Expert survey
Deliverable 3.1.1. | Version 1

Table of contents

1. INTRODUCTION

The Danube Region is a functional area defined by its river basin. It extends over 14 states, among them nine EU-member states (Germany, Austria, the Czech Republic, Slovakia, Hungary, Slovenia, Croatia, Bulgaria and Romania) and five countries which are not presently EU-members (Serbia, Montenegro, Bosnia and Herzegovina, the Ukraine and Moldova). The Danube Region has a total population of 150 million. In socio-economic regard, the region shows disparity since it includes some of the most affluent but also some of the poorest regions in the European Union. The prevalence of dementia among people aged 60 years and older is not uniform across the area. Rates of about 5 % have been reported in Slovakia and Romania, whereas prevalence is as high as 7 % in Austria, Germany, and Bulgaria. An even higher prevalence of dementia (10%) has been found in the Ukraine but the validity of this data is questionable. Taken together, at least 3 million older adults are affected with dementia in the countries of the Danube Region.

Due to increasing life expectancy the number of people affected with dementia is predicted to rise by 50 % from 2015 to 2030 in eastern and southern Europe, and the dependency ratio (the ratio of people aged 65 or above relative to the working-age population) is expected to increase. An additional challenge in the Danube Region is the migration of health workers, predominantly Eastern part, („care drain“) and has resulted in a lack of qualified health personnel and reduced family support in the sending countries. The improvement and sustainability of dementia care and access to dementia-related knowledge has to be placed high on public and political agendas in the Danube Region. Here we report the results of a multi-national survey among dementia experts which was carried out by the INDEED consortium in order to obtain an up-to-date and comprehensive overview of the current state of dementia care in all 14 countries of the Danube region, and to assess the frameworks for entrepreneurial conditions. The fit of the findings with the strategy of the INDEED project and the implications for the three modules of the intervention will be discussed.

2. METHODS

This expert survey is an update of a previous review of dementia care that has been conducted in 10 Danubian countries in 2014. For INDEED, this review was extended to gain an up-to-date and more comprehensive overview of the current state of dementia education and care in all 14 countries of the Danube region, including regulatory and economic frameworks. Specifically, additional questions were incorporated regarding country-specific regulations for business in dementia care to explore the infrastructure for entrepreneurial innovation. A questionnaire was sent out to 2-3 experts in each country with knowledge in dementia and in business. To date, responses are not yet available from all countries. Part of the questionnaire, particularly regarding economics, was piloted in a selected group of experts in to determine feasibility, and clarity of items.

3. RESULTS

3.1 Diagnosis

People with dementia (PWD) diagnosed per year

The results are widely distributed between 5000 (in Romania) and 50000 (in Germany) diagnosed people with dementia per year in 5 Danubian countries. These numbers could be used for business planning of care services.

Diagnostic setting

By that moment data are insufficient but the tendency is that the diagnostic procedure is conducted in outpatient settings.

People with dementia receiving treatment

The results are equally distributed in wide range between 25% and 75-100% of people with dementia and are country-specific.

Place/specialist where PWD go first to obtain the diagnosis

- In metropoles and big towns - in most countries - key figures are General Practitioners (GP)/primary physicians (mean 40%) and neurologists (31%), followed by psychiatrists (19%) and memory centers/clinics (14%).
- In smaller towns (between 10000 and 100000 citizens) - in most countries - PWD go first to GPs/primary physicians (61%) to obtain the diagnosis followed by neurologists (22%) and psychiatrists (17%).
- In rural areas mainly GPs/primary physicians are those who are addressed for dementia diagnosis (mean 79%)

This indicates that the role of the GP/primary physician for the initiation of the diagnosis of dementia is greater in rural than in metropolitan areas.

Referrals from GPs to specialists

There are no big differences between urban and rural areas within given country in referral process.

The results are country-specific - very small percent of PWD are referred in Germany, greatest percent are referred in Bulgaria and Czech Republic (figure 1).

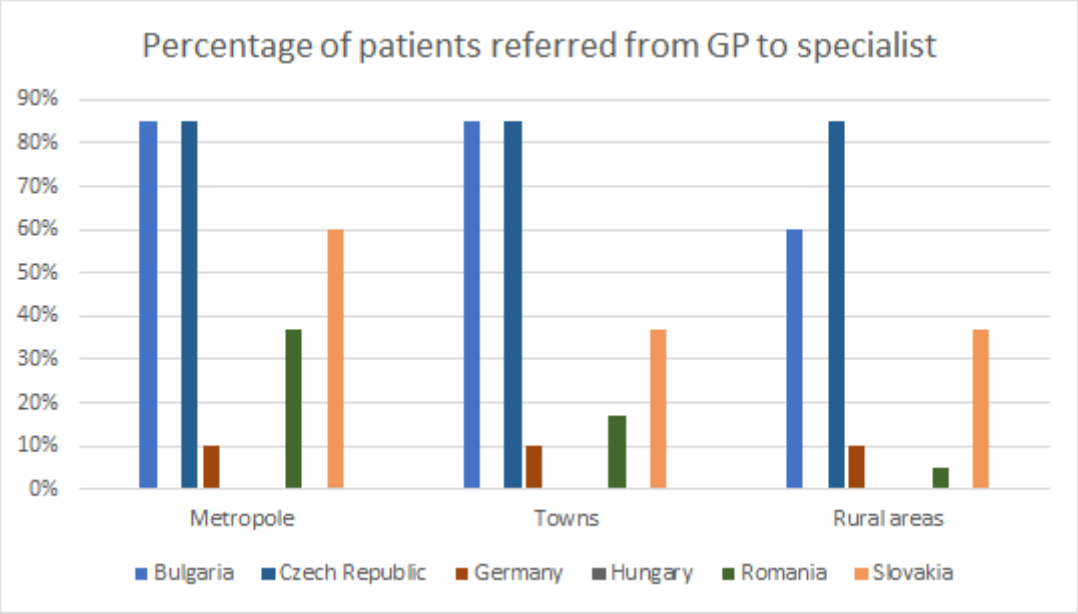


Figure 1

Contribution of specialists to dementia diagnosis and treatment

- Contribution to dementia diagnosis - neurologists have main contribution to dementia diagnosis (mean 38%, highest percent in Bulgaria 85%), followed by psychiatrists (mean 29%, highest percent in Germany 60%) and GPs (mean 26%, highest percent in Hungary 70%).
- Contribution to dementia treatment - neurologists are key figure in most of the countries concerning dementia treatment (mean 41%, highest percent in Bulgaria 85%), followed by psychiatrists (mean 29%, highest in Romania 50%) and GPs (mean 25%, highest percent in Germany 80%).

