the field of LTC and chronic care, the Valencian Region has created specific resources such as ‘Hospitals for the chronically ill’ or ‘Home hospitalization units’. To ensure equality in the health service delivery across the state, as a means to ensure citizens the right to health protection, several laws have been enacted. The last is the Law 16/2003 concerning cohesion and quality of the National Health System.

Nowadays the Law 16/2012, a consequence of the Spanish economic crisis, has been established with several urgent measures aimed to guarantee the sustainability of the health system. This law implies the establishment of some new co-payment strategies as, for example, the contribution by pensioners in the cost of medicines.

Regarding the social services system, fully decentralized, the regional government has the functions of planning, coordination, inspection, research, control and monitoring of social services. In the Valencian region, law 5/1997 on social services defines the organization of general and specialized services, and the basic benefits in all the system. The law established social services for older people, ensuring their implementation by the regional government in conjunction with local administrations.

Local governments play an important role in the production and management of basic services.
The Basic Law on Local Government (law 7/1985) establishes that municipalities over 20,000 inhabitants must provide social services. This law also establishes the necessary coordination of responsibilities of Local Authorities together with the national and regional government. In 1988 the ‘National Concerted Plan’ between the three administrations (national, regional and local) ensures the economic and technical cooperation in management, financing, information and assistance in community services. The ‘community level’ constitutes the basic structure of public social services (primary care closer to the user), and its aim the achievement of better living conditions through integrated and versatile care.

From the economic point of view, the financing of social services shall be charged to public budgets (national budget, social security, regions and local authorities). However, it is expected the cooperation of private initiative and the participation of users (according to their income level).

In the field of long-term care, from the social point of view, the National Law 39/2006 is the most important. This law regulates the basic conditions for the promotion of personal autonomy and care for dependent persons by means of the creation of a ‘System for Autonomy and Care for Dependency’ (SAAD), with the collaboration and participation of all of the Public Administrations (http://www.dependencia.imserso.es/dependencia_01/index.htm). The main aim of the System is to guarantee the basic conditions and the services to dependent people. In the Valencian region, Law 171/2007 establishes the procedure for recognizing the right to receive benefits under the Valencian system for dependents (amended by Law 18/2011). The Law 35/2007 creates a service for coordinating the system and the Law 38/2010 creates the Advisory Committee for the Valencian Dependency Care System. This Advisory Committee is set up as a forum for dialogue and social participation, which allow greater collaboration between government and the social forces involved so it is an effective channel of communication and cooperation on this topic.

The main weakness, linked to the regulatory framework, is the fragmentation between health and social services. There is not a law that regulates joint benefits for people who require long-term care. The laws do not define joint mechanisms or tools for the assessment of the health and social needs, and is not considered a unique portfolio of resources. The strength of the legal framework is which establishes health care and social benefits for dependents as rights.

**INITIATIVE**

**Rationale**

The demographic and epidemiological changes that Spain is facing have sharply increased hospital expansion in chronic and degenerative illnesses that require long-term care (LTC). The intervention can only be efficient if it is based on inter-disciplinary co-ordination and protocols between health and social systems. It is therefore essential to research, draw up and implement systems that can provide social and health information that can classify it well, using the new information technologies (ICT) that optimise decisions related to timing and hospital discharges or new pathways. Researchers at Polibienestar Institute, University of Valencia, with the support of national and regional governments, developed the initiative ‘the RAI system’ as a best practice in assessing frail older adults using comprehensive geriatric assessment (CGA). The main target groups are older people who need institutional health and social care as well as informal
caregivers, and professionals in need of support in their management tasks to improve the 
operation and provision of care.
The main aim of the initiative is the improvement of care continuity between ‘Hospitals for the 
chronically ill’, ‘nursing homes’ and home health care services (‘Home hospitalization units’), using 
the Resident Assessment Instrument (RAI) protocol. The specific objectives are:
- Start up the RAI system in a pilot sample of ‘Hospitals for the chronically ill’, ‘nursing homes’ and 
‘Home hospitalization units’.
- Training professionals involved in the care process in the use of RAI protocols.
- Monitor and control the quality of data collection, RUG III classification and care planning from 
the system.
- Define and agree protocols for referral of dependent people between resources, establishing care 
pathways with maximum efficiency.
- Validate the new care pathways and define their contribution to improving continuity of care.

This initiative seeks to address the lack of integrated care plans and pathways. This gap means that 
people who need LTC have different assessments, both medical and social. The initiative takes into 
account jointly social care needs and health of each patient through a standardized assessment 
tool (RAI).
The RAI is a powerful computerised tool that carries out inter-disciplinary assessment of the needs 
of people who require long-term care. It allows for the location of people in the most adequate 
place at all times and to estimate the future pathways between the social and health systems. The 
knowledge gained from this initiative helps to improve the co-ordination between the different 
systems that provide care for dependent people, and the operational development of the ‘System 
for Autonomy and Care for Dependency’ (SAAD).
Since it was launched at the end of 2009, this initiative has allowed to support carers in their 
activity, through creating individual care plans with specific needs and tasks. And the use of RAI 
assessments allows professionals to have more structured information about patients.

Specificities and innovation
The care setting is LTC for older people through hospitals for the chronically ill, nursing homes and 
home hospitalization units. The agreements with the regional government and the initial tests 
were conducted between 2004 and 2008, and the initiative was activated in 2009. The 
geographical scope is the region of Valencia, with 835,426 people over 65 in 2009. The RAI system 
has been implemented in a pilot in 4 hospitals for chronically ill (‘hospital Dr. Moliner’ and ‘hospital 
Pare Jofre’ in Valencia, ‘hospital San Vicente del Raspeig’ in Alicante and ‘hospital Magdalena’ in 
Castellón), a nursing home (in Alicante), and a home hospitalization unit in an acute care hospital 
(‘hospital Arnau de Vilanova’ in Valencia). At the moment, its use has been stopped. This is due to 
political decisions as there is no agreement about the tools that have to be used. The system and 
the data remain in the hospitals and nursing home unused. The average of patients assessed in a 
year is 1020 in hospitals for the chronically ill, 110 older people in nursing homes and 186 patients 
in home hospitalization units. Once implemented the system is universal accessibility, the needs
assessment can be applied to elderly patients who use these resources. This initiative is essential to improve the management and provision of services in the framework of ‘System for Autonomy and Care for Dependency’ (SAAD) and its connection with the health system, and can guide decision-making of the governance in LTC. An innovative aspect in 2009 was the use of ICT in the LTC sector, which lacks global information systems that enable the classification of dependent people and their referral between health and social resources using international standards. In the Spanish market there was not any tool designed to be used over the Internet fit to compete with the proposal in this initiative (RAI assessment system). The tools available are partial and are not computerized, such as the Barthel test that measures the dependence in basic activities of daily living (Mahoney, FI, 1965), Frenchay test for instrumental activities of daily living (BOND MJ, HARRIS RD, SMITH, DS & CLARK MS, 1992) or MiniMental for cognitive ability (Folstein MF, Folstein SE & McHugh PR, 1975).

Service model and integration patterns

| Level of organisational integration of care | Linkage: users are appropriately cared for within systems that serve the whole population (not for specific target groups), e.g. older people are cared for by services addressing all people with long-term care needs (and not by special services for older people only). | X |
| Coordinated: explicit structures and individual managers are installed to coordinate benefits and care across different providers; structures are still separate, e.g. sharing clinical information in a planned manner, managing transitions between settings, assigning primary responsibility for coordinating care |
| Networking: different care providers establish detailed protocols and intervention models, as part of a joint programme |
| Full integration: creation of new structures or units dedicated to the specific user needs where resources from multiple providers/systems are pooled, e.g. organisation of multidisciplinary teams managing all care, control or direct provision in all care settings |

The initiative introduced does not create new coordination structures, so it could be placed in the category of 'linkage'. This initiative involves the use of new assessment tools, RAI protocols, by professionals from health and social resources. The information obtained should be transmitted to the coordination structures that already exist in the healthcare system, to improve the effectiveness of care plans and the connection between health and social resources. In the Valencian Community there are 'case managers', specifically 'nurses', who are responsible for facilitating processes of continuity of care between the hospital and home, and vice versa.

The RAI system provides a comprehensive standardised assessment of patients, which identifies problems to be considered in the design of individual care plans through Clinical Assessment Protocols (CAPs) and the classification of patients according to their functional profile and care required through Resource Utilisation Groups (RUGIII). It helps to optimise the management of long-term care services by establishing criteria for resource allocation of dependent older people, in the best setting and according to needs. This tool provides the possibility to use the 'Michigan
Choice’ algorithm to decide the first option for referral of the patient.

The initiative was conducted in two main steps. The first one is to implement the RAI system and create the institutional web database (with limited access to health care professionals). To gather the data, the professionals used two tools: SV NURSING HOME.NET (MDS2 for hospitals and nursing homes) and SV HOME CARE.NET (MDS2 for home health care). Data collection (as a functional capacity, cognitive status, skin condition or diagnosis) is made through a web-based platform and the data is linked through the patient’s assessment. For this purpose a web-based software tool has been developed in Spain (http://www.e-valoras.com/sv_web/portal/portada_dir/portada.aspx). In order to have a correct use of the RAI tool, Polibienestar researchers have trained social and health care professionals and managers. The training process includes learning five topics:

- assessment
- care planning
- leadership and management
- quality improvement
- statistical database in SPSS.

For the second step, Polibienestar researchers together with professionals analyzed the compiled data in order to: give feedback to the organisations (the global reports are updated every 6 months and are only available to service managers); define efficient health and social care pathways; develop individual care plans; and develop quality indicators. Finally, social and health care pathways will be validated by health care professionals (doctors, nurses, physiotherapists, nutritionists and psychologists).

**Target population**

The main characteristics of the target users were:

- In hospitals for the chronically ill, the average age was 67.5; approximately 52.4% were men and 47.6 women. 61.1% of patients had a dependency moderate / severe / total for BADL. All patients had chronic diseases, 8.1% were patients requiring palliative care. However, 30.8% had low clinical complexity.

- In home hospitalization units, the average age was 72.2, approximately 50.2% men and 49.8% women. 84.0% had multiple chronic diseases, 18.6% required palliative care. Only 12.2% had low clinical complexity.

- In nursing homes, the average age was 78.8, 34.4 and 65.6 were men women. 32.8% have a moderate / severe / total dependency for BADL, and 62.6% have a cognitive problem. 90.5% have multiple chronic diseases. But, 58% had a low clinical complexity.

When using the RAI system approximately 1,200 patients per year have been assessed. For each patient there are at least two annual assessments, although in some hospitals more assessments were made because the tool was included as a routine in nursing protocols. In the Valencian Community, the population over 65 with risk of dependence is estimated at approximately 278,500
people (INE, 2009), this is the maximum population that the RAI could assess. However, as the system has been used in nursing homes, hospitals for the chronically ill and home hospitalization units, the initiative could reach an assessment of approximately 26,000 over 65.

Financial aspects and sustainability strategies
The Initiative is a time-limited project that was funded by national and regional governments (Government of Valencia) between 2009 and 2012. The project did not involve co-payment by users. The annual budget for the development of the initiative was about € 70,000 per year. This budget includes the following: RAI software licenses, training material, adaptation of the existing systems to specific contexts, maintenance of services, support for the elaboration of technical protocols, and personnel costs (researchers and trainers). The political change that affects the priorities and care models, along with the country’s economic situation has prevented the continuation of the proposed initiative. The tools are still available in the health and social resources involved in the study, but it is not to be extended to new centers.

One way to make this initiative sustainable would be: linking the use of RAI tool to finance the services offered by private operators who want to participate in the ‘System for Autonomy and Care for Dependency’. The initiative was implemented only in public facilities, but could be feasible if it is linked to private services.

Partners involved
This initiative involves, from the point of view of financial support, the Spanish Ministry of Science and Innovation (national) and the Ministry of Education of the Valencian Community. The organizations involved in the implementation are three: a research center, Polibienestar at the University of Valencia, and two ministries of the Valencian Community, the Ministry of Health and the Ministry of Social Welfare.

POLIBIENESTAR (www.polibienestar.org) is a Public Research Institute belonging to the University of Valencia (Spain). It is specialized in research, innovation and social technology, technical advice and training in the field of public policies. Its final mission is the improvement of the Welfare and Quality of Life of society. POLIBIENESTAR develops interdisciplinary research applied in social sciences, related to long-term care, informal care or sustainability of social systems.

