

# Danube Transnational Programme

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# STRATEGY STATEMENT

PROJECT **INDEED** |

Innovation for Dementia in the Danube Region

A stream of cooperation

**STRATEGY STATEMENT**  
VERSION: 2



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## 1. Introduction

1.1. The INDEED proposal is governed by **three principles**:

- a) the World Health Organization concept of dementia as a biopsychosocial disease
- b) Principle of person-centered care approach for people with dementia and
- c) United Nations' Convention of the Rights of People with Disabilities.

These principles are incorporated in all project activities.

1.2 The goal of INDEED is to improve dementia care and contribute to the development and implementation of dementia plans in the Danube region through a **coherent educational strategy** that addresses the institutions involved in dementia care. The aim of this educational strategy is to **enhance** the knowledge, expertise, competence and skills of the dementia related institutions, to **enrich** their collaboration and possibilities to **exchange** information and experience in the field within and between Danube countries. One core goal of the INDEED project is to promote entrepreneurial activity in the field of dementia care.

1.3 By targeting **institutions** (e. g. higher education bodies, medical and nursing schools, professional boards, municipal authorities, policy makers, business schools, chambers of commerce) rather than individual healthcare professionals, INDEED employs a **top-down strategy** of information delivery. The institutions will act as distributor of the information provided, ensure a broad outreach and sustain the project's outputs after its termination. Representatives of targeted institutions will be involved from the beginning of the project throughout its course to ensure that their needs, views and preferences are met.

1.4 The INDEED project does not attempt to replace existing curricula on dementia for the various health and social care professions. Rather, it **complements occupation-specific education** by contents that incorporate most recent research findings, promote the mutual understanding and collaboration of professional groups and help to implement a holistic person-centered model of dementia care.

1.5 To facilitate take-up of its outputs within and beyond the project area, contents and formats will be developed in a **transnational collaborative effort** of all involved partners/countries. In this way, INDEED contributes to improving and harmonizing dementia care across borders, and thus enhances **territorial cohesion** in the Danube region.



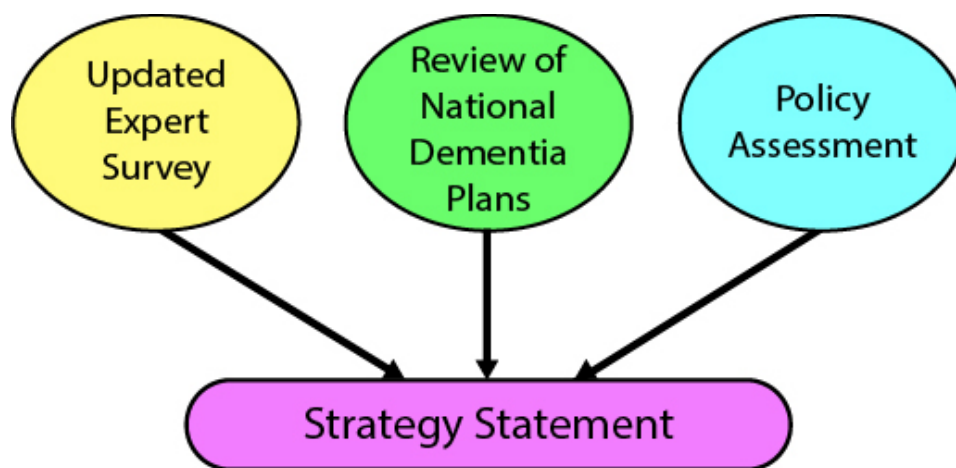
## 2. Background

The Strategy Statement represents a roadmap of the INDEED project for the planned interventions responding to the major unmet needs in the countries involved.

Three major already identified unmet needs are:

- Lack of knowledge and skills of healthcare professionals,
- Poor interaction of involved parties and insufficient coordination of services,
- Deficiency of appropriate care facilities.

The Strategy Statement is based on converging evidence from **three sources**:



- An expert survey on dementia care,
- A review of national dementia plans (existing or in preparation);
- A policy assessment carried out at the kick-off meeting of the project.

### 2.1. Review of National Dementia Plans

This document uses the term “Dementia Plan” as an umbrella term for dementia-related initiatives at national level summarizing all kinds of dementia plans, action plans, strategies, programmes, etc.

The review of the documents that have been provided by 10 project partners reveals the following **common objectives and fields of action**:

- Providing **education and training of healthcare professionals**, in particular focusing on timely diagnosis and appropriate treatment.
- **Increasing the awareness of the public authorities, civil servants, health and social service providers and other groups of the society.**
- **Developing high-quality services at home, community and institutional levels** for people with dementia and their caregivers.