Available dementia-related diagnostic services

- GPs consultation is available in all regions in all countries except Hungary.
- Specialist consultation and neuroimaging facilities are available in all regions in Bulgaria, Czech Republic and Germany. These services are available only in metropolitan regions in Hungary, Romania and Slovakia.
- Neuropsychologists/psychologists are available only in metropolitan regions in most countries
- Memory centers as well as Cerebro-Spinal Fluid (CSF) biomarkers are rarely available (all figure 2)

Country	GP consultation	Neuropsychologist / psychologist consultation	Specialist consultation	Memory centre	Neuroimaging facilities	CSF biomarkers
Austria						
Bosnia-Hercegovina						
Bulgaria						
Croatia						
Czech Republic						
Germany						
Hungary					?	?
Moldova						
Montenegro						
Romania						
Serbia						
Slovakia						
Slovenia						
Ukraine						

Legend	
Yes, in all regions	
Yes, only in metropolitan regions	
Yes, only in selected regions	
No, would be required	
No, and not required	
I do not know	?

Figure 2

Utilization of dementia-related diagnostic services

GP consultation is relatively highly used in almost all countries. PWD in most of countries use specialist consultations, neuroimaging facilities and memory centers/clinics. CSF biomarkers are rarely used (figure 3).

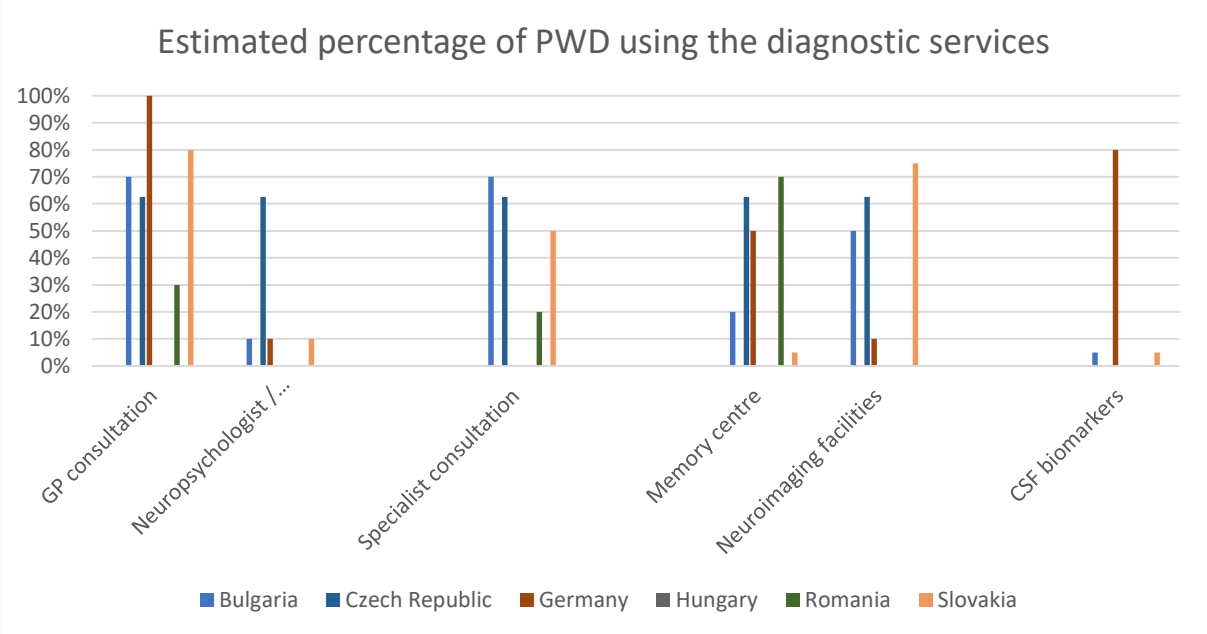


Figure 3

Current need of dementia-related diagnostic services

Experts from all countries agree that all kind of diagnostic services are strongly needed or needed (figure 4).

Country	GP consultation	Neuropsychologist / psychologist consultation	Specialist consultation	Memory centre	Neuroimaging facilities	CSF biomarkers
Austria						
Bosnia-Hercegovina						
Bulgaria						
Croatia						
Czech Republic						
Germany	?	?	?	?	?	?
Hungary						
Moldova						
Montenegro						
Romania						
Serbia						
Slovakia						
Slovenia						
Ukraine						

Legend	
strongly needed	
needed	
little needed	
not needed at all	
I do not know	?

Figure 4

Organizations providing dementia-related diagnostic services

Governmental organizations (public hospitals) and self-employed professionals most frequently provide diagnostic services. Profit organizations/ Enterprises also contribute to provision of dementia-related diagnostic services. Social Businesses/ Social Entrepreneurship do not provide dementia-related services (figure 5).

