INTERREG Danube Proposal Draft (Revision)

Preliminary Title: Improving Institutional Capacities for Dementia Management in the Danube Region

1. Project overview

The project aims at improving the capacity of national and local institutions in the Danube Region to deal with the societal challenge of an increasing number of people affected with dementia by means of modern information technology (IT) and medical engineering. Institutions to be addressed include health ministries, local authorities, nursing schools, medical chambers, health insurances and patient advocacy groups. Specifically, we propose to enhance the vocational education and training of workforce involved in dementia care, to stimulate the coordination and knowledge transfer between dementia experts, medical specialists and general physicians, and to promote the use of assistive technologies to support care in the community.

2. Own previous work

In a one-year project funded by the German Ministry of Education and Research (Danubian Network for Dementia Education and Care, DANDEC) from 2013-2014 (Grant 01DS13011) a research network was formed consisting of twelve partner institutions including university departments, patient organisations and small-to-medium enterprises. The partners represented six countries of the Danube region (Bulgaria, Czech Republic, Germany / Bavaria, Romania, Slovenia, and Ukraine). The network was later complemented by another four institutions in four countries (Austria, Croatia, Hungary, and Serbia). In addition, contacts have been established with academic partners in Bosnia-Hercegovina, Moldova, Montenegro and Slovakia. The group conducted a survey among health care professionals and patient organisations in the partner countries to assess the quality of dementia care, the organisation of professional dementia education, the access to services and the availability of assistive technology. The major results of the survey were:

- Dementia is a top medical and social challenge in all countries of the Danube region;
- Quality of dementia care is highly heterogeneous countries, particularly between the upstream and downstream part of the Danube region;
- Non-pharmacological interventions, which are an essential part of dementia management according to current medical guidelines (Hort, O’Brien et al. 2010), such as cognitive stimulation or training, occupational therapy or physical activity programmes, are rarely available in practice;
- Day care centres and respite care facilities are largely lacking;
- In all countries of the Danube region there is a gradient of dementia care quality and access to services from urban to rural areas;
- In all countries of the Danube region there is a need for educating health professionals about dementia management and carer support, particularly primary physicians and nurses;
- In all countries of the Danube region the role of general physicians is to detect dementia and refer patients to specialists (neurologists and psychiatrists) who are responsible for differential diagnosis and dementia-specific treatment;
- Modern information technology such as e-learning programmes, online courses and webinars, is considered to be an appropriate means for professional education;
• Assistive technologies to enhance safety, communication, mobility, participation and comfort
  of people with dementia while at the same time reducing the burden on informal carers, are
  underused.

Based on this evidence the group decided to design an online learning programme for healthcare
and allied professionals with the following core features:

• Focusing on awareness, knowledge and implementation of assistive technology for people with
dementia and their informal carers;

• Addressing the most important unmet needs in dementia care in the Danube region including
timely diagnosis, pharmacological and non-pharmacological treatments, management
of problem behaviours, and communication with patients and carers.

This decision was laid down in a Memorandum of Understanding, establishing a frame for the
future collaboration.

In the present proposal the online learning programme is expanded to a comprehensive strategy
which consists of three interlinked modules: primary-level professional education, secondary-level
knowledge transfer, and implementation of assistive technology. The strategy takes advantage
of up-to-date information technology and medical engineering. It is aimed at improving the capacity
of existing institutions and infrastructures in the Danube region to tackle major societal challenges
that are associated with demographic change:

• The increasing number of people with dementia;

• The emigration of health workers („care drain“).

The previous work and the memorandum of understanding includes more: the three pillars of the
intervention:
  a) web-based information and education program for front-line health professionals involved with
  people with dementia (also addresses horizontal integration of care);
  b) IT-based platform for knowledge exchange between dementia specialists / experts and GPs,
  also to promote and better target referrals (also addresses vertical integration of care);
  c) application of assistive technologies (linked to the education program).

In the second phase of the DANDEC preparatory program the Consortium was expanded
to partners from all 14 countries of the Danube Region (9 EU member states and 5 EU non-
member states). The partners from all countries will be asked to identify key institutions and
keyholders on a local / national level who will be needed for the implementation of the improved
dementia care strategy which will be proposed in the INTERREG-Danube application. The key
institutions and keyholders will form the national / local hubs of the project (see below).

