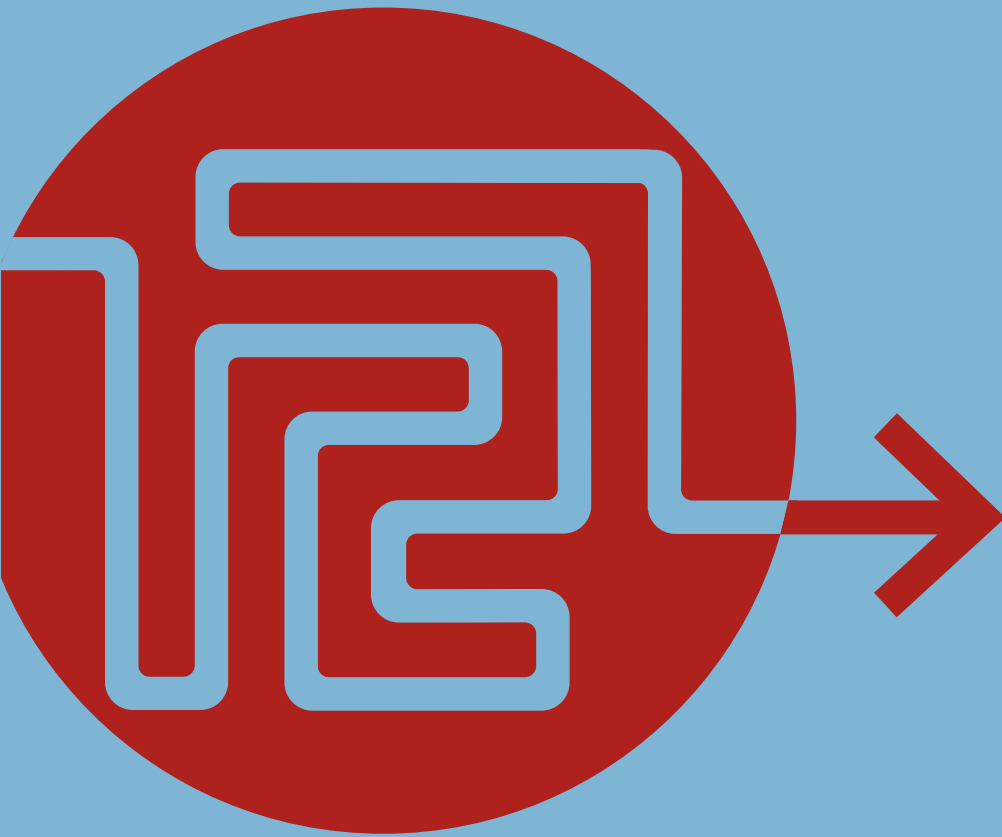




Federal Ministry for  
Family Affairs, Senior Citizens,  
Women and Youth



Federal Ministry  
of Health



# Alliance for People with Dementia

Report on the Implementation of the Agenda of the  
Alliance for People with Dementia 2014-2018



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## Joint Foreword

# Federal Ministry for Family Affairs, Senior Citizens, Women and Youth & Federal Ministry of Health

Dementia is one of the greatest challenges facing our society. Around 1.7 million people in Germany already suffer from it. 300,000 people every year are diagnosed with dementia. In 2050, over 3 million people will have been diagnosed with Alzheimer's or another form of dementia. These figures also reflect the fates of those affected and their families. Dementia affects us all. People with dementia can be parents, close family members, friends, neighbours, former work colleagues, football coaches, actresses or simply people we meet on the bus or in the supermarket. We all therefore need to learn how to deal with the issue of dementia, how to recognise and accept it. This also includes recognising that people with dementia have abilities and potential that they can bring to bear, especially in the early stages of the disease. People with dementia are part of our society.

Four years ago, the German government launched the "Alliance for People with Dementia" to promote greater understanding and sensitivity for people with dementia and their relatives as well as to further expand opportunities for help and support. The Alliance is made up of members from politics and civil society who are better able to assert the interests of dementia patients and their families in all areas of life. Together, we have done and achieved a lot - as shown in this final report. With a wide range of ideas, projects and initiatives on small and large issues, every partner in the Alliance has contributed to furthering people with dementia and their families.

From the federal government's point of view, the key measures have been the founding of 500 new Local Alliances and redefining the term "need for care" within the scope of long-term care enhancement laws. As a result, patients with dementia now

also have equal access to long-term care insurance, which have also been further expanded. But we will not stop there. With the emergency programme for better staffing and working conditions in nursing care for the sick and the elderly, nursing staff should be given immediate, noticeable burden relief as quickly as possible. In addition to this, all available ideas and stakeholders should also be mobilised in a concerted action on nursing care to enable caregivers to receive greater appreciation, support and burden relief.

The Alliance has already achieved a great deal, but it is not giving up yet because it is still to reach its goal. Improving the living conditions for people with dementia and their relatives and anchoring awareness of dementia throughout society still remain our major concerns. This task was also enshrined in the coalition agreement of the German government.

We would like to thank everyone for their commitment and look forward to continuing our joint work in supporting people with dementia and their families!



A handwritten signature in black ink that reads "Dr. Franziska Giffey".

Dr. Franziska Giffey  
Federal Minister for Family Affairs,  
Senior Citizens, Women and Youth

A handwritten signature in black ink that reads "Jens Spahn".

Jens Spahn  
Federal Minister of Health

## Foreword

# German Alzheimer Society



Under the leadership of the Federal Ministry of Family Affairs, Senior Citizens, Women and Youth and the Federal Ministry of Health, representatives of associations of service providers and various professional groups, representatives of the federal states, committed members of civil society and self-help, as well as representatives of other ministries, have been working together on the topic of dementia for four years. As co-chairperson, the German Alzheimer Society e.V. Dementia Self-Help (DAIzG) has been involved in shaping this process. In these four years, the stakeholders had set themselves a number of goals, some of which were very specific small projects whereas others were major schemes, such as jointly educating people about dementia - a task which cannot be completed in just four years. The work in the Alliance has brought together various stakeholders and promoted cooperation. The involvement of many different stakeholders has demonstrated that dementia affects us all. The monitoring procedure, which was of particular importance to the DAIzG, has helped in keeping an eye on measures and in making their implementation more mandatory.

Often by using our own resources, much has been achieved during this time but some tasks require additional effort. The number of dementia patients will continue to rise. At the same time, we know that professional care has already reached its limit. It is therefore necessary, for example, to improve prevention, to empower relatives, to raise awareness of dementia in the general environment and to promote support for people with dementia and their relatives.

As co-chairperson, I would like to thank all organisation partners and supporters for their time and resources in contributing over the last few years to the joint work. Representing the interests of people with dementia and their relatives, the German Alzheimer Society sees an urgent need to continue this joint work and to develop and implement new goals as part of a dementia strategy.

A handwritten signature in black ink that reads "Monika Kaus". The script is cursive and fluid.

Monika Kaus  
Chairperson  
German Alzheimer Society



## Preface

# Prof. Dr. Andreas Kruse

Looking at old age - both scientifically and practically - suggests a double perspective: the first can be described with the term vulnerability, the second with the term maturity. When talking about double perspective, this also means that “vulnerability” and “maturity” must always be looked at together.<sup>1</sup> How do people succeed in taking steps towards development and maturity in some areas, despite the losses in other personal, individual areas? And what contribution can the social, spatial and, ultimately, the institutional environment make to reduce or compensate for losses and to promote processes for development?



Questions such as these also arise with regard to people suffering from dementia. Showing the limits of human life, dementia confronts us with the vulnerability of our existence. On closer inspection, however, it can be seen that not all personal areas are affected by the disease to the same extent. Particularly in the area of emotions, differentiated forms of experience and expression can be observed well into the later stages of dementia.

The following paper makes a very important contribution to the social co-responsibility for the quality of life of people with dementia. Politics, social and cultural practice, therapy, rehabilitation and care, counselling and support for relatives, a wide variety of scientific disciplines are addressed in their specific areas of responsibility. Research results and innovative practical projects are cited. Civic commitment is appreciated for its specific potentials.

Emboldening us, the following paper thus succeeds in developing scientific and practice-oriented perspectives for the future. It succeeds in showing that supporting people with dementia and their relatives is a task that “permeates” our society - and this also with a view to unconditional respect for human dignity.

A handwritten signature in black ink, appearing to read 'Andreas Kruse'. The signature is fluid and cursive, with the first name 'Andreas' and the last name 'Kruse' clearly distinguishable.

Prof. Dr. Andreas Kruse  
Heidelberg University

<sup>1</sup> For further details, see Kruse A. (2017), Lebensphase hohes Alter: Verletzlichkeit und Reife. Heidelberg: Springer



# I.

## Introduction

These days, we live in a society of long life. The number of people in Germany aged over 65 has multiplied in the last hundred years and will continue to do so. As life expectancy continues to rise and increase in its perspective, there will also be more people suffering from dementia.

In Germany, there are currently around 1.7 million people living with dementia, almost two-thirds of them in familiar social surroundings: in their families, in their neighbourhoods, in their local areas. This topic is given plenty of attention; nevertheless, being inflicted with dementia still has a shameful connotation and is frequently considered to be a taboo subject. The federal government recognised this early on and initiated the Alliance for People with Dementia in 2012.

Dementia should not lead to sufferers being excluded from participating in society. The agenda of the Alliance for People with Dementia is therefore characterised by the guiding principle of inclusion. It thus respects the wish of most people, even with dementia, to remain in their usual home environment. The agenda thus implements the objective of the United Nations Convention on the Rights of Persons with Disabilities. With regard to enabling people with dementia to lead a self-determined life, there is a particular need for action to support caregiving relatives in the best possible way and, in a straightforward manner, to provide help in meeting their needs.

### **Inclusion as a guiding principle**

To be able to respectfully and equitably interact with affected persons and their relatives, it is necessary to possess both knowledge of the disease pattern and to understand the affected persons' individual situations. New forms of cooperation must be developed and voluntary commitment further expanded - in addition to reliable support for people with dementia through a family and neighbourly environment.

Towns and villages must be designed in such a way that people with dementia and their relatives can be appreciated for their potential. To this end, accessibility must be guaranteed and a close network of supply and support services must be established. Beyond local responsibilities and individual goals, joint responsibility at all levels of society makes a significant contribution to improving the lives and daily routines of people with dementia.

For this to succeed, the public must be made aware of the issue of dementia. Information and health education measures must focus on the nature of the disease and

its effects. This includes comprehensive and far-reaching public relations work that also specifically reaches stakeholders in society.

### **Maintaining quality of life**

Maintaining the quality of life of people with dementia and their families and stabilising their social environment are key challenges facing society. Research plays just as important a role here as stakeholders in society. Everyone must take responsibility to enable people with dementia to be integrated into social relationships according to their wishes and abilities and to allow them to lead life on equal footing with their environment.

### **Political challenges**

Dealing with dementia is also a major challenge when it comes to health and social policy. Germany is home to Europe's most ageing society. As in other countries in Europe and around the world, the number of people with dementia is continuously on the rise here. Other European countries are also recording steady growth rates in dementia. Therefore, in January 2011, the European Parliament called on the member states to make dementia a health policy priority within the European Union. National plans and strategies should be developed to counter the consequences of dementia on society and the health system and to offer support to those affected and their families. The Federal Ministry for Family Affairs, Senior Citizens, Women and Youth (BMFSFJ) and the Federal Ministry of Health (BMG) founded the Alliance for People with Dementia as an inter-ministerial working group in 2012.

### **Participatory approach**

An analysis of international plans on dementia and interviews with experts initially showed that there is no master plan for dealing with dementia that could simply be applied to Germany. However, the results have shown that different priorities need to be set in terms of content.<sup>2</sup> Until now, the Alliance for People with Dementia has taken this into account in its work by agreeing on a participatory approach with the following functions:

1. The participation of a large number of non-governmental stakeholders opens up potential for possible solutions based on experience and expert knowledge.
2. The participation process can already be seen as a step of social mobilisation and sensitisation, which is a central component for the topic of dementia.

Through cooperation between politics and society, the experience of the last four years has shown that a large number of specific measures have been initiated and successfully implemented. Continuing the cooperation is desirable. The aim is still to establish awareness of the special concerns of people with dementia as a matter of course in all aspects of social life. Only in this way can real improvements be achieved for people with dementia and their relatives.

<sup>2</sup> [www.iso-institut.de/download/Nationale\\_Demenzstrategien\\_Endbericht\\_BMFSFJ.pdf](http://www.iso-institut.de/download/Nationale_Demenzstrategien_Endbericht_BMFSFJ.pdf)

## II. Alliance for People with Dementia

### 1. Origin and aims of the Alliance

The “Alliance for People with Dementia” was initiated by the federal government and is one of ten working groups within the federal government’s demography strategy. The objective of the demographic strategy is to give all individuals, in accordance with their living situation and age, the opportunity to develop their full potential and skills and to live life as they envision it. In relation to the circumstances of people with dementia and their relatives, there is a special need for action here.

The Alliance is partnered with representatives of the federal government, the federal states, umbrella associations, associations and organisations in the fields of health and care, science and civil society bearing responsibility for people with dementia. The partners’ common goals are to ensure the quality of life of people with dementia and their relatives and to promote understanding and sensitivity for them in society.

In a joint statement made at an inaugural meeting on World Alzheimer’s Day in September 2012, the Alliance for People with Dementia presented its goals and ways of implementing them to the public. As a confederation of politics and civil society, the Alliance forms a nationwide network that focuses in particular on issues of dignified ageing and high-quality care and support. Together, the aim is to promote education on the disease and to increase understanding and sensitivity to it. Social exclusion of those affected should be counteracted and people with dementia should be ensured participation in society. The various initiatives and measures should be effectively linked and further developed, and assistance should be provided in the formation of support networks in the living environment of those affected (Local Alliances).

With specific agreements and contributions to be implemented according to different sponsorships and the responsibilities of all partners, the asserted goals were set out in the agenda “Together for people with dementia”.

#### **The federal government’s demography strategy**

#### **Goals of the Alliance**

#### **Development of the agenda**

**Fields of action** The four fields of action on the agenda are:

- science and research,
- social responsibility,
- support for people with dementia and their families, and
- configuration of the support and care system.