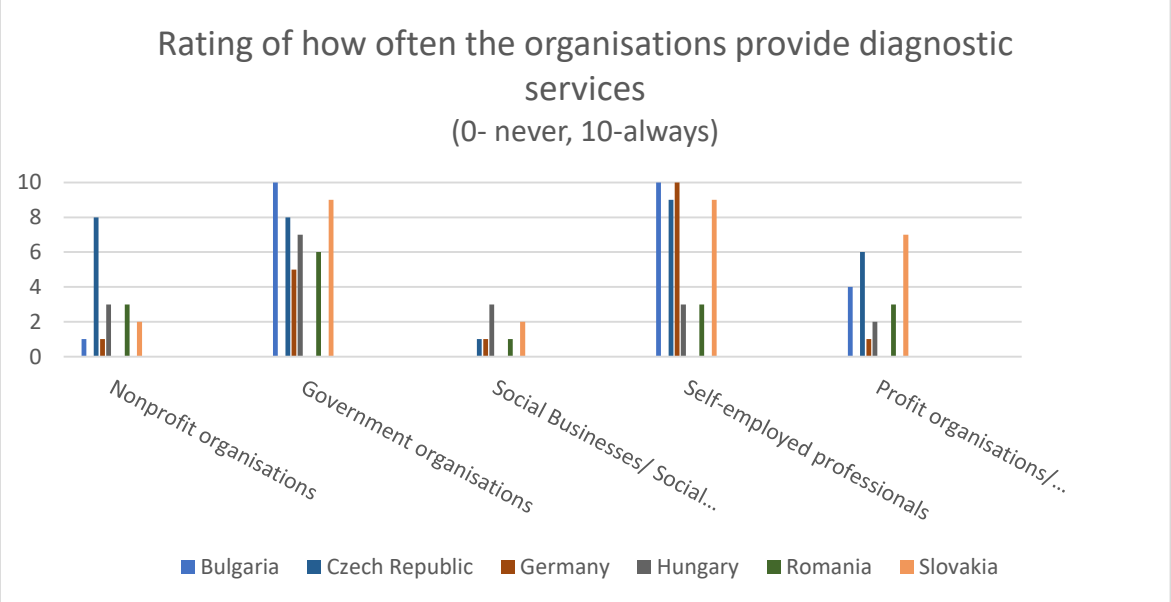


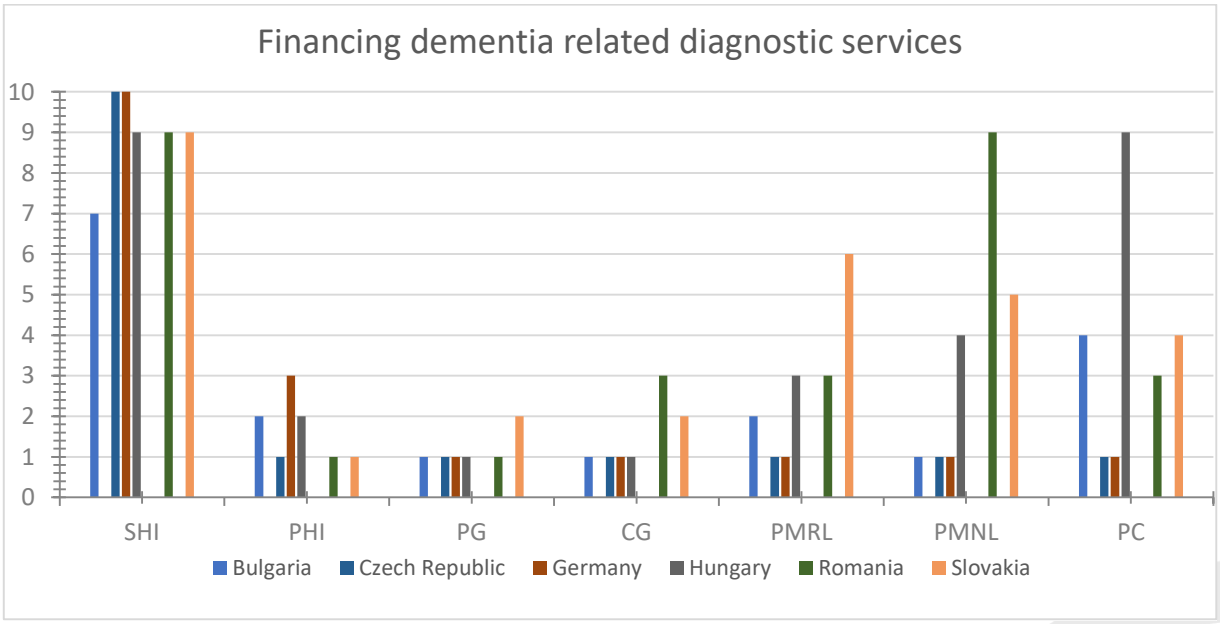
Figure 5

Regulation of dementia-related diagnostic services

In most of the countries regulation of diagnostic services is rather strict.

Sources of financing for dementia-related diagnostic services

In all countries sources of financing come mainly from statutory health insurance.
Patient contribution in Hungary is very high. Public money at national and regional level also take place in Romania, Slovakia and Hungary (figure 6).



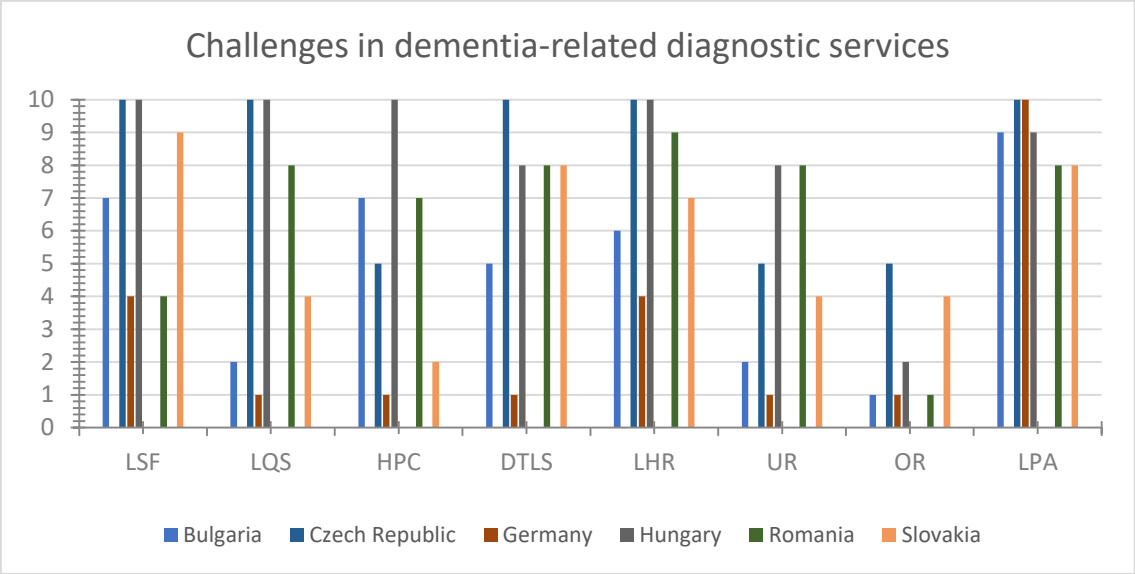
SHI – statutory health insurance; PHI – private health insurance; PG – private giving (foundations); CG – corporative giving (sponsoring); PMRL – public money at regional level; PMNL – public money at national level; PC – patient contribution

