

**STAR** | Skills Training and Re-Skilling  
for Carers of People with Dementia



# D5.1 Stakeholder Analysis

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# Contents

1.	Introduction.....	4
1.1.	The STAR Project.....	4
1.2.	This Report .....	4
2.	European stakeholders.....	5
2.1.	Alzheimer’s Disease International.....	5
2.2.	Alzheimer Europe .....	5
2.3.	The AGE Platform.....	6
2.4.	European Dementia Consensus Network (EDCON) .....	7
2.5.	RemoDem project.....	7
2.6.	Dem@Care project .....	8
2.7.	Innovate Dementia project .....	9
2.8.	CEDEFOP .....	9
3.	UK stakeholders .....	10
3.1.	Age UK .....	10
3.2.	Alzheimer Scotland.....	10
3.3.	Alzheimer’s Society.....	11
3.4.	Dementia UK .....	11
3.5.	SCIE (Social Care Institute of Excellence) .....	12
3.6.	AT dementia .....	12
3.7.	Essex dementia care .....	13
3.8.	Bromley MindCare .....	13
3.9.	BUDS (better understanding of dementia for Sandwell) .....	13
3.10.	Approach, Staffordshire .....	13
3.11.	Older Peoples Mental Health Liaison Team, South Staffordshire .....	14
3.12.	Carers Association Southern Staffordshire.....	14
3.13.	Staffordshire Fire & Rescue Service .....	15
3.14.	The MASE group .....	15
3.15.	CLS Care Services .....	15
3.16.	Housing Twenty One .....	15
3.17.	Other relevant organisations .....	16
4.	Netherlands stakeholders .....	17
4.1.	Alzheimer Nederland (Dutch Alzheimer’s Association).....	17
4.2.	Amsterdam Center on Aging VUmc-VU (ACA).....	17
4.3.	Ideon.....	18
4.4.	Gerion.....	18
4.5.	Meeting centres for people with dementia.....	19
4.6.	Odense Houses .....	19
4.7.	Mezzo .....	19
4.8.	Zet .....	20
4.9.	Hogeschool inHolland .....	20
4.10.	Vrijwilligers Academie Amsterdam (Academy for Volunteers Amsterdam) .....	20
4.11.	Reed Business Education .....	21
4.12.	Health care insurers.....	21
4.13.	Trimbos Institute .....	21
4.14.	Leyden Academy .....	22
4.15.	Into D’mentia.....	22
5.	Italy stakeholders.....	24
5.1.	Auser Regione Lombardia .....	24
5.2.	A.I.M.A. - Associazione Italiana Malattia di Alzheimer .....	25
5.3.	AMA – Associazione Malattia Alzheimer .....	26
5.4.	Federation Alzheimer Italia .....	26
5.5.	Società Italiana di Gerontologia e Geriatria.....	26
5.6.	Associazione Alzheimer Bergamo.....	27

6.	Sweden stakeholders .....	28
6.1.	Svenskt Demenscentrum .....	28
6.2.	Vuxenskolan .....	29
6.3.	Demensföreningen.....	29
6.4.	Demensförbundet .....	29
6.5.	Alzheimerföreningen .....	30
6.6.	Norrbottnen Regional Health Council .....	30
6.7.	Demens Kunskap & Tips.....	31
6.8.	Om Alzheimer .....	31
7.	Malta stakeholders.....	32
7.1.	Malta Dementia Society. ....	32
7.2.	Ministry of Health, the Elderly and Community Care .....	33
7.3.	Care Malta Ltd. ....	33
7.4.	Care Malta Ltd. ....	34
7.5.	Caritas Malta.....	35
7.6.	MCAST .....	36
7.7.	University of Malta - Faculty of Health Science .....	38
7.8.	University of Malta - European Centre for Gerontology .....	39
7.9.	Other relevant organisations .....	39
8.	Romania stakeholders .....	41
8.1.	Societatea Romana Alzheimer (SRA) .....	42
8.2.	Centrul Medical de Diagnostic si Tratament Promemoria.....	42
8.3.	Centrul Memoriei.....	42
8.4.	Asociatia Tinerilor Medici Geriatri.....	43
8.5.	Hospice Casa Sperantei Brasov .....	44
9.	Conclusions .....	44
9.1.	Differences Between Countries.....	44
9.2.	STAR Collaboration Network .....	46
9.3.	Next Steps .....	46

# 1. Introduction

## 1.1. The STAR Project

<http://startraining.eu>

The STAR project is creating an educational platform with associated methodology and content for improving the skills of carers for People with Dementia. The content is based on leading dementia expertise and will be distributed in a dual-layer online community structure. In particular, new technology-based interventions for monitoring and supporting will be covered by the educational modules. Web-based access (also in mobiles and TV sets) is supported.

This will enable skilling and re-skilling for appropriate professional care for persons with dementia, even when still living in their homes and with their family.

STAR started in December 2010 and will complete in November 2013. Training pilots in UK, Netherlands, Sweden and Italy will begin after recruitment of stakeholders and pilot users from September 2012 and onwards. Vocational training organizations, care providers and dementia associations in all countries are welcome to contact us for possible collaboration on making online courses available in more languages.

In *WP5 Vocational Stakeholders Workshops*, a stakeholders meeting at a European level has been held in Stafford UK on 2012-05-23, to promote the portal, as well as to meet with UK and European stakeholders. The workshop was recorded and can be seen again at the project website.

Smaller stakeholder meetings for promoting the STAR portal and engage stakeholders for pilots have been organized in The Netherlands, Sweden, Malta, Italy and Romania. The European Workshop 25<sup>th</sup> May 2012 also served also as the UK stakeholder meeting.

In the European and national stakeholder meetings, various stakeholders (medical experts, carers and members of the general public) were presented the STAR platform, with possibilities for users to test early versions of the portal and give their feedback. Moreover, unions of nurses, medical staff, carers, employment agencies, unions of old people and other organisations deemed valid contributors and beneficiaries the project have been invited. External technological experts were not specifically invited, since the STAR consortium has technological expertise from the Ulster University, I+, Vilau and AcrossLimits partners.

## 1.2. This Report

This report *D5.1 Stakeholder Analysis* describes stakeholders relevant for piloting. It is the result of an early inventory of providers of training for carers of persons with dementia, and also the European and national stakeholder workshops. The stakeholder meetings have thus been used to inform the stakeholder analysis, while they also served to support recruiting stakeholders and users for the piloting phase.

It consists of one chapter each for the STAR Countries: UK, Sweden, The Netherlands, Italy, Malta and Romania. In Chapter 2 it briefly reflects upon which European level stakeholders that exist. In the Conclusions chapter, it is described how the European and national stakeholders could work together during the piloting stage, and for preparing sustainable operations after the end of the project.

## **2. European stakeholders**

### **2.1. Alzheimer's Disease International**

<http://www.alz.co.uk/>

#### **2.1.1. Aims and Activities**

Alzheimer's Disease International (ADI) believes that the key to winning the fight against dementia lies in a unique combination of global solutions and local knowledge. As such, it works locally, by empowering Alzheimer associations to promote and offer care and support for people with dementia and their carers, while working globally to focus attention on dementia. The steering board is composed of people from around the world, while the staff team is based in London.

ADI is an international federation of the Alzheimer associations around the world, in official relations with the World Health Organization. Each member is the Alzheimer association in their country who support people with dementia and their families. ADI's vision is an improved quality of life for people with dementia and their families throughout the world.

*STAR project partner VUMC is an active contributor to the ADI community.*

#### **2.1.2. Possible STAR Win-Win Collaboration**

The main potential of ADI is in linking to dementia associations across the world. A collaboration would enable STAR to access global expertise. However, as an international federation the ADI does not itself engage in training and regional activities.

## **2.2. Alzheimer Europe**

<http://www.alzheimer-europe.org/>

#### **2.2.1. Aims and Activities**

Alzheimer Europe (AE) is a non-governmental organisation aimed at raising awareness of all forms of dementia by creating a common European platform through co-ordination and co-operation between Alzheimer organisations throughout Europe. Alzheimer Europe is also a source of information on all aspects of dementia.

AE hopes, through its activities, to answer a growing need in society, and especially among the community of people affected by the existence of the disease. The exchange of experience and knowledge as well as collaboration on new approaches will stimulate and motivate these people.

Further to this, it will ensure that information on best practice in the care of Alzheimer sufferers is available throughout Europe and beyond. As set out in the statutes, the activities are geared towards attaining the following objectives:

- to improve the exchange of information between Alzheimer help associations;

- to stimulate the development of projects in the domains of information, support and caregiving for demented people;
- to establish contacts between Alzheimer help associations in view of setting up and coordinating common transnational projects;
- to arrange for the translation of booklets, pamphlets and other material of interest to various organisations in the member states of the European Union;
- to organise an annual international conference offering participants the possibility to inform themselves about new findings in the fields of research on, and treatment of the Alzheimer disease.

According to their website,

*It is helpful to develop relationships with other organisations in the field whereby we can exchange our experiences and information in order to better achieve success in our campaigns. The development of strategic partnerships is a part of Alzheimer Europe's work plan.*

Alzheimer Europe currently has strategic partnerships with:

- Alzheimer's Disease International
- European Alzheimer's Disease Consortium
- European Patients' Forum
- INTERDEM
- European Association for Palliative Care

## **2.2.2. Possible STAR Win-Win Collaboration**

AE provides information pages similar in overall structure as the STAR modules. AE could provide a route for dissemination of materials and may even provide or share a platform for the expert communities and modules themselves.

Alzheimer Europe could also endorse and promote the STAR training portal.

In October 2013, Alzheimer Europe organises its annual conference, expected to attract more than 400 dementia researchers, experts and practitioners from all of Europe. This conference is a perfect dissemination opportunity for STAR, since it is organised in Malta and we can reschedule a project meeting to coincide with the conference. A strong STAR presence at this conference will bring value also to Alzheimer Europe, since training interventions is strongly in focus for many of their members.