The agenda is shaped by the guiding principle of inclusion: self-determination and participation of people with dementia are at the forefront of every process. The agenda was signed by the leading ministries and all top-level organisation partners in September 2014. The implementation process of the specifically agreed contributions began with this signal of voluntary commitment by all partners.

**Interim Report** An initial status of the Alliance's work was documented with the publication in September 2016 of the Interim Report on the Agenda's implementation. The Interim Report describes the status of measures already implemented at that time in the field of "Unterstützung von Menschen mit Demenz und deren Familien" (Support for people with dementia and their families) and highlights further measures with central significance from the other fields of action.

### Report on the implementation of the Agenda 2014-2018

This report documents the results of the implementation of the "Together for People with Dementia" Agenda between 2014 and 2018. It is based on reports from Alliance partners on measures in all areas of action and was prepared by the Office for People with Dementia at the Bundesamt für Familie und zivilgesellschaftliche Aufgaben (Federal Office of Family Affairs and Civil Society Functions, BAFzA). The report also identifies areas where action is still required. It thus represents a pointed approach of the agenda's important implementation steps and is a central building block for the Alliance's further development. In addition to the measures and projects described in this report, there are numerous initiatives, measures and projects by the organisation and cooperation partners that pursue and support the objectives formulated in the agenda. The **Standing Conference of the Ministers of Education and Cultural Affairs (KMK)** has presented a detailed, exemplary overview in which universities and colleges provide an overview of current scientific research in the field of dementia. The overview can be found in the appendix to this report.

In the following, the report describes the structure of the "Together for people with



dementia” agenda and provides explanations on members and the Alliance’s working groups. After describing the monitoring process that has accompanied the Alliance’s work, the subsequent main part of the report analyses in detail the individual areas of action, topics, agreements and contributions by the Alliance’s partners. The focus here is on presenting the examples selected by the partners from the multitude of measures, projects and initiatives implemented within the framework of the agenda. Finally, the tasks and challenges arising for the future will be described in a forecast. The report ends with an overview of all organisation and cooperation partners, a collection of various offers for information and an index of abbreviations and illustrations. The editorial deadline was 8 June 2018. Any ongoing updates of the measures presented here can therefore not be guaranteed in this report.

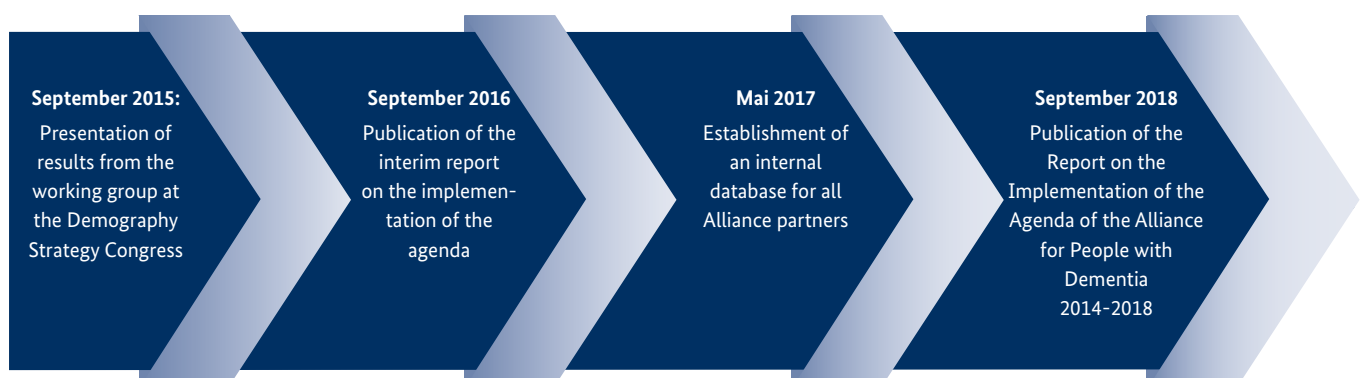
In individual sentences, the masculine form has been chosen for better legibility. The respective statements nevertheless always refer to both genders.

## 2. Members of the Alliance

In addition to eight federal ministries, the Alliance for People with Dementia brings together representatives of the federal states, national associations of local authorities and numerous organisations from the fields of care and health, science and civil society. They all work together to improve the quality of life of people with dementia and their relatives. The Alliance is chaired by the Federal Minister for Family Affairs, Senior Citizens, Women and Youth and the Federal Minister of Health. The first chairperson of the German Alzheimer Society has taken the co-chairmanship.

The organisation partners are the founding members of the Alliance for People with Dementia, who jointly developed the “Together for People with Dementia” agenda. A total of ten cooperation partnerships were concluded at the beginning of the agenda’s implementation phase to further strengthen the Alliance. The cooperation partners have committed themselves to the Alliance’s objectives. With their own activities and measures, they participate in the implementation process and support the organisation partners’ networking initiatives. The Alliance for People with Dementia meets the current and future challenges on a broad social and health policy as well as on the basis of civil society.

### Organisation and cooperation partners

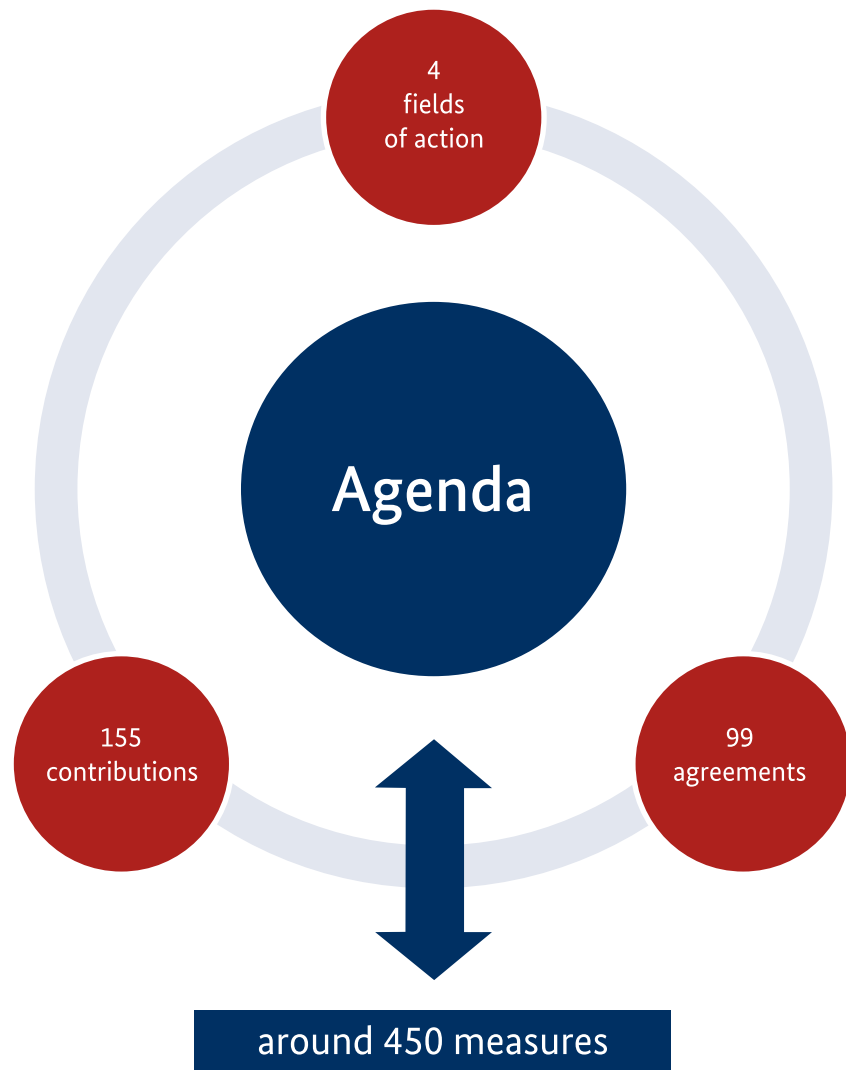


Timeline

### 3. The agenda's structure

#### From fields of action to measures

The “Together for People with Dementia” agenda was drawn up in an intensive two-year work process by all organisation partners in the Alliance for People with Dementia. It is divided into four fields of action, which are structured in a total of ten thematic areas. A total of almost 100 target agreements have been defined for the thematic focal points. These agreements are followed by 155 specific contributions with which the Alliance’s partners intend to achieve the goals, either individually or jointly. The contributions include the project, tasks or measures as well as the partner(s) involved. Around 450 different measures were allocated to the contributions during the agenda’s implementation phase.



The agenda's structure



## 4. Working groups in the Alliance

Two working groups were set up within the Alliance for People with Dementia to deal with the issues of “Safety and independence in dementia” and “Public Relations”.

In the areas of traffic participation and legal capacity, the “Safety and independence in dementia” working group has developed proposals for a more independent life with dementia. The working group was headed by the German Alzheimer Society. In addition to the German federal government, the other members were the Deutsche Gesellschaft für Gerontopsychiatrie und -psychotherapie e.V. (German Society of Geronto-Psychiatry and Psychotherapy) Hamburg’s official service centre, the German Association for Public and Private Welfare, the AGP Institute for Social Research at the Protestant University of Applied Sciences Freiburg, practitioners from the Alzheimer societies and one person suffering from dementia.

The “Public Relations” working group has coordinated the Alliance’s joint public relations work. Since 2015, it has been organising Dementia Week around the time of World Alzheimer’s Day, which is held annually in September and raises awareness and offers support for dementia at numerous events throughout Germany. The group was headed by the then Chairman of the Board of Trustees at the Deutsche Altershilfe (the German society for the aged). Besides the federal government and the national associations of local authorities, the other members consisted of the German Center for Neurodegenerative Diseases, the German Alzheimer Society, the GKV central association, the Zentrum für Qualität in der Pflege (Centre for quality in care), the company “compass private pflegeberatung”, the Bundesverband privater Anbieter sozialer Dienste (Federal Association of Private Social Service Providers), the Federal Association of Non-Statutory Welfare and the Deutsche Fernsehlotterie (German television lottery).

## 5. The monitoring process for implementing the agenda

The implementation phase of the agreed contributions began when the “Together for People with Dementia” agenda was signed in September 2014. As part of their voluntary commitments and to achieve the respective objectives, the partners involved were asked to implement the specific measures and projects they had agreed upon.

With ongoing coordination and recording of relevant measures and projects, direct support of the Alliance partners was ensured within the framework of a monitoring procedure. In this way, it was also possible to call up the implementation’s results and to prepare interim financial statements.

**Office Alliance for People with Dementia**

The agenda's implementation process was coordinated and accompanied by the Office of the Alliance for People with Dementia at the Federal Office of Family Affairs and Civil Society Functions (BAFzA). The office processed the measures reported by the organisation and cooperation partners into a database which is available as a working aid to the partners and can be accessed individually. The database was also used to assist in the preparation of this report.

**Working group meetings**

A total of nine Alliance plenary meetings, in which the implementation process was initiated and accompanied, have taken place since the Agenda was signed on 15 September 2014. Since 2016, the individual working group meetings have been separately examining the fields of action on the agenda and observing the further development of the measures in the implementation phase. The sessions have been regularly enriched by keynote speeches on various Alliance topics (dementia plans in other countries, tasks and concerns on dementia of commissioners from medical associations, immigration and dementia, sports and dementia, dementia networks, dementia and hospital, basic research dementia, dementia care management as well as prevention and dementia).

## III. Measures to implement the agenda

The following section is dedicated to describing the measures reported by Alliance partners on the agenda's individual fields of action. The fields of action and their corresponding subject areas are presented consecutively. The projects and results announced by the partners for the report are subsequently taken up in detail. In addition to the measures described below, the partners have implemented a large number of other projects and continue to support the improvement of living conditions of people with dementia through a variety of projects and activities. The partners have already reported a total of around 450 measures in all four fields of action.

### 1. Field of action I: Science and research

To improve the qualified treatment and support of people with dementia, field of activity I is dedicated to the scientific research of dementia and the communication of its results. It is divided into two subject areas: research and research structures. In the agenda, the organisation partners have defined eight agreements and twelve contributions. Almost all contributions could be supported by measures. A total of 46 measures were reported in this field of action. In addition, an updated overview is available as part of the survey of universities conducted on behalf of the **Standing Conference of Ministers of Education and Cultural Affairs (KMK)**. This can be found in the appendix to this report.

#### Subject areas

To better understand how dementia develops and to recognise the potential for prevention, diagnosis, therapy and rehabilitation, the partners have agreed that increased efforts are necessary in every area of research. The research tasks therefore include clarifying the causes for the development of dementia, analysing and further developing care structures, improving the coordination of research areas and informing the public about current research results in a comprehensive way. The agenda describes five relevant research areas devoted to various aspects of dementia: biomedical and clinical research, health care research, social and behavioural ageing research, nursing research and epidemiological research.

#### Research tasks

#### Research areas

To maintain and further improve performance, these research areas require permanent, interdisciplinary research structures. To make new findings from dementia research immediately available and to increase the research's effectiveness, the aim of the interdisciplinary cooperation is to efficiently link the individual phases of the research process, from basic research to clinical studies and population studies. To

this end, it was also agreed that international scientific exchange must be intensified. To illustrate how diverse and comprehensive the research structures in the field of dementia have become in the meantime, this section uses structural conditions and many examples with regard to project or research-related cooperation.