Figure 6

Challenges in provision of dementia-related diagnostic services

Experts from most countries agree that the following challenges in dementia-related diagnostic services are very important (figure 7):

- Limited public awareness
- Limited human recourses
- Diagnosis and treatment in late/severe stages
- Insufficient services and poor quality of services



LSF - lack of specialized facilities; LQS - lack of quality of services; HPC - high personal contribution (pay-out-of-pocket); DTLS - diagnosis and treatment in late/severe stages; LHR - limited human resources; UR - underregulation; OR - overregulation; LPA - limited public awareness.

Figure 7

3.2 Treatment

Availability of dementia-related treatment

All countries have available outpatient medical treatment, including drug treatment in all regions. Most of other types of dementia-related therapies (cognitive training, cognitive rehabilitation, music therapy, speech and language therapy, physiotherapy, occupational therapy) are available in selected regions or only in big cities (figure 8).

Country	OMC	CT	SLT	OT	PT	RT	ST	MAT	Other
Austria									
Bosnia-Hercegovina									
Bulgaria									
Croatia									
Czech Republic									
Germany									
Hungary						?	?		
Moldova									
Montenegro									
Romania									
Serbia									
Slovakia									
Slovenia									
Ukraine									

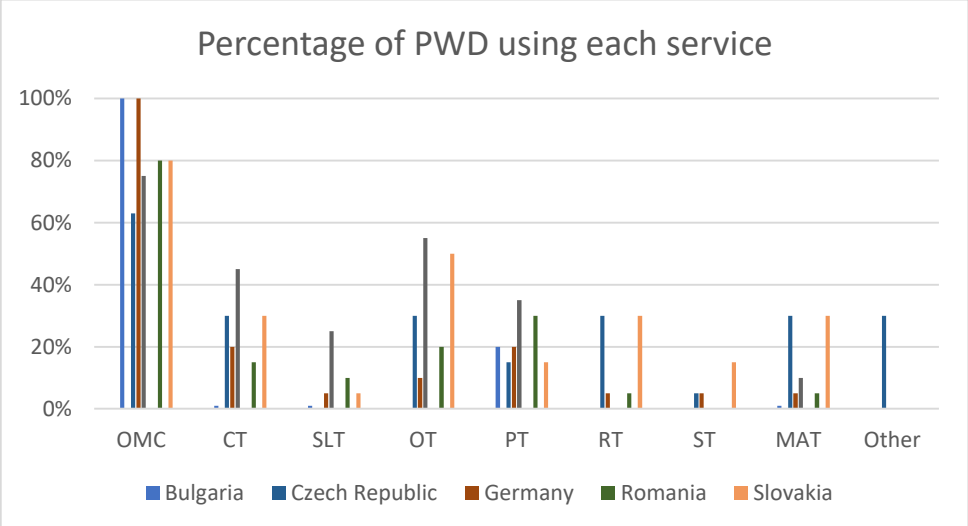
Legend	
Yes, in all regions	
Yes, only in metropolitan regions	
Yes, only in selected regions	
No, would be required	
No, and not required	
I do not know	?

OMC	Outpatient medical care (including drug treatment)
CT	Cognitive training/ stimulation/ rehabilitation
SLT	Speech and language therapy
OT	Occupational therapy
PT	Physiotherapy
RT	Reminiscene therapy
ST	Snoezelen therapy
MAT	Music/ art therapy

Figure 8

Utilization of dementia-related treatments

Outpatient medical care therapy services are highly used in all countries (mean 83%).
33% of PWD use occupational therapy in countries where such specialists are available. Cognitive training/rehabilitation and physiotherapy are used by less than 30% of PWD. Other types of therapies are very rarely used (figure 9).



OMC – Outpatient medical care (including drug treatment); CT – Cognitive training / stimulation / rehabilitation; SLT – Speech and language therapy; OT – Occupational therapy; PT – Physiotherapy; RT – Reminiscence therapy; ST – Snoezelen therapy; MAT – Music and art therapy

Figure 9

Current need of dementia-related treatments

Experts from all countries except Germany (where all treatments are available) agree that most of these therapies are needed or strongly needed. Concerning snoezelen, reminiscence – they are estimated as little needed.

There is a need and place for developing services for cognitive training/rehabilitation, speech therapy, physiotherapy, music/art therapy for PWD (figure 10).

Country	OMC	CT	SLT	OT	PT	RT	ST	MAT
Austria								
Bosnia-Hercegovina								
Bulgaria								
Croatia								
Czech Republic								?
Germany	?	?	?	?	?	?	?	?
Hungary						?	?	
Moldova								
Montenegro								
Romania								
Serbia								
Slovakia								
Slovenia								
Ukraine								

Legend	
strongly needed	
needed	
little needed	
not needed at all	
I do not know	?

Figure 10

Organizations providing dementia-related treatments

Great part of existing dementia-related treatments are provided by government organizations and to less extend by self-employed professional or profit organizations. Social business organizations are rarely involved in providing dementia-related therapies (figure 11).