3. Demographic change in the Danube Region

3.1 Population ageing

In the EU as a whole life expectancy at age 65 is projected to increase by 4.8 years for males and
by 4.6 years for females over the projection period 2013-2060, with above-average increases
expected to occur in countries of the Danube region (Appendix, Figure 4). The increased longevity
in combination with a low birth rate implies that the age structure of the EU population will change
dramatically. While the proportion of young people (aged 0-19) is projected to remain fairly
constant, those aged 80 and over will almost become as numerous as the young population
in 2060. In the countries of the Danube Region the proportion of people older than 65 years will
rise from 17.6% on average in 2013 to 30.4 % on average in 2060 (European-Commission 2015a). As a result of the different trends among age-groups, the old-age dependency ratio (people aged 65 or above relative to those aged 15-64) is projected to rise from 27.8% to 50.1% in the EU as a whole over the projection period (Appendix, Figure 5). The increase of this ratio is above EU average in countries of the Danube region (European-Commission 2015b).

3.2 Increasing number of people with dementia

In 2012, the number of individuals aged 60 years and over affected by dementia in the Danube Region ranged between 5.5 % in Bulgaria and 7.1 % in Austria (EU average 7.0) (OECD 2014) (Appendix, Figure 6). As a consequence of population ageing, the number of people with dementia in Europe is predicted to increase from approximately 11 million in 2015 to approximately 14 million in 2030. In eastern Europe alone, the number of affected individuals is expected to rise during this period from approximately 3.6 million to approximately 4.5 million (Wimo, Jönnson et al. 2011) (Appendix, Figure 7).

3.3 Emigration of health workers („Care drain“)

International migration which is mainly driven by economic and job-related reasons is directed from sending countries the south eastern part of the Danube region preferentially to Austria, Germany and Slovenia (Müller, Klee et al. 2014). Migration particularly affects rural areas which suffer from depopulation (Winiwarter and Haidvogl 2015). Emigration is selective, with doctors, medical personnel and engineers being overrepresented among migrants (Gal, Lux et al. 2013). According to the World Health Organization, the migration of health workers, particularly of females („care drain“), from in south and eastern Europe has resulted in a lack of qualified health personnel (Siyam and Dal-Poz 2014) and in reduced family support in their home countries.

4. Strategy

4.1 Evidence base

We propose a strategy which is aimed at improving the institutional capacity in the Danube Region to deal with the increasing number of people with dementia in the face of weakened traditional structures of care and drain of qualified workforce. The strategy is based on the results of a survey which was conducted as part of the DANDEC project, and is informed by national European dementia plans or their precursors. The most relevant results of our survey for the strategy are:

- General physicians (GPs) are the entry point to dementia diagnosis and treatment in all countries of the Danube Region. However, with few exceptions, their medical training schedule largely excludes, so that they are considered to be in need of dementia-specific education, as are nurses, social workers and occupational therapists. The contribution of GPs to the diagnosis of dementia is particularly high in Germany and Slovenia.

- Specialists, in particular neurologists and psychiatrists, are involved in dementia diagnosis and treatment. Their tasks include differential diagnosis, prescription of dementia-specific medications and management or consulting in case of unusual symptoms or course. The contribution of specialists is especially high in Austria and Bulgaria.

- Access to assistive technology to support autonomy, mobility, activity, communication and safety of people with dementia is unequal across countries of the Danube Region. Dissemination and utilisation rates are generally very low. A high rate of availability is reported from the Czech Republic.
The national dementia plans which have been put in place in France, England and Scotland and are being prepared in other countries (Austria, Bulgaria, Czech Republic, Germany) highlight as key components (Alzheimer-Europe 2016):

- Dementia-specific professional education;
- Timely diagnosis;
- Networking among health professionals and integration of services;
- Support of informal carers.

4.2 The three modules

On the basis of the information gathered in the DANDEC survey and the priorities put forward in the national dementia plans we propose to develop three interlinked modules: STUDIO, ACADEMY, and TOOLBOX (Figure 1).

- **STUDIO: Primary care level professional education.** We will develop an online learning programme to improve the skills of healthcare and allied professionals in the management of dementia, including general physicians, nurses, social workers and occupational therapists. Emphasis will be laid on interdisciplinary cooperation and integration of medical and social services.

- **ACADEMY: Secondary care level knowledge transfer.** We will develop a telemedicine platform for knowledge transfer between dementia experts, medical specialists (neurologists, psychiatrists, geriatricians) and GPs. Methods of knowledge transfer will include an online resource (e.g. diagnostic and treatment guidelines), virtual case studies and demonstrations, and an dedicated discussion forum.

- **TOOLBOX: Promotion of assistive technology.** We will develop a set of assistive technology devices and systems to support autonomy, mobility, participation, communication and safety of people with dementia, and to reduce the burden of their informal carers. The use of assistive devices will be promoted by means of a dedicated website including video examples, and through written materials for physician officaes, community centres and patient advocacy groups.