#### Basic activities of daily life

At the **Standing Conference of Ministers of Education and Cultural Affairs (KMK)**, the federal states coordinate all relevant topics in the field of science and university medicine. Particularly the university clinics supported by the federal states' science departments fulfil a whole range of special functions: Moreover, are training centres, especially for prospective physicians and nursing staff. They are also research facilities for basic medical research, clinical research and health care research. Finally, they make a significant contribution to the population's medical care, including dementia. The following examples from university medicine are intended

#### Early stages of the disease

to illustrate this. Bathing and showering activities, as they show deficits relatively early on in the ageing process, are among the basic activities of daily life which are of particular importance for self-dependence. They are associated with a very high risk of accidents. Surprisingly, there are hardly any technical support systems that support human activity in these activities. Together with international partners, one project of German research institutions aims at developing an innovative, modular, robotic system that helps people with disabilities in bathing/showering to perform showering activities successfully, safely and independently. During development, special attention is paid to aspects of behaviour and acceptance, as well as on aspects regarding sociology, ethics and safety. Clinical evaluation focuses on human-machine interaction, especially in persons who are cognitively impaired. The DELCODE study is a multicentre study conducted at the German sites of the **German Centre for Neurodegenerative Diseases (DZNE)** in Tübingen, Bonn, Berlin, Göttingen, Cologne, Munich, Rostock and Magdeburg. In this study, risk groups for cognitive disorders and persons in an early stage of dementia are examined over several years. The aim is to develop methods that characterise early stages of the disease, enable an improved prediction of the disease's stages and identify new markers for the early diagnosis of Alzheimer's disease. This includes people without any symptoms (healthy control subjects), patients with mild memory disorders or mild dementia and relatives of patients diagnosed with Alzheimer's disease. The minimum age is 60. A study by the Ludwig Maximilian University of Munich is directed at people shortly after being diagnosed with Alzheimer's dementia at an early stage and should support them and their relatives in planning, health and social decision-making processes. The intervention is to consist of a discussion process and a supporting brochure, which will first be developed in a structured, multi-stage process and then tested for applicability in a pilot study. In the end, there should be an intervention that meets the abilities and needs of future users. Existing measures for health promotion, prevention and care are not always equally effective for women and men. This is due to gender-specific differences in the diseases' development and course as well as personal lifestyles, e.g. nutrition and health-related behaviour, and different needs and requirements in care. To enable the development of new, effective concepts, gender-sensitive comparative studies to maintain and improve the health of women and men and to develop and validate innovative methods for gender-sensitive research are necessary

#### Gender-specific research

prerequisites. The research project of the Hannover Medical School focuses on the evaluation of gender-specific health inequalities in old age. The aim of the study is to develop the basis for cost-effective prevention and care services for the long-term preservation of physical-mental functionality and quality of life in the very elderly. The study is carried out in close cooperation with the study centres in Leipzig, Bonn, Hamburg and Hanover. A project of the Charité Universitätsmedizin Berlin on biomarkers of Alzheimer's disease in brain water brought together experts from the field of neurodegeneration research. They work in a consortium with specialists for cellular processes that play an important role in Alzheimer's disease. The cooperating teams analyse the very complex interaction of proteins in the nerve cells affected by Alzheimer's disease. In the translational approach of this project, new biomedical methods are being investigated for their relevance with the disease and for patients. The objective is to develop better diagnostic tools for Alzheimer's disease and to test active therapeutic agents. Dementia has found great significance in teaching, research and medical treatment at universities and in science. In addition, the topic of dementia is becoming increasingly important in medical courses of study and in training courses for the health professions. In addition, special qualification modules are being developed and offered at colleges and universities. Details can be found in a comprehensive overview of the projects from science and research on the website of the Standing Conference of Ministers of Education and Cultural Affairs.<sup>3</sup> Due to the overarching importance of the topic of dementia, various federal state governments have identified nationwide fields of action and solution strategies and bundled together stakeholders, initiatives and projects.

### New biomedical methods

### Research effectiveness

The **federal government** (BMG) has set itself the goal of improving the availability of routine data from the statutory health insurance companies (GKV) for health care research. The regulations on data transparency (Sections 303 a-e SGB V; use of the GKV routine data from statutory health insurance funds for care research) were redesigned along the lines of the GKV Versorgungsstrukturgesetz (Act on Care Structure, GKV-VStG) and implemented with the Regulation on Data Transparency (DaTraV) which came into force on 18 September 2013. The German Institute of Medical Documentation and Information (DIMDI) was entrusted with the tasks of a trust centre (pseudonymisation of data) and a data processing centre (preparation and provision of data). Since 2014, the Supply Data Information System at DIMDI has been ready to process requests from authorised institutions for evaluations of routine data.

In the nationwide population-based enquiry and questionnaire surveys of the Robert Koch Institute (RKI) in Germany, which operates in the **federal government's** business area, data are collected on dementia risk factors for adults, in particular on cardiometabolic risk factors, socio-economic factors and cognitive performance. So far, however, the RKI's health surveys have not or not sufficiently included elderly people of high age and persons with physical or cognitive impairments. Using the established survey methodology, it is particularly difficult to reach people in need

### Risk factors for dementia

<sup>3</sup> [www.kmk.org](http://www.kmk.org)

### Health monitoring

of care. As part of the “Improving Health Monitoring in Old Age (IMOA)” project funded by the **Robert Bosch Stiftung**, the RKI is currently developing a framework concept for the expansion of continuous health monitoring in Germany for the population aged 65 and over. This also includes conceptual work on the further development of sample and survey design with the development of adaptive survey methods to integrate previously excluded or underrepresented groups of older people. Within the framework of IMOA, a feasibility study was carried out to develop successful access routes (e.g. the involvement of legal carers). The results of the study are expected to be available by the end of 2018. On this basis, the RKI will develop proposals for extending the study methodology, especially for very old people, cognitively or physically impaired persons and persons cared for at home or in care institutions. Subject to appropriate financing and the involvement of external cooperation partners, the project results will subsequently be used to expand health monitoring for older people. Especially regarding people with dementia, it must be further investigated by means of methodological studies if improved integration of population groups affected by dementia into the health surveys of the RKI ultimately also enables representative statements to be made. Methodological challenges include, for example, informed study consent, case definitions for dementia and data collection from relatives and caregivers.

### International cooperation

In the field of research into neurodegenerative diseases, the **federal government** (BMBF) is also involved in international cooperation. The EU member states and other partners support the “EU Joint Programme - Neurodegenerative Disease Research (JPND)” initiative. Joint programming and research activities will make better use of existing resources and pool research capacities. The joint initiative aims to improve understanding of the causes and mechanisms of neurodegenerative diseases, in particular Alzheimer’s disease. At the same time, therapy procedures and diagnostic possibilities are to be developed and improved. JPND has funded and is currently funding some 70 research collaborations.<sup>4</sup> They cover a wide range of topics. For example, researchers in the international joint “NAB3” project are investigating the disease-related processes at the blood-brain barrier in Alzheimer’s disease. As a German partner, Charité Universitätsmedizin Berlin is developing a complex in-vitro model of patient cells that takes these processes into account. The model is intended to provide new insights into the development and course of Alzheimer’s disease. In addition, it could be used in the future to develop more effective medication. The aim of the joint “Rhapsody” project is to improve the lives of younger people with dementia and of their families. In this project, which also involves the **German Alzheimer Society**, the help structures in six European countries regarding those affected have been investigated and an online information service has been developed for this target group.<sup>5</sup>

<sup>4</sup> [www.neurodegenerationresearch.eu/supported-projects](http://www.neurodegenerationresearch.eu/supported-projects)

<sup>5</sup> [www.deutsche-alzheimer.de/die-krankheit/demenz-im-juengeren-lebensalter/ratgeber-junge-demenz.html](http://www.deutsche-alzheimer.de/die-krankheit/demenz-im-juengeren-lebensalter/ratgeber-junge-demenz.html)

In addition, the **federal government** (BMBF) is part of the “ERA network NEURON”, which, with bundled resources, coordinates the research activities and programmes of the participating European countries in the field of neurosciences to effectively advance research into brain diseases.<sup>6</sup> As part of this measure, the BMBF also funds research projects related to dementia. For example, the TraCInflam international association is investigating how acute inflammatory processes become chronic. The scientists want to use their findings to develop new therapies. In particular, the German partner analyses the immune responses in Alzheimer’s and septic encephalopathy, in which an infection leads to disturbances of consciousness.

## Research in Europe

With the NAKO Health Study (NAKO), a nationwide long-term cohort of the general population is being established. It is funded by the **federal government** (BMBF), 13 participating federal states and four Helmholtz Centres. The NAKO aims at investigating the development of important widespread diseases and their precursors. Possibilities of prevention and early detection should also be identified. In 18 study centres, 200,000 men and women aged 20-69 are being comprehensively examined and interviewed. In addition, various biosamples, such as blood and saliva, are being collected. At regular intervals, the participants should be examined and repeatedly interviewed over a long period of time. By means of interviews, tests and magnetic resonance imaging of the brain, the NAKO collects relevant information on cognition and dementias. Thus, the course of cognitive limitations and the development of dementias and their risk factors can be investigated with the help of the NAKO.

## Long-term cohorts

With the “Innovative care for people with dementia” funding priority, the **federal government** (BMBF) funds research and development projects on innovative human-technology interaction in care that support and relieve burden from people with dementia, relatives and professional carers and go beyond the current state of the technologies developed to date. The key objective is to increase self-determination and the quality of life of all those affected. Funding is provided for application-oriented collaborative projects that develop innovations in human-technological interaction to support people with dementia and their environment in an interdisciplinary approach, for example from engineering and technology sciences, natural sciences, health care and nursing research, psychology as well as social, legal and economic sciences. To ensure the responsible use of technical systems in care, special attention is paid to the ethical, legal and social implications when using technology. In the sense of a participative and user-centred approach, which are specifically oriented towards the needs of people with dementia, their relatives and professional carers, the development of suitable solutions of human-technological interaction is being funded. Special requirements are placed on simple and appropriate operability.

## Human-technological interaction

<sup>6</sup> [www.bmbf.de/foerderungen/bekanntmachung-1534.html](http://www.bmbf.de/foerderungen/bekanntmachung-1534.html)

**Sociotechnical systems** The ten funded projects cover a wide range of topics. These include socio-technical systems that strengthen social participation and mental well-being. For example, the “QuartrBack” project deals with the issue of how people with dementia can move around their neighbourhoods as independently as possible, even with increasing disorientation. Miniaturised location transmitters are attached to everyday objects such as a dementia patient’s wristwatch and are also worn by people in the individual helper network, such as relatives or professional services. Software is used to identify risks in the individual social space of dementia patients and to define areas in which they can move at low risk. Via a smartphone app, helpers activate the location of their own position “at the touch of a button” and signal their willingness to provide support. The app also includes navigation software that can lead helpers to the affected person if necessary.

**Digital instruments** The “InterMem” project is developing various digital instruments to facilitate memory work with people with dementia in both outpatient and inpatient environments. To ensure that the appropriate content and media (music, images, etc.) are available at the right time, authoring tools are also being developed that enable the creation of biographical content with relatives.

To support relatives in caring for people with dementia at home and to deal with challenging behaviour, such as screaming or running away, the “InsideDEM” project is developing a sensor-based system for recording the behaviour of people with dementia.<sup>7</sup> Based on an innovative assessment system for inpatient care, the evaluation of the data collected is intended to provide relatives with information on causes and possible interventions.

**Participatory approaches to research** All projects are concerned with finding suitable methods and standards for participatory research with people with dementia. In addition, they are looking for solutions on how the desired technical systems can be implemented in the processes of home care and the work processes of institutional care. Ten projects are being funded under the measure.<sup>8</sup> The total volume of the funding measure amounts to around EUR 15 million.

**Strengthening body, mind and psyche** The **federal government** (BMBF) is funding two research networks related to dementia as part of the “Studies in care and nursing research for elderly and very elderly people” programme: solving crossword puzzles, taking regular exercise and consuming a balanced diet - these and other activities are intended to prevent Alzheimer’s dementia. However, so far there is no scientific evidence as to which activities really are useful. The scientists of the “AgeWell.de” joint project want to provide this proof. Elderly people in need of care, who have been diagnosed with an increased risk of Alzheimer’s disease, can participate in the research. They are offered a broad programme to strengthen body, mind and psyche, including

<sup>7</sup> [www.dzne.de/forschung/studien/projekte-der-versorgungsforschung/insidedem/](http://www.dzne.de/forschung/studien/projekte-der-versorgungsforschung/insidedem/)

<sup>8</sup> [www.technik-zum-menschen-bringen.de/foerderung/bekanntmachungen/pflegeinnovationen-fuer-menschen-mit-demenz](http://www.technik-zum-menschen-bringen.de/foerderung/bekanntmachungen/pflegeinnovationen-fuer-menschen-mit-demenz)



nutritional counselling, cognitive training, physical exercises, medication optimisation and social activities. The participants are comprehensively supervised during the study. If the measures show the desired success, the participating scientists will work out recommendations on how the programme can be integrated into the everyday lives of older people. The aim of the “intersec-CM” joint project is to investigate if the transition between hospital and outpatient care can be improved.<sup>9</sup> In close cooperation with the hospitals and the general practitioner, the researchers draw up a treatment and care plan individually tailored to the person in need of care.

### Transition from hospital to outpatient care



The “Studies in care and nursing research for older and very elderly people” support measure by the Federal Ministry of Education and Research (BMBF) is part of the “Healthy - your whole life long” funding initiative.<sup>10</sup> The initiative’s aim is to create the basis to better consider the needs and living conditions of elderly and very elderly people in care and nursing. Functionality, self-determination, social participation and health-related quality of life should be in the foreground. Funding is provided for projects that develop age-appropriate concepts and investigate their effects under everyday conditions. The total volume of the funding measure amounts to around EUR 12 million.

### “Healthy - your whole life long” support initiative

The **federal and state governments** support research on the medical, health, ethical, legal and social aspects of dementia, on improving quality of life and health services and on preserving the independence and human dignity of people with dementia, among other things, by supporting the **German Centre for Neurodegenerative Diseases (DZNE)**.

### Independence and dignity

<sup>9</sup> [www.gesundheitsforschung-bmbf.de/de/intersec-cm-sektoreubergreifendes-care-management-zur-unterstuetzung-kognitiv-6665.php](http://www.gesundheitsforschung-bmbf.de/de/intersec-cm-sektoreubergreifendes-care-management-zur-unterstuetzung-kognitiv-6665.php)

<sup>10</sup> [www.bmbf.de/foerderungen/bekanntmachung-1113.html](http://www.bmbf.de/foerderungen/bekanntmachung-1113.html)

**Linking different research areas** The DZNE has been continuously advancing research in this area since its foundation in 2009. With the aim of developing new preventive and therapeutic approaches, more than 1,000 employees in more than 80 working groups at nine locations in Germany were involved in researching commonalities and differences in various brain diseases in 2017. At the DZNE, basic research is closely linked to clinical research, care research and population studies. The aim is to find new diagnostic markers and enable the rapid development of new therapies.

**Clinical network of the DZNE** The DZNE's clinical research aims at developing new and effective therapies for neurodegenerative diseases. To achieve this, not only studies on treatment are necessary. Rather, diagnostic procedures must also be improved in order to be able to detect diseases earlier and to classify them better. Clinical research at the DZNE is carried out by the Klinisches Netzwerk (Clinical network), which is coordinated from the DZNE sites in Berlin, Bonn, Dresden, Göttingen, Magdeburg, Munich, Rostock/Greifswald and Tübingen. The clinical network enables large multicentre studies to be conducted according to uniform standards.