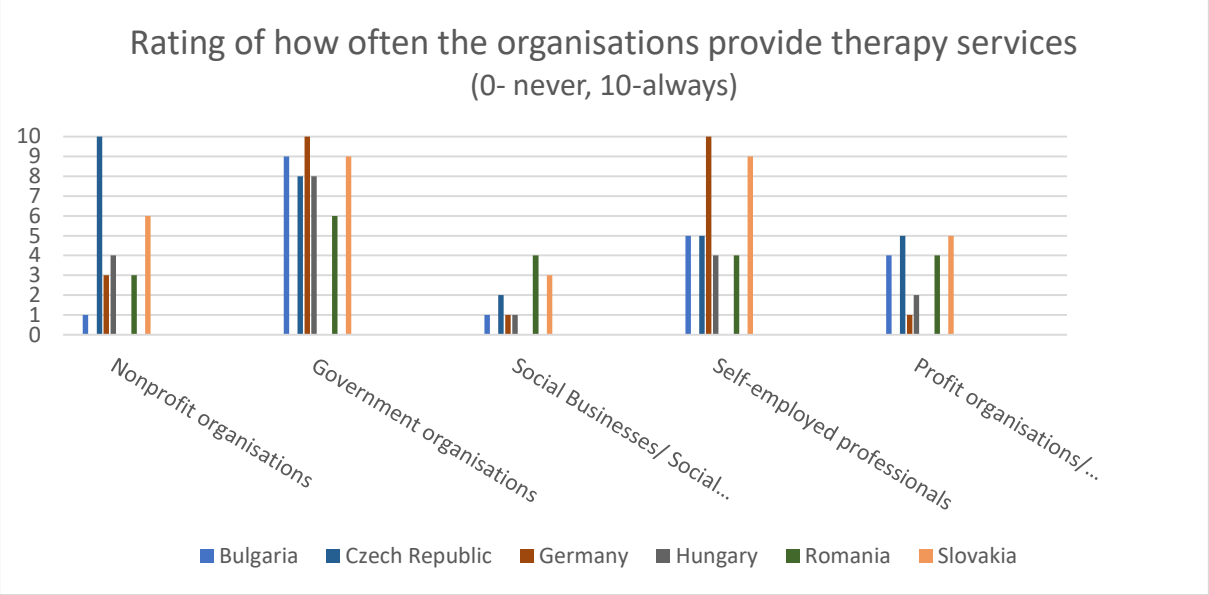


Figure 11

Nonprofit organisations refer to (private) charitable organisations that are not oriented towards financial return and have a non-distribution constraint, that is, they are not allowed to distribute profits to owners (e.g. International Red Cross).

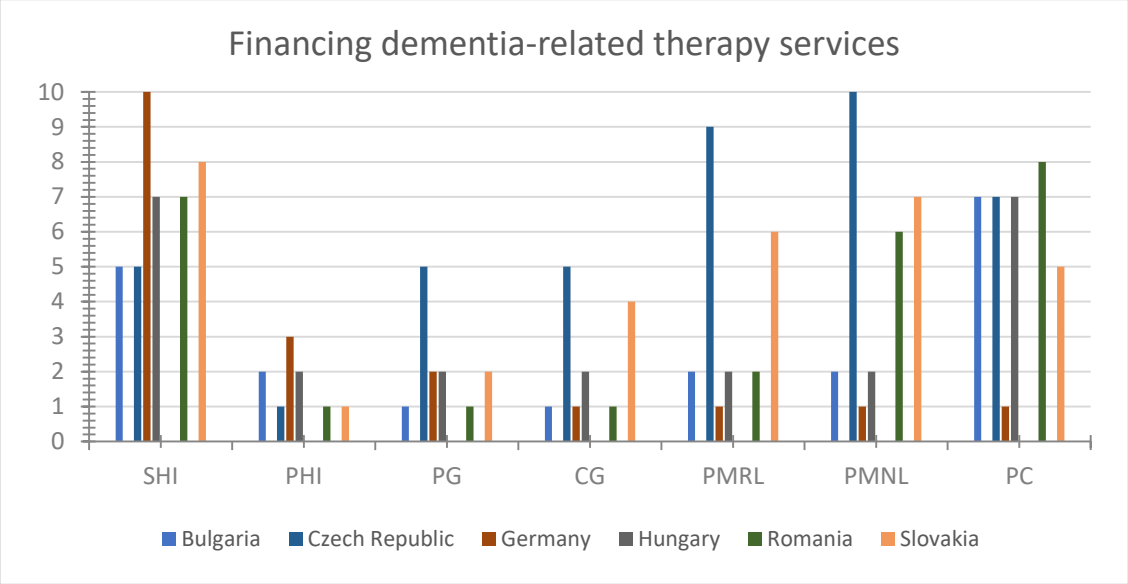
Government organisations refer to organisations that are owned by the municipality, the state, or the federal government (e.g. public hospitals).
Social Businesses/Social Entrepreneurship refer/s to organisations that primarily aim to generate a social value using (innovative) business models that allow them to operate in a financial sustainable way. They are allowed to distribute profits to owners.
Self-employed professionals refer to self-employed care givers, general practitioners, or other self-employed professionals that are not employed, for example, in a hospital.
Profit organisations/Enterprises refer to profit-oriented organisations and/or companies that do not have a non-distribution constraint. As opposed to Social Businesses/Social Entrepreneurship, the financial return is usually paramount.
Informal carers refer, for example, to family members or neighbours.

Regulation of dementia-related treatments

Regulatory restrictions are diverse and country-specific. They have to be explored and discussed during educational workshops.

Sources of financing for dementia-related treatments

Statutory health insurance and patient contribution (pay-out-of-pocket) are main sources of financing for dementia-related therapy services. In some Danubian countries public money at national level also represents a substantial financing resource. In most countries private health insurance, donations, sponsoring are of very limited importance for funding dementia-related therapy services (figure 12).