*STAR project partner VUMC actively monitors and contributes to Alzheimer Europe.*

## **2.3. The AGE Platform**

<http://www.age-platform.eu/en>

### **2.3.1. Aims and Activities**

**AGE Platform Europe** (AGE) is a European network of around 167 organisations of and for people aged 50+ which aims to voice and promote the interests of the 150 million senior citizens in the European Union and to raise awareness on the issues that concern them most.

However, AGE Platform does not have a particular interest in dementia, and the term does not appear on their website

### **2.3.2. Possible STAR Win-Win Collaboration**

Its main potential lies in the fact that it is closely concerned with EU policy. AGE could provide a means of publicising STAR outputs and a network for dissemination; and does have an interest in aspects of ageing, including dementia.

*STAR project partners InterNIT and AcrossLimits are collaborating with AGE in the area of ageing at work.*

## **2.4. European Dementia Consensus Network (EDCON)**

<http://www.madariaga.org/publications/57-old/289-edcon-european-dementia-consensus-network>

### **2.4.1. Aims and Activities**

EDCON, hosted by MEF, is a network of European experts in the field of dementia supported by the pharmaceutical company Janssen-Cilag. Its aims are to identify controversial issues concerning the care for people with dementia, to build consensus among all concerned on these issues, and to promote the use of the recommendations developed on the basis of the consensus statement so as to improve care for patients and their caregivers. MEF provided support to EDCON in approaching European institutions, media and decision-makers for the dissemination of EDCON consensus statements.

In 2006, EDCON worked to develop consensus statements on topics such as criteria of the outcomes in the treatment of dementia, a system of care for elderly demented patients, and the possibilities for preventing Alzheimer's disease.

### **2.4.2. Possible STAR Win-Win Collaboration**

EDCON has a weak web presence, and may not be particularly active at present. They have however produced authoritative expert statements on dementia care across Europe, so may have potential for networking.

## **2.5. RemoDem project**

<http://www.northernperiphery.eu/en/projects/show/&tid=107>

### **2.5.1. Aims and Activities**

The Remodem project will develop and test an integrated service package for people with dementia living in remote rural communities which allows and supports them to continue living in their current homes and postpones their placement in institutional care. This will be achieved through modules of support incorporating tested ICT services. The modules will give people with dementia improved access to qualified dementia-specific community support and enable

more cost-efficient care. The modules will respond both to the direct support needs of people with dementia and the needs of others who support them among family and friends, health and care professionals, and care providers. The project is transnational and involves partners in Scotland, Sweden, Norway, the Faeroe Islands, and Greenland.

The project is expected to inform dementia policy development by providing robust evaluation results on the impacts of technology on quality of dementia support and health economics.

The RemoDem will develop a service package that is a decision support tool for use in planning the provision of dementia-related services in remote rural areas. It provides access to technical data and to information on the available evidence on acceptability and efficacy of deployment of different technologies. Dementia-related services include: the direct support of people with dementia; services for informal supporters; professional support services; and services aimed at communities and community members.

RemoDem will be able to support organisations in planning the implementation of national and local dementia strategies. RemoDem modules are arranged so that users can access information on different areas of service provision in line with local priorities.

### **2.5.2. Possible STAR Win-Win Collaboration**

*STAR partner InterNIT is indirectly involved in RemoDem.*

*RemoDem sees training for carers as an important module to be offered as part of its "integrated care template". There is preliminary agreement to make STAR available for this purpose.*

*A joint session "ICT and Dementia" at an international conference is aimed for (to be announced).*

## **2.6. Dem@Care project**

<http://www.demcare.eu>

### **2.6.1. Aims and Activities**

Dem@Care aspires to contribute to the timely diagnosis, assessment, maintenance and promotion of self-independence of people with dementia, by deepening the understanding of how the disease affects their everyday life and behaviour

It implements a multi-parametric closed-loop remote management solution that affords adaptive feedback to the person with dementia, while at the same time including clinicians into the remote follow-up, enabling them to maintain a comprehensive view of the health status and progress of the affected person.

It is an Integrated Project within the 7<sup>th</sup> Framework Programme, with a budget of over 7 million EUR.

### **2.6.2. Possible STAR Win-Win Collaboration**

Possible joint dissemination with Dem@Care.

*STAR partners InterNIT and Ulster University are indirectly involved in Dem@Care. A joint session "ICT and Dementia" at an international conference is aimed for (to be announced).*

## 2.7. Innovate Dementia project

<http://www.innovatedementia.eu/en>

### 2.7.1. Aims and Activities

Ageing is a large socio-economic threat in North West Europe and a top priority issue at European level. The Innovate Dementia project aims at boosting innovation and employment by strengthened cooperation at the international level. Therefore the project has been developed with seven partners from Northwest Europe. The Innovate Dementia project has been made possible by the INTERREG IVB NWE programme. It started in April 2012 and will end in March 2015.

Innovate Dementia is a project to promote innovative care for people living with dementia. Dementia is a leading psychiatric condition for people over 60. It is a slowly progressing, non curable, condition with approximately 70% having Alzheimer disease. 60% of all care is given by informal (family) carers and most of them are overburdened. Dementia needs higher recognition as cases are expected to double in 2025. Managing this potential threat to North West Europe (NWE) society in a cost-efficient way requires innovative approaches presenting opportunities for new businesses and employment as well as concerted action by business and policy makers at all regional levels.

Innovative and sustainable solutions will be developed and tested in Living Labs and will take account of the socio-economic challenges concerned with ageing and dementia.

### 2.7.2. Possible STAR Win-Win Collaboration

Possible dissemination via Innovate Dementia of the STAR portal as an innovative intervention.

## 2.8. CEDEFOP

<http://www.cedefop.europa.eu>

### 2.8.1. Aims and Activities

Cedefop's mission is to support development of European VET policies and contribute to their implementation.

Cedefop's strategic objective is to 'strengthen European cooperation and support the European Commission, Member States and social partners in designing and implementing policies for an attractive VET that promotes excellence and social inclusion'.

The strategic objective is supported by three medium-term priorities for 2012-14:

- Supporting modernisation of VET systems Careers and transitions
- Continuing VET, adult and work-based learning Analysing skills and
- competence needs to inform VET provision

### 2.8.2. Possible STAR Win-Win Collaboration

CEDEFOP manages the ECVET system, for possible certification resulting from STAR training. In many countries, certification is essential for proving qualifications for professional dementia care jobs. In order for STAR to benefit from certification within the ECVET system, endorsement by a high-profile international organisation (for example Alzheimer Europe) and national recognition of the certification will be important milestones for the future.

## 3. UK stakeholders

This chapter provides brief notes on charities, statutory bodies and other stakeholders which are relevant to the development, piloting and contribution of STAR in the UK. Although there are hundreds of small local charities and regional bodies, the majority of the stakeholders analysed here represent the main national bodies. A few local or regional bodies have been included because they are already involved with STAR, or have something distinctive to offer to its activity.

Essential details for each entry are presented here in narrative form.

### 3.1. Age UK

<http://www.ageuk.org.uk/>

#### 3.1.1. Aims and Activities

Age UK was formed from Help the Aged and Age Concern, two UK charities with a national reach. As dementia becomes an increasingly important issue for charities concerned with Ageing, this subject will rise in prominence for Age UK.

A world in which older people flourish is a world in which older people will:

- be equal citizens with equal rights
- have enough money for a secure and decent life, and have access as consumers to the products and services they need at a price they can afford
- have access to the healthcare and social care they need
- have the opportunity to live healthier longer lives and to enjoy a sense of well-being
- live in homes and neighbourhoods that are safe and comfortable and which enable them to lead fulfilling lives
- have opportunities to participate and contribute as volunteers, active citizens, good neighbours, family members, and workers
- enjoy the benefits of longer life, wherever they are in the world.

#### 3.1.2. Possible STAR Win-Win Collaboration

Age UK could provide a link to the STAR site and disseminate information materials. Age UK has some material on dementia among other age-related conditions

### 3.2. Alzheimer Scotland

<http://www.alzscot.org/>

#### 3.2.1. Aims and activities

Alzheimer Scotland helps people with dementia, their carers and families. Their members include carers, relatives, people with dementia, professionals, groups and organisations. The local services may include:

- day centres providing the chance to socialise and enjoy activities and outings, and giving carers a break (some centres open in the evenings and at weekends too)
- home support services providing company and help to maintain skills and independence at home, while the carer is free to go out (sometimes this is also available overnight)

- drop-in centres where people with dementia and carers can socialise
- support groups for carers and for people with dementia
- carer education helping carers learn more about the illness and how to cope
- one-to-one support to help people with dementia and their families cope with the illness
- welfare rights service
- information and advice on a wide range of dementia related subjects.

### **3.2.2. Possible STAR Win-Win Collaboration**

Potential collaborator/competitor. Runs short face-to-face courses which are accredited in the Professional Excellence Framework. These are different in scope and purpose to the STAR offering but could be complementary

## **3.3. Alzheimer's Society**

<http://alzheimers.org.uk/>

### **3.3.1. Aims and activities**

“Our education and development service aims to transform the culture of dementia care and change lives through the development of an informed and effective workforce. We aim to improve knowledge, skills and understanding of dementia by providing effective support, high quality information, education and training.”

### **3.3.2. Possible STAR Win-Win Collaboration**

By far the most prominent dementia charity. Range of training resources (although nothing like STAR) for professionals, and information sheets for carers. They also run an online forum.

Potential collaborator or links to material. Source of materials.

## **3.4. Dementia UK**

<http://www.dementiauk.org/>

### **3.4.1. Aims and activities**

- Promote and develop Admiral Nursing - a specialist nursing intervention focused on meeting the needs of carers and families of people with dementia
- Provide high quality training for professionals working with older people, carers and people with dementia
- Empower carers to have a voice through Uniting Carers our national network of family carers
- Promote good practice in dementia care
- Work in partnership with the NHS, social services, other voluntary groups, carers and people with dementia
- Contribute to national policy on dementia, older people and carers' issues
- Influence practice and policy development

### **3.4.2. Possible STAR Win-Win Collaboration**

Potential competitor, but catering to a different market. There is a significant overlap between its modules and those of STAR, but they require payment and is aimed at health professionals.