POLIBIENESTAR is composed of academics and expert analysts in political science, sociology, physiology, social work, economy, enterprise, law and medicine. The Think Tank POLIBIENESTAR collaborates, through agreements and contracts, with public and private organisations developing prospective and strategic analysis and implementing designs to improve the wellbeing and quality of life of the elderly and society. The ideas, researchers and projects of the Think Tank POLIBIENESTAR allow reliable governance to decide and to develop actions, considering the sustainability of social policies and social protection systems. The use of network analysis, through computer systems that respond to different problems, makes it possible to POLIBIENESTAR to face social, economic, entrepreneurial, political, and environmental challenges that impact on the quality of life and wellbeing of current and future European society. The Think tank POLIBIENESTAR
uses marketing strategies that facilitate, with social media, knowledge transference and access of society, impacting on the public debate and contributing to offer objective criteria to public opinion.

The Ministry of Health of Valencia manages public health services in the region (http://www.san.gva.es/index.html). The health management model is based in the decentralization, there are 24 health departments and potentiates public / private collaboration (http://www.san.gva.es/val/comun/plansalud/pdf/Pla_de_Salut_10_13.pdf). In the public health system, 60,842 people are working (about 36,000 are health professionals-doctors, nurses ...) and among its resources, there are 34 hospitals and 245 primary health care centers. The project involved two types of resources: hospitals for the chronically ill, for patients requiring long-term health care, intensive rehabilitation or palliative care (there are 5 hospitals in the region); and one home hospitalization unit, this provides specialised healthcare at home after hospital discharge.

The Ministry of Social Welfare of the Valencian community (http://www.bsocial.gva.es/portal/portal) is responsible for social services for dependent people and the elderly, among other groups. The model of care is based on public / private collaboration, with co-financing from the user. The initiative involving a public nursing home, this provides support for the activities of daily life, health supervision, rehabilitation programmes and geriatric care. The nursing homes are centers designed to serve as a stable, communal home for elderly persons having problems of dependency and social problems which prevent them from continuing to live in their own homes.

The proposed initiative aims to facilitate the connection between nursing homes and hospitals, and between hospitals and health care at home.

**Strengths and weaknesses**

**The strengths** of the initiative would be:
- In the Spanish system of long-term care there is no an assessment tool used by both health and social care resources. In this sense, the use of the RAI system in health and social care resources would simplify their coordination, making the pathways of people in need of LTC easier. The creation of individual care plans will provide important benefits such as cost savings and the improvement of quality and efficacy of health care and social services.
- The management system promoted by the Spanish Dependency Law (Law 39/2006) can be supported by the use of these types of tools. This is an opportunity to implement tools such as RAI. RAI helps to build a good management system that enables cooperation between different professionals and different management levels.

**The weaknesses** of the initiative would be:
- One of the main threats is how to motivate staff to use the RAI system and instruments correctly. RAI assessment tools have many items, and although the computerization of the tool facilitates its use, it remains a tool that requires quite some time to complete.
- The motivation and involvement of stakeholders (policy-makers and managers) is low, currently their concern is the detection of patients at different risk situations, such as hospital readmission.
The economic situation and the difficulties encountered in the implementation of the Spanish Dependency Law due to the lack of economic resources. These facts make scarce the available economic provisions for the implementation of these assessment systems within the Spanish context.

**Impact assessment and performance evaluation**

It is difficult to establish the impact of this initiative because the implementation of the RAI system has stopped in Valencian Community. The evaluation of the experience in hospitals and nursing homes, where it was implemented, allows to establish the following impacts:

- Changes in relationships between professionals within centers. The use of the tool requires involving different professionals (doctors, nurses, social workers, physiotherapists...), it allowed to create new interdisciplinary teams in hospitals and nursing home.
- Changes in the way of conduct assessments. In one of the hospitals, nursing management agreed to use the RAI as an assessment tool and using it weekly for planning the work schedule for nurses.
- During the time of implementation, some RAI quality indicators (falls, ulcers or infection) were included in the management agreements for hospitals for the chronically ill (to define goals). These agreements provide access to economic complements.
- It was verified that there are patients with similar care profiles located in nursing home and hospitals for the chronically ill, allowing the referral between both types of resources, through using a common professional language and the design of efficient care pathways.
- In the field of home health care, assessment of patients showed the possibility of referral from hospital to the home. For example, 16.7% of patients in a home hospitalization unit had the same profile as patients in a hospital for the chronically ill.
- New protocols were designed pathways for health care.

However it takes a long time to build a benchmarking system upon which to compare results from different organisations and to learn from the best practice.

**Reproducibility and transferability**

Other international studies show many similarities with the Spanish initiative, supporting the idea that it would be easily replicable and transferred to other contexts. The RAI system has been used in other European countries, with the aim of improving the quality of care, such as in Finland ([http://interlinks.euro.centre.org/model/example/RAIBenchmarkingAnInstrumentForLeadershipAndDevelopment](http://interlinks.euro.centre.org/model/example/RAIBenchmarkingAnInstrumentForLeadershipAndDevelopment)). The study of Christy M. Nishita, Kathleen H. Wilber, Saki Matsumoto and John F. Schnelle (2008) discusses the possibilities of referral, using the RAI, from nursing homes to home and community. Other studies used the RAI to identify, through telephone protocols, those older people with requirements for receiving long-term care home or community care, reducing costs (Brant E. Fries, Mary James, Susan S. Hammer, Lisa R. Shugarman and John N. Morris, 2004). And
also been studied, through the RAI, the risk of hospitalization for people using the U.S. Medicaid system, to determine which chronic conditions could be satisfied using other resources such as nursing homes or home care (Gruneir, A. Miller, SC Intrator, O. Mor, V., 2007).

The RAI system can be used for other target groups requiring long-term care, using the appropriate version. For example, using the 'Palliative-care' or 'mental health' (http://www.interrai.org).

**Future developments and possible implementations**

The approach in the short and medium term in order to reactivate the proposed initiative would be to add value to RAI screening tools and try to use them in other running programs, such as the initiative "Valcronic" from the Ministry of Health of the Valencian Community. The goal of 'Valcronic' is improving care for chronic patients, with one of the following conditions: diabetes mellitus type 2, COPD, heart failure or hypertension. Healthcare professionals performing control and monitoring of the chronic disease through the patient telemonitoring (blood pressure, weight, blood glucose, pulse oximeter, heart rate / respiratory). And to carry out educational interventions to promote healthy lifestyles and self-care. To insert the RAI system in this initiative, it would be necessary to study how to connect some parts of the RAI system with other instruments, such as those that are being used for the segmentation of the population as 'The Community Assessment Risk Screen' (CARS), or with care pathways.

In the long term, changes should be introduced in the models of needs assessment of older people requiring long-term care. These changes should be reflected in the laws that regulate the system for dependency care and the access to health services for chronic patients.

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The programme VALCRONIC-CARS, improving the process of chronic care

El programa VALCRONIC-CARS, mejora del proceso de atención a pacientes crónicos

Author: Dr. Francisco J. Ródenas Rigla
Affiliation: University of Valencia (Spain), Polibienestar Research Institute

Abstract

'Valcronic-CARS' is an initiative of the Valencia Health Agency addressed to chronic patients, in collaboration with the Research Institute Polibienestar at the University of Valencia and Telefonica Spain. This initiative has incorporated advancements in models of managing patients with chronic diseases and the introduction of ICTs. The programme, which began in March 2012, is currently ongoing on a pilot basis in four health centers in the Valencian Community, two in Alicante (Elche and Santa Pola) and two in Valencia (Sagunto and Puerto de Sagunto). It is aimed at improving the quality of patient care with any of the following chronic diseases: Type 2 diabetes mellitus, COPD, heart failure and hypertension, and the combination of these in patients with multiple comorbidities. It was expected to attend 12,000 patients, of which 2,928 were elderly patients (+65).

The initiative is based on the stratification of patients with chronic diseases in three risk levels (using CARS): High risk (level 3), patients with more complex and frequent comorbidity; Medium risk (level 2), low complexity with respect to their comorbidity; and Low risk (level 1), chronic patients in early stages. The programme includes technological devices at patients’ homes; these enable one to obtain biomedical information that is transmitted to the health center professionals through different systems (Tablet PC or Smartphone). ICTs enable remote monitoring, telecare and support for the clinical decision.

Once patients are detected through the CARS system (this information appears as an alert in the electronic health record of patients) and confirmed by a doctor, it is included in 'Valcronic-CARS' and activates a training programme for the patient and caregiver, taking place in person at a health center. Depending on the level of risk, a service for each segment of the chronically ill has been designed (a matrix of 16 actions has been built and adapted to the needs for the care of each patient). The chronic patients (level 3 and 2) from home should take their bio-measurement and filling out health questionnaires, the results will be assessed remotely by health care professionals at the health center. Thus, professionals, monitor daily possible alerts that are generated in the system, with values recorded by the patient the previous day that may indicate a worsening of his/her health. They may also carry out regular monitoring of historical data corresponding to a particular patient. In the case of patients in high risk (level 3), taking bio-measurements and filling out questionnaires are raised more frequently than patients in medium risk, so that monitoring is more intensive.
**Leader organisation(s)**
- Agencia Valenciana de Salud, Conselleria de Sanidad (Generalitat Valenciana)
  Valencian Health Agency, Regional Ministry of Health (Government of Valencia)

**Other organisations**
- Telefónica España, SA (Socio tecnológico)
  Telefonica Spain, SA (Technological partner)
- Instituto de Investigación Polibienestar, Universidad de Valencia
  Polibienestar Research Institute, University of Valencia

**Contact details**
Francisco J. Ródenas Rigla
University of Valencia
Faculty of Social Sciences
Campus Tarongers, Avd. Dels Tarongers s/n
46022 Valencia (Spain)
Tel. +34 963828202
francisco.rodenas@uv.es

**Website**

**Date of data collection**
March, 2013

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**BACKGROUND**

**The socio-demographic context**

In recent decades the Spanish population of those over 65 years of age has grown considerably. According to the Spanish National Statistics Institute (INE) in 2012 the elderly population accounts for 17.4% of the total population (more than 8.2 million people), and people of 80 and over is 5.3% (about 2.5 million people) (INE, 2012a). In Valencia, the region where the initiative is applied, the population over 65 reaches 17.5% of the total (896,472 people) and people over 80 is 4.8% (246,302 people). This situation is linked to the increase in life expectancy (in 2010 life expectancy at birth in Spain was 84.9 years for women and 78.9 years for men) (INE, 2012b). With age increases the risk of chronic disease, disability or dependence, and the likelihood of developing comorbidity. The aging population is associated with an increase in the number of chronically ill. According to the World Health Organization, it is estimated that chronic diseases will be the main cause of disability in 2020 and that by 2030 the current incidence of chronic disease in people over 65 years will double in this age group. Chronic diseases are the cause of 60% of deaths worldwide and are associated with 75% of public health expenditure (WHO, 2005).

In the Spanish region where the Initiative 'Valcronic-CARS' is developed, the Valencia Health Agency estimates that 60% of the adult population has a chronic disease, and chronic diseases consume between 70% and 80% of total health expenditure, this implies the need to improve the management of patients with chronic diseases to help the sustainability of the health system. Chronic patient care involves, for example, 80% of visits to primary care and 60% of hospital admissions, and in addition the high consumption of drugs (Department of Health, 2012).

The major chronic diseases, due to its importance and prevalence in the population, also generate
greater activity in primary care and use of hospital resources are (Department of Health, 2012): heart failure, chronic obstructive pulmonary disease (COPD), asthma, ischemic heart disease, hypertension and diabetes mellitus. In terms of hospital stays, for example, according to the national survey of hospital morbidity (INE 2013a) in the Valencia Region hospital admissions for heart failure were about 227 per 100,000, and in 2011 generating a total of 79,731 stays with an average stay of 7.03 days; in the case of COPD were 199 per 100,000, with a total of 63,479 stays and an average stay of 6.37 days.

Economically, asthma causes such a high demand and consumption of health resources and generates a great social impact and has a high cost. It is estimated that the average annual cost of an asthmatic patient is € 1,726 and if this is for a person 65 and over is € 2,078. Some 70% of the cost is attributed to poor asthma control (Department of Health, 2012).

In terms of mortality, cardiovascular and cerebrovascular diseases, which represent the leading causes of death, most often are caused or aggravated by diabetes. The gross mortality rate for diabetes in the Valencia Region is 26.2 per 100,000 inhabitants. In 2009, ischemic heart disease accounted for 9.3% of all deaths (10.2% in men and 8.2% for women), with a gross mortality rate of 71.2 per 100,000 inhabitants. The poorly controlled hypertension involves a higher incidence, hospitalization and mortality in patients with cardiovascular disease (myocardial infarction, stroke), kidney disease, stroke and heart failure, and it is estimated that hypertension is related to the deaths of some 40,000 people per year in the Spanish population of over 50 years of age (Department of Health, 2012).

