

Dementia Study 2022/2023

**Part A – Research Study**

# **Best-practice dementia strategies**

Conducted by Centre for Social Innovation on behalf of Vienna  
Social Fund



# Dementia Study 2022/2023

The following research study is part of a comprehensive study by Vienna Social Fund which is composed of three parts:

## **Part A: Research of best practice examples**

Part A provides an overview of successful national strategies and measures adopted across Europe to deal with dementia and outlines the experiences in implementing these measures as a knowledge base to support the implementation of Vienna's Dementia Strategy. It also contains research on dementia counselling centres in Austria.

## **Part B: Qualitative study**

Part B illustrates problems and requirements of people with dementia and their (caregiving) relatives and identifies obstacles to the use of services within the existing system.

## **Part C: Quantitative study**

Part C consists of a representative online survey among Vienna's residents (18 years and older) about society's knowledge and perception of the term dementia and the illness it describes and of available offers of information and support.

All part studies serve as a knowledge base that will help to priorities measures for implementation within the fields of action defined under Vienna's Dementia Strategy. Deductions from the results will be integrated into the evaluation of the nursing and care services of Vienna Social Fund and for strategies to develop new service offers for people with dementia.

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# Best-practice dementia strategies

## Study description

Vienna Social Fund has commissioned a research study to be carried out from March 2023 to December 2023 to identify best practice examples of national or regional dementia strategies adopted across Europe. The aim for Vienna Social Fund was to learn from comparable cities in Europe how they have developed and implemented national or regional dementia strategies.

Hamburg, Oslo, Glasgow and Manchester were the cities selected for the study. A total of 12 interviews was conducted with 1 or 2 experts per institution in the surveyed cities. Interviews were held with experts at the regional and national levels.

In addition, interviews were also conducted with two researchers in this field: Prof. Dr. Elisa Pozo Menéndez (Spain), an architect and researcher working at the interface between urban planning and dementia, and Prof. Dr. René Thyrian (Germany), who currently is a researcher at the German Centre for Neurodegenerative Diseases (DZNE – Deutsches Zentrum für Neurodegenerative Erkrankungen e. V.) and looks into international differences of various dementia strategies. To facilitate learning from each other the study team, on 23 November 2023, held an online peer learning workshop with FSW staff members and the persons responsible for the dementia strategies in the selected cities.

## Overview of interviews conducted

| Hamburg  | Oslo  | Glasgow                                  | Manchester                                   |
|--|---|--|--|
| Hamburgerische Arbeitsgemeinschaft für Gesundheitsförderung e. V. (health promotion association) | City of Oslo  | Alzheimer Scotland (Scottish Government) | Dementia United                              |
| Alzheimergesellschaft Hamburg e. V. (self-help organisation)                                     | Nasjonalt senter for aldring og Helse (Norwegian National Centre for Ageing and Health) | Alzheimer Glasgow                        | NHS Greater Manchester Integrated Care Board |
| Geschäftsstelle Nationale Demenzstrategie (Office of the National Dementia Strategy)             | Nasjonalforeningen for folkehelsen (volunteer organisation)                             |  |  |
| Deutsches Zentrum für Altersfragen – DZA (German Centre of Gerontology)                          |   |  |  |

## Best practice findings

The purpose of the best-practice dementia study is to illustrate the dementia strategies adopted by the cities of Hamburg, Oslo, Glasgow and Manchester and to outline how they are implemented. The cities were chosen on the basis of different criteria, such as a similar population to Vienna and a comparable system of long-term care.

Interviews with experts from relevant institutions and researchers working in this field as well as an online peer-learning workshop helped to map out the characteristics of the strategies.

### Hamburg

Hamburg organises an annual *open forum*, which is intended to facilitate exchange among interested parties, such as representatives from hospitals, the housing sector and city institutions. The open forum subsequently develops into an *expert group*, which looks more deeply into some of the issues raised at the open forum.

### Oslo

Oslo provides free transport services for elderly people to enable them to live longer at home. The city also builds new accommodation facilities, the *Care+* residential care homes, which offer both safety and activities. Other offers include *podcasts* and dementia support *apps*.

### Glasgow

Glasgow uses the *Herbert Protocol*, a standardised form that contains biographical information such as a person's basic details, health information or places of interest. The protocol helps police and other agencies to communicate with people who have dementia and to locate them when they go missing. Another project in Glasgow are the *TEC Clinics*, which test technological support devices with people who have dementia and offer instructions. So-called "*link workers*" provide support with non-medical problems related to dementia.

### Manchester

Manchester stands out by its large number of diagnosed people with dementia. About 67% of people with dementia have a formal diagnosis. This can be attributed to the very close cooperation between hospitals, research institutions and care centres. "*Delirium Leaflets*" are available in 16 different languages and accessible to a large part of society. They provide information about largely unknown conditions that suggest dementia.

# Challenges

The dementia strategies of the best-practice cities of Hamburg, Oslo, Glasgow and Manchester have in common that social inclusion and participation of people living with dementia are important goals and/or fields of action. Moreover, people with dementia should be able to live at home as long as possible.