**Neurodegenerative diseases** In neurodegenerative diseases, the first brain changes occur more than ten years before the onset of any disease symptoms. At the time of diagnosis, extensive irreversible brain damage is already present, meaning it is already too late for many therapies. Clinical research is developing new biomarkers that enable earlier diagnosis and define subgroups of diseases through detailed research of high-risk individuals and people in need of care. In future, these markers will be used to test therapy approaches in early stages of diseases and to apply therapies more individually. Treatment studies are conducted by the DZNE as self-initiated studies and in cooperation with partners from the pharmaceutical industry. Particular attention is paid to the rapid transfer of basic research results into clinical application.

**Rheinland Study** The "Rheinland Study" is a prospective cohort study focusing on neurodegenerative diseases.<sup>11</sup> It is carried out by the **DZNE** and funded by the **federal government** (BMBF) and the state of **North Rhine-Westphalia**. The study examines which protection and risk factors influence the health of adults throughout their life span into old age. Spanning several decades, the interplay of genetic factors, lifestyle and environmental influences as well as their impact on human health will be studied using up to 30,000 participants. What does our good health depend on? What does "healthy" mean? Is it a freedom from discomfort or is it not rather the constant ability to adapt to new social, physical and mental challenges? Are the foundations for healthy ageing laid already years or decades before? By answering these questions, the "Rheinland Study" aims at contributing to health promotion and disease prevention. The development of the brain in the course of life is the focus of these considerations. It plays an important role for the physical and mental well-being of people and changes throughout their lives.

<sup>11</sup> [www.dzne.de/forschung/forschungsbereiche/populationsforschung/](http://www.dzne.de/forschung/forschungsbereiche/populationsforschung/)

The “DelpHi Study (Dementia: living environment and person-centred help for people with dementia)” is a scientific study to analyse the effectiveness of Dementia Care Management (DCM) for people with dementia living at home. It is implemented by the **DZNE**.<sup>12</sup> DCM improves the living and care situation of people with dementia living at home. These are medicamentously better aligned compared to people in need of care who are treated without DCM. They are also less affected by neuropsychiatric symptoms, such as depression. At the same time, caring relatives are relieved of burden. Thanks to care management, those who live with relatives have moreover a better quality of life. These are the first scientific results of the DZNE study, in which the situation of over 600 people living with dementia in Mecklenburg-Western Pomerania has been investigated in a prospective randomised design since 2012. Some of the participants were supported for up to one year by structured, individual care management (Dementia Care Management). The examination was carried out in close cooperation with more than 130 general practitioners. Since completing the efficacy analysis, the health economic effects are now being investigated. Initial results are promising. If the result is positive, the concept should be transferred to routine care. For one thing, this is planned using through pilot projects, but also through adaptations of the DCM in various settings.

## Dementia Care Management

The project “intersec-CM”, in which the DZNE is involved, aims at improving the care, treatment and support of those affected and focuses on the transition from inpatient treatment in hospitals to outpatient care. A cross-sectoral Dementia Care Management system, that addresses the needs and requirements of those affected and systematically integrates the professional stakeholders involved, is being implemented and tested. In close cooperation with the hospital and the general practitioners, the researchers draw up a treatment and care plan individually tailored to the person in need of care. In the form of a randomised controlled intervention study in longitudinal design, the effectiveness and health economic efficiency of DCM are examined on the basis of the accompanying evaluation. The target criteria are patient-related health and social outcomes (including quality of life, social integration, re-hospitalisation) and other indicators, such as the subjective burden on relatives. Supporting and inhibiting implementation conditions are also analysed in the context of a quantitative and qualitative process evaluation. The aim of the research team is to provide an evidence-based concept for implementation in standard care and to thus optimise dementia care.

## Transition management research project

The “AHead study (future division of tasks for nursing staff and general practitioners in outpatient dementia care; tasks, acceptance, qualification)” funded by the Innovation Fund of the Joint Federal Committee (G-BA) and carried out by the DZNE in cooperation with the Institute for Community Medicine of University Medicine Greifswald examines how outpatient care for people with dementia can be organised in the future with a changed division of labour between nursing staff and general practitioners and how this will be accepted by both patients and their

## Task sharing in outpatient dementia care

<sup>12</sup> [www.dzne.de/aktuelles/presse-und-oeffentlichkeitsarbeit/pressemitteilungen/presse/detail/mehr-lebensqualitaet-fuer-menschen-mit-demenz-und-angehoerige/](http://www.dzne.de/aktuelles/presse-und-oeffentlichkeitsarbeit/pressemitteilungen/presse/detail/mehr-lebensqualitaet-fuer-menschen-mit-demenz-und-angehoerige/)

relatives. The study results will be used to design a new care concept (according to Section 63 paragraph 3c SGB V). This should form the basis for the further development of the existing G-BA guideline for the transfer of healing tasks in this area of care. The directive regulates which medical activities may be transferred to members of the nursing staff and professions connected with care for the elderly.

#### **Social participation and self-empowerment**

The EU MinD project (Designing for People with Dementia: designing for mindful self-empowerment and social engagement), supported by the **German Society for Psychiatry and Psychotherapy, Psychosomatics and Neurology** (DGPPN) within the framework of Horizon 2020, is developing and investigating support strategies and aids to strengthen the social participation and self-empowerment of people with dementia.<sup>13</sup> Between 2016 and 2019, physicians and psychologists have been working together with design specialists from six European countries (Germany, Great Britain, Italy, the Netherlands, Luxembourg and Spain) to develop prototypes for the EU. Sankt Hedwig Clinics Berlin (Hedwigshöhe Hospital) and Technische Universität Dresden are responsible project partners for Germany.

#### **“Dementia in the General Hospital” study**

The “Dementia in the General Hospital. Prevalence and care situation” study, supported by the **Robert Bosch Stiftung** (RBS) at the Mannheim University of Applied Sciences and the Technical University of Munich has been completed.<sup>14</sup> With this study, data are now available for the first time to the extent on what hospitals expect from people with cognitive disorders and dementias in need of care and which resources they must make available for this. Overall, 40 percent of all people over 65 years of age who are in need of care in general hospitals have cognitive impairments.

#### **Health care research**

In recent years, the **German Society of Geronto-Psychiatry and Psychotherapy** (DGGPP) has initiated, started and implemented some specific projects with university partners on care research for people with dementia. With regard to the quality of life in old age, the PAWEL (Patient Safety, Efficiency and Quality of Life) care research project funded by the Innovation Fund is investigating, for example, patient safety and efficiency in elective operations. With regard to effect (40 percent reduction in delirium) and cost neutrality (SGB V and SGB XI combined), an individualised, non-medicamentous, multimodal and multi-professional intervention to reduce the risk of delirium and its long-term consequences (postoperative cognitive dysfunction - POCDF) are to be examined. The ComPetenz project (offers for nurses within the community for the development of health competence) focuses on the implementation of a counselling programme for relatives and affected persons in rural Brandenburg (partners: Charité and Centre for Quality in Care (ZQP)). Options for the prevention of care dependency, health promotion, geriatric multi-morbidity and measures to strengthen the health literacy of the elderly population are being investigated.

<sup>13</sup> [www.designingfordementia.eu](http://www.designingfordementia.eu)

<sup>14</sup> [www.bosch-stiftung.de/sites/default/files/publications/pdf\\_import/Studie\\_Demenz\\_im\\_Akutenkrankenhaus.pdf](http://www.bosch-stiftung.de/sites/default/files/publications/pdf_import/Studie_Demenz_im_Akutenkrankenhaus.pdf)

The **federal and state governments** have agreed to work on the further development of health professions. The federal states are responsible for intensifying the topic of dementia in the professional curricula of the training courses.

## Development of health professionals

The **federal government** (BMG) shares this view on the importance of dementia. Corresponding requirements are usually also incorporated into the training and examination regulations for the respective laws. According to the Nursing Act (KrPflG) and the Ordinance on the Training and Examinations Qualifying for Nursing Professions (KrPflAPrV), and as far as training in health and nursing care are concerned, these already provide for graduates to be able to comprehensively identify, record and evaluate nursing situations among people of all age groups and to select, implement and evaluate appropriate nursing measures. This also includes the area of dementia. However, as the federal states implement law on their own responsibility, they are primarily responsible for the curricula's more detailed design and specification of the training, as well as to what extent corresponding content is included in the training. In connection with the law to reform the nursing professions, which has already partly come into force, it will continue to be ensured that the Alliance's concerns regarding people with dementia are met. The law of 25 September 2009, which introduced a model clause in the professional laws of midwives, speech therapists, physiotherapists and occupational therapists created the prerequisites for testing training opportunities that are intended to serve the further development of the mentioned professions, taking into account the requirements specific to the occupational field and modern vocational educational findings. The testing also includes the possibility of carrying out initial academic training in the professions concerned. In 2016, the BMG reported to the German Bundestag on the results of the pilot projects in the four health professions. In view of the lack of knowledge on long-term effects, the testing has been extended until the end of 2021. If the topic of dementia is to be intensified in the training courses, this is the task of the federal states which should take this topic into account when designing the technical curricula of the various training courses for the health professions.

## Law on nursing professions

The **Standing Conference of Ministers of Education and Cultural Affairs** (KMK) coordinates all relevant topics in the field of science and research at federal state level. The universities have presented a detailed, exemplary and thus not conclusive overview which, among other things, shows the development of the specialist curricula of the training courses and the study courses in the health professions. The overview can be found in the appendix to this report.

The **Robert Bosch Stiftung** subsidises the "Care of People with Dementia" (M. A.) Master's course at the University of Witten/Herdecke.<sup>15</sup> The course is not only aimed at therapeutic or nursing professions, but also at all other professions that want to contribute to innovative solutions. In the six semesters of this part-time course of study, students learn the basics of understanding dementia as a medical, civil society, economic and socio-political topic. The course of studies qualifies

## Master's course in caring for people with dementia

<sup>15</sup> [www.bosch-stiftung.de/de/projekt/masterstudiengang-versorgung-von-menschen-mit-demenz-ma](http://www.bosch-stiftung.de/de/projekt/masterstudiengang-versorgung-von-menschen-mit-demenz-ma)

students to work on a cross-professional and interdisciplinary basis and to fill key positions - especially in the acute inpatient sector.

### Dementia Graduate College

The Dementia Graduate College, in the “Network Ageing Research” (NAR) at the University of Heidelberg, has been funded by the **Robert Bosch Stiftung** since 2010.<sup>16</sup> The college’s new thematic focus is on the special situation of people with dementia in acute hospitals. With interdisciplinary cooperation, new scientific findings are to be developed to promote the quality of life of people with dementia during and after their stay in the acute care hospital. Among other things, 13 young scientists are dealing with the ability of older people with cognitive disorders in need of care to consent to epidemiological analyses or to using measures to deprive geriatric people in need of care of their liberty in everyday hospital life, such as fixations with belts in bed. The graduate college contributes to the promotion and qualification of academically educated specialists for medical and nursing practice, as well as to teaching in relevant courses of study. The college’s cooperation with acute hospitals in Heidelberg, Mannheim and Karlsruhe-Rüppurr guarantees the research’s practical relevance, whilst the cooperation with the Greek Aristotle University underlines the college’s international orientation and cultural diversity.

The **Federal Association of Non-statutory Welfare** (BAGFW) has created communication structures which are available to research institutes when searching for participating institutions to carry out their research. The associations cooperating in the BAGFW at national level, as well as the respective associations at state level, establish contacts for a number of inquiries. This will continue in the future.

### Pilot programmes of the GKV central association

In accordance with Section 8 Paragraph 3 SGB XI, the **GKV central association** supports seven projects focusing on dementia within the framework of the model programme for the further development of long-term care insurance. The projects include “PflegeTab: Technology for a better quality of life despite the need for care for dementia”, “Speaking time. Telephone support groups for relatives of people with dementia”, “SEBKam. Cross-sectoral deployment of care personnel at the interface of hospitals and outpatient care”, “AniTa. Relatives of people with dementia in exchange: a supra-regional exchange platform for the activation of unused care potential”, “Individualised music for people with dementia”, PfADe. Preventive care structures for dependents of people with dementia”. The SEBKam project has been recognised as the best integrated utility project.<sup>17</sup>

### Quality assurance and practice-oriented concepts in nursing

With the establishment of the non-profit foundation **Centre for Quality in Care** (ZQP), the **Association of Private Health Insurers** (PKV) is helping to improve care practice. The ZQP was established in 2009 and has since then initiated a large number of projects and studies on the subject of quality in nursing care. In addition, online portals, databases and specialist and consumer brochures are freely available. The founding mission of the ZQP comprises, on the one hand, an inventory of me-

<sup>16</sup> [www.bosch-stiftung.de/de/projekt/graduierntenkolleg-menschen-mit-demenz-im-akutkrankenhaus](http://www.bosch-stiftung.de/de/projekt/graduierntenkolleg-menschen-mit-demenz-im-akutkrankenhaus)

<sup>17</sup> [www.gkv-spitzenverband.de/pflegeversicherung/forschung/modellprojekte/modellprojekte.jsp](http://www.gkv-spitzenverband.de/pflegeversicherung/forschung/modellprojekte/modellprojekte.jsp)



thods and procedures of quality assurance in nursing care and, on the other hand, the development of practice-oriented concepts for high-quality and needs-oriented care for elderly, needy and disabled people. With its services, the ZQP supports all those who are committed to people in need of care - in family, practice, politics and science. The range of offers is available on the Internet.<sup>18</sup>

One goal of long-term care insurance is for the long-term care insurance funds and the **federal states** to set up pilot projects to test new care concepts and structures, especially for people suffering from dementia and in need of care. Among other things, the long-term care insurance funds annually make EUR 25 million available for this support; ten percent of this amount is provided by the private insurance companies that have private compulsory long-term care insurance. Including co-financing by the federal states and communal local authorities, up to EUR 50 million per year can thus be allocated to the funding.