In the context of chronic diseases described, the Valencian Government estimates that in 2020 78% of health actions will be directed to the care of chronic diseases, creating a growing need for change in the healthcare model, including the prediction and prevention targeted at patients with chronic diseases.

The needs of patients with chronic diseases are attended through the health resources that the Valencia Health Agency offers Valencian citizens, these resources are (Ministry of Health, 2012; Garcés, Ródenas & Sanjosé, 2006):

- The primary care is the first level of citizens' access to health care (245 health centers and 620 clinics).
- Acute hospitals, which stabilize the chronic patients who suffer an acute process through emergency care and hospitalization (28 hospitals).
- Short-stay medical units (SSMU) are responsible for assessing and attending in an integral way, frail elderly patients, chronic long evolution patients and terminally ill patients who come to the hospital requesting acute health care (there are 15 SSMU in the region). After assessing and caring for the sick, the SSMU are coordinated with the various medical units to provide the best treatment option for patients. In case of referral, they are carried out to Home hospitalization units, Hospitals for the chronically ill or palliative units.
- Home hospitalization units keeps the sick in their environment avoiding unnecessary hospital admissions of chronic and terminal patients or by shortening the stay of patients admitted (there are 24 Home hospitalization units).
- Hospitals for the chronically ill identify problems and provide individualized care plan for elderly patients in a state of advanced dependence. These hospitals can receive patients from any acute
The legislative framework

The health system attends, through primary care services and hospitals, the elderly and chronic patients requiring long-term care. In 1978 the Spanish Constitution establishes the right of all citizens to health protection (Article 43) and the powers of the regional governments in the field of health (Article 148). Following the decentralization planned by the Spanish Constitution, each region has received adequate transfers to provide the health services. In the case of Valencian Region powers were transferred in 1987 (Law 1612/1987), the Valencian Health Agency currently manages the system.

The General Health Law (Law 14/1986) recognizes the right to medical benefits under the health system for all citizens and foreigners residing in Spain. The administrative tool proposed by this law is the establishment of a National Health System (NHS), as the regions are responsible for health in their respective territories. To ensure equality in the health service delivery across the state, as a means to ensure citizens the right to health protection, several laws have been enacted. The last is the Law 16/2003 concerning cohesion and quality of the National Health System. The state funded the system through general tax revenues (and co-financing of patients for some services such as pharmaceuticals), but this budget is distributed among the different regions based on several criteria for allocation. The regions within the scope of their powers may adopt their respective portfolios of services, which include at least the service portfolio of the National Health System. For example, in the Valencian Community, Law 3/2003 provides the portfolio and structure of the healthcare system in this region, or Law 1/2003 regulates patient rights and data. In the field of LTC and chronic care, the Valencian Region has created specific resources such as ‘Hospitals for the chronically ill’ or ‘Home hospitalization units’.

Healthcare in the Valencian Community is organized into 24 Health Departments, with a single management as a mechanism for the integration of organizational and financial care. This model overcomes the division between care settings (primary and hospital), so that the patient can move without barriers in different areas of care or within the same level of care. This has contributed to this law as law 72/2001 which regulates continuing care in the area of primary health care.

The organizational model of chronic care in the Valencian Community takes into account the needs and features of patients with chronic diseases, along with the need to optimize the current resources without creating new structures. To this end, the model incorporates new technologies (ICT) to facilitate the monitoring and management of patients. The model involves the continuous monitoring of the patient, not only when accessing health system resources, but also when he/she is at home or using social-health resources (such as nursing homes). The integration of information in the electronic health record shared by both levels of care (hospitals and primary) enables care coordination in a single health record by patient. And from the point of view of professionals, the model ensures that communication, data exchange and monitoring of patients are shared. Coordination also contributes to current development of new nursing profiles, such as case management nurses (Garcés, Ródenas & Hammar, 2012), located in hospitals and primary care centers.
In addition to using laws, the Valencian Government implements its policies through the development of specific plans, such as the general framework of the Regional Health Plan (the last one is the Health Plan III 2010-2013). Within the field of chronicity we can highlight the following plans, whose development is one of the main lines on which the Valencian public health system has worked in recent years (available at http://www.san.gva.es/web/conselleria-sanitat/planificacion):

- Comprehensive Health Care Plan for the Elderly and Chronically Ill in the Valencian Community 2007-2011, and 2012
- Stroke Care Plan in the Valencian Community 2011-2015
- Comprehensive Palliative Care Plan of the Valencian Community 2010-2013
- Health Plan of Chronic Obstructive Pulmonary Disease (COPD) 2010-2014
- Diabetes Plan of the Valencian Community 2006-2010
- Prevention of Cardiovascular Disease Plan of the Valencian Community.

Presently, Law 16/2012, a consequence of the Spanish economic crisis, has been established with several urgent measures aimed to guarantee the sustainability of the health system. This law implies the establishment of some new co-payment strategies such as, the contribution by pensioners in the cost of medicines. These types of regulations have also been developed at the regional level; for example, Law 2/2013 of the Valencian Regional Government on urgent measures to management and efficiency in providing pharmaceuticals and orthopedics.

**INITIATIVE**

**Rationale**

'Valcronic-CARS' is an initiative of the Valencia Health Agency addressed to chronic patients. This initiative has incorporated advancements in models of managing patients with chronic diseases (Hisashige, 2013) and the introduction of ICTs. The programme, which began in March 2012, is currently ongoing. The gaps in previous care delivery were discovered are:

- Deficiencies in the traditional organizational model of care to address chronic diseases. The traditional model has focused mainly on acute care; a chronic patient was treated only when his health worsened. The traditional approach was face to face, reactive, focused on healing, in which the patient is passive, and is not suitable for treating chronic patients. It requires a proactive model of medicine, more focused on prevention and care (including long term care). This new approach is based on the segmentation of patients, necessary to determine the risk of disease and identification of care needs, by assigning individualized care plans (Grimaldo, 2013).
- Increased health care costs associated with the care of chronic patients. The costs of care for patients with more than one chronic disease, is multiplied by 6 compared to those who have no chronic disease or only have one. In this line, two thirds of health expenditure of some organizations is motivated by patients with five or more chronic conditions, multiplying by twenty-five hospital expenditure (Department of Health, 2012). If this problem is not dealt with suitably, it can consume the majority of health system resources and contribute to bankruptcy of its sustainability.
The lack of information in real time and being able to share this information between professionals of different levels of care (hospitals and primary). For professionals, the introduction of eHealth in the field of chronic care is associated with an improvement in access to relevant information, electronic prescribing or bio-measurements control, all through the electronic health record. For healthcare managers eHealth can help to control the efficiency and sustainability of the system, directing it towards preventive models. And for citizens eHealth provides information that helps them promote their health, self-care and even getting alternative diagnoses.

The overall goal of the programme 'Valcronic-CARS' is to improve integrated care to patients with chronic diseases in the Valencian Community. The specific objectives are the following (Ministry of Health, 2012):

1. Improving the quality of care, patient communication, easier access to more information and improving the degree of control of chronic diseases.
2. Improving the efficiency and effectiveness of care provided in health centers, reducing bureaucratic visits or underperforming.
3. Facilitate the patient stays in their environment (at home), avoiding the de-compensation of patients and preventing hospital admissions.
4. Improving communication between professionals, developing joint and agile communication paths.

Specificities and innovation

The programme 'Valcronic-CARS' has been running a year, and was introduced in March 2012, on a pilot basis in four health centers in the Valencian Community, two in Alicante (Elche and Santa Pola) and two in Valencia (Sagunto and Puerto de Sagunto). It is aimed at improving the quality of patient care with any of the following chronic diseases: Type 2 diabetes mellitus, COPD, heart failure and hypertension, and the combination of these in patients with multiple comorbidities. It was expected to attend to 12,000 patients, 500 high risks, 1,500 medium risk and 10,000 low risks. Of which 2,928 elderly patients (+65): High risk 146 (5%), moderate risk 439 (15%), and low risk 2,343 (80%). To access the programme one has to be classified as risk patient by CARS and have a clinical confirmation of a primary care physician.

The programme includes technological devices at patient’s homes, which provides by the technology partner (Telefonica Spain), these enable one to obtain biomedical information that are transmitted to the health center professionals through different systems (Tablet PC or Smartphone). ICTs enable remote monitoring, telecare and support for the clinical decision. Another innovative feature is the introduction of tools for segmentation of the whole population, depending on the risk level associated with chronicity, using the CARS (Community Assessment Risk Screen). This uses data in the current health information system as a chronic disease diagnosis, hospital admissions or emergency, and consumption of drugs. This model has been validated by Polibienestar Research Institute at the University of Valencia, and shows a good specificity and sensibility. The levels of risk stratification were applied to all of the population of the Valencian
Community (with 5,129,266 inhabitants, INE 2013b) using the regional health system databases, and later it was used as a criterion for inclusion in the programme Valcronic-CARS. Patients risk / no risk are marked as such in the electronic health record in order for the professional to identify them. The segmentation results will be recorded and will be accessible to all professionals in the Valencia Health Agency (respecting data protection laws). This will allow professionals to know the status of the population at greatest risk assigned to each professional and establish proactive measures to improve its control or to prevent disease evolution, as does the Valcronic-CARS initiative.

Service model and integration patterns

<table>
<thead>
<tr>
<th>Level of organisational integration of care</th>
<th>Linkage: users are appropriately cared for within systems that serve the whole population (not for specific target groups), e.g. older people are cared for by services addressing all people with long-term care needs (and not by special services for older people only).</th>
<th>X</th>
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<tr>
<td></td>
<td>Coordination: explicit structures and individual managers are installed to coordinate benefits and care across different providers; structures are still separate, e.g. sharing clinical information in a planned manner, managing transitions between settings, assigning primary responsibility for coordinating care</td>
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<td></td>
<td>Networking: different care providers establish detailed protocols and intervention models, as part of a joint programme</td>
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<td></td>
<td>Full integration: creation of new structures or units dedicated to the specific user needs where resources from multiple providers/systems are pooled, e.g. organisation of multidisciplinary teams managing all care, control or direct provision in all care settings</td>
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</table>

The Valcronic-CARS initiative can be placed in the category 'Linkage', because although the programme is mainly attending older people, it is aimed at any chronic patient that meets the inclusion criteria (pathologies and CARS risk level). The programme does not create new coordinating structures, but uses existing ones. This eHealth service is designed to replace other treatments for these patients (according to changes of the operating model), to improve the management of patients with chronic diseases.

The initiative is based on the stratification of patients with chronic diseases in three risk levels:

- High risk (level 3): Patients with more complex and frequent comorbidity.
- Medium risk (level 2): Low complexity with respect to their comorbidity.
- Low risk (level 1): Chronic patients in early stages. To promote prevention and awareness, in order to prevent them from reaching a condition with a higher complexity state.

Once patients are detected through the CARS system (this information appears as an alert in the electronic health record of patients) and confirmed by a doctor, it is included in 'Valcronic-CARS' and activates a training programme for the patient and caregiver, taking place in person at a health center. Depending on the level of risk, a service for each segment of the chronically ill has been
designed (a matrix of 16 actions has been built and adapted to the needs for the care of each patient). For example, in the high risk level the following are used: a Tablet PC, connected with tensiometer, pulsometer or glucometer, and nursing visits are activated, scheduled calls, and personalized messages or alarms. The patient may be removed from the programme on their own initiative (the patient expresses his desire to unsubscribe) or by professional initiative motivated by technological questions (for example, the patient does not use telemonitoring often enough) or changes in the patient's condition (for example, the patient loses autonomy and has no caregiver, and then goes to a nursing home or dies).

The initiative offers patients (levels 3 and 2) and professionals the following services (Department of Health, 2012):

- Telemonitoring of biological variables of patients (blood pressure, oxygen saturation and blood glucose levels).
- Filling questionnaires on the health status of the patient about symptoms, daily activities, diet or circumstances in which monitoring are performed (for example, EuroQol-5D).
- Automatic analysis of monitoring data and support systems for decision making, allowing the doctor to detect possible exacerbation of the disease before symptoms appear. The telemedicine application has an alarm system that alerts the healthcare team when variations occur in the biimeasurements or abnormal health questionnaires completed by patients.
- E-learning of patients, supported by multimedia technologies (with educational videos about the understanding and management of various chronic diseases as well as devices for making biimeasurements).
- Semi-automated implementation of clinical guidelines, which support all actions carried out with patients.
- Availability of new channels of communication between the patient and the care team (control of appointments, PDA...).

In addition, the technology partner provides a technical help desk to manage incidents and equipment failures (remote and onsite).