While many measures for people living with dementia have already been implemented successfully, the research and peer-learning processes have highlighted several challenges.

## Moving from strategy to implementation

### **Prepare concrete plans to make strategies operational**

Actionable plans comprising specific target indicators, measures, time schedules and related budgets are necessary to make strategy implementation measurable and thus improve dementia provision. The German Dementia Strategy, for example, contains specific quantifiable goals which must be attained within a certain period of time. Manchester and Glasgow, on the other hand, have prepared specific sub-plans which address particular dementia-related issues within a shorter time frame.

### **Ensure, as far as possible, that measures are financed**

The research findings show that the financing of measures to implement the dementia strategies constitutes a challenge for all cities. A lack of funding means not only that there are actually no resources for implementation, but also that it will become more difficult for those working in this field to focus on measures to improve the situation of people living with dementia alongside their “daily business”. It is therefore vital to secure sufficient funding for measures that contribute significantly to accomplishing the goals of the strategy.

### **Design a targeted monitoring process**

Monitoring allows to identify delays, gaps or challenges in implementation. In addition, establishing a monitoring system also sharpens the efforts to put the strategy into operation, as success indicators, implementation periods and effects will be coordinated and recorded by all stakeholders. Practitioners point out that when carrying out the monitoring it should be made sure that those implementing the measures will have the capacities and resources to contribute to the monitoring process. It may be reasonable to involve the implementing actors in the selection of indicators to ensure that they also will be able to draw meaningful conclusions for devising their measures. One possibility to reduce the workload for implementing actors who have to collect data for monitoring purposes is to use secondary data.

## **Involving stakeholders and those concerned in a meaningful way**

### **Enable low-threshold cooperation with people with dementia and their families**

Integrating the perspectives of people with dementia and their families is essential to ensure that measures and services are tailored to the living situations of those concerned and are accepted by them. Therefore, it takes low-threshold formats which strengthen cooperation between people with dementia, family members, stakeholders and organisations involved in implementing the dementia strategy.

### **Tailor participation of people with dementia to their living situations**

From the perspective of the practitioners involved it is essential that participation means having a voice in deciding the choices available and that people with dementia are not merely assigned the role of “giving their blessing” to offers that have been created for them. It is important to engage people with dementia in all stages of the process. The engagement of people with dementia will be more successful if they are well prepared for meetings or the like. Participation of people with dementia must be compatible with their living situations. This means, for example, that meetings should be scheduled at a time and place which is convenient for them.

### **Focus on participation of people with different backgrounds**

The engagement of people with migration histories, people with different religious affiliations or people identifying as LGBTQIA+ is particularly challenging. In some cultures, dementia is still strongly stigmatised, which makes it more difficult to use support offers or medical and care services. For this reason, culture-sensitive, inclusive offers and good relations with gatekeepers are needed to reach out to these groups.

### **Combine top-down and bottom-up approaches in involving actors and stakeholders**

When involving actors and stakeholders it is important to differentiate and choose the appropriate approach for each group of individuals or organisations. Local actors, groups, networks or volunteers can be effectively involved through bottom-up processes, while a top-down approach may be the method of choice for hierarchically structured organisations and national or international actors.

### **Implement information campaigns and education measures:**

Awareness-raising campaigns and education offers for the public and for professionals who are in contact with people who have dementia are important to increase understanding and confidence in dealing with people with dementia. An increased use of newer media can also help to disseminate information and raise public visibility of the issue. Examples include podcasts, information videos and support apps like those used in Oslo for example.

## **Holistic improvement for people with dementia and their families**

### **Improve diagnostics and data management**

A sound data basis on dementia diagnoses is vital to provide appropriate care and support services and allow predictions of future demand. Thus, major emphasis should be placed on diagnosing dementia and on efficient data management. The cities of Manchester and Glasgow have already put a focus on these aspects. Germany also carries out an annual monitoring of the institutions involved in implementing the national dementia strategy.

### **Expand case management and step up quick support following diagnosis**

The provision of quick and easily accessible support following diagnosis is essential to positively influence the course of the disease and promote social participation. Glasgow and Oslo are role models in this respect. In Glasgow, “link workers” ensure that people who are newly diagnosed with dementia receive legally guaranteed individual support and information. In Oslo, integrated advice and support is provided by dementia coordination teams.

### **Establish and use helpful tools and protocols**

A large number of technological solutions for the care of people (with dementia) have been developed over the last few years. If they are used to accommodate the needs of people with dementia and their environment, these technological tools and solutions can contribute to maintaining the quality of life of people living with dementia. The Herbert Protocol can speed up the search for people with dementia who have gone missing. The Protocol has been tested in Glasgow and has been described as extremely helpful by the interviewees. Such protocols provide useful information about vulnerable persons and especially helps to locate persons with more severe dementia who are at risk of going missing.

### **Dementia-friendly city (planning)**

Urban planning should take account of the needs of people living with dementia. Landmarks, clear signage and places to rest in public space are key features in this respect. Cooperation between people with dementia, family members and urban planners is vital for this purpose.