To introduce the new concept of the care dependency, the **GKV central association** (GKV-SV) has carried out studies on manageability and factual appropriateness as well as on the specific care costs and benefits of patients in inpatient facilities. The model programme's conceptual basis and methodological approach for promoting new forms of housing, also mentioned in the Interim Report, were published in advance in May 2018. The publication of a so-called practice-oriented "Arbeitshilfe für neue Wohnformen" (Work aid for new forms of housing) is planned for the end of 2018. Accompanying the introduction of the new term "need for care", the GKV-SV has adapted the assessment guidelines and further developed the Joint Circular on the benefit regulations for long-term care insurance.

The overview of the federal states, created in the context of a survey of universities by the **Standing Conference of Ministers of Education and Cultural Affairs** (KMK), contains detailed information on developments in care research in the field of dementia. The overview is attached to this report.

**Bavaria** supports the Bavarian Dementia Survey research project of the Interdisciplinary Centre for Health Technology Assessment and Public Health (IZPH) of the Friedrich-Alexander-University Erlangen-Nuremberg (FAU). Better understanding is to be gained on the effects of dementia on those affected and their families, as well as an improvement in their care situation, on the basis of data on the course of the disease, the amount of care required and the burden on relatives. The data are collected at three different locations in urban and rural regions in Bavaria. In addition, an extended scientific evaluation of the data material will take place in 2018; among other things, it is planned to identify any open requirements and corresponding remedial measures.

With "PräSenZ - Prevention für Senioren Zuhause", (Prevention for seniors at home) **Baden-Württemberg** has developed a programme that tests preventive home visits

### Testing new care concepts

### Studies by the National Association of Statutory Health Insurance Funds (GKV-SV)

### Review Guidelines and Joint Circular

### Bavarian Dementia Survey

### Preventive home visits

<sup>18</sup> [www.zqp.de](http://www.zqp.de)

in three municipalities of different sizes: in Ulm as a major city, Rheinfelden as a medium-sized centre and Neuweiler as a municipality. The target group is older people with an incipient need for support, who are visited, interviewed, informed and advised by qualified advisors (nursing staff, social workers, etc.) at home. The aim is to reach people who are not actively seeking advice and support, including people in precarious social and psychosocial situations. The aim is to initiate contacts and encourage the acceptance of support so that these people can live at home longer and as independently as possible. In addition, links are to be established at the municipal level for offers of support in everyday life and voluntary initiatives.

#### Living with (incipient) dementia pilot scheme

In accordance with Section 45c SGB XI, a pilot project has been carried out in **Hamburg** in cooperation with the long-term care insurance funds: “Living with (incipient) dementia in Hamburg – LeDeHa” was implemented within the Competence Center Health (CCG) of the Hamburg University of Applied Sciences. With the chosen participatory approach and the attempt of network analyses, some important suggestions for local stakeholders and the state initiative Living with Dementia were able to be developed. A basic qualification for employees in service occupations (BasisQ) was developed. As further sub-projects, it has been possible to conduct a survey of Hamburg general practitioners and specialists on the transition to the non-medical help system and an adaptation with a test run of the course book Dementia.<sup>19</sup>

#### Dementia Service federal state initiative

In cooperation with state long-term care insurance funds and private long-term care insurance, the federal state of **North Rhine-Westphalia** has been gradually establishing the state initiative Dementia Service since 2004, in which twelve dementia service centres with regional responsibility, another one for people with immigration backgrounds and, starting in 2018, yet another one for people with hearing impairments, to perform a general advisory, innovation and networking function for dementia-related activities. The federal state initiative also includes an information and coordination office at the **Kuratorium Deutsche Altershilfe** (Advisory board at the German Society for the Aged, KDA) and a knowledge transfer centre at the University of Witten-Herdecke for the exchange of knowledge on dementia between science and practice.

#### Dementia Regional Office

Improving the living conditions of the approximately 20,000 people suffering from dementia and their relatives in **Saarland** is one of the federal state government’s key challenges for the future. For this reason, together with the long-term care insurance funds, the Saarland’s Ministry of Social Affairs, Health, Women and Family has been supporting the “Landesfachstelle Demenz” pilot project since November 2012, sponsored by the Saarlouis Dementia Association, to provide special support for people with dementia and their relatives. At the beginning, the focus was on providing consultation. Meanwhile, the regional office is working successfully in various fields of action: networking, qualification and advice for professional carers, information and public relations. Following the expiry of the model funding, additional funds were approved within the framework of the budget discussions for 2018, so

<sup>19</sup> [www.hag-gesundheit.de/lebenswelt/leben-mit-demenz/dokumentationen](http://www.hag-gesundheit.de/lebenswelt/leben-mit-demenz/dokumentationen)



that more training, networking, institutional consultations and public relations work can now take place.

With the financial support of the state and the regional long-term care insurance associations, a network for care support is being set up in **Thuringia** along the lines of the federal “pflegeBegleitung” pilot project. The aim of the Care Counsellor Initiative is to focus on social responsibility in the field of care by supporting caregiving relatives with care counselling support. For this purpose, network structures are being created where volunteers can meet. Local initiatives, which are currently represented at eleven different locations, are responsible for local coordination. In the Care Counsellor Initiatives, specially qualified care counsellors work on a voluntary basis to make personal contact with caregiving relatives. They are active in the sense of a close and low-threshold neighbourhood help and provide assistance for self-help. In addition to accompanying the caring relatives, there is on-site advice on possibilities to relieve burden and offers of assistance.

The **organisation partners** have also set the objective of informing the public on validated results in dementia research, for example by events, brochures and internet portals.

As part of the **federal government’s** “Local Alliances for People with Dementia” (BMFSFJ) programme, the Alzheimer Gesellschaft München launched the “EinBlickDemenz” project in autumn 2014. In cooperation with Munich Cluster for Systems Neurology (SyNergy) and the **German Centre for Neurodegenerative Diseases (DZNE)**, scientific research results are clearly formulated and made accessible to everyone. The “EinBlickDemenz” project is an internet platform on which leading scientists and employees of the Synergy Cluster Munich discuss current research results and explain them neutrally in simple words. This should help relatives and affected persons to be able to better evaluate the topics presented in the media themselves. Furthermore, the possibility exists to ask individual questions or write comments which are answered by experts. The **German Alzheimer Society** provides the framework and serves as a network partner to link social experts, scientists and clinical personnel. To further intensify networking, there will be additional specialist lectures from all sectors for the various target groups.

By means of press releases on its website<sup>20</sup>, the **DZNE** regularly informs the public on new information by organising events (e.g. Music & Brain), specific annual conferences at the individual locations (e.g. the annual conference in Witten) and training sessions. It also organises a regular international conference on ethical issues in research. In addition, the DZNE has developed an Internet portal for imparting knowledge in the evidence-based reconstruction or further development of dementia networks. The Internet portal was activated in September 2015.<sup>21</sup> The portal’s operation has initially been secured for five years.

<sup>20</sup> [www.dzne.de](http://www.dzne.de)

<sup>21</sup> [www.demenznetzwerke.de](http://www.demenznetzwerke.de)

## Care Counsellor Initiative

## Research and the Public

## “EinBlickDemenz” project

The **GKV central association** makes the ongoing results of scientific research and further information on the subject of dementia available on its homepage, including, for example, press releases and comprehensive information brochures.<sup>22</sup> In May 2018, the “Pflege@Quartier” pilot project was reported on as an example, and in April 2018 the “Cross-sectoral deployment of care personnel at the interface of hospital and outpatient care” (SEBKam) pilot project. The interim results of the conference on pilot projects for the further development of long-term care insurance in accordance with Section 8 Paragraph 3 SGB XI were presented in October 2017. Publications of the Long-term Care Insurance Research Centre of the **GKV central association** are available on the Internet.<sup>23</sup>

## 2. Field of action II: Social responsibility

To enable people with dementia to participate in society in a self-determined way, they need understanding and competent contacts and a dementia-friendly environment. An appreciative encounter with affected people requires sufficient knowledge of the clinical picture and understanding of their needs and concerns. Neighbourly help and offers of voluntary and civic engagement can provide good support to patients and their relatives.

**Subject areas** Field of action II deals with issues of overall social responsibility for people with dementia. The field of action is divided into the subject areas of social participation, networking, legal issues as well as information and public relations. In Agenda 24, the organisation partners have defined 24 agreements and 50 contributions, of which 154 measures have already been identified.

### 2.1 Social Participation

**Target: inclusion** People with disabilities, including those with dementia, have a right to self-determination, non-discrimination, equal opportunity and equal participation in society. Inclusion is enshrined as an objective of this right in the UN Convention on the Rights of Persons with Disabilities. The creation of suitable framework conditions for this is a task for society as a whole.

#### 2.1.1 Milieu creation

The specific goals formulated in the agenda of a so-called milieu creation serve the partners’ various specific measures through a sustainable change in voluntary and neighbourly offers of assistance, as well as through measures to intensify resources and counteract exclusion of those affected.

<sup>22</sup> [www.gkv-spitzenverband.de](http://www.gkv-spitzenverband.de)

<sup>23</sup> [www.gkv-spitzenverband.de/pflegeversicherung/forschung/forschung.jsp](http://www.gkv-spitzenverband.de/pflegeversicherung/forschung/forschung.jsp)

As part of a research project funded by the **federal government** (BMFSFJ) at the University of Cologne, the special needs of people with severe dementia in their last phase of life were identified and taken into account in this project's practical working aid developed to improve the (palliative) care situation. The working aid makes it possible to grasp the needs of people with dementia at the end of their lives, even when they have lost their linguistic expression. The application was tested in outpatient and inpatient care for the elderly, reflected upon and adapted to the respective work situation. The final report and tool are available on the Internet.<sup>24</sup>

### Palliative care situation

Due to the complex effects of their hearing impairment and their special conditions for socialisation, deaf people experience many barriers. The risk of isolation, misdiagnosis and lack of health care is very high in care needs and dementia, especially in old age. Communication barriers and information deficits also prevent deaf people from participating in general services for the elderly or those in need of care. The **federal government** (BMFSFJ) has supported various projects at the University of Cologne to improve the care situation for deaf people in old age.<sup>25</sup> Between February 2011 and June 2014, two competence centres were developed and implemented to improve the care situation of deaf people with dementia. Due to the acceptance and effectiveness of this model, the BMFSFJ funded the project (Project GIA 2.0) until December 2017. The focus here was on improving the care situation in the various countries. Within the framework of the federal state's initiative, the competence centre in Essen is now being established by the federal state of **North Rhine-Westphalia** and the federal state's associations of the long-term care insurance funds to promote the 14th Dementia Service Centre.

### Deaf people

To improve the situation of elderly immigrants in Germany, who make less use of existing support and services, the **federal government** (BMFSFJ) supports the project "Dementia and Migration", in which the **German Alzheimer Society**, in cooperation with migrant self-help associations, is expanding its advisory services, bundling existing foreign-language help and materials and making them available on the "Dementia and Migration" website.<sup>26</sup> Also in Turkish, Polish and Russian, the site provides essential information on the topic of dementia and lists mother-tongue counselling centres.

### People with immigrant backgrounds

The project "DeMigranz - Nationwide Dementia and Migration Initiative" by the **Robert Bosch Stiftung** (RBS) also aims at improving the quality of life of people with an immigration background who suffer from dementia.<sup>27</sup> In a process lasting several years, the objective of the "DeMigranz" project is to bring together stakeholders and networks from politics and practice to be able to develop information services and to facilitate networking on a national basis. Specifically, the aim is to

<sup>24</sup> [www.palliativzentrum.uk-koeln.de/forschung/arbeitshilfe-bei-demenz](http://www.palliativzentrum.uk-koeln.de/forschung/arbeitshilfe-bei-demenz)

<sup>25</sup> [www.kompetenzzentren-gia.de](http://www.kompetenzzentren-gia.de)

<sup>26</sup> [www.demenz-und-migration.de](http://www.demenz-und-migration.de)

<sup>27</sup> [www.bosch-stiftung.de/de/projekt/demigranz-bundesweite-initiative-demenz-und-migration](http://www.bosch-stiftung.de/de/projekt/demigranz-bundesweite-initiative-demenz-und-migration)

ensure that people and their families living in Germany are better informed on the topic of dementia, find access to support services and make use of them.



The “iiDeMM (Initiative and information for people with immigrant backgrounds who suffer from dementia)” project at the Klinikum Stuttgart, initiated by the **German Society of Geronto-Psychiatry and Psychotherapy (DGGPP)**, aims at using already established network structures within and outside of the clinic and to give migration-specific care services greater focus. Advances are made for this group of people by professionally good and immigrant-sensitive treatment and support. iiDeMM provides information material on dementia, delirium and depression in old age, which is available in various languages, works in culturally sensitive working groups and also offers delirium screening in 25 languages.

#### “People with Dementia in the Community” study

In cooperation with the University of Giessen and the **Robert Bosch Stiftung (RBS)**, **Aktion Demenz** conducted the “Dementia in families with an immigrant background” study. The detailed study results were published in book form in October 2017.<sup>28</sup> Aktion Demenz has also implemented the “People with Dementia in the Community” programme with the RBS, thus sensitising numerous cities and communities to the topic of “Dementia-friendly communities”. In addition to medical and nursing considerations of the dementia issue, it has been recognised in situ that it is increasingly important to take social and civil society aspects into account. The programme has enabled various examples, approaches, experiences and results to be collected and commented on, thus providing impetus, assistance and other urgent fields of action, as well as highlighting research topics (including social aspects, subject orientation, qualitative and quantitative involvement of those affected, new forms). A revitalised community and municipality should be created together local-

<sup>28</sup> “Die fremde Seele ist ein dunkler Wald - Über den Umgang mit Demenz in Familien mit Migrationshintergrund”, Psychosozial Verlag

ly and transferred from the project structure to a process structure of support.<sup>29</sup> The programme's results and experiences are balanced, and search movements, stumbling blocks and first solution-approaches are illustrated in a book.<sup>30</sup>

In 2017, the Ministry of Social Affairs and Integration in **Baden-Württemberg** launched a "Quartier 2020 - Create. Together." competition of ideas. 53 municipalities were awarded prizes of up to EUR 100,000 for their ideas on developing neighbourhoods which are age and cross-generationally appropriate.<sup>31</sup>

### Competition for ideas

The competition for ideas was an effective impetus that began with the implementation of the long-term strategy "Quartier 2020 - Create. Together." is to be carried into the area and sustainably anchored. The aim of the neighbourhood strategy is to support local authorities and stakeholders in civil society in establishing and further developing neighbourhoods suitable for the elderly. Among other things, municipalities and stakeholders from civil society can receive vouchers for counselling as well as financial support, which can also be used to set up needs-oriented structures for people with dementia. The great importance of this topic is demonstrated not least by the fact that a total of EUR 12 million has been allocated to it in the 2018/2019 double budget. The strategy is both a learning and a continuous process. In addition to the participation of stakeholders from politics, associations, science and civil society, especially suggestions from the ideas competition flow into the strategy's development. When designing sustainable village and city districts, the submissions showed that the municipalities are focusing on the areas of consulting and process support, housing, meeting places, care infrastructure, participation formats, neighbourhood coordination as well as mobility and care concepts are the main areas of concentration and those for which they would like to receive support. Taking these needs into account, five building blocks of the state strategy were developed, whose services will be expanded as of 2018 and then be available to all municipalities in Baden-Württemberg:

- establishing advisory and support structures,
- networking and exchanging experiences,
- transfer of mobilisation and information,
- training and qualifications,
- scientific monitoring.