**Target population**

For inclusion of a patient in ‘Valcronic-CARS’ is required that this has been identified with CARS and confirmed by your physician at a health center, and they do not meet any of the characteristics listed in the exclusion criteria (Ministry of Health, 2012):

- Patient dependent for activities of daily living without a caregiver.
- Lack of acceptance and commitment document signed by the patient.
- Patient institutionalized (for example, in nursing home).
- Acute phase of cancer treatment.
- Patient in advanced disease stage.
- Technological criteria that hamper the development of the programme.
- Other: Any patient that judgment of the practitioner will not be able to receive programme benefits.

The Initiative was addressed to a total of 12,000 patients of the Valencia Region of two health departments. In the first year, the intervention has focused on patients with high and medium risk the real users have been approximately 1,000 patients in these groups. The potential target groups are those citizens who may have any of the chronic diseases that are treated from 'Valcronic-CARS', or a combination of these. So according to the prevalence of these diseases the Department of Health (2012) estimates that there are: 172,167 patients in the Valencia Region with heart failure (4% population prevalence of 16 and over), 254,179 patients with chronic obstructive pulmonary disease (COPD) (10% prevalence in population aged 40 and over), 215,209 patients with asthma (5% of population 16 and over), 117,080 patients with ischemic heart disease (5.5% in population aged 45 and over), 1,471,512 patients with hypertension (35% in population aged 18 and over) and 344,334 patients with diabetes mellitus (8% in the population aged 16 and over).

**Financial aspects and sustainability strategies**

The initiative is a time-limited project that was funded by the Government of Valencia, co-financed by the company Telefonica Spain which provides technology and training tools for patients / caregiver and professionals, between 2012 and 2013. Generally the project did not involve co-payment by users, but for example, in the case of medium risk level it is necessary that the patient has a smartphone and internet access at home.

The annual budget for the development of the Initiative was about €100,000 per year. This budget includes the following: software and devices (Tablet PC, tensiometer, pulsometer, glucometer, etc.), training material, adaptation of the existing systems to specific contexts, technical help desk, support for the elaboration of technical protocols, and personnel costs (researchers and trainers).

The political change that affects the priorities and care models, along with the country's economic situation has prevented the continuation of the proposed Initiative. It is being evaluated, from a point of view of economic efficiency and effectiveness of treatments, to decide if it extends to other centers.

If the assessments show its effectiveness and efficiency, one way to make this Initiative would be sustainable which was co-financed by the users and offered by private operators who want to participate in the Healthcare System. The initiative was implemented only in public facilities, but it could be feasible if it is linked to private services.

**Partners involved**

The three organizations involved in the implementation of this Initiative are as follows: the Ministry of Health of the Valencian Community (leads and coordinates the other partners), Polibienestar Research Center at the University of Valencia, and a technology partner (Telefonica Spain). The Ministry of Health in November 2011 signed a research contract with Polibienestar and has a collaboration agreement with Telefonica Spain (Resolution of August 2, 2012, Valencia Official
The **Ministry of Health of the Valencian Community** manages public health services in the region ([http://www.san.gva.es/index.html](http://www.san.gva.es/index.html)). One of the main objectives of the Ministry of Health is to offer citizens of Valencia a high level of health services, which continually evolve to meet effectively the new challenges and needs of society, by encouraging scientific research in the health field. The health management model is based in the decentralization, there are 24 health departments and potentiates public / private collaboration ([http://www.san.gva.es/val/comun/plansalud/pdf/Pla_de_Salut_10_13.pdf](http://www.san.gva.es/val/comun/plansalud/pdf/Pla_de_Salut_10_13.pdf)). In the public health system, 60,842 people are working (about 36,000 are health staff), and among its resources, there are 28 acute hospitals and 245 primary health care centers. In this project the Ministry facilitates the use of their health databases, and allows the pilot programme to be developed in four primary health care centers, with the support of two acute care hospitals.

**Polibienestar** ([http://www.polibienestar.org](http://www.polibienestar.org)) is a Public Research Institute belonging to the University of Valencia (Spain). It is specialized in research, innovation and social technology, technical advice and training in the field of public policies. Polibienestar develops interdisciplinary research applied in social sciences, related to long-term care, informal care or sustainability of health and social systems. Polibienestar is composed of academics and expert analysts in political science, sociology, physiology, social work, economy, enterprise, law and medicine. The Think Tank Polibienestar collaborates, through agreements and contracts, with public and private organisations developing prospective and strategic analysis and implementing designs to improve the wellbeing and quality of life of the society. The ideas, researchers and projects of the Think Tank Polibienestar allow reliable governance to decide and to develop actions, considering the sustainability of social and health policies. In this project Polibienestar contributes to the segmentation of the population, in qualitative assessment and its dissemination.

**Telefonica Spain SA** is a company with a strong presence and expertise in providing services in the telecommunications sector, and has recently created a Global eHealth Unit whose mission is to support companies and governments in this sector, so that they can find better ways of delivering health and social services through ICTs. It aims to become a strategic partner to boost and accelerate the transformation of healthcare, providing better quality and efficiency of services through eHealth. Telefonica works in conjunction with the other two organizations, providing their eHealth platform for the management of chronic patients, as well as devices and required training.

**Strengths and weaknesses**

**The strengths** of the initiative would be:
- For the public health system, leading to improved demand management through ICT, with the adequacy of the supply of services and the way it covers the needs of chronic patients.
- For patients, it provides them greater ability of self-care, improving their knowledge of the disease and gaining more responsibility in the management and control of their disease. Also increases adherence to treatment and improve their time management by reducing the number of trips to primary care or other services, such as emergency services.
- For primary care health professionals, the programme allows them to improve monitoring and
continuity of care for chronic patients without physical presence at consultation, and empowerment of nurses in this field. Among the weaknesses of this initiative the Ministry of Health highlights the following (Ministry of Health, 2011):

- The pilot programme does not ensure the monitoring and identification of the chronic patient throughout the care process, because their patient ID included in the programme is not visible in all health resources.
- The programme ensures a reactive monitoring of patients through the management platform for chronic patients, with the use of alerts (detection of incidents in the values of the bio-measurements or health questionnaires). It would be necessary to strengthen and develop proactive monitoring of the patient, with telephone contact to inquire about his/her health, provide health advice or know how they are using the services offered by the platform.
- There is a potential risk of saturation of the nursing staff at the health centers that can be overwhelmed by the work overload involved in monitoring alerts and clinical care of patients. This risk could be controlled if a professional figure is created to support the nursing staff in health centers.

Impact assessment and performance evaluation

To evaluate the results of the programme, a scorecard has been defined; the indicators will be obtained directly and automatically from the database systems of the Valencia Health Agency. They have defined ten key indicators, and four secondary indicators (Ministry of Health, 2012). Among the key indicators are the 'hospital emergency room visits by patients included in the chronic programme', 'hospital admissions of patients by health problems directly related to their chronic disease' or 'stay in hospital for health problems related to chronic disease'. Among the secondary indicators one will find the 'Quality of life patients enrolled in the chronic programme'. The programme dropout rate of chronic patients over 65 years of age, associated with the use of ICT is below 15%.

For a consistent assessment it is considered that there must be a year since the implementation of the programme (this began in March 2012), at the time of this report has not been made this assessment. Preliminary data, evaluation at 3 months of key indicators, show us that in the period before patients 'Valcronic-CARS' had more emergency hospital admissions and stays associated with these admissions, as well as emergency room visits, but fewer hospital admissions and stays scheduled. In the post, the programme patients tend to have more of everything (including admissions and stays scheduled). The reason is that when starting the programme more problems are detected and these activate other resources (e.g., hospital care). This initial increase in the consumption of resources was predictable. Therefore, the assessment at 12 months is very important.

Regarding the quality of life, the assessment at 6 months on a sample of 100 patients enrolled in the programme using the EuroQol-5D do not obtain statistically significant differences between pre and post. In both periods, women presented more problems in all of the Health-related Quality Of Life (HRQOL) dimensions, with the most significant being ‘pain/discomfort’, ‘anxiety/depression’
and ‘daily activities’. The profile with the highest risk of hospitalization within the ‘Valcronic-CARS’ programme is an older women (75 and over) with a mean of 0.396 in the HRQOL index.

Reproducibility and transferability

This initiative could be transferred to other European contexts, so the Polibienestar Institute and the Ministry of Health, together with other Spanish partners are involved in 'European Innovation Partnership on Active and Healthy Ageing', promoted by the European Commission (http://ec.europa.eu/research/innovation-union/index_en.cfm?section=active-healthy-ageing).

Specifically collaborate in group B3 'Building a comprehensive system of care for chronically ill', which includes remote monitoring at the regional level. The actions of this group aim to reduce unnecessary hospitalizations of older people with chronic diseases with the effective implementation of comprehensive care programs and new management models. One of them could be the Valcronic-CARS program.

The effort to transfer to other European contexts is also shown in international dissemination, for example, in November 2012 the Minister of Health of the Valencian Community presented the program in Brussels, in the framework of the International Meeting ‘Advancing eHealth in Europe: Empowering Patients, Supporting Health Professionals’, organized by the International Centre for Parliamentary Studies.

Within the national level, we also try to transfer the results to other regions, raising its inclusion as a good practice in the 'model of chronic care' of the Spanish Ministry of Health (Ministry of Health, Social Services and Equality, 2012). This ministry is very interested in stratification tools used in the ‘Valcronic-CARS’ program.

Future developments and possible implementations

To continue implementing the program it is necessary to prove that this new eHealth service, gets in the midterm to improve the health of chronically ill patients (the initiative has focused on patients with medium and high risk) and their quality of life, without increasing health system costs and decreasing their use of these patients from other more expensive resources, such as acute care hospitals or from hospital emergencies. Since the resources of the Regional Health Ministry are at present very limited, it will not assume the risk of extending the program if the above requirements are met.

One way of ensuring the continuity of the program would be to deploy a new phase focused on intervention with low-risk patients. This phase would promote healthy habits and educational activities, by creating a website with all this content. Within this website, the low-risk patient will be able to manually record their bio-measurements. Also these historical bio-measurements may be consulted by practitioners from primary health care when the patient goes to medical consultation.
References
Athens Association of Alzheimer Disease and Related Disorders (AAADRD)

Author: Judy Triantafillou
Affiliation: 50plus Hellas NGO

Abstract
The Athens Association of Alzheimer Disease and Related Disorders (AAADRD) is a non-profit organization founded in 2002 by dementia patients’ relatives, doctors, psychologists and other health and social care professionals interested in Alzheimer disease. It belongs to a Greek federation of 29 independent but linked Alzheimer organizations, which aim to address all aspects of the disease and its consequences and to promote social inclusion through understanding, support and action on behalf of patients, their families and all involved in their care. These aims are achieved through: public information campaigns and easy access to neuropsychological assessment for early diagnosis and treatment; programs of education and training for health professionals, professional formal caregivers, volunteers, and informal family carers; community based and residential care centres; informal carer support groups; participation in research programs; lobbying for improved public services, free drug treatment, financial support benefits for patients and/or family carers. Achievements include access to free medication (which has recently become problematic) and limited financial support for an “accompanying person” from some Insurance funds. At present AAADRD has 2,450 official members and is run by a seven member elected board, including representatives of older people and family carers.

AAADRD and other linked Alzheimer associations, provide the only organized informal carer support groups and practical and psychological assistance for dementia patients and their families throughout Greece. Alzheimer non-governmental organizations, by uniting professionals, patients, informal carers and all involved in the care of dementia sufferers, provide an effective, integrated, multi-dimensional approach to the growing problem of dementia, which could be optimized by more secure public funding.

<table>
<thead>
<tr>
<th>Leader organisation(s)</th>
<th>Athens Alzheimer Association Εταιρεία Νόσου Alzheimer και Συναφών Διαταραχών Αθηνών</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other organisations</td>
<td>1) Dr. Paraskevi Sakka, Honorary President AAADRD, Markou Mousourou 89 and 33 Stilponos, 11636 Pangrati, Athens. Tel +30 210 7013271 Fax: +30 210 6012239 2) Areti Efthymiou, Eurocarers Association Mob. +30 6948 40 9254 <a href="mailto:areti@eurocarers.org">areti@eurocarers.org</a></td>
</tr>
<tr>
<td>Contact details</td>
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<tr>
<td>Website</td>
<td><a href="http://www.alzheimerathens.gr/?page_id=1560">http://www.alzheimerathens.gr/?page_id=1560</a></td>
</tr>
<tr>
<td>Date of data collection</td>
<td>April-May 2013</td>
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</tbody>
</table>
BACKGROUND

The socio-demographic context in Greece

In Greece there are an estimated 200,000 people with dementia. The National Health System, implemented since the mid 1980s at the secondary/hospital care level, provides diagnosis and treatment services for dementia patients through the neurological outpatient clinics of the main General Hospitals in all regions throughout Greece. Primary Health Care services are provided by the Health Insurance funds, which depend on the occupational health insurance of the patient, but have recently been more or less unified into a single provider system, the EOPYY (National Organization of Health Care Providers), which should reduce inequalities in access to primary health care, but currently has organizational problems which may impact negatively on users’ access to primary health care. These problems include limitations in access to free health consultations, involving direct costs to the user, as well as co-payments (or, intermittently, full payments) for all medications, including those for Alzheimer disease, which were previously free to the user, but now may need out-of-pocket payments, which may be reimbursed after a lengthy bureaucratic process. Regarding long-term care for patients with advanced dementia, public care provision is very limited and the mainstay of care provision is through informal care by families. Residential care provision through Elderly Care Units (MFI), several of which specialize in the care of dementia patients, is dependent upon the ability to pay and during the current financial crisis there are indications that patients are being withdrawn from such care due to inability to meet costs. The other main alternative is the use of privately paid migrant care workers who provide live-in or live-out care to older people with long-term care needs, but there are also indications that this choice is being limited by reduced family income. This background information is necessary to understand the context in which the Alzheimer Associations function in Greece.