**Dementia UK Training** “provides a wide range of courses to suit practitioners working in the field of health and social care.” Includes a privately-developed e-learning course.

Course Content:

- Module 1 What is dementia?
- Module 2 How does dementia affect behaviour?
- Module 3 Supporting people with mild dementia
- Module 4 Caring well for people with moderate to severe dementia
- Module 5 Caring for yourself and other carers

## **3.5. SCIE (Social Care Institute of Excellence)**

[www.scie.org.uk](http://www.scie.org.uk)

### **3.5.1. Aims and activities**

The Social Care Institute for Excellence (SCIE) improves the lives of people who use care services by sharing knowledge about what works.

They gather and analyse knowledge about what works and translate that knowledge into practical resources, learning materials and services including training and consultancy. Their work includes managers, frontline staff, commissioners and trainers. People and their families who use these services also use their resources.

### **3.5.2. Possible STAR Win-Win Collaboration**

Possible collaborator. Wide range of resources including an e-learning course aimed at professional carers. This provides some good ideas, although the STAR offering will be aimed more at relatives/families.

## **3.6. AT dementia**

<http://www.atdementia.org.uk/>

### **3.6.1. Aims and activities**

Assistive technology for people with dementia.

### **3.6.2. Possible relationship to STAR and further notes**

Possible collaborative partner.

## **3.7. Essex dementia care**

<http://www.essexdementiacare.org.uk/>

### **3.7.1. Aims and activities**

Essex dementia care provides a range of specialist services aimed at promoting activity both mentally and physically for the special needs of the person with dementia. They also provide tailored support for carers including, respite, information, training and the opportunity to meet with other carers sharing similar experiences.

### **3.7.2. Possible STAR Win-Win Collaboration**

Possible collaborator.

## **3.8. Bromley MindCare**

<http://www.bromleymind.org.uk/dementia-services/>

### **3.8.1. Aims and activities**

Range of services for people with dementia and their carers.

### **3.8.2. Possible STAR Win-Win Collaboration**

Possible collaborator.

## **3.9. BUDS (better understanding of dementia for Sandwell)**

<http://www.buds.co.uk/>

### **3.9.1. Aims and activities**

BUDS has developed the following three services in response to local need:

- Befriending Service
- BUDS Clubs
- Carer Support Service

### **3.9.2. Possible STAR Win-Win Collaboration**

Possible collaborator.

## **3.10. Approach, Staffordshire**

<http://www.approachstaffordshire.co.uk/>

### **3.10.1. Aims and activities**

To promote the welfare of older people with mental health needs.

### **3.10.2. Possible STAR Win-Win Collaboration**

A collaborator that is local to STAR partner Staffordshire University so a potential pilot organisation. Approach presented at the STAR European Workshop 23<sup>rd</sup> May 2012.

### **3.10.3. Katharine House Hospice**

<https://www.khhospice.org.uk/>

### **3.10.4. Aims and activities**

Katharine House Hospice provides a range of services offering help, care and support for people with advanced life-limiting conditions across mid-Staffordshire. These conditions include Multiple Sclerosis, Motor Neurone Disease, End Stage Renal failure and Cancer. All services are free of charge.

### **3.10.5. Possible STAR Win-Win Collaboration**

A possible collaborator that is local to STAR partner Staffordshire University, so a potential participant in the piloting stage.

## **3.11. Older Peoples Mental Health Liaison Team, South Staffordshire**

<http://www.southstaffsandshropshealthcareft.nhs.uk/Services/Adult-Mental-Health-Services/Mental-Health-Liaison-Service/Older-Peoples-Mental-Health-Liaison-Team.aspx>

### **3.11.1. Aims and activities**

A local government social care agency.

### **3.11.2. Possible STAR Win-Win Collaboration**

A possible collaborator that is local to STAR partner Staffordshire University, so a potential participant in the piloting stage.

## **3.12. Carers Association Southern Staffordshire**

<http://carersinformation.org.uk/>

### **3.12.1. Aims and activities**

We support unpaid carers of any age in southern Staffordshire, who are looking after a friend or relative, who because of disability, illness or the effects of old age, cannot manage at home without help.

### **3.12.2. Possible STAR Win-Win Collaboration**

A possible collaborator that is local to STAR partner Staffordshire University, so a potential participant in the piloting stage.

### **3.13. Staffordshire Fire & Rescue Service**

<http://www.staffordshirefire.gov.uk/>

#### **3.13.1. Aims and activities**

Statutory fire service, now developing training in early detection of dementia for employees  
They have pioneered dementia training for emergency services.

#### **3.13.2. Possible STAR Win-Win Collaboration**

A possible collaborator that is local to STAR partner Staffordshire University, so a potential participant in the piloting stage.

### **3.14. The MASE group**

<http://themasegroup.org/>

#### **3.14.1. Aims and activities**

**Monthly Alzheimer's Support Evening.**

#### **3.14.2. Possible STAR Win-Win Collaboration**

A possible collaborator that is local to STAR partner Staffordshire University, so a potential participant in the piloting stage.

### **3.15. CLS Care Services**

<http://www.clsgroup.org.uk/>

#### **3.15.1. Aims and activities**

CLS is a charitable organisation operating 26 residential care homes including specialist dementia households at eight locations in the North West.

#### **3.15.2. Possible STAR Win-Win Collaboration**

A possible collaborator that is local to STAR partner Staffordshire University, so a potential participant in the piloting stage.

### **3.16. Housing Twenty One**

<http://www.housing21.co.uk/>

### **3.16.1. Aims and activities**

Housing 21 is a social enterprise for older people. We:

- provide homes and services that enable people to enjoy a good later life
- help people increase their independence and take control of the services they receive
- bring communities together to create active, supportive environments which value older people.

### **3.16.2. Possible STAR Win-Win Collaboration**

Housing association specialising in people with dementia.

## **3.17. Other relevant organisations**

Alzheimer's research UK, <http://www.alzheimersresearchuk.org/>

Bradford dementia group, <http://www.brad.ac.uk/health/dementia/>

Care Quality Commission <http://www.cqc.org.uk/>

Carers UK <http://www.carersuk.org/>

Contented dementia trust <http://www.contenteddementiastrust.org/>

Guideposts Trust <http://www.guidepoststrust.org.uk/>

Methodist Homes for the Aged <http://www.mha.org.uk/HomePage.aspx>

## 4. Netherlands stakeholders

This chapter provides brief notes on possible stakeholders which are relevant to the development, piloting and contribution of STAR in the Netherlands.

### 4.1. Alzheimer Nederland (Dutch Alzheimer's Association)

<http://www.alzheimer-nederland.nl/>

#### 4.1.1. Aims and Activities

Alzheimer Nederland (AN) provides support and information to people with dementia and their carers. AN also provides financial support and advocacy for scientific research and increases awareness on dementia by initiating national media campaigns. AN is a foundation and relies on volunteers, donations and the revenue from the yearly national collection week. AN contains of one national office and 52 regional departments. AN has 50 persons staff and over 5500 volunteers.

##### Activities of AN:

- *Providing information* by publishing the Alzheimer Magazine four times a year, a digital news letter, information material (brochures, books, DVD's), information material is downloadable from the website. AN is present on public symposia and conferences for professionals. AN raises public awareness on dementia by initiating media campaigns.
- *Providing support to people with dementia and their carers* by organizing Alzheimer Cafés on a monthly base, supporting an online forum and chat, and providing activities for people with young onset dementia.
- *Interactive place for volunteers of AN (Vrijwilligersplein)*
- *Influence policy makers, professional cares, and politicians* to improve care for people with dementia.
- *Providing financial support* for scientific research on dementia.

#### 4.1.2. Possible STAR Win-Win Collaboration

Potential collaborator. The STAR training could be embedded on the website of AN and can be used to train volunteers of AN, but also support carers of people with dementia who seek information on caring for their relatives.

### 4.2. Amsterdam Center on Aging VUmc-VU (ACA)

<http://www.vumc.nl/afdelingen/Amsterdam-Center-on-Aging/>

#### 4.2.1. Aims and Activities

ACA has the following aims:

- 1) Stimulating research on aging and collaboration between aging researchers within and outside the VU University medical center and VU University

2) Dissemination of knowledge gained from scientific research in the area of ageing performed at the VU University and the VU University medical center by means of brochures, factsheets, movies, a website and educational courses. Professionals or organisations can contact ACA for all types of knowledge transfer and questions about research on elderly and aging.

#### **4.2.2. Possible STAR Win-Win Collaboration**

Facilitator and possible collaborator. ACA collaborates in writing the advanced levels of the STAR course. ACA brings together knowledge and experts in elderly care research. ACA can potentially disseminate the STAR course. Moreover, ACA can be an intermediary for recruiting dementia care experts for the STAR EU community.

### **4.3. Ideon**

<http://www.ideon-dementie.nl/>

#### **4.3.1. Aims and Activities**

Ideon is a social enterprise with the mission to contribute to the improvement of quality of life of people with dementia. Ideon provides (applied) knowledge for professionals in dementia care. Ideon is for everybody who does paid or unpaid work for people with dementia (from care professionals to architects who build a nursing home).

Activities of Ideon:

- Liaising with (inter)national universities, in this way Ideon gains and keeps up with the state-of-the-art knowledge on dementia care.
- Provision of (online) training, education and seminars for professionals.
- Development of the Dementia Monitor, to inventory the available knowledge dementia care professionals and identify possible gaps in this knowledge.
- Provision of consultancy for care organisations.
- Connecting people and organisations that work with dementia, with the aim to share knowledge.

#### **4.3.2. Possible STAR Win-Win Collaboration**

Possible collaborator/competitor. Ideon offers a similar service as STAR training, but from a commercial perspective. Ideon might be a possible long-term stakeholder.

### **4.4. Gerion**

<http://gerion.nl/>

#### **4.4.1. Aims and Activities**

Gerion provides (vocational) education and re-education for academics and graduates in elderly care and elderly care medicine. It is part of the VU University medical centre.