- **Improving the cooperation among healthcare professionals and enhancing the coordination of health and social care services.**

Thus, the review of national dementia plans underscore the need for **raising public awareness, education and training** of all partners in dementia care, **networking the health and social services** for people with dementia and their caregivers, and **providing appropriate and distributed care services**. These issues highlight the appropriateness of INDEED intervention package including the awareness campaigns that will accompany the pilot actions.

## 2.2. Updated Expert Survey

The expert survey has been updated on the base of a survey on dementia education and care in the Danube region already conducted in 10 Danubian countries in 2014. For INDEED, the survey has been expanded to gain up-to-date and more comprehensive overview of the current situation of dementia education and care in all 14 countries of the Danube region. Furthermore, key questions regarding region-specific regulations for business in dementia care related sectors have been incorporated to assess the conditions for entrepreneurial innovation. We currently present results of the responses from six project participant countries (Bulgaria, Czech Republic, Germany, Hungary, Slovakia, Romania):

- **Diagnosis and treatment: The entry point to the management of dementia varies in Danube countries, however the general practitioner (GP) appears to be a key figure in dementia care. The role of the GP/primary physician is higher in rural than in metropolitan areas with regard to the initiation of the diagnostic process. Diagnosis and treatment are mainly provided by specialists (neurologists and psychiatrists). Experts from all countries agree that all kinds of diagnostic services are strongly needed.**
- **Care: Lack of day care, respite care services and dementia residential communities have been emphasized. Most 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 Enterprises that provide dementia-related services have not been developed.**
- **The greatest challenges in provision of dementia-related care services are: limited human resources, lack of specialized facilities, diagnosis and treatment in late/severe stages, high personal financial contribution (pay-out-of-pocket), limited public awareness. Business expertise in the field (concerning marketing, business plan development, fundraising 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, daily care staff.
- Educational format: **classical forms of training** are useful for representatives of higher education institutions, professional organizations of healthcare specialists and 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 extent, 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

### 2.3. Policy assessment

Policy assessment aims to gain an overview of unmet needs in dementia care from the perspective of key stakeholders in the Danube countries. **Stakeholders represented three groups: a) decision makers, public administrators; b) service providers, and c) representatives of educational institutions.**

Their visions regarding the improvement of dementia care were addressed by questionnaires, and a workshop at kick-off meeting in Munich. Resulting from the discussions, six key points to improving dementia care have been identified:

- early diagnosis,
- raising public awareness,
- improving education and training of healthcare professionals on dementia,
- providing support for informal and professional carers,
- enhancing the collaboration among healthcare professionals and
- increasing the importance of dementia care in the national policies.

## 2.4. Summary

In summary, evidence from the three sources proved that the most needed interventions to improve dementia care in the Danube region are:

- **campaigns to raise public awareness**
- **dementia-related education and training of multiple professions** involved in dementia care,
- **instruments to facilitate the interaction and collaboration** of healthcare professionals, and
- **measures to promote the setting-up of community-based services** for people with dementia and informal carers.

The INDEED educational strategy is an appropriate intervention for all partners at regional and national level. Combined method of training (classic and e-learning) is acceptable. Issues about motivation of institutions for attending and implementation of educational intervention should be incorporated.

## 3. Design of the intervention

### 3.1. Target group

The INDEED target groups include **both institutions directly involved in dementia care provision and institutions in charge of health and social care policies**. Target groups are:

- Policy makers, governmental authorities, public administrations in health and social care
- Institutions involved in education and training of health and social care professionals (universities, medical schools, nursing schools, vocational training institutions)
- Boards of medical and social care institutions and providers (hospitals, care centers, nursing homes, community care units, city councils)
- Professional organizations (for GPs, nurses, other healthcare specialists)
- NGOs (associations of patients and caregivers, charities etc.)
- Boards of private enterprises, social entrepreneurs, business schools, start-up networks, health insurance and social insurance companies.