The main activity of the Athens Association of Alzheimer’s Disease and Related Disorders is based in the Region of Attica, nevertheless AAADRD organizes activities nationally promoting awareness and early diagnosis of Alzheimer disease. In the Attica region, 6 Dementia Care Centers and 2 Help-at-Home programs have been developed and run under funding of Ministry of Health and EU. AAADRD runs 3 Dementia Centres in the Municipality of Athens and the Municipality of Maroussi. The total number of users, on a monthly basis is around 250 users for the Dementia Centre in Pagrati, 90 users for the Dementia Centre in Panormou and 85 users for the Dementia Centre in the Municipality of Maroussi, whilst the Home-care program serves 80 older people and 70 family carers monthly.

Each Dementia Centre runs Memory Clinics, which can also be found in General Hospitals throughout Greece, apart from the Dementia Centers. In the Region of Attica there are 6 Memory Clinics within outpatient departments of General Hospitals.

The AAADRD through the Dementia Care Centers operate a wide variety of services for the support of dementia patients and their relatives, which are described in more detail below.

The legislative framework

In Greece, there is no national dementia strategy and no specific legislation for this vulnerable section of the population.

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AAADRD is registered at national and regional level as a Social Care Non-profit organization, number: 09111FSE12026068N/0637). The association is governed by a seven member Board of Directors and an eight-member scientific committee, elected every three years.

**INITIATIVE**

**Rationale**

The increasing incidence and prevalence of Alzheimer disease with the ageing of the Greek population, together with the lack of formal policy and practice in long-term care provision particularly for this condition, led to various initiatives by the NGO sector to address the specific problems of Alzheimer patients and their families.

AAADRD was developed in 2002 to address the full spectrum of problems arising from the disease and to offer continuity of care, by linking the formal and informal care sectors in a holistic and integrated approach to the management of Alzheimer patients and their families and to bridge the gap between medical practice and the complex and multi-sectorial problems of everyday care of patients.

It also attempts to compensate for the gaps in the primary care sector in Greece through facilitating and creating the necessary links and pathways for patients throughout the health care system by using experienced professionals and developing new support services e.g. day care centers, respite care, training of carers, carers’ support groups and bereavement counselling, addressing the needs of both patients and their informal family carers.

Since February 2009, the Association has launched the ‘Greek Alzheimer’s Initiative, a signature-collection campaign, designed as the first step towards a National Action Plan against Alzheimer’s disease. These signatures are symbolically presented to the Mayor of Athens after the Memory Walk, a highly publicised walk that takes place through central Athens each September to commemorate World Alzheimer’s Day, with the slogan “Dealing with Alzheimer’s disease step-by-step”.

As a result of these continuous efforts and achievements, the Municipality of Maroussi created its own Alzheimer’s Day Centre, in December 2010, with health professionals and running costs paid by the municipality and the scientific supervision and responsibility undertaken by AAADRD.

**Specificities and innovation**

The AAADRD attempts in a unique way to address the multi-sectoral needs of Alzheimer patients and their families. The close collaboration between the formal care sector, patients and their informal caregivers, is an example of the “hand-in-hand” approach identified in other projects as being a major factor contributing to good long-term care.

AAADRD has developed a number of services: dementia day care facilities, home care program, awareness campaigns, Alzheimer Cafe, educational program for Children: how to understand grandpa”, research on non pharmacological interventions, memory clinics, awareness campaign for Elderly clubs and prevention programs for Alzheimer disease.
Additionally, AAADRD participates in research and training programs at local, national and EU levels:

ASPASIA – a Set-Care e-training program in the home for paid carers of dementia patients

The 2-year (2011-2013) Grundtvig Learning Partnership, a small-scale, transnational cooperation between institutions and organizations active in the field of adult education. The theme of the partnership is "We are Family! - Mobile Communications of Seniors between Generations" http://family.platinic.net

The SOCIABLE program of mental exercise via computers, is aimed at people aged 60+ years experiencing mild to moderate memory impairment and/or other cognitive functions, but also to healthy seniors who want to exercise mentally with the aim of preventing cognitive decline. It was implemented in 4 European countries. in 2009-2012 with the participation of the Ygeia Hospital in Attiki and can also be used in the home. www.cognitivetraining.eu www.sociable-project.eu.

One of the Day-Care centers participated in the LLM – Long-lasting Memories program, which provides older people not only with the potential to improve their mental and physical condition, but also to continue to participate as active members of society. http://www.longlastingmemories.eu/

Completed programs include:

Continuing education in dementia for health professionals, through a Leonardo Da Vinci project

The “Life after Care” program for bereaved carers, mainly relatives, through a Grundvig project.

Service model and integration patterns

<table>
<thead>
<tr>
<th>Level of organisational integration of care</th>
<th>Linkage: users are appropriately cared for within systems that serve the whole population (not for specific target groups), e.g. older people are cared for by services addressing all people with long-term care needs (and not by special services for older people only).</th>
</tr>
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<tbody>
<tr>
<td>Coordination: explicit structures and individual managers are installed to coordinate benefits and care across different providers; structures are still separate, e.g. sharing clinical information in a planned manner, managing transitions between settings, assigning primary responsibility for coordinating care</td>
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<tr>
<td>Networking: different care providers establish detailed protocols and intervention models, as part of a joint programme</td>
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<tr>
<td>Full integration: creation of new structures or units dedicated to the specific user needs where resources from multiple providers/systems are pooled, e.g. organisation of multidisciplinary teams managing all care, control or direct provision in all care settings</td>
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The Association’s approach is to address the full spectrum of Alzheimer’s disease through programs including: the early diagnosis of dementia by professionals; the promotion of research; the development of Day Care and short and long term Residential Care Units; the provision of useful information and advice (helpline) on dementia problems (caring, legal or financial issues); the presentation of lectures by health professionals and informal carers, covering all aspects of Alzheimer’s Disease; the development of professional seminars throughout the year; public
information campaigns to increase awareness of the problems and social needs of the population affected.

Specific services are provided by the Day-care Centres and Help-at-Home program, which offer people with dementia the opportunity to socialize and help them maintain independence and enjoy a better quality of life. Users benefit from Centre services on a weekly basis. A multidisciplinary team of healthcare professionals provides a comprehensive array of services, including:

- Memory clinic
- Sessions for people with dementia: cognitive training, speech and occupational therapy, reminiscence therapy, art therapy, physical exercise
- Training, counselling and psychotherapy for carers, in groups or individually
- Alzheimer’s Cafe
- Physical/practical training for carers in caring techniques and all aspects of care for dementia sufferers
- ICT interventions for people with MCI

Health Professionals: psychologists, nurses, neurologists, occupational therapists, social workers, physiotherapists and physical trainers organize the daily program of users.

Non-pharmacological interventions are organised in 2 sections:

a) For people with Mild Cognitive Impairment (MCI) who attend day care twice a week for 6 hours in total

b) For people with dementia, who can attend the program daily, either in the morning or during the evening sessions

All programmes depend heavily on the supportive activities of volunteers.

**Target population**

The target population includes:

a) People with dementia,

b) People with MCI,

c) Carers (mainly relatives and other informal carers, but also privately paid (usually migrant care workers).

Monthly estimated number of users at the 3 Dementia Centres in Attiki: Pagrati Centre: 250, Panourmou Centre: 90 and at Maroussi Centre: 85.

The Help-at-Home programme is based in the Dementia Centre at Pagrati and serves 150 users, 80 older people with dementia and 70 family carers, on a monthly basis.
Financial aspects and sustainability strategies

The start-up costs and funding for the first year of operation for the first Dementia Centre at Pagrati, were covered by European Social Funding (3rd Community Support Framework - 70%) and the Greek Ministry of Health (30%).

The total cost of the service on a yearly basis is around 300,000 euros. The Help-at-Home program, which operates with the support of 3 psychologists, has a total yearly operational cost of around 40,000 euros.

Funding of the activities, programs and services run by the organization is partly supported by the state, but this has to be supplemented by fund-raising, donations and sponsorships.

The costs of the service have been altered in the last 2-3 years due to the economic crisis, with cuts in funding necessitating cut-backs in salaries and reductions in service provision.

Donations and sponsorships cover the costs of campaigns and activities for the promotion of wider awareness of the problems of Alzheimer disease and its consequences.

All services are supported by an extensive network of volunteers who, by working on an unpaid basis, contribute significantly to reducing the costs.

Partners involved

The AAADRD belongs to the Greek federation of 29 linked but independent Alzheimer organisations throughout Greece, including Alzheimer Hellas, the Greek Association of Alzheimer’s Disease and Related Disorders http://www.alzheimer-hellas.gr/english.php

As already described, AAADRD involves partnerships between a wide spectrum of health and social care professionals, patients themselves and their informal carers, as well as an extensive network of volunteers.

Strengths and weaknesses

Strengths

- The AAADRD attempts in a unique and integrated way to address the multi-sectoral needs of Alzheimer’s patients and their families. The close collaboration between the formal care sector, patients and their informal caregivers, is an example of the “hand-in-hand” approach identified in other projects, as being a major factor contributing to good long-term care.

- The numbers of Alzheimer’s patients are predicted to continue to rise over the coming decades, making their informal and formal care an urgent concern for civil society. The local initiative of Maroussi Municipality in opening their own Day-Care centre may act as an example for other municipalities to follow.

Weaknesses

- Funding of the activities, program and services run by all the member organizations is insecurely supported by the state and therefore highly dependent on the abilities of each to raise their own funds. The issue of the necessary and permanent commitment of public
funding for running essential NGO services for Alzheimer patients and their families has not yet been effectively resolved.

- The impact of the current financial crisis is already being seen in increasing numbers of patients and their families unable to pay for private care at home or in Residential Care Units. The higher burden on informal carers is likely to be reflected in more Alzheimer’s patients “abandoned” and dependent on inadequate public LTC services (there are indications that this is already happening) and a higher demand for NGO services, without however the necessary associated public funding to ensure that they can respond to increasing needs.

**Impact assessment and performance evaluation**

1) Alzheimer Cooperative Valuation in Europe (ALCOVE) [http://www.alcove-project.eu/](http://www.alcove-project.eu/)

AAADR D participates in the Joint Action Alzheimer Cooperative Valuation in Europe, which is aimed at understanding, preventing and treating Alzheimer’s disease and related disorders and evaluating outcomes. The program ALCOVE Joint Action (JA) seeks to improve the knowledge and design guidelines for four areas of activity:

- Improving collection of epidemiological data on Dementia
- Improving prevention and early diagnosis with emphasis on early diagnosis
- Improvement of existing practices medical social care
- Improve the content and use of the Declaration on the rights of people with memory disorders

2) AAADR D acts as a consultant to the Municipality of Trikala within the European project ISISEMD (Intelligent System for independent Living and self - Care of Seniors with Cognitive problems or mild dementia), which aims to develop e-Health applications to support patients with dementia to live independently and improve quality of life for themselves and their relatives, as well as reducing health and social care costs [www.isisemd.eu](http://www.isisemd.eu)

3) In collaboration with the City of Athens, cognitive training groups for healthy older people are run by psychologists in the Municipal ‘Friendship Clubs’, with education on memory function, ways of dealing with memory problems and memory training. From July 2008 to December 2010, 1,800 older people from 24 ‘Friendship Clubs’ participated; following the intervention, the vast majority of the participants reported significant improvement in day-to-day memory functioning. Currently, 10 cognitive training groups of 6-12 older people per group (105 participants in total) are being run in sessions of 60-90 minutes.