#### **4.4.2. Possible STAR Win-Win Collaboration**

Possible facilitator. Gerion might contribute to the content of the STAR training and/or provide dementia care experts for the EU community.

## **4.5. Meeting centres for people with dementia**

<http://www.vumc.nl/afdelingen/ontmoetingcentradementie/>

### **4.5.1. Aims and Activities**

In Meeting centres for people with dementia and their carers practical, emotional and social support is provided on an 'easy access' location in the neighbourhood. From the start in 1993 with two centres in Amsterdam, currently around 90 Meeting centres are established in various regions in the Netherlands.

The meeting centres provide a combined support program for both community dwelling people with dementia and their carers consisting of a social day club (3 days a week) for the people with dementia, informative meetings and discussion groups for the informal carers, and a consultation hour, regular centre meetings, social activities and outings for both.

### **4.5.2. Possible STAR Win-Win Collaboration**

Potential piloting area. A lot of volunteers work in the Meeting centres who could use the course to inform themselves better on dementia and the cognitive, emotional and social consequences in daily life. This would help them to develop an empathic, experience oriented and person centred attitude in working with people with dementia. Face-to-face training is provided to new volunteers, but the STAR training can be a beneficial additional resource of training, to follow at home, or wherever they want.

## **4.6. Odense Houses**

<http://www.odensehuis.nl/>

### **4.6.1. Aims and Activities**

In districts in several cities in the Netherlands Odense Houses are established. Their origin lays in Denmark. In the Odense Houses people with memory problems, and their relatives, are welcome during the day, they do not have to be a member. The Odense Houses offer support and information, but also peer contact, and activities. The initiative tries to fill the gap after being diagnosed, when people do not yet use professional support and care. They help people with dementia to participate actively in the society. People with dementia can help others by sharing their experiences. The Odense Houses are voluntary organisations, often funded by municipal resources.

### **4.6.2. Possible STAR Win-Win Collaboration**

Potential piloting area: The Odense Houses are voluntary organisations, they provide information and support to people with dementia and their relatives. (New) volunteers can benefit from the STAR training, also visiting relatives of people with dementia can benefit from the training.

## **4.7. Mezzo**

<http://www.mezzo.nl/>

#### **4.7.1. Aims and Activities**

Mezzo is a national association for informal carers and volunteer work. Mezzo provides information, advice and practical support. They have a free support phone line and 285 support centres in the Netherlands. Besides providing support, Mezzo represents the interests of informal carers and volunteers on national, regional, and local levels.

#### **4.7.2. Possible STAR Win-Win Collaboration**

Potential collaborator for dissemination and implementation of the STAR course.

### **4.8. Zet**

<http://www.zet-brabant.nl/>

#### **4.8.1. Aims and Activities**

Zet is the Centre for Societal Development in Brabant. The organisation provides advice on the areas of living, welfare and care, and aims to contribute to a society in which everybody can participate. Zet works for voluntary, as well as professional and governmental organisations.

#### **4.8.2. Possible STAR Win-Win Collaboration**

Possible collaborator: Zet showed interest in the STAR course.

### **4.9. Hogeschool inHolland**

<http://www.in-holland.nl/>

#### **4.9.1. Aims and Activities**

Hogeschool inHolland offers bachelor programs on numerous disciplines and offers a few associate degree programs and master programs. InHolland has several lectorates, amongst others for e-learning, educational services, mental health nursing, and quality and innovation in health care. These knowledge circles perform practical research and transfer the results to education, thereby contributing to knowledge dissemination towards stakeholders and the society.

#### **4.9.2. Possible STAR Win-Win Collaboration**

Possible facilitator and collaborator. They are in contact with potential stakeholders (nursing students), has the potential to disseminate the STAR course, and can provide additional content for the course.

### **4.10. Vrijwilligers Academie Amsterdam (Academy for Volunteers Amsterdam)**

<http://vrijwilligersacademie.net/nl/opleiding/verdieping/44/dementie>

#### **4.10.1. Aims and Activities**

This organisation offers training on basic, intermediate and advanced levels to volunteers in the area of care and welfare. These training programs enable people to do their volunteer work (better). By training volunteers, the organisation aims to improve the quality of care, and to improve the alignment between client demand and the offer of volunteers. VAA provides face-to-face training, e-learning, but also combined training programs (e-learning with personal contact). One face-to-face training specific on dementia is offered to volunteers.

#### **4.10.2. Possible STAR Win-Win Collaboration**

Potential collaborator. The STAR course could be embedded within the organisation.

### **4.11. Reed Business Education**

<http://www.egz.cluster32.e-active.nl/>

#### **4.11.1. Aims and Activities**

Reed Business Education is a publisher of educational materials, its main focus was on health care and nursing. The publisher is seeking innovative ways to publish materials and books, in order to keep up with the needs of students, teachers, and authors. More and more books are being published in the StudieCloud (digital books with deeplinks with access to additional material), or as e-book or app.

#### **4.11.2. Possible STAR Win-Win Collaboration**

Possible collaborator/competitor, Reed Business Education has not yet published e-courses.

### **4.12. Health care insurers**

Different insurers (e.g. Agis, Achmea, CZ)

#### **4.12.1. Aims and Activities**

Provision of health care insurances to the general public, but also the provision of funding to research and best practices that have the potential to decrease care costs.

#### **4.12.2. Possible STAR Win-Win Collaboration**

Possible facilitator/funder; the STAR course can support informal carers and decrease or prevent carer (over)burdening (incl. frequently present psychosomatic complaints) for little costs.

### **4.13. Trimbos Institute**

<http://trimbosinstituut.nl>

#### **4.13.1. Aims and Activities**

The Trimbos Institute seeks to enhance quality of life by engaging in the development and application of knowledge about mental health, addiction and associated physical illnesses.

The activities of the Institute are intended to contribute to and facilitate changes in mental health and addiction care in order to elicit individual health gains within the Dutch population, promote more effective treatment methods and provide models for more efficient care.

With a focus on knowledge sharing, the Trimbos Institute aims to undertake evidence-based activities which are innovative and can be implemented in professional settings. For example an e-mental health course on dementia.

The Trimbos Institute is organised in a number of programmes, each of which focuses on a specific area. Output typically includes research reports, articles in peer-reviewed journals, new interventions and implementation strategies, policy evaluations and recommendations, monitoring reports, seminars, conferences and training programmes.

#### **4.13.2. Possible STAR Win-Win Collaboration**

Possible facilitator and collaborator. The Trimbos Institute can provide content for the STAR course and is a potential partner for implementation of the STAR course.

### **4.14. Leyden Academy**

<http://www.leydenacademy.nl/>

#### **4.14.1. Aims and Activities**

Leyden Academy on Vitality and Ageing is a knowledge centre established in 2008. It is committed to delivering a high quality academic standard and international level of education and training, while participating actively in research and initiating developments in the field of vitality and aging.

Leyden Academy believes that an integrated, holistic approach is essential to achieve its core mission: to promote and improve the quality of life for the elderly. Leyden Academy works together with Leiden University Medical Centre and Leiden University

#### **4.14.2. Possible STAR Win-Win Collaboration**

Possible facilitator. Leyden Academy might contribute to the content of the STAR training and/or provide dementia care experts for the STAR EU community.

### **4.15. Into D'mentia**

<https://www.intodmentia.nl>

#### **4.15.1. Aims and Activities**

Into D'mentia is a simulation training that provides informal carers and professionals the experience of having dementia. The aim of Into D'mentia is to raise awareness and provide understanding for people with dementia and the problems they experience as a consequence of their disease. By understanding, empathy of carers will increase and this will help them to provide better care. Into D'mentia is developed in cooperation with various academic partners and care organisations: Minase, De Wever, VU University medical center, Tilburg University,

Gleijm & v.d. Waart, Ideon, en Zorggroep Eelde. Commissioned by this consortium Ijsfontein Interactive Spaces elaborated Into D'mentia and built the simulator.

Into D'mentia has a partnership with parties who are active in the field of dementia training (Ideon, De Keerzijde and DAZ).

#### **4.15.2. Possible STAR Win-Win Collaboration**

Possible collaborator. Into D'mentia can be a partner in disseminating the STAR course, the course could also be embedded within the Into D'mentia training.

## 5. Italy stakeholders

This chapter provides an overview of some of the main dementia associations in Italy with the goal to provide support in the dementia field and points out which can be relevant contributions they can provide for the development and piloting STAR in Italy.

In Italy a person can apply for a financial support such as sick pay, disability financial support for people not self-sufficient attended at home. This further reflects on a high level of request for care givers. The problem is that in most cases the primary caregiver is assisted by unspecialized caregivers, who do not have any education in dementia.

The main dementia associations provide specific dementia care education but we still notice a lack in training initiatives.

As a conclusion, it seems likely that in Italy could be easily found relevant stakeholders interested in piloting and using the STAR Training.

In particular the addressed stakeholders are the following:

Informal caregivers	<ul style="list-style-type: none"><li>• Family members</li><li>• Volunteers, neighbours, migrant care workers, etc.</li></ul>
Formal caregivers	<ul style="list-style-type: none"><li>• Medical professionals, nurses</li></ul>
The Institutions	<ul style="list-style-type: none"><li>• Central and local governments</li><li>• Healthcare and Social care National Services</li></ul>
The Organizations	<ul style="list-style-type: none"><li>• No profit organizations</li><li>• User Associations</li><li>• Church and charity organizations</li></ul>

### 5.1. Auser Regione Lombardia

<http://www1.auser.it/IT/>

#### 5.1.1. Aims and activities

The AUSER Association was established in Italy in 1989 through the initiative of the Union of Retired People (SPI/CGIL) and the Federation of Italian Trade Unions (CGIL).

It works through 1,412 local associations around the country and has 260,000 members as well as 40,000 active volunteers organized on a national, regional and local level.