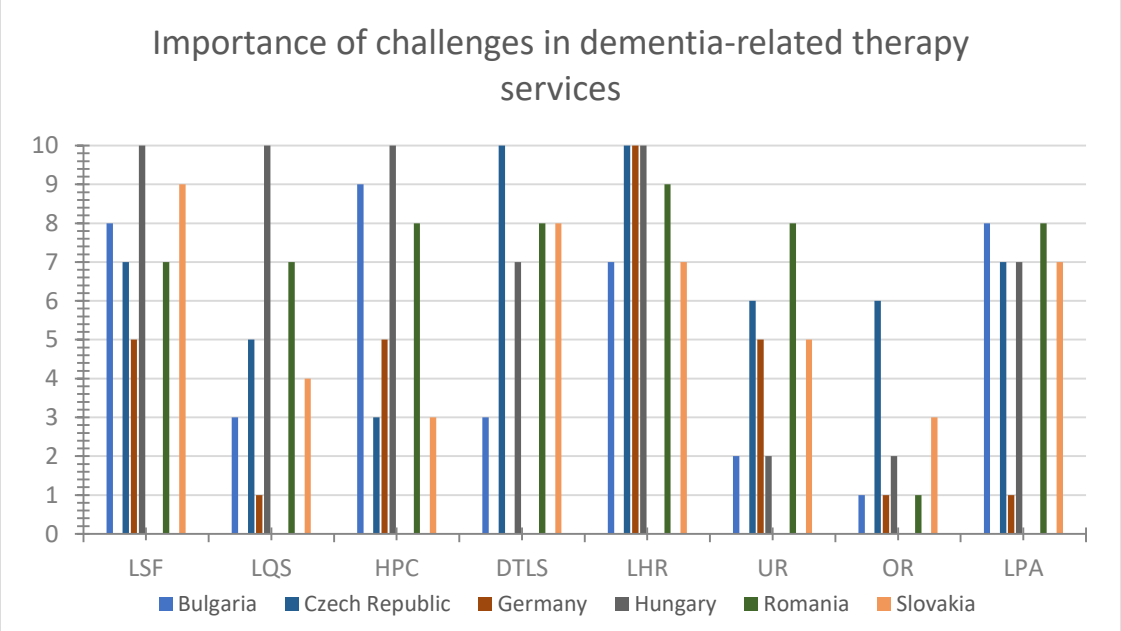


SHI – statutory health insurance; PHI – private health insurance; PG – private giving (foundations); CG – corporative giving (sponsoring); PMRL – public money at regional level; PMNL – public money at national level; PC – patient contribution

Figure 12

Challenges in provision of dementia-related treatments

The greatest challenges concern lack of human resources, lack of specialized facilities, diagnosis and treatment in late/severe stages and high personal contribution (pay-out-of-pocket). Limited public awareness is also considered very important in this issue. Regulatory requirements are not viewed as big challenge in provision therapy services (figure 13).



LSF - lack of specialized facilities; LQS - lack of quality of services; HPC - high personal contribution (pay-out-of-pocket); DTLS - diagnosis and treatment in late/severe stages; LHR - limited human resources; UR - underregulation; OR - overregulation; LPA - limited public awareness.

Figure 13

Business expertise concerning dementia-related treatments

It is difficult to analyse the business expertise of the organizations because of insufficient data but some tendencies could be pointed out – the dementia-related services business expertise (concerning marketing, business plan development, fund raising and human resource management) is estimated to be not at satisfactory professional level.

3.3 Care facilities

Availability of dementia care facilities

In most of the countries services like outpatient medical care, hospital treatment, and nursing home care are available in all regions. Home care assistance and mobile services are not available in all countries. Lack of day care, respite care services and dementia residential communities in Danubian countries is observed (figure 14).

Country	OMC	HC	DC	RC	IC	HT	DRC	MS	CSC	PC
Austria										
Bosnia-Hercegovina										
Bulgaria										
Croatia										
Czech Republic										
Germany										
Hungary				?				?	?	
Moldova										
Montenegro										
Romania										
Serbia										
Slovakia										
Slovenia										
Ukraine										

Legend	
Yes, in all regions	
Yes, only in metropolitan regions	
Yes, only in selected regions	
No, would be required	
No, and not required	
I do not know	?

OMC	Outpatient medical care (including drug treatment)
HC	Home care/ assistance with ADL
DC	Day care
RC	Respite care
IC	Inpatient care (e.g. nursing homes)
HT	Hospital treatment
DRC	Dementia residential communities
MS	Mobile services (e.g. meals on wheels)
CSC	Caregiver support and counseling
PC	Palliative care

Figure 14

Utilization of care facilities

Great part of PWD uses the available outpatient medical care (mean 71%). About 30% of PWD use inpatient care (like nursing homes) in most of the countries. Only 17% of PWD use hospital treatment.

Most of PWD are cared for at home but home care assistance is rarely used. Family members are uniformly involved in everyday care but caregiver support and counselling is used in only 12% of the dementia patients and their caregivers.

Results indicate very limited use/ availability of day care, respite care services and dementia residential communities.

Current need for care facilities

Experts from all countries agree that most of dementia-care services are strongly needed – outpatient, inpatient, medical and social care services (figure 15).

Country	OMC	HC	DC	RC	IC	HT	DRC	MS	CSC	PC
Austria										
Bosnia-Hercegovina										
Bulgaria										
Croatia										
Czech Republic										
Germany	?	?	?	?	?	?	?	?	?	?
Hungary				?		?		?		
Moldova										
Montenegro										
Romania										
Serbia										
Slovakia										
Slovenia										
Ukraine										

strongly needed	
needed	
little needed	
not needed at all	
I do not know	?

OMC	Outpatient medical care (including drug treatment)
HC	Home care/ assistance with ADL
DC	Day care
RC	Respite care
IC	Inpatient care (e.g. nursing homes)
HT	Hospital treatment
DRC	Dementia residential communities
MS	Mobile services (e.g. meals on wheels)
CSC	Caregiver support and counseling
PC	Palliative care

Figure 15

Organizations providing care facilities

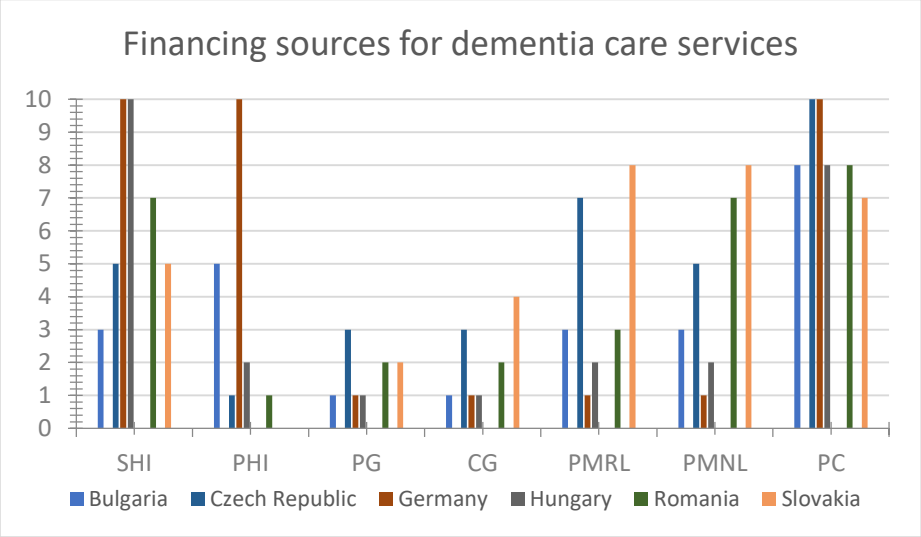
There is great number of country-specific models of providing dementia-related care services, but the percent of providing governmental organizations is relatively high, followed by profit and non-organizations providers and self-employed professionals.
Social Businesses and Social Entrepreneurship who provide dementia-related care services are not developed in Danube countries.