Through targeted public relations work, each organisation partner advocates greater awareness of the disease and the needs of those affected. With their actions, they contribute to opening up the living environment of those affected to make it

### Stimulating awareness in society

<sup>29</sup> [www.demenzfreundliche-kommunen.de](http://www.demenzfreundliche-kommunen.de)

<sup>30</sup> [www.transcript-verlag.de/978-3-8376-2996-5/im-leben-bleiben](http://www.transcript-verlag.de/978-3-8376-2996-5/im-leben-bleiben)  
 Rothe, V., Kreutzner, G., Gronemeyer, R. (2015): Staying in Life - on The Way to Dementia-Friendly Communities.(2015): R. (2015): Im Leben bleiben – Unterwegs zu Demenzfreundlichen Kommunen. Bielefeld (transcript). Rothe, V., Kreutzner, G., Gronemeyer, R. (2017): Staying in Life: on the Way to Dementia-Friendly Communities. Bielefeld (transcript).

<sup>31</sup> [www.quartier2020-bw.de](http://www.quartier2020-bw.de)

possible and permanent to meet and exchange with others as well as to participate in society. They get involved at new and existing locations and promote opportunities for joint activities.

With brochures, websites and an exhibition, the **federal government** (BMG) has been expanding the range of information available on dementia. Among other things, the “Ratgeber Demenz” (Dementia advice) brochure has been created. The BMG has furthermore provided intensive information in various media on long-term care insurance benefits for people with dementia in need of care and their caregiving relatives (such as additional care services and the related support offers), for example in the publications “Long-Term Care Guide”, “Everything you need to know about the benefits”, and with the information poster “This is how we enhance care. The 20 most important measures” and also in the online guideline on dementia. The “Lighthouse Project Dementia” is also documented in a brochure. The brochures listed here have been and continue to be in high demand.

A BMG website provides detailed information on the improvements and offers for people with dementia and their relatives, which include the laws on long-term care insurance.<sup>32</sup> An online guide to dementia deals particularly intensively with what is important for those affected and their relatives.<sup>33</sup> Also in the context of general public relations work, the BMG has repeatedly brought the topic of dementia into focus and thus stimulated social attention on this disease - as well as the personal and social challenges which come associated with it. As part of the information campaign for the long-term care enhancement laws, the topic has also been made public in advertisements. In addition, the “DaSein - Ein neuer Blick auf die Pflege” (Being there - a new look at nursing) exhibitions and the event “Miteinander – Für-einander” (Together - for each other) event also demonstrated the disease’s social dimension.

### Dementia in Art

### “A Guide to Dementia” information Portal

With the “Guide to Dementia” central online portal directory, which has been in existence since 2010 and is constantly being further developed, the **federal government** (BMFSFJ) offers comprehensible information and opportunities to facilitate the exchange of information between patients and caregivers.<sup>34</sup> Current topics are addressed via central stage reports and advice, information and exchange opportunities are promoted via forums and a weblog. Through a newly offered e-learning program, the dementia directory offers people who are starting to care for people with dementia the opportunity to receive flexible information and training, independent of time and location. The range of offers in the “Guide to Dementia” directory is regularly advertised at trade fairs and events.

<sup>32</sup> [www.wir-stärken-die-pflege.de](http://www.wir-stärken-die-pflege.de)

<sup>33</sup> [www.bundesgesundheitsministerium.de/themen/pflege/online-ratgeber-demenz](http://www.bundesgesundheitsministerium.de/themen/pflege/online-ratgeber-demenz)

<sup>34</sup> [www.wegweiser-demenz.de](http://www.wegweiser-demenz.de)



The 500 projects involved in the **federal government's** "Local Alliances for People with Dementia" model programme (BMFSFJ) provide the population in the local catchment area with information on dementia and, through specific press work, events, publications and on their own website, respective offers.<sup>35</sup> Targeted public relations work is used to determine the target group's needs, from which tailor-made offers can be developed. The BMFSFJ supports the Local Alliances with a PR handbook and event materials. Every year, the Local Alliances are given advice and support in preparation for Dementia Week in September. Numerous project sponsors of the programme have developed training concepts for volunteers who provide low-threshold neighbourhood assistance and visiting and support services for people suffering from dementia. Regular references and links to successful pilot projects to support people with dementia are made available on the online portals of the BMFSFJ, the "Guide to Dementia" directory, the portal of the Alliance for People with Dementia and the portal of the Local Alliances. The "Guide to Dementia" directory provides an overview of good practice examples for care and therapy.

### Local Alliances for People with Dementia

As part of a state dementia campaign, the federal state of **Rhineland-Palatinate** publishes on the Internet a wide range of information and education materials for the population and in brochures as a guide for relatives and professionals.<sup>36</sup> This range of offers is supplemented by numerous other measures such as conferences, exhibitions and training courses.

### Publications of the dementia federal state initiative

After analysing the initial situation and coordinating the tasks, many stakeholders in working groups have been able to jointly develop various products in **Hamburg**: the transparency demanded by all sides on the abundance of offers in Hamburg on the topic of dementia, which have been collected, sorted and summarised in the brochure "Leben mit Demenz - Rat und Hilfe für Betroffene und ihre Angehörigen" (Living with dementia - advice and help for affected persons and their relatives) and whose contents were incorporated into the city's website is of central importance. After consultations with family GPs in Hamburg, the guidebook with information on offers of burden relief and assistance was made available to all practices. A newsletter from the federal state initiative's liaison office also provides regular information on new developments and events in Hamburg and beyond.<sup>37</sup> With a newly developed advanced training curriculum, Hamburg's care support bases, as central points of contact for all queries concerning offers for help and burden relief or care, have been especially sensitised and trained on the topic of dementia. Among other things, an information brochure with recommendations for hospitals in Hamburg to improve care for patients with cognitive impairments has been established or new forms of inpatient care have been discussed, tried out and evaluated.

<sup>35</sup> [www.lokale-allianzen.de](http://www.lokale-allianzen.de)

<sup>36</sup> [www.lzg-rlp.de](http://www.lzg-rlp.de)

<sup>37</sup> [www.hamburg.de/pflege](http://www.hamburg.de/pflege)

With websites, printed guides, courses and events to raise public awareness of forms of dementia, the **Centre for Quality in Care (ZQP)** continuously runs nationwide educational work on the topic of dementia, for example with

- the ZQP's central Internet platform<sup>38</sup> and the "Gewaltprävention in der Pflege" (Violence prevention in care) online portal<sup>39</sup>,
- the ZQP guidebooks on dementia - impulses and ideas for family caregivers, coping with shame in care, and eating and drinking,
- the ZQP report on violence prevention in care,
- together with the **German Alzheimer Society (DAIzG)**, the "Demenz Partner" compact course as part of the Berlin Foundation Week 2017,
- the joint event "Remembrance" Dementia Forum of the ZQP with the St. Augustinus Memory-Zentrum Neuss and participation by the Federal Minister of Health in July 2017,
- the publication of the results of a representative ZQP population survey on dementia in Dementia Week 2017 and
- the "Remembrance" forum held by ZQP and BMG for Dementia Week in 2016.

On its "Pflegerberatung" (care advice) website, the **Association of Private Health Insurers (PKV)** provides a wide range of information on the subject of dementia.<sup>40</sup> The insurance companies, "compass private pflegerberatung" and the Centre for Quality in Care publish additional information on their online portals.<sup>41</sup> The MEDICPROOF medical service of the private health insurance companies provides supplementary information, particularly on the subject of nursing care assessments.<sup>42</sup> compass private pflegerberatung also provides outreach nursing advice. For this purpose and in cooperation with the DAIzG, nursing consultants have been trained as multipliers to become "dementia experts".

### 2.1.2 Accessibility

#### Barriers for people with dementia

For people suffering from dementia, barriers can arise in everyday relationships and situations with regard to their ability to think, orientation, communication, behaviour or time requirements. The removal of such barriers can enable those affected to act independently and spontaneously without repeatedly being confronted with their own limits. Among other things, the Alliance's partners have agreed to make it possible to adapt the home and living environment to the needs of people with dementia while avoiding or reducing structural barriers.

<sup>38</sup> [www.zqp.de](http://www.zqp.de)

<sup>39</sup> [www.pflege-gewalt.de](http://www.pflege-gewalt.de)

<sup>40</sup> [www.pflegerberatung.de](http://www.pflegerberatung.de)

<sup>41</sup> [www.compass-pflegerberatung.de](http://www.compass-pflegerberatung.de)

<sup>42</sup> [www.medicproof.de](http://www.medicproof.de)



The **federal government** (BMG, BMI, BMU<sup>43</sup>), the **federal states** and the **central municipal associations** are particularly committed to this.), the federal states and the central municipal associations are particularly committed to this.

The **federal government** (BMU) has updated and published online the “Barrierefreies Bauen” (barrier-free building) guideline, introduced for the administration of federal construction.<sup>44</sup> It serves as a working aid for planners, architects, specialist planners and representatives of severely disabled people. Due to the great national interest in the guideline and the importance of accessibility at the international level, the guideline has also been translated into English.

### Barrier-free buildings

The new edition of the “Altersgerecht Umbauen” (Age-oriented conversions) subsidy programme of the Kreditanstalt für Wiederaufbau (KfW banking group) in 2014 has been one of the most important measures of the **federal government** (BMU). Under the programme, owner-occupied home owners and tenants - irrespective of income and age - can apply for investment grants to remove barriers in residential buildings and to take structural measures for burglary prevention. Support is available for people with dementia to adapt their homes, for example with colour concepts, dismantling barriers or technical assistance systems. Applications may also be submitted by housing companies and housing cooperatives or municipal enterprises for the type of loan on offer by the KfW Programme (KfW's own funds programme since 2012). Between the programme's commencement in October 2014 and the end of 2017, federal investment grants supported measures to remove barriers from approximately 112,000 residential units. The programme's continuation is part of the coalition agreement for the 19th legislative period. For the years 2018 to 2021, programme's funds for grants have been set at EUR 75 million each in the government's second draft budget for 2018. Under certain conditions, long-term care insurance also provides financial subsidies in individual cases if an adjustment of the living environment makes home care possible, considerably easier or restores as independent a lifestyle as possible for those in need of care. For example, it is possible to install a stair lift or to convert the shower to a barrier-free zone. In accordance with Section 40 SGB XI, this benefit was significantly increased as of 1 January 2015. Persons in need of care in the new nursing level 1 have also been entitled to this benefit since 1 January 2017.

### Age-oriented conversions

In the area of law covering regulations for implementation on a nationwide basis, the **GKV central association** (ensures implementation of statutory long-term care insurance in the “Joint Circular on the benefit regulations for long-term care insurance”).

<sup>43</sup> früher BMUB. Seit März 2018 liegt die Zuständigkeit für den Themenbereich “Bauen und Wohnen” beim Bundesministerium des Innern, für Bau und Heimat (BMI).

<sup>44</sup> [www.leitfadenbarrierefreiesbauen.de](http://www.leitfadenbarrierefreiesbauen.de)

### Inspection of regulations in Saxony-Anhalt's construction sector

With regard to taking into account the interests of people with dementia, the federal state of **Saxony-Anhalt** is examining the funding guidelines for age-appropriate conversions or adaptation of apartments and residential buildings, the guidelines for urban development funding, the Modern Living funding programme and building regulations. The concerns of people with dementia are also being taken into account in the amendment of the Housing and Participation Act (WTG) and in the drafting of the Minimum Construction Ordinance for the WTG. The “Selbstbestimmtes Leben” association in Sachsen-Anhalt is cooperating on a voluntary basis with the general association for the disabled in Saxony-Anhalt at the association “Kompetenzzentrum für Barrierefreiheit”, the association for the blind and visually impaired and the “PiA - Gesellschaft für Prävention im Alter” (Society for prevention in age). Among other things, they provide general advice on issues of housing adaptation and measures to improve the living environment. For many years, the PiA association in particular has been working throughout the federal state on professional expertise in the field of housing advice for people in need of care. Local authorities, welfare organisations and house construction companies have the opportunity to make use of a pilot project, which is financed by the federal state and the long-term care insurance funds, to train multipliers at the association to become regional housing consultants for people with mobile disabilities and those in need of care. The one-year training course aims at making self-determined life in the municipalities even more attractive.

### Housing advice in Saxony-Anhalt

### People with learning difficulties

In 2017, the **federal government** (BMFSFJ) published a brochure entitled “Hat Mama Demenz?” (“Does Mama have dementia?”) which is aimed at people with learning difficulties and shows what dementia can mean for someone who is affected by it, which assistance is possible and how patients can get help.<sup>45</sup> The “Does Mama have dementia?” brochure was made in the form of a film and is also read aloud.<sup>46</sup> Six short films for people with learning difficulties have been produced in the project “Challenge Dementia”, funded by the **federal government** (BMFSFJ) in cooperation with Dementia Support Stuttgart and Lebenshilfe Baden Württemberg. The films give information on the project design, illustrate how the topic of dementia was conveyed to employees in a disabled-persons workshop and allows people with learning difficulties to have their say. The film about people with learning difficulties and memory problems is intended to stimulate imitation for institutions providing assistance for the disabled. To raise the awareness of specialist staff in disability assistance, environmental stressors were taken into account.