The mission of the AUSER Association is to promote the self-management of services and actions for solidarity, supporting the right of older people to continue to play an active role on a social and economic level by making the most of their specific experiences, skills and abilities.

Older people work as volunteers in several areas of activity:

- Training and education: through the Università Popolare (UNIAUSER) initiative providing continuing education for senior citizens
- Health education
- Solidarity: by developing the Filo d'Argento associations, local telephone help lines for older people who need practical, psychological and emotional support
- Social utility: by finding ways to enhance the artistic, cultural and environmental heritage of traditional crafts and skills
- International solidarity

On a European level, the AUSER Association is a member of SOLIDAR, a European network of 50 NGOs active in over 90 countries working to advance social justice in Europe and worldwide. SOLIDAR lobbies the EU and international institutions in three primary areas: social affairs (more social Europe), international cooperation (development cooperation) and education (lifelong learning for all).

In the field of dementia the Auser Association works in order to give assistance, behavioural guidance, information and home care services.

In particular some of the most important projects carried out by the Auser Association are:

“Cercò Alzheimer”, with the goal to help, support and attend people affected by Alzheimer and their families.

“Caffè Alzheimer”. The Auser Association in the Veneto Region organized monthly meetings where Alzheimer patients families can meet each other and built a solidarity network to fight against isolation and to meet at the same time experts able to give information on medical, legal and psychological issues.

“Ti aiuto a ricordare”. The Auser Association in the Calabria Region arranged a course planning a large number of meetings to discuss about nursing problems of people affected by dementia, the relationships with families and non professional careers and problems related to the home daily life.

### **5.1.2. Possible STAR Win-Win Collaboration**

Possible help with disseminating the STAR Project and piloting the elearning platform suggesting interested volunteers.

## **5.2. A.I.M.A. - Associazione Italiana Malattia di Alzheimer**

Italian Association Alzheimer <http://www.alzheimer-aima.it>

### **5.2.1. Aims and activities**

The A.I.M.A. Association was established in Italy in 1985 as a “voice” from patients and families.

The aim is to move at political and social level to establish and recognize services and to provide assistance to people affected by Alzheimer.

In the last few years the association has been involved in particular in the families assistance and the results are:

a thousand calls per year to the national committee

training

support groups (in particular psychological support to caregivers)

seminars and round tables

publicity materials, press activities, circulation of information pack

personnel training

advisory legal service

scientific research

The A.I.M.A. Association has provided assistance to the patients families in the difficult path of the disease.

## **5.2.2. Possible STAR Win-Win Collaboration**

Possible help with disseminating the STAR Project and piloting the elearning platform suggesting interested volunteers. They can also provide experts for contents and training.

## **5.3. AMA – Associazione Malattia Alzheimer**

Association for the Alzheimer disease <http://www.amaferrara.it/>

### **5.3.1. Aims and activities**

The AMA Association was established in Italy in 1998.

The aim is to manage social awareness initiatives on the Alzheimer disease and on the related set of problems.

The main activities are:

- Trainings
- Information campaigns
- Listening centers

### **5.3.2. Possible STAR Win-Win Collaboration**

Possible help with disseminating the project and volunteers for the piloting phase.

## **5.4. Federation Alzheimer Italia**

National organization of volunteers <http://www.alzheimer.it/>

### **5.4.1. Aims and activities**

The Federation Alzheimer Italia is the main Italian voluntary organization working on medical and scientific research on Alzheimer causes, care and assistance procedures. It also supports sick people and their families also from the legal and administrative point of view.

It collects and manages 46 organizations working on the Alzheimer disease with the main goal to build a national network able to support people affected by the disease and relatives.

The Federation represents in Italy the Alzheimer's Disease International (A.D.I.) and takes part in Alzheimer Europe, National Council of Disability, League for the Rights of Disabled People, Italian Federation of Neurological Associations.

### **5.4.2. Possible STAR Win-Win Collaboration**

Possible help with disseminating the STAR Project and piloting the elearning platform suggesting interested volunteers. They can also provide experts for contents and training.

## **5.5. Società Italiana di Gerontologia e Geriatria**

Italian Association of Geriatricians <http://www.sigg.it/link.asp>

### **5.5.1. Aims and activities**

The Italian Association of geriatricians was established in Florence, Italy in 1950 with the aim to promote and coordinate research and studies on the pathophysiology of aging and to face problems related to the old age.

### **5.5.2. Possible STAR Win-Win Collaboration**

The association can provide experts and doctors for contents and training.

## **5.6. Associazione Alzheimer Bergamo**

Voluntary organisation <http://www.alzheimerbergamo.it/>

### **5.6.1. Aims and activities**

The Associazione Alzheimer Bergamo was established in Italy in 1992 and is a voluntary organisation.

In Italy we have 600.000 cases of dementia and the 65% are affected by Alzheimer. People affected need daily assistance and involved relatives need to know the disease progression and which are the social and health services that can give the needed support.

The association:

- plans information meetings with patients relatives and experts (neurologists, geriatricians, psychologists, social workers and nurses)
- provides information on existing centers that play an active role on Dementia diagnosis, on public and private services available (home care services, day care centers), on procedures to obtain economic benefits (disability pension, accompaniment benefits)
- Suggests experts for legal advices
- Organizes national workshops in order to sensitize public awareness on dementia.

### **5.6.2. Possible STAR Win-Win Collaboration**

Possible help with disseminating the STAR Project and piloting the elearning platform suggesting interested volunteers. The can also provide experts for contents and training.

## 6. Sweden stakeholders

This chapter provides brief notes on vocational educational training organisations, dementia associations and other stakeholders which are relevant to the development, piloting and sustainable operation of STAR in Sweden.

### 6.1. Svenskt Demenscentrum

<http://www.demenscentrum.se/>

#### 6.1.1. Aims and activities

The Swedish Dementia Centre is a non-profit organisation. The commission of creating a national centre for excellence in dementia care was given to the two foundations: Silviahemmet and Stockholm Gerontology Research Center. It is also commissioned by the National Board of Health and Welfare. The Swedish Dementia Centre was established in February 2008.

The mission is to;

- Collect, structure and disseminate knowledge about dementia and dementia care with special attention to gender and ethnic issues
- Compile evaluations and research results
- Develop more practically orientated knowledge
- Facilitate translation of research and implementation of new knowledge into nursing and care, interventions and social policy
- Be a link between research, practice and decision makers
- Be the hub of a national network for research and development units

The vision is to be a centre of excellence that gradually builds up a bank of knowledge within the area of dementia and actively promotes future development in care of persons with dementia.

SDC provides the online training material Demens ABC, which focuses on knowledge according to the national guidelines for dementia care that were published 2010.

#### 6.1.2. Possible STAR Win-Win Collaboration

There is potential synergy between the Demens ABC curriculum from SDC and STAR. However, the basic philosophy is very different, where SDC aims to create strongly controlled content and refers all queries to professional organisations. STAR in contrast aims to provide online training in collaboration with other countries and involving a community of Swedish experts and practitioners. STAR also aims to expand its curriculum beyond what is offered by Demens ABC.

SDC has agreed to promote the STAR service when launched

## **6.2. Vuxenskolan**

### **6.2.1. Aims and activities**

Vuxenskolan is a nation-wide VET provider with previous experience from vocational training in the area of dementia. They are involved planning for exploiting the finished LLP Else project.

### **6.2.2. Possible STAR Win-Win Collaboration**

*Vuxenskolan together with the social care centre in Luleå is part of the Sweden piloting of STAR with already 20 pilot users recruited. Vuxenskolan was already involved in the Sweden national workshop 2012-08-29.*

## **6.3. Demensföreningen**

<http://www.demensforeningen.se>

### **6.3.1. Aims and activities**

This is the largest dementia association in Sweden, with many local chapters. It works to raise awareness of dementia in support of people with dementia and their families. They want to deepen everybody's knowledge of dementia and how persons with dementia are affected: medically, psychologically and socially.

Demensföreningen organises family meetings at residential care homes and nursing homes , and also facilitate training for health professionals.

### **6.3.2. Possible STAR Win-Win Collaboration**

Demensföreningen can be expected to promote STAR in Sweden, and were already involved in the Sweden national workshop 2012-08-29.

## **6.4. Demensförbundet**

<http://www.demensforbundet.se/>

### **6.4.1. Aims and activities**

Demensförbundet (The Dementia Association - The National Association for the Rights of the Demented) protects the interests of the dementia stricken as well as their relatives.

Demensförbundet which was founded in 1984 is expanding and has now 11 000 members. There are 130 local organisations and contact points covering most parts of Sweden.

Demensförbundet demands:

- Better knowledge of dementia within care, nursing and social service and more information to the public.
- Examination resources to make it possible for all persons with an assumed dementia to get a correct diagnosis and receive correct treatment.

- More medical, psychological and social research on dementia
- Qualified and sufficient personnel in dementia care and nursing.
- Better use and redistribution of available resources by the following measures:
  - visiting work
  - development and increase of home support, day-care and contact persons for demented people who live at home
  - increase and development of group living centres and similar small units for those who can not remain at home.
  - development and increase of home support, day-care and contact persons for demented people who live at home
  - increase and development of group living centres and similar small units for those who can not remain at home.
  - support and relief for families/relatives

#### **6.4.2. Possible STAR Win-Win Collaboration**

Demensförbundet can be expected to promote STAR.

## **6.5. Alzheimerföreningen**

<http://www.alzheimerforeningen.se/>

#### **6.5.1. Aims and activities**

Alzheimer's Association's mission is to:

- Provide relatives of persons with dementia the opportunity to come into contact with each other, support each other and share experiences.
- Increase interest in Alzheimer's and other dementias, and disseminate knowledge about them.
- Promote increased research and education related to the dementia care and treatment.
- Work to ensure that the situation of people with dementia identified in community planning so that independent living easier.
- Alzheimer's Association will work to develop alternative forms of care.

#### **6.5.2. Possible STAR Win-Win Collaboration**

Demensförbundet can be expected to promote STAR in Sweden.