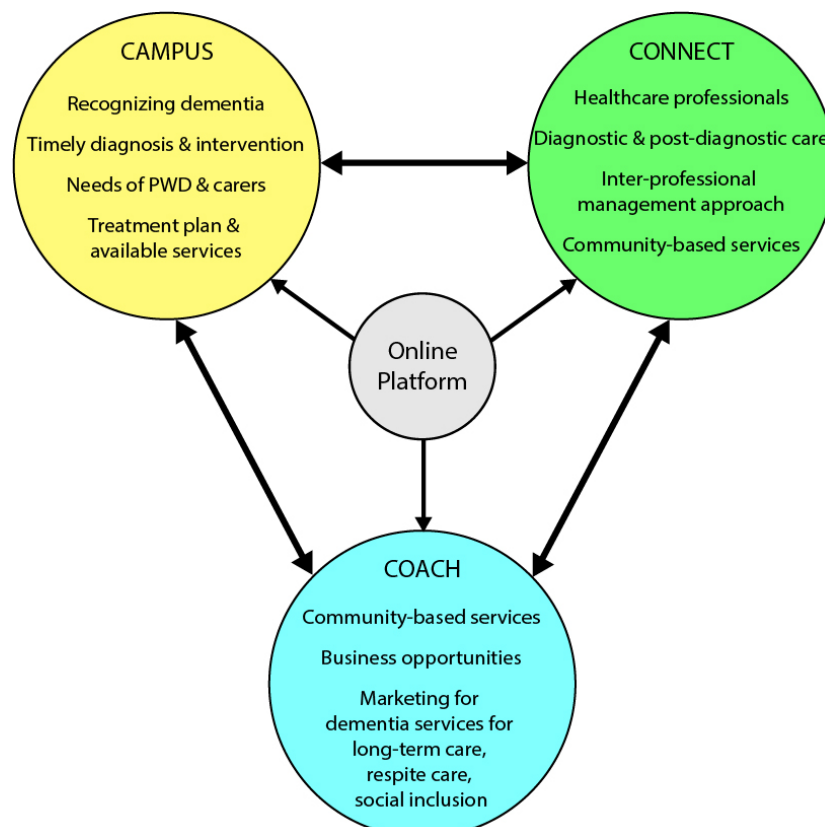


### 3.2. Structure

In accordance with the above, the INDEED project provides a comprehensive, interdisciplinary educational strategy with modular structure. The educational intervention comprises **three modules**:

- a) a **set of shared common knowledge** about dementia for all relevant professional groups encompassing epidemiology and prevention (demonstrating the magnitude of the problem), the importance of timely intervention (early diagnosis and treatment), the complexity of needs and treatment options (requiring an inter-professional management approach), and economy (putting the emphasis on development of community-based services) (CAMPUS);
- b) a **networking tool** to enhance mutual understanding and collaboration between the advocates involved, to facilitate connection and interaction of all available resources for care and treatment, to enhance horizontal and vertical integration of services, and to improve the coordination of all participants in dementia care (CONNECT);
- c) a **business consulting service** for professionals working with dementia, social entrepreneurs and start-ups to outline business opportunities and models in dementia care, budget planning, marketing, as well as focusing on community-based services (COACH).

#### INDEED intervention model



An important and innovative feature of INDEED is that the **three modules are closely interrelated**. For example, the focus in CAMPUS on early recognition and intervention will be reflected in CONNECT by demonstrating the contributions of medical and allied professions to timely diagnosis and post-diagnostic care, and will also be mirrored in COACH by putting an emphasis on business opportunities for community-based services that are needed at the early and moderate stages of dementia. Vice versa, CAMPUS and CONNECT will refer to such services as parts of a comprehensive treatment plan. Likewise, CAMPUS will outline activity, participation and social inclusion as factors that determine quality of life for people with dementia. In CONNECT, this will be picked up by demonstrating that collaboration of professional groups is needed to provide these benefits, and COACH will discuss what community-based services can contribute. Another feature linking the three modules is the **online platform** through which they will be delivered.

The concept of INDEED intervention is to bring together diverse advocates of dementia care with aim to affirm multidisciplinary care approach, to introduce business oriented networking tool and to facilitate development of economically effective social enterprises. The complexity of the target groups underscores the need for **different motivational messages** with regard to attendance of the training workshops and implementation of the model.

### 3.3. Pilot studies

This intervention model will be **field-tested and evaluated** in 4 countries (Bulgaria, Romania, Slovakia, Slovenia) by organizing 6 workshops in each country - **overall 24 workshops**. The workshops will be embedded in „dementia awareness days“ in cooperation with local patient organizations to involve the general public. An “info days guide“ will be developed. Anti-stigma issues will be embedded concerning principles of dementia care, person-centered care, empowering people with dementia, participation in decision-making for treatment and care.

The pilot actions will provide information on:

- **Need for local adaptations, acceptability, feasibility of the intervention in different administrative and economical infrastructures;**
- **Country-specific details** that should be considered with regard the participants/target groups, content prioritization, motivation for attendance of training modules and implementation of the educational product

It is hoped that the workshops will become the center of local networks for dementia care. The final result of the pilot actions will be a policy recommendation catalogue containing suggestions for policy makers how to improve dementia care in their respective countries.