As part of the Alliance for People with Dementia, the **German Alzheimer Society** engaged expert partners to conduct a workshop and, in this context, developed and subsequently published the brochure “Ways to increase accessibility for people with dementia”.<sup>47</sup>

<sup>45</sup> [www.bmfsfj.de/bmfsfj/service/publikationen/hat-mama-demenz-/111782](http://www.bmfsfj.de/bmfsfj/service/publikationen/hat-mama-demenz-/111782)

<sup>46</sup> [www.bmfsfj.de/bmfsfj/service/publikationen/-herausforderung-demenz--fuer-menschen-mit-lernschwierigkeiten/116086](http://www.bmfsfj.de/bmfsfj/service/publikationen/-herausforderung-demenz--fuer-menschen-mit-lernschwierigkeiten/116086)

<sup>47</sup> [www.deutsche-alzheimer.de/fileadmin/alz/broschueren/Wege\\_zu\\_mehr\\_Barrierefreiheit.pdf](http://www.deutsche-alzheimer.de/fileadmin/alz/broschueren/Wege_zu_mehr_Barrierefreiheit.pdf)

In September 2013, the leading organisations of dentists and doctors held a joint specialist conference on “Removing barriers”.<sup>48</sup> Additionally, in April 2015, the **Kassenzahnärztliche Bundesvereinigung** (the federal association of statutory dentists, KZBV) together with the **Kassenärztliche Bundesvereinigung** (National Association of Statutory Health Insurance Physicians, KBV) and the **Federal Association of Non-statutory Welfare** (BAGFW) held a conference on the further development of care for patients in need.<sup>49</sup> The dental care “Oral health despite handicap and old age” concept developed by the KZBV, which sets out needs-oriented care for people with dementia among others, was a successful example of outreach care at the heart of the **federal government’s** practices dialogue. In 2014, the KZBV presented the digital “Virtual tour of a barrier-free dental practice” project on its website. The KZBV has also drawn up a checklist to enable dentists to check accessibility in their own practices. Barrier-free access to dental care was the main topic at the meeting of KZBV representatives in summer 2014. In addition, the federal association of statutory dentists (KZBV) uses corresponding circulars to provide regular information on current discussions and developments.

## 2.2 Networking

To be able to use the best possible support with well-networked help and support structures, transparency of existing offers is particularly important for people with dementia and their relatives. The federal, state and local governments therefore support the establishment of networks and the bundling together and coordination of educational and information services. The Alliance’s organisation partners are particularly committed to facilitating the availability and accessibility of services in rural areas. They support previously uninvolved local stakeholders in establishing networks.

The support programme of the 500 Local Alliances is one key measure on the agenda of the **federal government** (BMFSFJ). This allowed 500 help networks to be created in the living environment of dementia patients, helping them to stay in their familiar social environment for as long as possible. In addition to local authorities, network partners include associations, hospitals, multi-generation buildings, doctors and companies. Using PR work, the Local Alliances reach the population and thus serve in raising awareness on the topic of dementia. They create counselling and support services close to their homes to relieve the burden on carers and recruit volunteers to help in the neighbourhood, for example, by providing visiting and support services in hospitals and inpatient facilities. They support local authorities, especially in rural areas, by coordinating and networking local stakeholders. Between 2012 and 2016, 500 local networks were selected in five funding rounds. The projects were funded for two years with a one-time payment of EUR 10,000. The last funding round ended in September 2018. The tender rounds were advertised for bids with different areas of focus: multi-generational houses, communities,

### Removing barriers in medicine

### Transparency of offers

### Local Alliances for People with Dementia

<sup>48</sup> [www.kzbv.de/barrieren-abbauen.783.de.html](http://www.kzbv.de/barrieren-abbauen.783.de.html)

<sup>49</sup> [www.kzbv.de/versorgung-von-pflegebeduerftigen-menschen.912.de.html](http://www.kzbv.de/versorgung-von-pflegebeduerftigen-menschen.912.de.html)

networks in rural areas, people from immigrant backgrounds, intergenerational measures to support the early-affected (middle-aged people with dementia), integration of associations and doctors, as well as hospitals, as network partners.

### Impact analysis of the programme

In December 2017, a scientific impact analysis was launched to investigate the extent to which dementia structures in Germany have improved and which effects have been achieved through the federal pilot programme - also in addition and in connection with other regional or supraregional dementia networks. The results of this analysis are to be incorporated into the development of a national dementia strategy. A network office, to ensure good integration and sustainability of the structures created throughout Germany, was set up at the “Bundesarbeitsgemeinschaft der Senioren-Organisationen” (German National Association of Senior Citizens’ Organisations, BAGSO) in 2017. It is also supposed to contribute to the establishment of further Local Alliances and to integrate existing networks which operate outside of the federal programme. An Internet site facilitates access to information on the 500 locations.<sup>50</sup> After the programme’s completion, it will be transferred to the “Guide to Dementia” directory and will continue to be supported by BAGSO.<sup>51</sup>

### Exchanging experience

The 500 networks have been offered various event formats to support the establishment of further networks and promote the exchange of experiences: kick-off events for each of the five funding rounds, two national meetings, four regional conferences, two specialist conferences on the topics of clinics and municipalities. In addition, the federal states regularly invite the Local Alliances and federally-funded networks which exist outside of the federal programme to exchange their experiences with each other.

### Symposia

The **Deutscher Verein für öffentliche und private Fürsorge** (German Association of Public and Private Welfare, DV) regularly holds specialist conferences to accompany the federal “Local Alliances for People with Dementia” pilot programme. The thematic focal points of the symposia so far have concerned areas which should enable people with dementia and their relatives to have a life worth living, to consider special conditions in rural areas and point out the connections between dementia and migrant history. The conferences have reached more than 250 participants; the presentations are available on the DV homepage.<sup>52</sup> Due to a general increase in life expectancy, a changed perception of dementia and new approaches to care, the topic of “dementia and community” is growing in significance. Individual action concepts are required which cover both big cities with their various boroughs as well as rural areas. 140 representatives from communities, towns and districts, federal states, associations and science met in Bremen to discuss concepts for dementia-friendly structures in communities at the specialist “Living with dementia in the community - Networked local action” conference, organised by the **federal government** (BMFSFJ), on 31

<sup>50</sup> [www.lokale-allianzen.de](http://www.lokale-allianzen.de)

<sup>51</sup> [www.wegweiser-demenz.de](http://www.wegweiser-demenz.de)

<sup>52</sup> [www.deutscher-verein.de/de/](http://www.deutscher-verein.de/de/)

January and 1 February 2018. In a variety of ways, mayors and district councillors support the Local Alliances' networking as well as the development and coordination of individual counselling, burden relief and offers for participation. This existing know-how should be made visible. Other communities should be encouraged and motivated to actively shape the topic of dementia. The care of people with dementia places increased demands on the communities. Of the 3.1 million people in need of care in the social long-term care insurance system in 2017, 2.33 million were being cared for at home. Three quarters of dementia patients in need of care also live at home and are looked after and cared for there by relatives. As relatives provide most of the care is the reason why every dementia strategy, every dementia plan, every dementia project must also bear the relatives in mind. In addition to providing adequate counselling and support services, this also includes creating a dementia-sensitive environment in the neighbourhood, in shops, in local clubs and in cultural activities. The aim of the conference is to provide impetus beyond local activities and to win over further communities and towns for the development of dementia-friendly structures. Supported by the Deutscher Städte- und Gemeindebund (an association of towns and municipalities in Germany), the results of the conference will be summarised and published in a handbook. The networks created or further developed in the federal Local Alliances for People with Dementia pilot programme are regularly given the opportunity to present their work at congresses, events and trade fairs (German Senior Citizens' Conference, Congress of the German Alzheimer Society, events by the BMFSFJ and the federal states). The website of the Local Alliances has some good examples on display in the "In Focus" section. The "Wir unterstützen Menschen mit Demenz" (We support people with dementia) brochure contains a selection of networks on specific topics such as sports-movement-leisure, immigration, community, clinic, art-culture, old and young, religion, housing, education and care services.

A total of twelve Local Alliances have been established in **Hamburg** since 2012. With their very different small-scale project approaches, they have tested the topic of cooperation for and with people with dementia and demonstrated what can work. The city will continue to promote Local Alliances with its own funds.

**Saxony-Anhalt** supports the Local Alliances for People with Dementia and organises an annual symposium to promote the networking of services. In addition, Saxony-Anhalt supports the "Agentur zur Vermittlung und zur Aufbau von Angeboten zur Unterstützung im Alltag für Pflegebedürftige" (Agency for the placement and development of offers for support in everyday life for people in need of care, AUiA) pilot project. Among other tasks, it provides support and guidance on the range of offers concerning everyday life, collects data on the offers, holds network meetings on special topics for the providers, promotes the exchange of experiences and passes on information and develops information material for people in need of care and caregiving relatives.

#### Scheduling continuation

#### Pilot scheme offers of support

**Networking meetings** The Thuringian Ministry of Labour, Social Affairs, Health, Women and Family in **Thuringia**, regularly coordinates network meetings with those responsible for the project and the Alzheimer Society of Thuringia. The network meetings serve as an information platform, an exchange forum and a place for mutual assistance. Experts, for example, are invited to answer specific questions. With the objective of sustainable networking in mind, the aim is to encourage exchange between the participants beyond the respective funding period; and in doing so, the Alzheimer Society in Thuringia serves as a central contact and cooperation partner for the Local Alliances. The cooperation with the Alzheimer Society in Thuringia also facilitates the integration of new projects with existing care structures for people with dementia and their relatives. From 2018 on, the network meetings will be held by the Alzheimer Society in Thuringia. The Thuringian Ministry of Social Affairs will continue to provide technical and personnel support for the established network. One key objective is to open up the network to all stakeholders involved in the field of dementia.

**“Dementia-friendly initiatives” working group** The activities and results of the region’s Local Alliances for People with Dementia have been presented and discussed on several occasions at the meetings of the working group “Dementia-friendly initiatives” in **Berlin**. To date, 19 Local Alliances have been active in Berlin. The findings of the “Local Alliance for People with Dementia and their Families with Turkish-German Immigration Experience in Berlin-Mitte” project, for example, were presented by the head of the therapeutical services at the Sankt Hedwig Hospital Berlin in September 2017.

**“Dementia Workshop of the Future” programme** With its “Zukunftswerkstatt Demenz” (Dementia Workshop of the Future) funding programme, the **federal government** (BMG) supported projects from 2012 until 2015 in the fields of “Supporting caregiving relatives of people with dementia” and “Regional dementia networks” with a total of around EUR 3.3 m. The Workshop of the Future presents a number of examples of good practice, experience and help. The development of the “Werkzeugkasten Demenz” (Dementia Toolbox) deserves a special mention. The toolbox is the heart of a website which the DZNE and the Institute for Community Medicine of the University Medicine Greifswald have been operating in cooperation since September 2015.<sup>53</sup> It sees itself as a pool of information and knowledge for founders and operators of such networks. Scientifically proven information is made available here on how to establish networks, operate networks and finance networks, as well as on how to optimise them. The aim is to provide long-term support for the establishment of care networks. The results of the “Dementia Workshop of the Future” research project have shown that self-organised regional networks of service providers, municipalities, self-help groups and other stakeholders can improve care and stabilise the domestic situation of people in need of care and their relatives. From this, the following legal regulation for the promotion of regional networks by long-term care insurance has been developed:

<sup>53</sup> [www.demenznetzwerke.de](http://www.demenznetzwerke.de)

In accordance with Section 45c Para. 9 SGB XI, the legislature has created the option through funding that, since 1 January 2017, long-term care insurance and private compulsory long-term care insurance companies can individually or jointly participate at district or municipal level in the costs of networking with up to EUR 20,000 per calendar year in self-organised networks for structured cooperation in care. Financing is provided by the long-term care insurance compensation fund. Regional networking offers considerable potential for improving cooperation in the care of people with dementia and other persons in need of care. To this end, the long-term care insurance companies have created the necessary regulations for uniform implementation by the long-term care insurance funds throughout Germany. By the end of 2017, eight networks had received funding and another four had applied for funding and were waiting for a response. The BMG supports the parties involved in implementing the regulation. To enable sustainable continuation if necessary, the BMG has commissioned the “Institut für Organisationskommunikation” (Institute for Organisation Communication, IFOK) with the implementation of the inaugural meeting for municipal nursing roundtable committees (if local municipal stakeholders so wish) and in accordance with Section 45c Para. 9 SGB XI, within the scope of this mandate, requested that reference be made to the possibility of funding.

### Network funding according to SGB XI

The **German Centre for Neurodegenerative Diseases (DZNE)** is discussing the necessary framework conditions to better use of the funding. The DZNE and IFOK have jointly designed a form to support interested parties in submitting applications to long-term care insurance funds and private compulsory long-term care insurance companies. The DZNE also supports the exchange of experience for the development of further networks through scientific expertise. Scientists are involved in shaping the specialist conferences and national meetings of the Local Alliances for People with Dementia and the annual conferences of established dementia networks. In addition, regular public workshops are offered to disseminate the scientific results of projects carried out. The DZNE was also represented in a group of experts from the **Bundeszentrale für gesundheitliche Aufklärung (BZgA)** (Federal Centre for Health Education) on the topic of dementia in 2014.

### Scientific support for dementia networks

To evaluate the “dementia network” form of care, the DZNE conducted the “DemNet-D study”. In Germany, care for people with dementia in need of help and is primarily provided in their own homes, or in families or nursing homes. However, the outpatient care system is inadequately adapted to the various needs of those affected and their relatives. Against the background of changes in demography, new care models, such as regional networks in which different professional groups and institutions work together in helping people with dementia and their relatives (dementia networks), are therefore becoming increasingly interesting. The “DemNet-D Study”, a multicentre, interdisciplinary evaluation study of dementia networks in Germany, was conducted for this purpose. The resulting recommendations for action have been transferred into a knowledge portal for the establishment and expansion of dementia networks.<sup>54</sup> Scientists from Berlin, Rostock/Greifswald,

### Study on the effectiveness of dementia networks

<sup>54</sup> [www.demenznetzwerke.de](http://www.demenznetzwerke.de)



Stuttgart and Witten have joined forces to form the “DemNet-D: multicentre, interdisciplinary evaluation study of dementia networks in Germany” research network to determine the success factors of regional dementia networks and thus contribute to their long-term establishment. Together, they conducted the study of the same name with 13 regional networks, which differ both geographically (city/country, north/west/east) and in terms of their structure. The results have been presented to the public at workshops and conferences and discussed there. An amendment has consequently been made to Germany’s Social Code, according to which networks can now receive financial support for their work. The goal of future activities is further systematic and sustainable, evidence-based establishment.