## **6.6. Norrbotten Regional Health Council**

[www.nll.se](http://www.nll.se)

Norrbotten is one of 24 regions in Sweden. The Norrbotten regional health council (NLL) is responsible for all healthcare in the region and coordinates dementia care by local administrations. NLL is heavily involved in the coordinated implementation of Sweden national dementia guidelines that were adopted 2010.

### **6.6.1. Possible STAR Win-Win Collaboration**

Demensförbundet can be expected to promote STAR in Sweden.

Norrbottn Health Council will pilot integrated templates for dementia care, as part of the Northern Periphery Programme project RemoDem which it coordinates. They have expressed a keen interest to evaluate the use of STAR Training starting late 2013, and if successful to facilitate its continued use. Their membership in national dementia care coordination groups provides a route to use of STAR across all of Sweden.

## **6.7. Demens Kunskap & Tips**

[www.dkt.se](http://www.dkt.se)

Helingsborg-based voluntary website for carers, professionals and people with dementia which aims to provide up-to-date information and links.

## **6.8. Omalzheimer**

<http://www.omalzheimer.se>

Site funded by the pharmaceutical company Novartis, offering well-presented information on various aspects of Alzheimers disease, aimed at sufferers and carers.

## 7. Malta stakeholders

The following is a report that gives a detailed summary of Maltese stakeholders who may be interested in taking part in the development, piloting and contribution of STAR in Malta. It must be mentioned that due to its size, the Maltese number of charities/ bodies/ stakeholders in the area are limited. Despite this all of these entities have experience and knowledge that could be invaluable to the activities that will be carried out in Malta for STAR.

Hereunder is a concise description of each entity.

### 7.1. Malta Dementia Society.

<https://sites.google.com/site/maltadementiasociety/>

#### 7.1.1. Declared aim

The aims and objectives for which the society is established are:

- To encourage and promote the best methods of care, education and treatment of persons with dementia and related disorders, generally throughout the Maltese islands and elsewhere.
- To provide and furnish support, help, assistance and information to the families, relatives and friends of persons with dementia, and related disorders.
- To instruct and train personnel necessary to provide services for persons with dementia and related disorders and, when possible, award scholarships, grants and prizes relating to research in dementia, its cause, effect, prevention, treatment and cure.
- To provide literature to disseminate knowledge of dementia, and related disorders to patients, carers and public in general.
- To provide and encourage courses, lectures and conferences, both to the general public as well as professionals in the health care centre, in the various areas relating to dementia and associated disorders.
- To influence the government and competent entities to ensure the development of suitable facilities and benefits for patients with dementia and related disorders.
- Foster international contacts with similar organisations abroad and participate in international fora.
- To raise funds, to assist in the furtherance of the aims and objectives of the society.

- To invite and receive contributions from any person/s or other entities whatsoever through subscription, donation or otherwise provided that this shall be without prejudice or lead to preference.

### **7.1.2. Possible relationship to STAR and further notes**

The Malta Dementia Society gives training to nurses; therefore it can help in the dissemination of the project as nurses will be working with people suffering from dementia and Alzheimer's more closely. The society can also provide us with a link to their website whenever there is data that STAR will be needing. We have also contacted two doctors from this society, who are willing to help in STAR as much as they can, since they are responsible for most of what goes on in Malta regarding to dementia.

## **7.2. Ministry of Health, the Elderly and Community Care**

[https://ehealth.gov.mt/HealthPortal/elderly/dementia/dementia\\_default.aspx](https://ehealth.gov.mt/HealthPortal/elderly/dementia/dementia_default.aspx)

### **7.2.1. Aims and activities**

"A society that fosters an environment that is conducive to persons attaining their maximum potential for health and well-being."

Dementia is a general term that refers to a group of brain diseases characterised by severe and progressive cognitive decline that interferes with normal daily functioning. This may include severe memory loss, mental confusion, language difficulties, mood variations and personality changes. It is estimated that more than 6 million people residing in EU member states have dementia. In Malta, more than 4,500 individuals have dementia, a figure that is expected to double in the next 25 years.

### **7.2.2. Possible relationship to STAR and further notes**

These entities train heads of homes, and day centres, governmental institutions and nurses, nursing aids. These people therefore have a lot of contacts, which would help us immensely in disseminating STAR to them and through them. We could also collaborate by integrating part of our training with theirs, or by introducing STAR during some of their courses. Our work could be complementary.

## **7.3. Care Malta Ltd.**

<http://www.caremalta.com/>

### **7.3.1. Aims and activities**

- To maintain a safe, comfortable and efficient environment recreating a home like atmosphere.

- To encourage independence where appropriate and provide sufficient privacy to maintain individual dignity.
- To promote at all times social interchange between our residents and our staff.
- To continuously train and support the physical and emotional well being of our residents.

### **7.3.2. Possible relationship to STAR and further notes**

As pioneers of private care providers for the older persons 18 years ago, Care Malta Group is Malta's market leaders in providing quality services in nursing and residential care, independent living for older persons, specialised dementia care, older persons care and certified courses in health. Today, Care Malta group cares for over 900 residents and employs a workforce of over 600 highly-dedicated and well- trained personnel. They also give a lot of different training programs for the aid of people suffering from dementia. One of the trainees who gives her own training to the Care Malta group- Ms. Rosette Farrugia Bonello, who has her own consulting company. She gives training to Informal carers (relatives/friends of older persons with Dementia), organized by CaremaltaLtd. In collaboration with Local Councils both in Malta and Gozo. Training is also offered to Caritas Malta HelpAge Volunteers (which will be mentioned later on). Rosette Farrugia Bonello Consulting services also provides training to formal carers and non-carers i.e. staff working in administration, kitchen, etc in private homes. Hence, Ms. Farrugia Bonello could be a good source of material and information; we could collaborate in areas of training as well as help in disseminating the project.

## **7.4. Care Malta Ltd.**

<http://www.caremalta.com/>

### **7.4.1. Aims and activities**

In 2010, Caremalta inaugurated the refurbishment of the Dementia Care Unit at Villa Messina in Rabat. The Marigold Unit, as it has been called, can host up to 31 residents and is divided into two main sections: the residents' rooms and the open space day room comprising of a lounge and dining area. The unit is entirely dedicated to making life easier for those living with dementia, a sanctuary place for residents making them feel comfortable and at ease, while offering peace of mind to their relatives as well.

Great care was taken in the design of the unit with expertise from Design for Dementia. Marigold has been designed with the needs of dementia sufferers in mind, and the incorporation of a number of special features, such as special graphical signage and colour-coded doors to indicate the different functions of the area, makes it that much easier for the said residents.

While it ensures that the area is as safe as possible, it also gives residents the freedom to wander around while remaining within the unit, and under the watchful eyes of the

carers on duty. The unit has a direct access to a beautiful garden, and thus residents can enjoy as much sunshine and fresh air as possible. All the residents at Marigold are given all the care they require from fully trained and professional care assistants and nurses who have undergone a reflective practice course in Best Practice in Dementia Care through the University of Stirling, which is recognised worldwide for its work in dementia care.

#### **7.4.2. Possible relationship to STAR and further notes**

Caremalta gives two courses for those trying to further their knowledge about the care for elderly with dementia: City & Guilds and Out Reach Programme.

City & Guilds is the UK's leading provider of vocational qualifications, offering over 500 awards across a wide range of industries, that progressing from entry level to the highest levels of professional achievement. With over 8500 centres in 100 countries, City & Guilds is recognised by employers worldwide for providing qualifications that offer proof of the skills they needed to get the job done.

The IVQs in health care have been designed to provide a comprehensive core of programming of learning and assessment for health and care workers or those who aspire to pursue a career in these fields. The qualification is divided into the Diploma in Health Care, and the Specialist Diploma in Health Care, that acts as a progression route.

In early 2010 Care Malta launched this innovative initiative with the assistance of a number of Local Councils, in both Malta and Gozo, and is actively reaching out to those individuals who are acting as carers to their parents, spouse, relatives or friends.

Attendance at these sessions was very high and the feedback gauged throughout the training sessions was encouraging.

The success of the initiatives has confirmed Caremalta's belief that there are a number of people within the community who are more than willing to improve their abilities and skills when it comes to caring for an older persons person in their lives. The first two training sessions that are currently being delivered focus on dementia and manual handling and lifting. The session on Dementia aims to raise awareness of the dynamics of the illness and the effects that it can have on sufferers themselves, on caregivers and on the family; whilst the one on manual handling and lifting is to give practical hints to caregivers on how to handle older persons in a manner which is both safe for them and for the person they are caring for.

The centre is planning to introduce a new course in Dementia Care next October 2011. This course may be a good way of working together since it is still in its trial stages and can be amended according to present needs.

Through these courses we can collaborate by exchanging knowledge and by also devising methods of integrating our course material and possibly some lessons together. We can also try to collaborate by working on disseminating STAR.

## **7.5. Caritas Malta**

<http://www.caritasmalta.org/>

### **7.5.1. Aims and activities**

Caritas' mission is to alleviate poverty and promote human development and social justice, reflecting to the Christian faith and Gospel values. To fulfil this mission, Caritas:

- Adheres to the guiding values and principles of the Pastoral Plan of the Diocese and the Strategic Plan of Caritas Internationals and Caritas Europa;
- Renews its preferential option for the poor and gives witness of this commitment within the Christian community;
- Raises public awareness of poverty and injustice;
- Facilitates co-operation within, and beyond, the Caritas organisation, in order to address the old and new faces of poverty;
- Acts as the voice of the poor, and enables the poor to become agents of change.

#### **The Vision**

Drawing upon the Scripture, the Church's Social teaching, and the experiences and hopes of people in difficulty, Caritas Malta works towards achieving a "civilisation of love" within the Maltese community where:

- the dignity and the fundamental rights of each person are safeguarded and respected;
- truth, charity, justice, peace, freedom and solidarity are lived and promoted;
- the common good prevails over individual interests;
- the environment is protected and embellished;
- disadvantaged persons are empowered to develop their resources, and helped to restore their sense of co-responsibility in building a better society, where all are gathered into a single human family, from which no one is excluded.