#### 4. Contents of the educational model

The contents of the three INDEED modules should be selected and presented in a way that enables **shared common learning** of the professional groups involved, supports **mutual understanding, multidisciplinary approach, promotes collaboration and networking**. The contents should also be chosen in view of their **strategic relevance** for bringing about change and improvement of dementia care, and in terms of making dementia an attractive business field. The contents should be based on best evidence for good practices of dementia care and management, and social entrepreneurship. Key content will be:

- a) **Magnitude of the problem and understanding dementia:** demographic change, population ageing, societal challenge, need to act now, work of professionals in the field of dementia is important for society; symptoms, course of the disease, stages of dementia; possibilities for long-term planning of dementia health and social care activities and services; possibilities for prevention.
- b) **Recognizing dementia:** focus on early recognition, benefits of timely diagnoses and intervention, diagnostic pathways and standardized procedures
- c) **Managing dementia:** complex needs and treatment options, psychological and social needs; multidisciplinary approach, inter-professional collaboration is required, professions can learn from each other, benefits of collaborative care, working together makes dementia management interesting and rewarding; care planning, prevention of crises, pro-active management of behavioral problems, early initiation of pharmacological and non-pharmacological treatments, supporting care in the community, community-based services, importance of individual treatment plans, avoidance of hospital and nursing home admissions, ethical aspects, legal aspects of care, assistive technologies, family support.
- d) **Financing of dementia services:** funding of dementia service is seen as a major barrier in the development of new services; funding is not only state responsibility, in most countries the public administration lacks resources to finance new services in the field of dementia; insufficient knowledge about social entrepreneurship; various financing models and forms of financing to be introduced and explained; real-life examples of good practices.
- e) **Business knowledge:** minimally available business knowledge in field of dementia, need of stimulation innovative business activities; introducing a basic knowledge in the development of a business plan; basic concepts of a business plan, explanation with simple examples; customer needs identification, the implementation of a market and competitive analysis, marketing, financing and human resource management.
- f) The workbook on „Interprofessional Management of Dementia“ which has been produced by some of the partners in a previous project (Dementia Master Classes) may serve as a resource.

## 5. Didactic concept

The didactic concept should consider that a **variety of materials** will be produced and that **multiple professions will be addressed** by the INDEED educational intervention which differ with regard to their informational needs and preferences (e. g. scientific precision and depth, economic data). Two main types of educational formats will be applied - classical and e-based.

- a) **Flyers, brochures and other written materials:** These materials should include images, info graphics and diagrams; the presentation of information should be consistent across materials and during the duration of the project. Texts should be brief and clear, with easily comprehensible messages, avoiding professional jargon.
- b) **Web-based platform:** The online presentations should be interactive, support individual choice of preferred educational modules, not represent a linear learning format, ensure simple and effective navigation, and include short videos. Options are quizzes and the use of a moderator.
- c) **Pilot action workshops:** Creating a shared knowledge base, stimulating interprofessional exchange, and promoting dementia related services are the goals of the pilot actions. In order to achieve this, among others, the following didactic tools will be used: work in small groups, moderated discussions and case rounds (face-to-face), brief expert lectures, introducing the “digital dementia market place”, videos, quizzes, pictures (all online).  
Experts will demonstrate good-practice examples of innovative and sustainable business models, and will provide information of different national regulatory frameworks to interested entrepreneurs.

The outputs that will be produced need to be scientifically valid, evidence-based, attractive, up-to date, and easily comprehensible for all professional groups involved. Traditional and web-based parts of the program (multimedia platform) need to be compatible with the real world.

## 6. Multimedia design

An important reason for incorporating an internet-based learning format is to overcome geographical and mobility-related barriers. However, personal contact and exchange is essential for a good learning effect. Therefore, a **blended learning format** of information delivery will be chosen. The outputs that will be produced need to be scientifically valid, evidence-based, attractive, up-to date, and easily comprehensible for all professional groups involved. Traditional and web-based parts of the programme (multimedia platform) need to be compatible with the real world (workshops etc. no longer than 3 hours).

The design of the networking tool (CONNECT) should stimulate the collaboration between local or regional healthcare professionals by providing information on focus of work and main interests (e.g. „dementia marketplace“) and might include a secure forum for exchange. Remote consultations of a telemedicine type will not be possible for time and economic reasons.

## 7. Dissemination

To ensure the sustainability of the INDEED outputs after project termination and to promote their implementation in care practice, representatives of selected target institutions will be involved throughout the lifetime of the project. Among other materials for stakeholder, a **project newsletter** and a **policy brief** will be developed. Stakeholder involvement will show which institutions are prepared to take over the intervention package, to adapt it to local requirements and to regularly update it.

The final intervention package will be made available to institutions outside the INDEED project area. All supporting documents will be available in an English masterversion.

## 8. Documents supporting the INDEED Strategy Statement

- Report on the updated expert survey
- Review of national dementia plans
- Policy assessment report



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