**Reproducibility and transferability**

The development and implementation of AAADR D was based on similar initiatives both in Greece and other EU countries and is eminently reproducible, either in part or as a whole. The use of the model by the Municipality of Marousi to open their own Dementia Day-Care centre, with consultant advice by members of AAADR D, indicates the usefulness to the community of such
services and the advantages gained by cross-sectoral working in the field of dementia care. Currently, the Alzheimer Associations offer the only informal/family carer support in Greece and their extensive experience in the field could be utilized by municipalities to organize similar, much needed, support networks for informal carers of older people with long-term care needs throughout Greece e.g. through the KAPIs (Open Care Community Centres for Older People) and the municipal Help-at-Home services.

**Future developments and possible implementations**

The financial crisis, which has been particularly acute during the past 3 years, has necessitated cuts in salaries, programs and services by AAADRD. At the same time, needs for support of dementia patients have increased, both due to the reduced ability of families to provide and cover the extra costs of care for their dependent relatives, as well as to having to pay for previously free-to-user health services and medications. Unless public funding is made available to cover some of the needs and costs of people with dementia and their family carers, the result is likely to be more older people “abandoned” by their families in hospital Emergency Departments and other locations. Crisis help-lines are reporting rapidly increasing numbers of calls for help by families unable to care for their dependent older relatives and NGO/Orthodox church initiatives, in partnership with other organisations are already supplying basic needs e.g. food, shelter, clothing, for people of all ages, but including a significant number of older people.

Secure public financial support for already functioning organisations such as AAADRD would seem to be an effective and essential approach to mitigating the negative effects of the crisis on vulnerable groups of older people with dementia and their families.

**References**


Participation of AAADRD in Projects for the improvement of Quality of Life of people with dementia and their families:

2010- ALCOVE Joint Action On Alzheimer’s Disease And Other Dementias [http://www.alcove-project.eu/](http://www.alcove-project.eu/)

GRUNDTVIG (2009-2011) [Life after Care](http://www.alcove-project.eu/)
LEONARDO DA VINCI (2009-2011) Continuous education of health professionals in dementia
PSP-ICT Long-lasting Memories (LLM)
PSP-ICT Intelligent System for Independent Living and Self care of seniors with cognitive problems of Mild Dementia (ISISEMD)
PSP-ICT Smart Home for elderly people (HOPE)
SET CARE: Self-study E-learning Tool for the Social Home-care Sector

Author: Areti Efthymiou
Affiliation: Athens Association of Alzheimer's Disease and Related Disorders

Abstract
The SET CARE: Self-study E-learning Tool for the Social Home-care Sector is an e-learning educational program for anyone who cares for an elderly person or a person suffering from dementia. It targets both unpaid and paid caregivers who wish to provide higher quality care. At the moment the project is adopted and translated in Greece and Bulgaria, as it was originally developed in Italy by Anziani e Non Solo Organization through the ASPASIA Project: the training programme has already been used by more than 3,000 paid caregivers. Participants have the opportunity to attend the educational program via internet or via DVDs.
This program aims at improving and indicating the professional skills that caregivers in Greece and Bulgaria should have in order to provide the appropriate help to the people that they are taking care of.
What is more, the program aims at developing a new common training tool in Greece and Bulgaria, so as the qualifications of anyone who wishes to migrate from one country to another and work as a caregiver to be recognized. So, for instance, Bulgarian citizens who wish to immigrate to Greece and Bulgarians that had been trained in Greece and want to return to their country will have the possibility to receive training that would be recognized by both countries.
One more aim is the creation of a network of entities involved in the home care sector in Greece and Bulgaria, in order to improve the quality of the care services offered to elderly people and people suffering from dementia. Finally, this educational program wishes to involve the public bodies, so as to provide a broad and effective action in support paid caregivers.
The basic didactic units of the program are:
1) Introduction of the educational program
2) Understanding the role of the caregiver
3) Relate and communicate with the elderly and the family
4) Pathologies in elderly people
5) Assisting people with Alzheimer’s disease and other Dementias
   5. 1) Understanding Memory function
   5.2) Getting to know about Dementia and Alzheimer’s disease
   5.3) Getting to know about behavioral Disorders in Dementia
   5.4) Care management of people with Dementia
   5.5) Simple activities for people suffering from dementia
   5.6) The caregivers’ burden
6) Take care and assist elderly and people with dementia
6.1) Physical mobility
6.2) Personal hygiene
6.3) Nutrition
6.4) Nutrition for the Elderly
6.5) Simple instructions about food Safety
6.6) Management of Emergencies
6.7) Simple instructions about the right body posture
6.8) Housekeeping advices
7) Health system and social system in Greece / in Bulgaria
8) Migration policy in Greece
9) Description of Carer’s Job
10) The use of the basic computer science and Internet
   10.1) Knowing computer components
   10.2) The use of the computer
   10.3) Learning more about Internet

<table>
<thead>
<tr>
<th>Leader organisation(s)</th>
<th>Athens Association of Alzheimer's Disease and Related Disorders Εταιρεία Νόσου Alzheimer και Συναφών Διαταραχών αθηνών</th>
</tr>
</thead>
</table>
| Other organisations    | • Family and Child Care Center  
                          • Anziani e Non Solo  
                          • BALKANplan Ltd  
                          • 01 PLIROFORIKI EKPEDEFTIKI  
                          • The municipality of Korydallos  
                          • National Patients’ Organization  
                          • The Greek-Bulgarian Culture Association |
| Contact details        | Athens Association of Alzheimer's Disease and Related Disorders  
                          Mrs Areti Efthymiou  
                          (+30) 210 7013271 |
| Website                | www.setcare.eu |
| Date of data collection| March, 2013 |

**BACKGROUND**

**The socio-demographic context in Greece**

Immigration in Greece is quite a new phenomenon as it started in the 1990’s. Nowadays, immigrants make up a large proportion of the Greek population. Particularly, the total number of documented immigrants from the 2001 census is 693,837. The majority of immigrants are nationals of neighboring Balkan countries, such as Albania and Bulgaria. Immigrants from Albania are estimated to be more than half of all immigrants (57,5%) and the second largest group are those from Bulgaria (4,6%), followed by immigrants from Georgia (3,0%), Romania (2,9%) and Russia (2,3%).

According to the 2001 census, nearly the half of the immigrants has completed secondary
education (including technical school). Comparing women to men immigrants, women seem to have a higher education level, as 16% of women compared to 7% of men have studied at the graduate level, 57% and 49% of women and men, respectively, have secondary education, and finally, 25% and 43% have primary education.

As we mentioned above the second largest migration population in Greece comes from Bulgaria. The majority of Bulgarian immigrants are women, in middle age, sometimes retired in Bulgaria with secondary education even with tertiary education. However, they choose to work in jobs with a low demand of competences, as babysitting, domestic help, carers of elderly persons, agriculture work. Bulgarian women were the 6.1% (21,216) of the immigrants women in Greece and the main reason for migration is for financial reasons. Migration rates depend on migration policy in Greece. In 2007, migration policy was simplified for Bulgarian people due to our participation in European Monetary Fund. In that state, the number of immigrants coming from Bulgaria has raised in comparison with previous years.

What is more, we observe that the ageing process of European population has impact not only on the health care field, but also on labour, Vocational and Educational Training (VET) and migration policies and process. The number of elderly people in Greece has increased in the last 10 years and has now reached almost the 19% of the population. 200.000 people are estimated to suffer from Dementia and require a qualified assistance which is currently not sufficiently available to most Greek families.

80% of patients with dementia are cared for at home in Greece, often with the support of informal care workers which normally are migrant women, middle aged, with secondary even tertiary education but without specific training in elderly care sector.

20% of home care workers are migrants (this figures includes only legal migrants): 2/3 comes from the ex-Soviet Union and Bulgaria. Migrant care workers usually cover long work-shifts, are often not regularly employed and/or without work permit, do jobs not related to their educational or professional skills and they are therefore not competent to deal with elderly care needs, especially with those related to the dementia disease (Liapi & Vouyoukas, 2006). This implies, beside a low quality of care service provided which can affect the life quality of the dependent person, also a high risk of burn out, low safety, low employability and career opportunities.

On the other hand, the Greek VET system currently does not offer a training which could fit the needs of this category of workers: flexibility, low cost, no language barriers. To answer these needs, the LDV- Tranfer of Innovation project: SET CARE: Self-study E-learning Tool for the Social Home-care Sector intends to transfer in Greece and Bulgaria a training tool (ASPASIA), originally developed in Italy, which provides training on elderly care making use of e-learning. The educational materials, currently available in 7 languages, have been adapted and translated in Greek and Bulgarian and are available either via internet or via DVDs.
The legislative framework
As mentioned above, the number of elderly people in Greece has increased in the last 10 years and has now reached almost the 19% of the population. 200,000 people are estimated to suffer from Dementia. However, the sector of demented or disabled elderly people care has started developing the last years. Consequently there are not many public or private structures to provide the help and care that these people need. The number of demented patients is quite large and it is impossible for all of them to access the care they need. Especially, people from rural areas do not have the same opportunities as people from urban areas. That is why we think that an e-learning education program will be very helpful for these people. Their caregivers, either unpaid family carers or paid ones will be able to attend the educative project and be informed on all the aspects referring to the elderly persons’ care.

INITIATIVE

Rationale
This program was first developed and implemented in Italy thanks to the nonprofit organization Anziani e non solo and was bearing the name Aspasia. It has been translated in 7 languages (Italian, English, French, Spanish, Russian, and Arabic). The program aimed at distance learning, thanks to technology and intended to include issues related to elderly people care. The present program however, has transferred in Greece and Bulgaria the program that firstly was developed in Italy and we aim at educating unpaid and paid caregivers, either from Greece or Bulgaria. However, at the moment, immigrants that have come to Greece from other countries and wish to participate will have the possibility to do so, as far as they know the Greek language. As said before most caregivers do not know how to deal with elderly people and are unaware of their special needs. In the meanwhile, the Greek Vocational and Educational Training (VET) does not offer a training which could fit the needs of this category of workers: flexibility, low cost, no language barriers. That is why we think that this program will be very useful for the carers. As all the distance learning program, the present as well gives them the ability to learn things in a flexible way. It is them that choose the “WHERE” and “WHEN” they will attend it. In addition, they assess “WHAT” they need to study again. Attending the new program, they will have the opportunity to be educated and learn information about older persons’ care. All of the participants have access to all the units mentioned above. The duration of each unit varies and depends on the topic developed and the amount of information that will meet their needs. The units are accompanied by video, assessment test and exercises and are all provided through an electronic platform both in Greek and Bulgarian language. The participants, who do not have access to the internet, can instead attend the courses via DVD, which contains the same material.

Specificities and innovation
SET CARE project for first time introduces the needs of this specific target population: migrant woman working in the care home sector in Greece and Bulgaria. There is no such initiative in this domain and no VET for this target population in these two countries. At this moment, the project is in the phase of dissemination. Through workshops, seminars, conferences the project is trying to
reach the target population. Women working in home care sector need motivation to attend educational programs during their day off. This program gives the alternative of being educated without leaving their daily routine.

SET CARE is an educational program for informal carers and paid carers of senior people with disabilities.

The educational program consists of units referring to all aspects relative to senior age: major health problems, dementia, every day care of disabled elderly people, helping them at home, etc. A caregiver participating in SET CARE program will learn how to manage all problems and difficulties that senior adults face and to recognize the real emergency cases. Furthermore, caregivers will learn to deal with the everyday life aspects of disabled people. Consequently, SET CARE provides all the necessary knowledge for a caregiver to take care of a senior person at home. What is more, caregivers have the chance to learn about the municipal services available (i.e. help at home programs, etc.), which can prove helpful in the management of the older person’s difficulties. So, we think that SET CARE matches with the main goal of AIDA project and contributes to the reduction of institutionalization of older adults. Caregivers will learn how to provide qualified care to the disabled person at home and in some cases delay the use of expertise help. We think that SET CARE can strengthen effectively the home care services network.

### Service model and integration patterns

<table>
<thead>
<tr>
<th>Level of organisational integration of care</th>
<th>Linkage: users are appropriately cared for within systems that serve the whole population (not for specific target groups), e.g. older people are cared for by services addressing all people with long-term care needs (and not by special services for older people only).</th>
<th>Coordination: explicit structures and individual managers are installed to coordinate benefits and care across different providers; structures are still separate, e.g. sharing clinical information in a planned manner, managing transitions between settings, assigning primary responsibility for coordinating care</th>
<th>Networking: different care providers establish detailed protocols and intervention models, as part of a joint program</th>
<th>Full integration: creation of new structures or units dedicated to the specific user needs where resources from multiple providers/systems are pooled, e.g. organisation of multidisciplinary teams managing all care, control or direct provision in all care settings</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
</tbody>
</table>

The services offered are e-learning courses for elderly care. Participants are able to receive Certification through examinations. This is an attempt to recognize paid carer as a profession with specific training needs. Before receiving the educational material, paid carers receive information of the way they can use the material and the possibility of certification.