4.3 Relationship of the modules to external institutions

The three modules will be designed, tested and implemented in close collaboration with domain-specific local and national institutions in order to ensure alignment with and complementation of existing policies and tools, and to enable sustainability beyond the project’s lifetime.

- **STUDIO:** Cooperation partners are institutions involved in postgraduate medical training, health and nursing schools, charitable organisations, and patient advocacy groups.

- **ACADEMY:** Cooperation partners are medical boards and medical associations. Educational content will be harmonised with the European Alzheimer’s Disease Consortium (EADC) and the International Psychogeriatric Association (IPA).

- **TOOLBOX:** Cooperation partners are technical chambers, medical engineering associations and IT providers.
4.4 Links between the modules

There are mutual relationships between the modules. STUDIO will provide information for health and allied professionals on the availability, indication, use, benefits, limitations, risks and ethical implications of assistive technology for people with dementia. This information is needed for the successful implementation of assistive devices by TOOLBOX. Conversely, TOOLBOX will gather data on the function, problems and gaps of assistive technology in practice which is essential for appropriate counseling in STUDIO. ACADEMY is aimed at supporting specialists (neurologists, psychiatrists, geriatricians) and GPs by establishing close links to experts with regard to early and differential diagnosis, rare forms of dementia, pharmacological and non-pharmacological treatment, dealing with problematic behaviours and managing atypical symptoms and course. Indirectly, this knowledge transfer translates to the primary care level. Conversely, best practice procedures including interdisciplinary integration developed by STUDIO are a background for decisions and guidance provided by ACADEMY. The secondary care level also requires information from STUDIO on the potential and limitations of assistive technologies, as this will impact on guidance regarding hospitalisations and nursing home admissions. To ensure the interaction between the modules regular telephone conferences or videoconferences will be held during Stage 1 of the project.

4.5 Three stages of the project

We propose to carry out the strategy in a stepwise fashion (Figure 2). Each module will be developed and evaluated in a pilot study with regard to feasibility and acceptance in selected countries of the Danube Region where appropriate expertise, practice and infrastructures are in place (Stage 1, current application). In Stage 2, we plan to extend the modules to other countries where infrastructures are less mature, e.g. to downstream countries or countries with large rural areas. At this stage, the added value of combining the three modules (at selected sites) as well as administrative, technical and cultural barriers will be explored. Refined and country-specific modifications of the modules will be applied. Finally, at Stage 3, the modules will be rolled out to the entire Danube Region. Implementation into the diverse existing infrastructures and sustainability will be determined, and a study of efficacy and cost-effectiveness will be performed.

This section must be changed. Partners in all 14 countries need to be involved.
Regarding the regional expansion of the project, we envision to involve five core countries in Stage 1, representing the upstream and downstream Danube region. At Stage 2 we plan to add another five countries. Finally, at Stage 3 the project may extend to 14 countries altogether, representing the entire Danube Region.

This section needs to be changed. Partners in all 14 countries will be involved from the start to build up the national / local hubs and the structure of the Consortium.
Targeting of pilot studies, based on the DANDEC Survey

The principle is to pilot the three strategies in countries where the respective infrastructure is favourable, and not the start where implementation is most difficult. The longer-term strategy of the project (beyond 30 months) may include piloting in additional countries. Pilots interventions will be models prepared in English as the common language. Translation into different language and country-specific adaptation will be the task of partners and is separate from the project.

**STUDIO**: to be piloted in countries where GPs have a significant role in dementia care (e.g. Germany, Slovenia). In these countries the contributions of nurses, social workers and occupational therapists is also large.

**ACADEMY**: to be piloted in countries where medical specialists (psychiatrists and neurologists) have a significant role in the management of dementia (e.g. Austria, Bulgaria, Croatia, Serbia).

**TOOLBOX**: to be piloted in countries where assistive technology is already in use and where the appropriate infrastructure exists (e.g. Czech Republic, Romania).
Appendix

Figure 4: Projection of life expectancy in European countries 2013-2060

Graph I.1.5: Projection of life expectancy at birth in EUROPOP2013, men (in years)

Source: Commission services, Eurostat, EUROPOP2013.

Graph I.1.6: Projection of life expectancy at birth in EUROPOP2013, women (in years)

Source: Commission services, Eurostat, EUROPOP2013.
Figure 5: Projection of old-age dependency ratio in European countries 2013-2060

Figure 6: Prevalence of dementia among people aged 60 and over
Figure 7: Number of people with dementia, projection until 2030
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