Regulation of care facilities

Results revealed high diversity of regulation for dementia-related services – from very strict to very permissive.

Sources of financing for care facilities

In most countries financial sources for dementia-related care services are misbalanced – patient contribution is very high. Two countries have very high state health insurance financing. Private health insurance is available exclusively in Germany. In some countries financing comes also from public money at regional and national level. Very small part of financing comes from donations, sponsoring etc (figure 16).



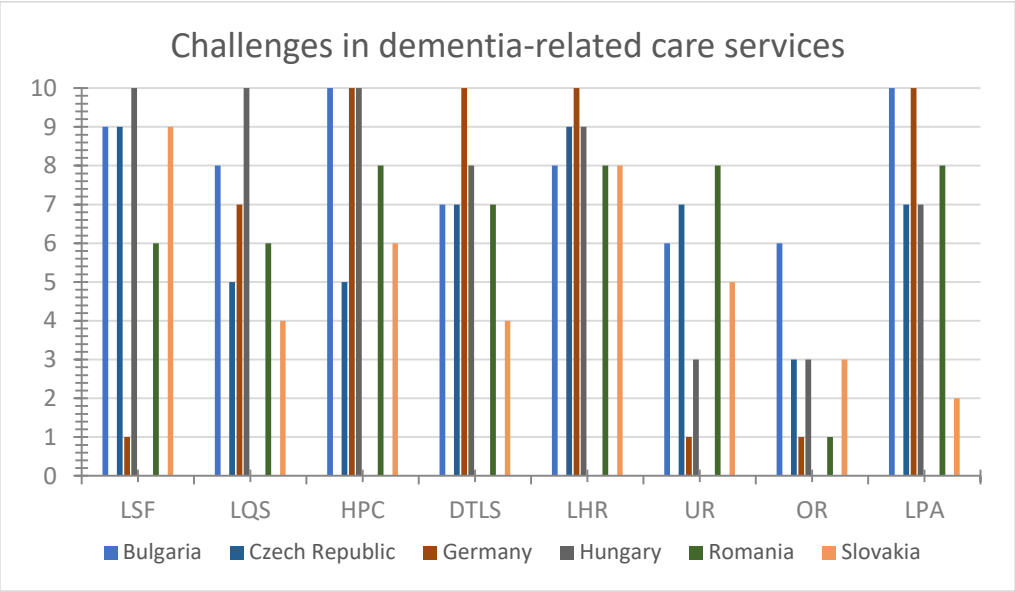
SHI – statutory health insurance; PHI – private health insurance; PG – private giving (foundations); CG – corporative giving (sponsoring); PMRL – public money at regional level; PMNL – public money at national level; PC – patient contribution

Figure 16

Challenges in provision of care facilities

Several very important challenges are outlined by the experts (figure 17):

- Limited human resources
- High personal contribution (pay-out-of-pocket)
- Lack of specialized facilities
- Limited public awareness
- Lack of quality of dementia-related services
- Diagnosis and treatment in late/severe stages



LSF - lack of specialized facilities; LQS - lack of quality of services; HPC - high personal contribution (pay-out-of-pocket); DTLS - diagnosis and treatment in late/severe stages; LHR - limited human resources; UR - underregulation; OR - overregulation; LPA - limited public awareness;

Figure 17

Business expertise concerning care facilities

There is not enough data to be analysed and no tendencies could be noticed. Data are very country-specific.

3.4 Target groups for dementia-related education

Dementia as a content of education/training of health and social care professions:

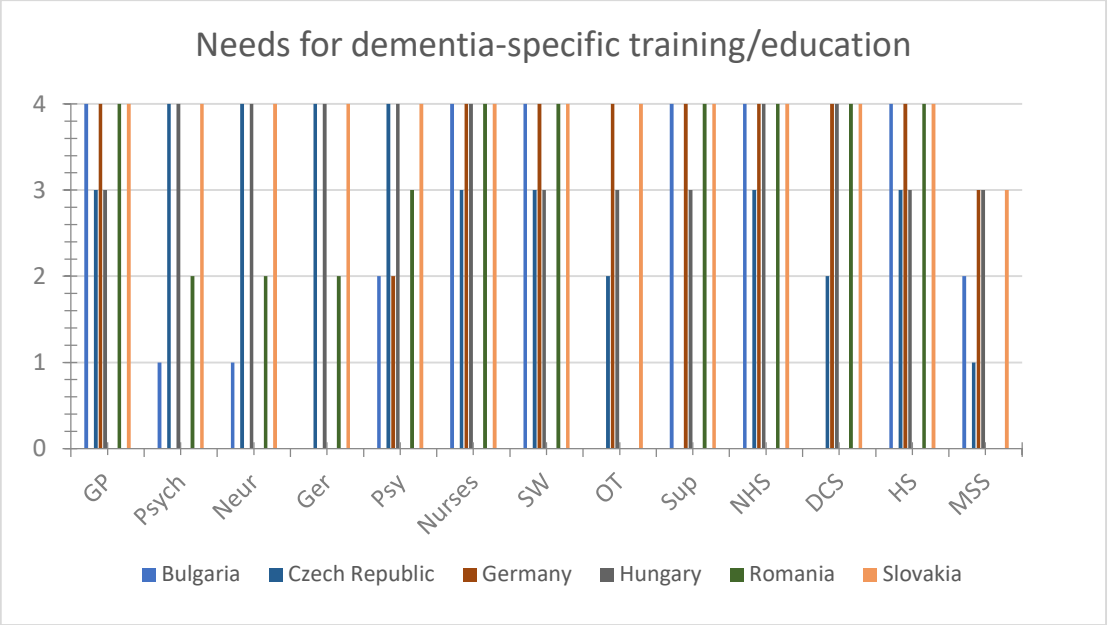
- This topic is included in regular education of health care professional in all countries; in most countries vocational education is available
- This topic is not included in regular education of nurses in some countries
- Continues education is rarely available and is delivered exclusively for neurologists, psychiatrists and geriatricians (where applicable)
- Dementia is not or insufficiently presented in education/training for social workers, nurses, care providers, nursing home and hospital staff

Results indicate that there is not enough continued dementia-related education and training with updated information for health and especially for social care professionals.