### **7.5.2. Possible relationship to STAR and further notes**

Caritas Malta focuses mainly on all that is needed to support drug abusers and people with addictions, as well as their families. However there is a short programme for "Caritas Help Age Volunteers" for people who have direct contact with the elderly. STAR can give a lesson as part of this programme, so that volunteers will be well-informed about the care of the elderly with dementia. Materials can be exchanged with the programme coordinators and dissemination of this project can also take place through this charity.

## **7.6. MCAST**

<http://www.mcast.edu.mt/default.asp>

### **7.6.1. Aims and activities**

" To provide universally accessible vocational and professional education and training with an international dimension, responsive to the needs of the individual and the economy. "

The following are some of the courses that MCAST gives to students who choose Health Care.

Introductory Certificate in Care

Foundation Certificate in Care

- Vocational Experience in a Health or Social Care Environment
- Science for Foundation in Care
- Health and Well-being for Care
- Health and Social Care
- Care within Society

Diploma in Health and Social Care

- Communication in Health and Social Care
- Individual Rights within the Health and Social Care Sectors
- Individual Needs in the Health and Social Care Sectors
- Ensuring Safe Environments in Health and Social Care
- Vocational Experience in a Health or Social Care Setting
- Anatomy and Physiology for Health and Social Care
- Human Lifespan Development
- The Impact of Diet on Health

Extended Diploma in Health and Social Care

- Developing effective communication in Health and Social Care  
Equality, Diversity and Rights in Health and Social Care
- Health, Safety and Security in Health and Social Care
- Development through the Life Stages
- Anatomy and Physiology for Health and Social Care
- Personal and Professional Development in Health and Social Care
- Values and Planning in Social Care
- Caring for Children and Young People
- Safeguarding Adults and Promoting Independence
- Sociological Perspectives for Health and Social Care
- Psychological Perspectives for Health and Social Care

Higher National Diploma in Health and Social Care

- Communicating in Health and Social Care Organisations
- Principles of Health and Social Care Practice
- Health and Safety in the Health and Social Care Workplace
- Personal and Professional Development in Health and Social Care
- Working in Partnership in Health and Social Care
- Research Project
- Managing Human Resources in Health and Social Care
- Managing Financial Resources in Health and Social Care

#### Bachelor of Arts in Health and Social Care

- Entrepreneurship
- Research Methodology and Dissertation
- Operations and Service Management
- Ethical Issues and Decision Making
- Issues with Different Client Groups
- Human Resource Management and Leadership
- Maltese Law and Social Policy
- Quality Assurance in Health and Social Care
- Placements in a Health and Social Care Management Environment

#### **7.6.2. Possible relationship to STAR and further notes**

We can exchange notes and other material with MCAST, as well as collaborate in disseminating the project with the students who might be interested in learning more about the care of people with dementia. If MCAST agrees we can also include some lessons about STAR in these courses, or as an extra session for all Health and Social Care students.

## **7.7. University of Malta - Faculty of Health Science**

<http://www.um.edu.mt/healthsciences/>

#### **7.7.1. Aims and activities**

The Faculty of Health Sciences was awarded faculty status in August 2010. Before then, it was the Institute of Health Care: a University Institute that was set up in 1987, for the education and training of Health Care professionals.

At the moment there are three departments for students who want to work with patients with dementia:

- Degree in Nursing

- Degree in Physiotherapy
- Degree in Occupational Therapy

### **7.7.2. Possible relationship to STAR and further notes**

The University of Malta is a possible collaborator for dissemination and may also allow us to give a lecture to University students who have chosen elderly-care related courses.

## **7.8. University of Malta - European Centre for Gerontology**

<http://www.um.edu.mt/eurgeront>

### **7.8.1. Aims and activities**

- To conduct research within the areas of aging and later life from a multidisciplinary framework that is sensitive to both gerontological and geriatric concerns
- To deliver postgraduate courses in gerontology and geriatrics which lead to outstanding academic qualifications
- To co-ordinate pre-retirement training programmes with private and public organisations
- To liaise with government departments, voluntary agencies and the private sector to enable the Centre to contribute to current gerontological developments.
- To research issues of gerontological concern
- To engage in public debates on issues that concern older people through the organisation of conferences and fora

### **7.8.2. Possible relationship to STAR and further notes**

The European Centre for Gerontology is a possible collaborator for dissemination and may also allow us to give a lecture to University students studying elderly care related courses.

## **7.9. Other relevant organisations**

Dominican Sisters in Malta - <http://www.dominicansisters.org.mt/convents.php>

Mental Health and Geriatric Services - [www.mentalhealthservices.gov.mt](http://www.mentalhealthservices.gov.mt)

Dar il-Ħanin Sammaritan - <http://www.sdcmuseum.org/>

Geriatric Medicine Section of UEMS - <http://www.uemsgeriatricmedicine.org/>

Health, the Elderly and Community care - Residential Homes for the Elderly -

[https://ehealth.gov.mt/HealthPortal/elderly/residential\\_homes\\_elderly.aspx](https://ehealth.gov.mt/HealthPortal/elderly/residential_homes_elderly.aspx)

Ministry for Health, the Elderly and Community care –  
<https://ehealth.gov.mt/HealthPortal/default.aspx>

MaterDei Hospital -

[https://ehealth.gov.mt/HealthPortal/health\\_institutions/hospital\\_services/mater\\_dei\\_hospital/mater\\_dei.aspx](https://ehealth.gov.mt/HealthPortal/health_institutions/hospital_services/mater_dei_hospital/mater_dei.aspx)

St. James Hospital - [www.stjameshospital.com](http://www.stjameshospital.com)

Inspire- <http://www.inspire.org.mt/>

The Malta Community Chest Fund - <http://maltacommunitychestfund.org/>

## 8. Romania stakeholders

This report provides an overview of the dementia care and education institutions in Romania, and notes relevant to the development, piloting and contribution of STAR in Romania. Although recently efforts have been made to increase dementia awareness in Romania, and to provide better access to care services, this area is still in development.

Access to treatment and care is difficult (particularly sufficient funds for free medication, a limited budget available to doctors for free prescriptions, limited availability of home medical care).

The Romanian Alzheimer Society reports difficulties for the people with dementia in accessing free or partly free medication and care due to a lack of social support.

A person can apply only for medical home care (not for a personal assistant/ a carer, but for medical personnel – nurses) on the strict conditions that do not always apply to persons with dementia, therefore, the cost of hiring a carer is almost always supported by the family. This further reflects on a low level of request for specialized care givers. Most families hire unspecialized carers, who do not have any education in dementia.

In Romania there are only a few institutions active in the field of dementia care and/or education, the majority of which (with the exception of Romanian Alzheimer's Society/ Societatea Romana Alzheimer) are not focused specifically on dementia care.

The lack of funding for charities or NGOs and a still-in-development health insurance system are among the factors that influence the limited availability of resources (either social or educational) in dementia care. The existing initiatives in the area are usually temporary (for as long as the funding supports the operating costs), developed locally, understaffed and very difficult to access and contact due to the lack of visibility.

At the present date in Romania there are no relevant institutions providing specific dementia care education. Several NGOs and private companies specialized in adult education provide face-to-face courses for the following related fields:

- Family Assistant/ Caregiver (not regulated learning programme)
- Caregiver for the elderly
- Care Operator (regulated by National law OMS 1470/2005 CVT course of 720 hours)

The competences acquired in non-formal and informal contexts are not yet recognised by the formal education system. Some of them are recognised on the labour market.

However, the process these training institutions have to undertake in order to get the courses recognized by the labor market makes them often reluctant to diversify their offer or change the curricula.

Most of the courses provided are occasional, depending on request and funding.

As a conclusion, it is unlikely that in Romania relevant stakeholders interested in using or piloting STAR Training could be found. However, due to the lack of availability of organized and easily accessible online information about dementia in Romanian language, the results of the project might present interest to the persons directly involved (families, informal carers with no training hired by families etc).

## **8.1. Societatea Romana Alzheimer (SRA)**

Romanian Alzheimer Society <http://www.alz.ro>

### **8.1.1. Aims and activities**

Creating educational programmes and supporting the people with dementia and their families to be active members of the society.

- Create awareness on dementia
- Promote good practice in dementia care
- Contribute to national policy on dementia, older people and carers' issues

The society provides access to basic information about Alzheimer's dementia on its website (informative brochure to download)

The society organises several events per year (lectures, conferences, fund-raisers) aiming to provide access to dementia and dementia care related information to both professionals and non-professionals.

The society no longer provides courses due to lack of funding.

### **8.1.2. Possible STAR Win-Win Collaboration**

- Possible help with disseminating the STAR Project, but due to its limited presence across the country and limited personnel, the SRA is difficult to contact and get involved.

## **8.2. Centrul Medical de Diagnostic si Tratament Promemoria**

Diagnose and Treatment Medical Centre Promemoria <http://www.pro-memoria.ro/servicii.html>

### **8.2.1. Aims and activities**

Promemoria provides personalized health medical care and counseling for persons with Alzheimer's dementia and their families (30 minute paid appointments). The Centre is located in Bucharest. Their services are aimed at those living in Bucharest.

### **8.2.2. Possible STAR Win-Win Collaboration**

The Centre might provide help with disseminating the STAR Project: link to the STAR website, dissemination of materials, verbally recommending to their patients the STAR Training courses.

## **8.3. Centrul Memoriei**

### **8.3.1. Aims and activities**

The Memory Centre began operations on October 20, 2000 representing a partnership project between the Alexandru Obregia Psychiatry Hospital and the Romanian Alzheimer Society. The

project was proposed at the initiative of the Romanian Alzheimer Society following studies of population needs and an assessment of its beneficiaries. R.A.S. has gained experience through programs held for 8 years for patients with Alzheimer's disease and their families. The Centre is located in Bucharest. Their services are aimed at those living in Bucharest.

The Memory Center is an ambulatory service that has as main purposes:

- early diagnosis of memory disorders
- early diagnosis of dementia disorders and establishing the type of dementia (differential diagnosis)
- diagnosis of affective disorders in the elderly.