Municipalities are involved in this project by trying to integrate e-learning training to Help at Home program of Municipalities.

Greek Bulgarian associations are also involved in order to communicate the tool to target population.
**Target population**
The project targets 4 main groups:

- Bulgarians living in Greece employed (or looking for a job) as care workers
- Bulgarians living in Bulgaria employed (or looking for a job) as care workers
- Persons engaged in the field of home care services, who want to qualify themselves in order to provide better quality of care and have more job opportunities
- Family carers who want to receive information about Dementia and other pathologies of Elderly and want to provide better quality of care

In order to assess the quality of the e-learning tool, a pilot phase was conducted in July 2012 in Greece and Bulgaria. Care workers and other Stakeholders had the opportunity to assess a demo of set care program.

We found that the majority of the participants have supported elderly with Dementia. As we have already discussed, 200.000 persons suffer from dementia in Greece and 100.000 in Bulgaria. This numbers will increase in next decades. 90% of people with dementia are cared for at home by family members and paid carers. Our participants think that this educational program will be very helpful for them especially for the management of the everyday care of the elderly. Finally, they stated that the training tool is clear and in plain language.

**Financial aspects and sustainability strategies**
The initiative in this stage is still financed by EU Lifelong learning funds. The costs of the project are: staff costs, development of e-learning courses, dissemination and exploitation costs. At the end of the funding period, the costs will involve mainly maintenance of the web platform and a well developed network to continue with training activities and to assist in making the program popular among paid carers.

**Partners involved**
- Athens Association of Alzheimer’s Disease and Related Disorders: is a non profit organisation founded in 2002 by dementia patients’ relatives, doctors, psychologists and other health professionals interested in Alzheimer’s disease. Its role to the project is the adaptation, translation of the program and the development of the new information added.
- Family and Child Care Center: is a leading Greek NGO with strong expertise in social inclusion, gender equality, immigrants, employability, VET and citizenship, with a focus on vulnerable social groups such as women, immigrants, one parent families and elderly people.
- Anziani e Non Solo: is a cooperative which associates professionals as well as other organisations working in the field of social innovation. ANS areas of expertise are social research, training, e-learning and community projects.
• BALKAN plan Ltd provides consultancy services, technical support and project materialization in the following sectors: Education and training; Information and communication technologies; Research and technological development; International relations. Its role in the project is the development of the tool and the translation in the Bulgarian language.

• 01 PLIROFORIKI EKPEDEFTIKI is a leader Greek based IT Company established in Athens, since 1987. It offers integrated services to organisations of the public and the private sector, both at national and international level, from qualified permanent staff and a pool of national and international experts in all relevant fields of IT consulting, IT integration systems, e-learning and vocational training. Its role to the project is to make the educational tool available in electronic form.

• The municipality of Korydallos is a local authority in the region of Attica, which is responsible by the law in a wide range of areas as the social sector, the environment, the public services, the local development and the training. The field of its activities is focused in the development of the city. Its role in the program has to do mainly with the dissemination of the project.

• National Patients’ Organization has built up a network of NGO partner organizations from all over Bulgaria. These organizations cover a huge variety of diseases. Since June 2010 National Patients’ Organization is proclaimed as a nationally representative patients’ rights organization by the Minister of Health of Bulgaria.

The Greek- Bulgarian Culture Association is a cultural and educational non-profit organization that has been established by Bulgarians immigrants who live and work in Athens.

**Strengths and weaknesses**

**Strengths:**

- Carers will have the chance to learn in details all the aspects of the everyday help and care of elderly persons
- They will be informed about the third age and the health problems that arise
- They will learn details about dementia and Alzheimer’s disease
- They will be able to cope with all the special problems that may arise when taking care a person with dementia
- Carers will learn more specific information about their work and the relationship they should develop with the elderly
- Immigrants will have the opportunity to learn about the immigration policy and to become aware of all the services that may prove helpful for them
- Bulgarian people will be helped to learn better the Greek language as the material is available on both Greek and Bulgarian language
- People can attend the educational program via internet or via DVDs. As a result, they can choose the day and the time of the day that they want to attend it. They also can decide how much time they can devote to each educational unit.
Participants will have the opportunity to receive a certification of attendance, after succeeding in the final examination. As a result they will be more competitive in the labor market.

**Weaknesses:**
We are not able at the moment to translate the whom project in other languages as well. For example as far as the needs of our country are concerned, we think that it would be useful to have our program translated in Albanian, Russian, Romanian and Georgian language as well.

**Impact assessment and performance evaluation**
In order to assess the quality of the e-learning tool, a pilot phase was conducted in July 2012 in Greece and Bulgaria. Careworkers and other Stakeholders had the opportunity to assess a demo of set care program. The demo contained 4 educative units about:

- pathologies of elderly people
- dementia and Alzheimer’s Disease
- mobility of elderly people and
- health services in Greece

In order to assess the educational material, two questionnaires were developed. The aim was to gather epidemiological data and to assess the units for:

1) understanding
2) appropriateness of scientific knowledge
3) language learning
4) quality of audiovisual elements
5) usability of the DVD

Most of the participants think that the program will help them in several ways (awareness about dementia, vocational training, management of practical issues, learning to use PC). They also think that the program will most importantly help them in management of everyday difficulties in caregiving. What is more the majority of the participants assessed the units as easy enough to understand.

As far as the stakeholders are concerned, they all have found the e-learning tool environment well designed, they would propose the program to others and they think that the program will offer vocational training.

**Reproducibility and transferability**
We think that it would be very useful if we could translate and adopt the programme to other languages as well. As we said before, the majority of immigrants in Greece come from Albania. Also, some other countries of origin of many immigrants are Georgia, Russia and Romania. Consequently the transfer of the programme and adaptation to these languages would prove to be very helpful. That way, our target groups would be more.
**Future developments and possible implementations**

As mentioned above an interesting future development is to adopt and translate the project into more languages, to involve in a higher degree Municipalities and receive funding from public resources.

**References**


You can also visit [www.setcare.eu](http://www.setcare.eu) and our facebook page [https://www.facebook.com/setcare.eu](https://www.facebook.com/setcare.eu)
References


Annex 1 - Validated list of selection criteria

<table>
<thead>
<tr>
<th>Column 1</th>
<th>Column 2</th>
<th>Column 3</th>
<th>Column 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>N.</td>
<td>Criteria</td>
<td>Values</td>
<td></td>
</tr>
</tbody>
</table>

**A - Inclusion criteria**

<table>
<thead>
<tr>
<th>1</th>
<th>Care setting(s) in which the initiative is implemented (multiple choice possible)</th>
<th>Private homes (e.g. dependent or semi-independent users receiving home care and/or telecare/telehealth at home)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Day and short-term care setting (e.g. dependent or semi-independent users receiving health, social or long-term care services in a location other than users’ own homes)</td>
<td>Assisted living facilities/sheltered housing (e.g. dependent or semi-independent users living in social or private housing that has been modified to suit people with long-term conditions or disabilities)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Nursing homes (e.g. dependent users living in residential care placements, including nursing homes and care homes)</td>
<td>Hospitals (e.g. dependent users receiving acute or post-acute care in an health care institution, which is however involved in a programme for integrated health and social care)</td>
<td></td>
</tr>
</tbody>
</table>

| 2 | What methods and strategies of integrated care the initiative applies (multiple choice possible) | Case and care management: to build up a network of services (resources) over time and across services and to empower the patient and his/her relatives to use it self-reliantly | |
|   |                                                                                       | Intermediate care: to provide to frail older people (and their family), who often do not know where to turn to in case of need and where to retrieve information, rapid intervention and quick, non-bureaucratic support (e.g. geriatric teams following up users at home) | |
|   |                                                                                       | Multiprofessional needs assessment and joint planning: assessment that considers social, psychological, medical and rehabilitation aspects, i.e. carried out by an interdisciplinary and multidimensional team | |
|   |                                                                                       | Housing, welfare and care: to create pro-active, open and innovative neighbourhood-centres (e.g. residential facilities) providing all kinds of services and facilities to the users | |
|   |                                                                                       | Supporting family carers: to empower family carers about prevention and actual support services available in co-operation with formal services (e.g. training and information services, respite services) | |

<p>| 3 | Practice guidelines and protocols are developed and implemented by a joint collaboration of different professionals | Yes | |
|   |                                                                                       | No | |
|   |                                                                                       | Do not know/information not available | |</p>
<table>
<thead>
<tr>
<th>N.</th>
<th>Criteria</th>
<th>Values</th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td>Maturity / Stage of development</td>
<td><strong>Terminated initiative</strong>: it covers all projects/services (i.e. at local, regional, national level) that have been implemented as pilots or as operational for a certain period prior to discontinuation</td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>Ongoing initiative</strong>: it covers all projects/services (i.e. at local, regional, national level) that are currently implemented as pilots or as operational for a certain period (they are not fully integrated with the care system and other stakeholders, future perspectives are not clear)</td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>Implemented practice</strong>: it regards all projects / services (i.e. at local, regional, national level) that have been running with success, are integrated with the care system and other stakeholders (they have a long-term activity plan)</td>
</tr>
</tbody>
</table>

### B - Selection criteria

**Operational aspects of the initiative**

<table>
<thead>
<tr>
<th>Column 1</th>
<th>Column 2</th>
<th>Column 3</th>
<th>Column 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>Length of time since the initiative was introduced</td>
<td>&lt;2 year</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>2-4 years</td>
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<tr>
<td></td>
<td></td>
<td>&gt;4 years</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Do not know/information not available</td>
</tr>
<tr>
<td>6</td>
<td>Geographical coverage</td>
<td>Local (one locality/city)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Local (multiple localities/cities)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Regional (coverage of one or more regions)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>National (full coverage)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Do not know/information not available</td>
</tr>
<tr>
<td>7</td>
<td>Number of users aged 65+ who accessed the initiative during last year</td>
<td>&lt;100 users</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>101-500</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>501-1,000</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>1,001-3,000 users</td>
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<td></td>
<td></td>
<td>3,001-10,000 users</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>&gt;10,000 users</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Do not know/information not available</td>
</tr>
<tr>
<td>8</td>
<td>Accessibility of the initiative</td>
<td>Universal (i.e. based on needs assessment only)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Means-tested</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Do not know/information not available</td>
</tr>
<tr>
<td>9</td>
<td>Financial sustainability of the initiative</td>
<td>Initiative is self-running without any financial problems/issues: it is financially sustainable in the long term (e.g. funds are retrieved from own, autonomous resources)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Initiative is only partially funded/could not continue due to financial problems/lack of stable support (e.g. funds are retrieved from one or multiple sources which can autonomously decide to change the amount over time)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Initiative will end when funds are time-limited and/or there is no long-term sustainability plan (e.g. funds are retrieved from specific research or intervention projects)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Do not know/information not available</td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>The initiative requires a co-</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>Column 1</td>
<td>Column 2</td>
<td>Column 3</td>
<td>Column 4</td>
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</tr>
<tr>
<td><strong>N.</strong></td>
<td>Criteria</td>
<td>Values</td>
<td></td>
</tr>
<tr>
<td>payment by users</td>
<td>No</td>
<td>Do not know/information not available</td>
<td></td>
</tr>
<tr>
<td>The initiative involves volunteers on a regular basis to deliver care to users and/or support to their families</td>
<td>Yes, volunteers are systematically involved in the process of delivering care and/or support</td>
<td>No, volunteers are rarely involved or not at all enrolled</td>
<td>Do not know/information not available</td>
</tr>
</tbody>
</table>

**Aspects of integration of the initiative**

12 Level of organisational integration of care

|  | Linkage: users are appropriately cared for within systems that serve the whole population (not for specific target groups), e.g. older people are cared for by services addressing all people with long-term care needs (and not by special services for older people only). | Coordination: explicit structures and individual managers are installed to coordinate benefits and care across different providers; structures are still separate, e.g. sharing clinical information in a planned manner, managing transitions between settings, assigning primary responsibility for coordinating care | Networking: different care providers establish detailed protocols and intervention models, as part of a joint programme | Full integration: creation of new structures or units dedicated to the specific user needs where resources from multiple providers/systems are pooled, e.g. organisation of multidisciplinary teams managing all care, control or direct provision in all care settings |
| 13 | Different care providers involved in the initiative integrate, share and contribute to personal user data via an ICT-based system | Yes | No | Do not know/information not available |
| 14 | A telecare and/or telehealth system is implemented within the initiative | Yes | No | Do not know/information not available |
| 15 | Care providers that run the initiative offer support to family carers | Yes, in terms of coordination of care and/or improved relations with formal care providers | Yes, in terms of tailored information | Yes, in terms of proper training and/or education courses | Yes, in terms of psychological and emotional support | Yes, in terms of relief and respite care | No | Do not know/information not available |
| 16 | Standard diagnostic criteria are used within the initiative | Yes, the initiative applies diagnostic criteria standardised at national or international level | No, the initiative applies diagnostic criteria not standardised at national or international level | Do not know/information not available |
| 17 | Joint/shared needs assessment | Yes | No | |