Need for dementia-specific education/training for health and social care professionals

Dementia experts from all countries underscore the greatest need of specific dementia-related education and training for nurses, nursing home staff, GPs, social workers, people who are supportive care providers, hospital staff, day care staff. Social care professionals are less educated and not trained for early diagnosis related issues, management of behavioural

problems, counselling and supporting family of PWD, delivery and coordination of care plan and services (figure 18).



GP – general practitioner; Psych – psychiatrist; Neur – neurologist; Ger – geriatrician; Psy – psychologist/neuropsychologist; SW – social workers; OT – occupational therapist; Sup – supportive care provider; NHS – nursing home staff; DCS – day care staff; HS – hospital staff; MSS – mobile service staff

Figure 18

Institutions that need to be contacted with regard dementia-related education and training. Experts from all countries agree that Governmental public authorities and Professional organizations should be contacted for collaboration in dementia education training. Other stakeholders that are important for educational intervention strategy are Higher education institutions for health and social care professionals, and Patient organizations. The names of the institutions suggested to be contacted are provided by the experts from six countries.

3.5 Format of educational programmes

Classical training

Experts from most of the countries agree that classical forms of training are useful for representatives of higher education institutions, professional organizations of healthcare specialists, public bodies (e.g. municipalities, public hospitals, national health and commissions). Country specific consideration concerning educational format for different target groups should be taken into account.
For representatives of business associations, managers of service providers, insurance organizations, NGOs and to some extend for governmental institutions classical training is not very appropriate. Educational format for these institutions should be precisely focused, with compact information, clear messages, more interactive approach and practically directed issues.

E-learning training

The results show country-specific tendencies for usefulness of e-learning educational format. Experts from most of the countries consider e-learning as more applicable for professional organizations and boards of medical doctors, nurses, other healthcare specialists, for higher education institutions as well as for business organizations. E-learning educational format is considered as appropriate complementary approach.

Need of pre-training information

Experts from all countries agree that providing pre-training materials and information will be useful in order to direct attention, enhance understanding and motivation for attending the training workshops.

4. CONCLUSIONS

The results reveal following key-points concerning dementia-related issues:

- Diagnosis and treatment: The **entry point** to the management of dementia **differs** in Danube countries but the general practitioner **(GP) appears to be a key figure in dementia care**. The role of GP/primary physician **increases in direction from metropolitan to rural areas** with regard to start of the diagnostic procedure. Diagnosis and treatment are mainly provided by specialists (neurologists and psychiatrists). Experts from all countries agree that **all kind of diagnostic services are strongly needed or needed**.

- Therapy and care: **Lack of day care, respite care services and dementia residential communities** is outlined. **Most of dementia-care services are strongly needed** – outpatient, inpatient, medical and social care services, cognitive training/rehabilitation, speech therapy, physiotherapy, music/art therapy for people with dementia. **Social Businesses and Social Entrepreneurship who provide dementia-related care services are not developed in Danube countries.**

- The greatest **challenges** in provision of dementia-related care services outlined are: limited human resources, lack of specialized facilities, diagnosis and treatment in late/severe stages, high personal contribution (pay-out-of-pocket), limited public awareness. Business expertise in the field (concerning marketing, business plan development, fund raising and human resource management) is estimated to be not at satisfactory professional level.

- Challenges/needs with regard to dementia-related **education and training**: **shortage of continuing dementia-specific education and training with updated information for health and especially for social care professionals**; greatest need for nurses, nursing home staff, GPs, social workers, people who are supportive care providers, hospital staff, day care staff.

- Educational format: **classical forms of training** are useful for representatives of higher education institutions, professional organizations of healthcare specialists, public bodies (e.g. municipalities, public hospitals, national health and commissions); educational format for different target groups should be adapted. For representatives of business associations, managers of service providers, insurance organizations, NGOs and to some extend for governmental institutions educational format should be precisely focused, with compact information, clear messages, more interactive approach and practically directed issues. **E-learning educational format is considered as appropriate complementary approach** to classical forms of training. Providing pre-training materials and information will be useful in order to direct attention, enhance understanding and motivation for attending the workshops

5. IMPLICATIONS FOR THE INDEED STRATEGY

Based on the results above, the following conclusions for CAMPUS are drawn:

- GP organisations need to be addressed by the educational intervention
- All professionals need to be informed about the available treatments and evidence
- The role of social occupations for the management of dementia needs to be strengthened
- The importance of a comprehensive diagnostic workup needs to highlighted, particularly regarding differential diagnosis and exclusion of treatable causes
- All professionals need a clear understanding of care facilities and the point of need along the course of dementia

Regarding CONNECT, the results of the expert survey show:

- Health and social care professionals need to know about each other, and their respective contributions to dementia care
- Improved networking could make professions involved in dementia care more attractive

The main implications from the expert survey for COACH are as follows:

- Community-based facilities (day care, respite care, meal on wheels, home helpers) are the most promising business areas in the management of dementia
- Lack of human resources is currently a major limiting factor

Additionally, evidence from the updated expert survey show that raising public awareness about dementia can contribute to improving the quality of dementia care in the Danube region. Particularly, the public must have a clear concept of:

- the difference between normal ageing and dementia
- where to obtain a diagnosis
- which treatments are available and what their efficiency is
- services and facilities that are needed in the course of the dementing illness
- the fact that multiple professions are needed for person-centered and high quality dementia care; and the roles of these professions need to be appreciated