### **8.3.2. Possible STAR Win-Win Collaboration**

Possible help with disseminating the project. Might refer Star Training Courses to its beneficiaries. Note: Currently the only contact provided by the Memory Center is a phone number for scheduling patients for consultation. (difficult to contact)

## **8.4. Asociația Tinerilor Medici Geriatri**

Romanian Association of Young Geriatricians <http://tinerigeriatri.ro/>

### **8.4.1. Aims and activities**

Romanian Association of Young Geriatricians has in its center the health care of older people. Romanian Association of Young Geriatricians supports the development of Geriatric Medicine and the professional interests of young doctors in Geriatrics and Gerontology.

Objectives: The Romanian Association of Young Geriatricians supports the professional interests of trainees and young doctors in Geriatrics and Gerontology from Romania. The association particularly supports the acknowledgement of Geriatrics and Gerontology as a complex medical specialty and the development of a geriatrics network on a national level;

- to support the professional development of trainees and young doctors in Geriatrics and Gerontology by organizing scientific activities (lectures, theme meetings, summer schools, congresses);
- to promote trainees and young doctors in the field of clinical and fundamental research in geriatrics and gerontology;
- to collaborate and organize expertise exchanges with physicians of other specialties and with other medical professional organizations;
- to initiate and run medical and social programs and projects for the elderly;
- to develop programs and means of information and education for patients and their families with regards to elderly specific disorders;
- to participate in mutual actions with institutions and organizations involved in the care of the elderly.

### **8.4.2. Possible STAR Win-Win Collaboration**

- Possible collaborator. Could help disseminate Star Training Courses and Community.

## 8.5. Hospice Casa Sperantei Brasov

House of Hope Hospice Brasov <http://www.studiipaliative.ro/upload/files/brosura%20online.pdf>

### 8.5.1. Aims and activities

House of Hope Hospice is a non-governmental charity organization founded in Brasov, in 1992, with the aim of introducing and developing specialized services to care for terminally ill patients in advanced stages. It is the first facility of its kind in Romania and a center of excellence for Eastern Europe in the field of palliative care.

Mission: Introduction and development of palliative care in Romania for terminally ill patients and promoting services nationwide through programs of education, information and advocacy.

Vision: We believe that all people suffering from serious diseases or incurable advanced to provide free and timely specialist palliative care services and their families should have access to support services and counseling.

### 8.5.2. Possible STAR Win-Win Collaboration

Possible competitor.

At the moment the only institution offering a palliative care course that has an online component (users receive course support material by email).

## 9. Conclusions

### 9.1. Differences Between Countries

A recent survey of resources for dementia care (Wimo et al 2010) demonstrated the wide variation in both the level of resources and their allocation across Europe (see Figure 1). Furthermore, where training exists at all, our own analysis (see *D2.1 Report on Existing Courses*) revealed a wide variation in the way such training is understood and delivered.

These two observations are in turn supported by the findings of this stakeholder analysis: that there is a wide variation in the number, range and resources of potential stakeholders across the range of STAR partner countries. Some are Europe-wide, well-financed and attract the support of political and medical authorities; others may be small and voluntary, relying on carers and volunteers. This means that the way in which STAR outputs are used, the collaborative arrangements achieved and the modes of dissemination and delivery used will be different for each country.

For example, some countries already have strong offerings in this such as UK (SCIE) and Sweden (Dementia ABC). Dementia ABC in Sweden is collaborating with Denmark and Norway to establish similar offerings also in these countries. STAR should not directly compete with these good national actors, but instead complement them. In other countries such as Romania however, there are no existing initiatives to provide online training for carers of persons with dementia, and in these countries STAR should pursue towards the goal of providing a complete curriculum of training modules.

## Comparative analysis: key facts

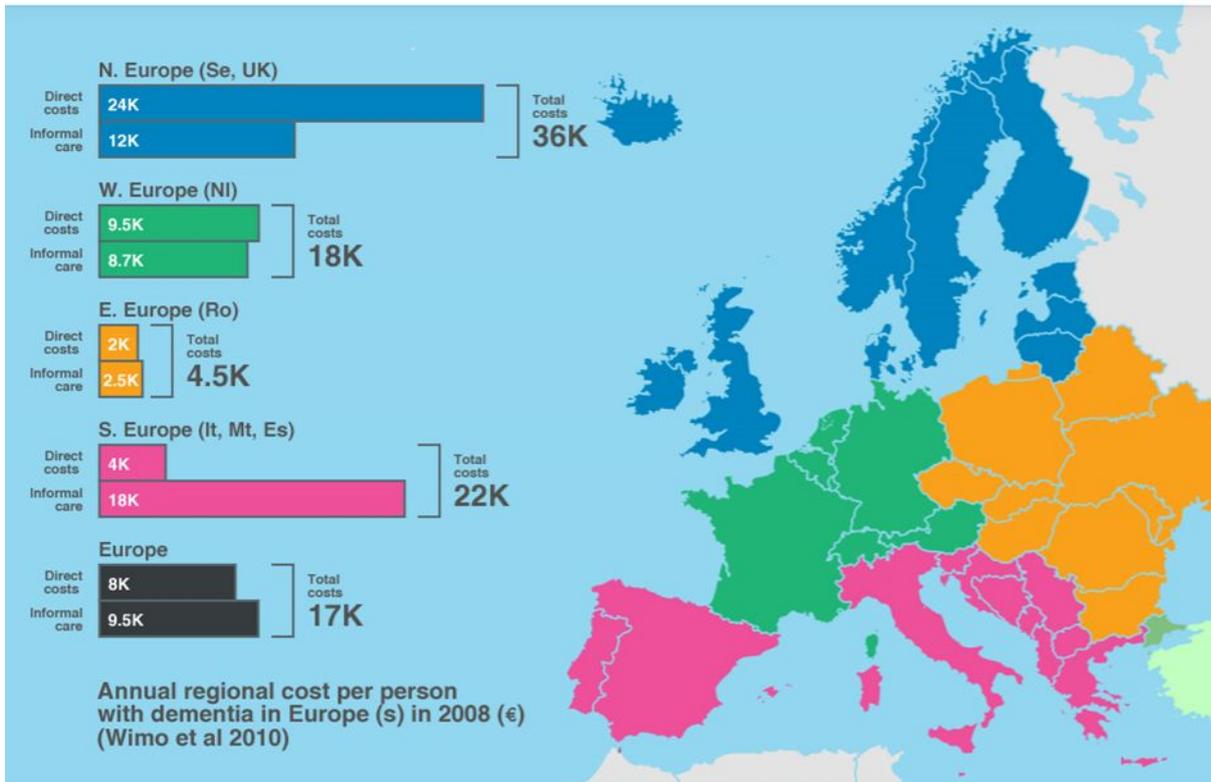


Figure 1

## Mode of Delivery of existing courses by Country

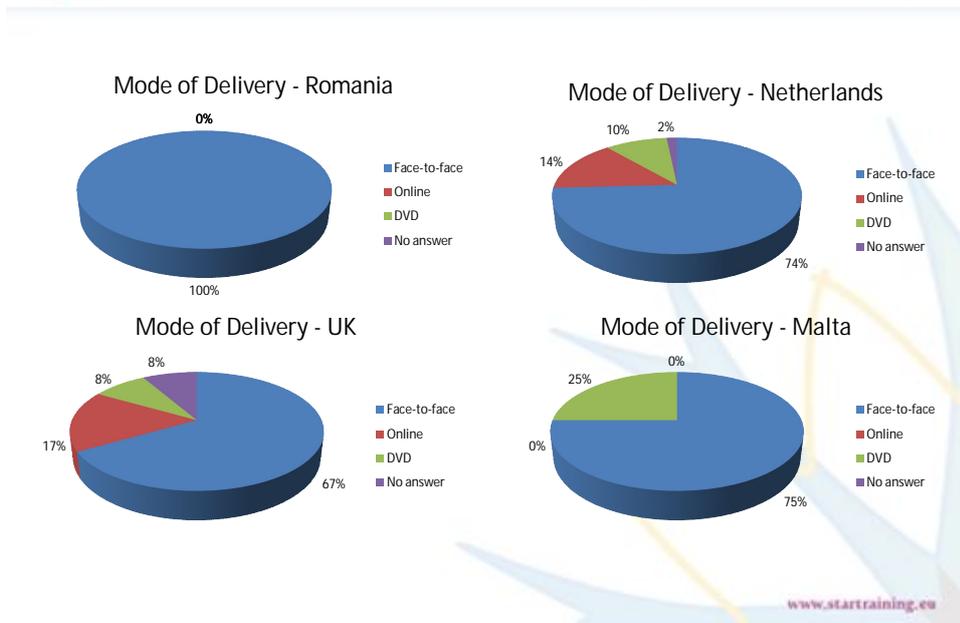


Figure 2

## 9.2. STAR Collaboration Network

As has been reported in D5.3 European Workshop, the STAR consortium has been approached by relevant actors from several other countries showing direct interest in adapting the STAR offering and to pilot it also in their countries.

The great interest has led us to expand the aims of the foreseen Expert Network, to be an open expert community on the LinkedIn social network. <http://www.linkedin.com/groups/Dementia-Care-Online-Training-4811608>

In addition, the STAR partners work continuously to expand their network of dementia experts and practitioners all across Europe, through participation in conferences and other dementia-related research, innovation, development and education activities.

Each STAR partner also nurtures own national networks of dementia experts and practitioners. A detailed database of contacts per-country exists.

## 9.3. Next Steps

The STAR project now invite all identified stakeholders to participate in *WP6 Training Pilot and Validation*, even those who do not wish to be part of the controlled piloting and evaluation. They will also be invited to become long-term members of the STAR national communities to be launched as Facebook pages.

The STAR project will also invite to its public launch event in Malta October 2013, in conjunction with the annual Alzheimer European Conference. At this meeting the project will develop a template for sustainability in the STAR countries and beyond, and recruit more interested countries to join the STAR community.