121
<table>
<thead>
<tr>
<th>N.</th>
<th>Criteria</th>
<th>Values</th>
</tr>
</thead>
<tbody>
<tr>
<td>and care planning are implemented within the initiative with the involvement of users and/or carers</td>
<td>Do not know/information not available</td>
<td></td>
</tr>
<tr>
<td>18</td>
<td>A quality management system concerning care provision is implemented</td>
<td>Yes, certified quality management system</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Yes, own quality management system</td>
</tr>
<tr>
<td></td>
<td></td>
<td>No</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Do not know/information not available</td>
</tr>
</tbody>
</table>

**Outcomes and impact of the initiative**

| 19 | An impact assessment of the initiative is carried out with positive results | Yes, the initiative is regularly assessed (e.g. routinely on a yearly basis) and positive results emerged |
| | | Yes, the initiative was assessed once or occasionally and positive results emerged |
| | | Partially, only some aspects have been assessed and/or partial positive results emerged |
| | | No evidence available of impact assessment or no positive results have been demonstrated |
| | | Do not know/information not available |
| 20 | A performance evaluation of the initiative is carried out with positive results | Yes, the initiative is regularly evaluated and positive results emerged |
| | | Yes, the initiative was evaluated once or occasionally and positive results emerged |
| | | Partially, only some aspects have been evaluated and/or partial positive results emerged |
| | | No evidence available of performance evaluation or no positive results have been demonstrated |
| | | Do not know/information not available |
| 21 | The initiative has been demonstrated to be cost-efficient / cost-effective | Yes |
| | | No |
| | | Do not know/information not available |
## Annex 2 - Long list of initiatives

<table>
<thead>
<tr>
<th>Name of the initiative</th>
<th>Country</th>
<th>Care regime</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care Trusts – Structural integration of health and social care</td>
<td>United Kingdom</td>
<td>Anglo-saxon</td>
<td>INTERLINKS</td>
</tr>
<tr>
<td>Single assessment process</td>
<td>United Kingdom</td>
<td>Anglo-saxon</td>
<td>INTERLINKS</td>
</tr>
<tr>
<td>Hospital discharge unit/lounge</td>
<td>United Kingdom</td>
<td>Anglo-saxon</td>
<td>INTERLINKS</td>
</tr>
<tr>
<td>Improving the hospital discharge of older people who are resident's of care homes</td>
<td>United Kingdom</td>
<td>Anglo-saxon</td>
<td>SSIA</td>
</tr>
<tr>
<td>Conferences of health and care related sectors at the local level</td>
<td>Germany</td>
<td>Continental</td>
<td>INTERLINKS</td>
</tr>
<tr>
<td>Quality labelling throughout the country for “Single points of contact”, the “Maisons pour l’intégration des malades Alzheimer (MAIA)”</td>
<td>France</td>
<td>Continental</td>
<td>Plan Alzheimer</td>
</tr>
<tr>
<td>HAH-OP: Hospital at home for older people</td>
<td>France</td>
<td>Continental</td>
<td>INTERLINKS</td>
</tr>
<tr>
<td>Living comfortably in Menterwolde</td>
<td>Netherlands</td>
<td>Continental</td>
<td>INTERLINKS</td>
</tr>
<tr>
<td>Mobile Palliative Teams (MPT)</td>
<td>Austria</td>
<td>Continental</td>
<td>INTERLINKS</td>
</tr>
<tr>
<td>Sunny Dale</td>
<td>Slovenia</td>
<td>Eastern European</td>
<td>EU Conference “Mental Health and Well-being in Older People”</td>
</tr>
<tr>
<td>Emergency Alarm</td>
<td>Hungary</td>
<td>Eastern European</td>
<td>CARICT</td>
</tr>
<tr>
<td>Integrated care in a Hospital with Polyclinic</td>
<td>Slovakia</td>
<td>Eastern European</td>
<td>INTERLINKS</td>
</tr>
<tr>
<td>Integrated psychiatric care in a hospital setting</td>
<td>Slovakia</td>
<td>Eastern European</td>
<td>INTERLINKS</td>
</tr>
<tr>
<td>Skype in eldercare</td>
<td>Hungary</td>
<td>Eastern European</td>
<td>CARICT</td>
</tr>
<tr>
<td>SAM:BO</td>
<td>Denmark</td>
<td>Nordic</td>
<td>INTERLINKS</td>
</tr>
<tr>
<td>ACTION</td>
<td>Sweden</td>
<td>Nordic</td>
<td>CARICT</td>
</tr>
<tr>
<td>Norrbotten</td>
<td>Sweden</td>
<td>Nordic</td>
<td>EXPERT</td>
</tr>
<tr>
<td>Vinnvård program</td>
<td>Sweden</td>
<td>Nordic</td>
<td>EXPERT</td>
</tr>
<tr>
<td>Skaevinge-Project</td>
<td>Denmark</td>
<td>Nordic</td>
<td>INTERLINKS</td>
</tr>
<tr>
<td>E-CARE</td>
<td>Italy</td>
<td>Southern</td>
<td>CARICT</td>
</tr>
<tr>
<td>Project Description</td>
<td>Country</td>
<td>Region</td>
<td>Programme</td>
</tr>
<tr>
<td>---------------------</td>
<td>-----------</td>
<td>------------------</td>
<td>------------</td>
</tr>
<tr>
<td>Integrated access point for older people</td>
<td>Italy</td>
<td>Southern European</td>
<td>INTERLINKS</td>
</tr>
<tr>
<td>The RAI System</td>
<td>Spain</td>
<td>Southern European</td>
<td>INTERLINKS</td>
</tr>
<tr>
<td>Protected hospital discharge and palliative care teams</td>
<td>Italy</td>
<td>Southern European</td>
<td>INTERLINKS</td>
</tr>
<tr>
<td>Andalusian Telecare Service</td>
<td>Spain</td>
<td>Southern European</td>
<td>CARICT</td>
</tr>
<tr>
<td>“Home Help for the Elderly”: The case of (multiple) public involvement</td>
<td>Greece</td>
<td>Southern European</td>
<td>PROCARE</td>
</tr>
<tr>
<td>Red cross Home Health Programme</td>
<td>Greece</td>
<td>Southern European</td>
<td>PROCARE</td>
</tr>
<tr>
<td>Alzheimer Hellas-Greek association of Alzheimer disease and relative Disorders</td>
<td>Greece</td>
<td>Southern European</td>
<td>WEDO</td>
</tr>
<tr>
<td>SET CARE: Self-study E-learning Tool for the Social Home-care Sector</td>
<td>Greece</td>
<td>Southern European</td>
<td>EXPERT</td>
</tr>
</tbody>
</table>
**Annex 3 - Inquiry Form for reporting information on 10 good practices**

[name of initiative in English]  
[name of initiative in original language]

[author(s)]  
[affiliation]

<table>
<thead>
<tr>
<th>Leader organisation(s)</th>
<th>[organisation(s) in charge of coordinating the initiative: name in original language and in English]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other organisations</td>
<td>[other organisations involved in implementing the initiative: names in original language and in English]</td>
</tr>
<tr>
<td>Contact details</td>
<td>[name of the contact person, address, phone number, e-mail]</td>
</tr>
<tr>
<td>Website</td>
<td>[if any]</td>
</tr>
<tr>
<td>Date of data collection</td>
<td>[month when the case study has been written]</td>
</tr>
</tbody>
</table>

**ABSTRACT**

[A brief description of the initiative, 400-600 words]
BACKGROUND

1.1. The socio-demographic context in the [region/country where the initiative is implemented]

In this section, you are kindly asked to describe the main social and demographic aspects of the area where the initiative is implemented. This includes a short overview concerning the characteristics of the targeted population (e.g. percentage of older people, socio-economic conditions, most relevant health problems) and of the public/private care system (including services provided and gaps). It would be helpful to underline recent social and demographic developments and future trends in the area where the initiative is implemented.

1.2. The legislative framework in the [region/country where the initiative is implemented]

In this section, you are kindly asked to describe the most important normative documents (both at local, regional and national levels, if it is relevant) that apply to the sector of long-term care services and benefits for older people in the area where the initiative is implemented. It would be helpful to underline points of strengths and weaknesses of the overall legislative framework.
INITIATIVE

2.1. Rationale

Text (300-500 words)

In this section, you are kindly asked to describe reasons why your initiative was developed, who was the initiating person/group, what needs/gaps in previous care delivery were discovered and what were the overarching goal and specific objectives your initiative aimed to achieve. This includes a brief overview of developments and improvements of the initiative during time (since its start up to these days).

2.2. Specificities and innovation

Text (200-400 words)

In this section, you are kindly asked to describe the main characteristics of your initiative, e.g. care setting, maturity of the implemented services, length of time since the initiative was introduced, geographical coverage, numbers of users per year, accessibility (e.g. universal, means-tested). It is required to underline the innovative aspects of the initiative, including how the initiative fills gaps of the care system or addresses in a better way user needs.

2.3. Service model and integration patterns

Please insert the level of organisational integration of your initiative by putting a cross near one of the following categories:

<table>
<thead>
<tr>
<th>Level of organisational integration of care</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Linkage:</strong> users are appropriately cared for within systems that serve the whole population (not for specific target groups), e.g. older people are cared for by services addressing all people with long-term care needs (and not by special services for older people only).</td>
<td></td>
</tr>
<tr>
<td><strong>Coordination:</strong> explicit structures and individual managers are installed to coordinate benefits and care across different providers; structures are still separate, e.g. sharing clinical information in a planned manner, managing transitions between settings, assigning primary responsibility for coordinating care</td>
<td></td>
</tr>
<tr>
<td><strong>Networking:</strong> different care providers establish detailed protocols and intervention models, as part of a joint programme</td>
<td></td>
</tr>
<tr>
<td><strong>Full integration:</strong> creation of new structures or units dedicated to the specific user needs where resources from multiple providers/systems are pooled, e.g. organisation of multidisciplinary teams managing all care, control or direct provision in all care settings</td>
<td></td>
</tr>
</tbody>
</table>

Text (300-500 words)

In this section, you are kindly asked to describe in detail how the initiative works, including what services are offered and what level of integration of health and social care is obtained. This includes a brief description concerning at least the following themes: level of organisational integration of care (description of the category chosen above), types of services provided, practice guidelines and protocols developed, human resource involvement (e.g. if volunteers are
engaged for delivering services), implementation of any telecare/telehealth system or technological devices, implementation of any support services for family carers, use of standard diagnostic criteria, joint needs assessment and care planning with user involvement, any quality management system.

2.4. Target population

In this section, you are kindly asked to describe the profile of your target users, including also eventual data and estimations on real users and potential target population in the geographical area covered by the initiative.

2.5. Financial aspects and sustainability strategies

In this section, you are kindly asked to present a general – rough – overview over financial aspects, among the others: the overall yearly budget of the initiative, what were the start up costs and current implementation costs (at least what types of costs you have), how the initiative is financed (e.g. if it is self-running in a long-term, funds are time-limited, there is a co-payment by users), if it became sustainable during time, what fund raising strategies were adopted, if it is a time-limited project or it constitutes a regular service to users.

2.6. Partners involved

In this section, you are kindly asked to briefly describe each organisation involved in implementing the initiative, including the description of how they work in an integrated way.

2.7. Strengths and weaknesses

In this section, you are kindly asked to indicate through “bullet points” what are the main points of strength and weakness, taking into account the level of innovation of the initiative (e.g. comparing it to ordinary care services) and the potential improvements and benchmarks (e.g. comparing it to other national or international good practices in the sector).
2.8. Impact assessment and performance evaluation

In this section, you are kindly asked to describe – if available – what results your initiative achieved in terms both of impact assessment and performance evaluation, including for instance outcomes for users, outcomes for initiative providers and care system, outcomes for stakeholders, and eventually any cost-efficiency / cost-benefit analysis.

2.9. Reproducibility and transferability

In this section, you are kindly asked to describe if and how your initiative could be reproduced and transferred to other contexts or adapted to other target groups.

2.10. Future developments and possible implementations

In this section, you are kindly asked to describe the medium- and long-term strategy of your initiative, i.e. how you planned to continue implementing it in the future and if any further improvement is scheduled for next years. It would be good to mention also any known change that will occur at organisational level, as well as at social, demographic and policy level if they affect the implementation of the initiative.

References

In this section, you are kindly asked to insert all publicly available materials concerning your initiative, including articles, reports, presentations, on-line resources, etc.