#### Regional conferences

In cooperation with the stakeholders in the federal states, the **Federal Centre for Health Education (BZgA)** is holding regional conferences on “Getting Older Healthier and Actively”, which will focus in particular on the topics of old age, care and dementia. The aim of the regional events is to sensitise, inform and motivate local decision-makers and stakeholders, to support the targeted establishment of alliances and networking, and to optimise local cooperation and care structures. The instrument of regional conferences has proven its worth in promoting the networking made by stakeholders and raising awareness of age-specific issues. The regional conferences often serve as an initial spark for a topic that can be deepened and consolidated in subsequent events. In cooperation with the federal states, the BZgA will therefore continue to organise regional conferences to promote cooperation between the federal, state and local levels as well as the exchange of information and networking of the key stakeholders in various living environments.

#### European foundation network

The **Robert Bosch Stiftung** is represented in the European Foundations’ Initiative on Dementia (EFID), which was founded in 2011.<sup>55</sup> The goal of EFID is to improve the quality of life of people with dementia in Europe and their environment, to support committed stakeholders and to network across borders. EFID includes the Robert Bosch Stiftung, the Fondation Médéric Alzheimer and the König Baudouin Stiftung. The initiative is coordinated by the Network of European Foundations (NEF).

#### Internationally affiliated tutors

In **Bavaria**, for example, networking is supported within the framework of the funded “Internationale Angehörigentutoren” (International relative tutors) project of the TIM association in Nuremberg, which uses trained native-speaker volunteers from immigrant backgrounds to set up an intercultural dementia network for older migrants. The tutors function as guides by supporting the families concerned with various questions on the subject of dementia, by informing them on appropriate offers and by accompanying them in the necessary administrative procedures and consultations. The project aims at improving the domestic care situation of immigrants suffering from dementia and their caregiving relatives. In addition, the so far insufficient offer of culture-specific support for immigrant families affected by dementia should be improved and the civic engagement of immigrants promoted.

<sup>55</sup> [www.bosch-stiftung.de/de/projekt/european-foundations-initiative-dementia-efid](http://www.bosch-stiftung.de/de/projekt/european-foundations-initiative-dementia-efid)



The Ministry of Health and Consumer Protection in **Hamburg** has launched the “Landesinitiative Leben mit Demenz in Hamburg” (Living with dementia federal state initiative, LLmD) to promote the establishment of further networks and to strengthen the exchange of experience and cooperation between different areas of society. Its aim is to improve living conditions for people with dementia and their relatives. There are already a large number of varying offers to support people with dementia and their social environment, but there is still a need for further action.<sup>56</sup> Innovative measures are to be implemented, existing offers coordinated, and then clearly presented and publicised. After the participatory start-up phase, the state initiative took on a new working structure in 2014. It is jointly coordinated between the Alzheimer Society in Hamburg, the Federal Association of Non-statutory Welfare, the Hamburgische Arbeitsgemeinschaft für Gesundheitsförderung (HAG) (Hamburg Committee for Health Promotion) and the Behörde für Gesundheit und Verbraucherschutz (Department of Social, Family and Health and Consumer Protection). In addition, various working groups, each of which exercises independent control and exchanges information at regular intervals, have become more stable. Since then, the initiative on federal state level has been coordinated by an employee of HAG hired for this purpose. The working groups and the organisation partners who are involved in the respective working groups can be viewed on the Internet.<sup>57</sup> The “Living with Dementia Campaign Week” was initiated to raise awareness of the special needs of people with dementia in public spaces; local so-called Confetti Cafés have also been created, a working group “Culture and Dementia” founded and the BasisQ basic qualification for non-medical settings developed and put on offer. In 2018, special attention is being paid to the often-neglected networking of small-scale approaches in the “Conferences and Alliances Forum” federal state initiative. Some of the measures of Hamburg’s federal state Living with Dementia

### Living with Dementia federal state initiative

### Campaign week



<sup>56</sup> [www.hamburg.de/demenz](http://www.hamburg.de/demenz)

<sup>57</sup> [www.hag-gesundheit.de/lebenswelt/leben-mit-demenz](http://www.hag-gesundheit.de/lebenswelt/leben-mit-demenz)

initiative have since been completed or transferred to standard care, others have not yet been feasible.

### Telephone helpline

Independent, neutral and free counselling for patients and relatives on all aspects of dementia has been established in **Bremen**. The range of offers there include the publication of information material (including manuals on outpatient and inpatient care), a dementia database, a telephone helpline for caregiving relatives and elderly people, Bremen's Dementia Newsletter, the initiation and support of relatives and self-help groups, the "Dementia Conference" event and further training courses, which are to be established and secured in the long term.

### Federal State Net-Work Dementia

The Landes-Netz-Werk Demenz (Federal State Net-Work Dementia) in **Rhineland-Palatinate**, which has been working on behalf of the Ministry of Social Affairs, Labour, Health and Demography since 2009 to connect structures, sees itself as a nationwide service centre for dementia. It aims at strengthening and promoting cooperation between specialists from various professions and volunteers, in and outside dementia networks. People who are dependent on help should find fast and comprehensive support through networked structures on site. The Federal State Net-Work Dementia supports 41 regional dementia networks in Rhineland-Palatinate and 33 Local Alliances for People with Dementia and connects them together. Information on diagnosis and therapy procedures, assistance and support services and on events and services of the Federal State Net-Work Dementia are published on the Internet.<sup>58</sup> The Federal State Net-Work Dementia network supports regional processes by bringing the measures, priorities and project results promoted on federal state level to the "basis" in terms of content. To allow affected people and their relatives to be provided for as fully as possible in their respective life situations, its aim is to stabilise regional processes and ensure that self-help, counselling, medical treatment and nursing care for people with dementia also work hand in hand at the interfaces on site.

### "Framework Strategy 80+"

A variety of activities have taken place in **Berlin** in recent years which provide information on the results of networking, initiatives at local level and successful models to support people with dementia, to promote stakeholder networking and to give impulses for the further development and increased use of the offer of care. The districts in Berlin have been establishing structures for networking stakeholders in the field of dementia (health, care, care for the elderly) with different structures or associations for more than 20 years already. The districts (district authorities, associations for geriatrics and elderly psychiatric patients, hospitals and other cooperation partners) have played a major role in implementing the Berlin-wide dialogue processes and developing the "Framework Strategy 80+". With the aim of analysing the current situation and subsequently developing recommendations for further developing networking, the 14 associations for geriatrics and elderly psychiatric patients in the state of Berlin took part in a one-year study in 2016 within the framework of implementing the Berlin-wide "Framework Strategy 80+". The study's

<sup>58</sup> [www.demenz-rlp.de](http://www.demenz-rlp.de)

final report was presented in November 2017 and the composite profiles with proposals for further qualitative development are currently being evaluated within the consortia of associations. In cooperation with the Senate Department for Health, Care and Equality, the exchange process has been intensified in the second quarter of 2018. State funds will provide structural support in 2018 and 2019. To the nationwide mission statement of “dementia-friendly communities”, there are also some joint initiatives at district and senate level (e.g. district health conferences, specialist conferences, training courses for relatives, police and fire brigade). Individual housing companies and housing cooperatives, as well as educational sectors, have been recruited to participate in the committees and associations and are actively involved in the topic of dementia and in implementing the goal of improving the quality of life and care of this group of people.

The “Dementia-Friendly Initiatives” working group has been intensively involved with the **German Alzheimer Society’s** (DAIzG) “Dementia Partner” campaign. Several members offer their own “Dementia Partner” training courses for various target groups. In addition, the Alzheimer Society in Berlin has held a “Train the Trainer” seminar. During Dementia Week 2018, “Dementia Partner” training courses will be on offer in all city districts. Within the scope of the working group, members’ activities are presented and coordinated in the course of the Dementia Week; in 2017, for example, there were dementia walks/“Move for Dementia” (at the Steglitz-Zehlendorf care support centre), a dementia field day with a choir and coffee (Demenzfreundlich! Initiative Treptow-Köpenick), sports festivals and a presentation of club activities in a community centre (Verein Demenzfreundliche Kommune in the district of Lichtenberg), as well as a dementia service on the Sunday after World Alzheimer Day at the Memorial Church). The regional Arbeitsgemeinschaft der Alten- und Angehörigenberatungsstellen (Working group of geriatric and family counselling centres, RAGA) annually publishes the “Offers for caring relatives” brochure. Among other things, it offers information on new initiatives and publicises networking offers for caregiving relatives – including for people with dementia. In recent years, it has been possible to strengthen the existing networks in Berlin. The cooperation between the participants and the exchange of information and experience on the results of their own work, activities and successful models have been intensified. This path is to be continued.

In 2015, to enable people in need of care to remain in their familiar environment as long as possible, the **federal government**, the **federal states** and **local umbrella associations** recommended the governmental-federal state working group intensify the role of local authorities in nursing care by the following measures: improving the municipal control and planning competence for the regional care structure, more intensively integrating the municipalities into care structures as well as developing social areas. Insofar as federal legislature is responsible, the results have been implemented by the third law on long-term care enhancement (PSG III), which has been in force since 1 January 2017. The regulations also improve the local care of dementia patients and their relatives with special needs for support.

### Dementia-friendly initiatives

### Role of the municipalities in nursing care

**“Dementia and community”  
project**

The “Demenz und Kommune” (Dementia and local authorities, DeKO) in **Baden-Württemberg**, by the Alzheimer Society in Baden-Württemberg, is funded by the federal state and long-term care insurance funds. The aim of the project is to strengthen the local authorities and to support all stakeholders. This is achieved by an impulse to expand municipal networking, existing offers and activities through an inter-communal exchange of experience and through the development of a nationwide information platform that offers support to local authorities and service providers with specific structural and development aids. The aim is to raise awareness in the field of dementia among decision-makers in cities and communities for adopting more communal responsibility. Needs-oriented and qualified services for people with dementia and their families are to be made an important component of general-interest municipal services. This means developing and intensifying local structures that enable those affected to participate in public life for as long as possible.

**Database for local authorities**

The Alzheimer Society in Baden-Württemberg is carrying out a comprehensive survey of the dementia-specific offers in the federal state and opening this database up for local authorities and decision-makers. At the same time, a comprehensive Internet search has been carried out on dementia-related offers throughout Baden-Württemberg, evaluated according to local authority, updated by telephone calls with all geriatric care advisors and an online survey of mayors. In a second step, kick-off events have been held in all four of the state’s administrative districts. The project has also been presented at various (specialist) events, including the meeting of the senior care advisors and the annual meeting of the federal state’s Senior Citizens’ Council. In 2018, the plan is to focus on an incentive paper, a planning tool for local authorities with basic information on dementia, a checklist for self-assessment (“How dementia-active is our local authority?”) and the development of building blocks for a dementia-active municipality. Furthermore, a step-by-step development of the “Dementia and local authorities” information portal - with information and links to existing projects as well as practical planning and development tools - is also in planning. Finally, the experts’ unit “Dementia and local authorities” will advise any interested municipalities.

**Participation of other municipal  
stakeholders**

The **federal government** (BMFSFJ) supports various stakeholders in the community, such as the police and fire brigade, in initiating networks. Numerous project sponsors in the Local Alliances for People with Dementia federal programme are developing training modules and compiling information for a wide variety of stakeholders at local level. They are also invited to round table or network meetings at the Local Alliances. As cooperation partners, they are actively supported in their work.<sup>59</sup>

<sup>59</sup> [www.lokale-allianzen.de](http://www.lokale-allianzen.de)

## 2.3 Legal issues

With an overall increasing limitation of the ability to think, act and make decisions, individually different courses of a dementia disease can lead to legal problems and legal uncertainty for patients and their relatives. At the same time, their legitimate desire for self-determination and participation must be accepted, but so must the need to provide legal protection. Legal issues also include ensuring appropriate help and care as well as protection against violence, abuse and lack of care.

**Field of tension**  
**self-determination - protection**

### 2.3.1 Legal capacity

A dementia diagnosis does not directly lead to the restriction or suspension of legal capacity. In case of dispute, legal capacity must be determined by a court of law.

### 2.3.2 Traffic and regulatory law

Already in the early stages of the disease, people with dementia can be limited in their reaction speed and their assessment of speed and distance. The extent to which it remains possible to drive safely should be checked again and again; there is only a clear legal ban on driving in cases of severe dementia.

To achieve in practice greater security in legal transactions and road use, the Alliance's partners are committed to providing more information on legal issues.

On the "Guide to Dementia" website's directory, the **federal government** (BMFSFJ) provides detailed information on legal services; legal issues are also demonstrated by means of practical examples.<sup>60</sup> Inquiries are answered individually in the advice forum. A video illustrates and discusses legal aspects of dementia.

As part of the "Safety and independence in dementia" working group, the **German Alzheimer Society** has developed the "Wege zu mehr Sicherheit im Verkehr und bei Rechtsgeschäften für Menschen mit Demenz" (Ways to more safety in transport and legal transactions) brochure.

### 2.3.3 Legal precautions

Particularly by means of health care proxy and living wills, it is possible to take legal precautions. In this regard, the partners of the Alliance have agreed to widely disseminate information to promote the implementation of legal options and to offer support by making professional and voluntary support staff available

**Power of attorney, care and living wills**

In accordance with Section 39b Para. 2 SGB V, the **GKV central association** has agreed on regulations for informing insured persons about the possibilities of personal provision needs in the last phase of their lives.

<sup>60</sup> [www.wegweiser-demenz.de/informationen/gesetzliche-leistungen.html](http://www.wegweiser-demenz.de/informationen/gesetzliche-leistungen.html)

- Legal support** The **federal government** (BMJV) has carried out two factual investigations regarding the structural improvement of guardianship law.
- Research proposal: Principle of necessity** The first research proposal examined the extent to which other (mainly social-legal) aids exist for which no representative has been appointed, whether they are suitable for avoiding the appointment of caregivers and whether the care authorities are in a position to provide this aid. In accordance with the UN Convention on the Rights of Persons with Disabilities, the avoidance of care through low-threshold assistance reinforces the right to self-determination of those affected.
- Research proposal: Quality in legal support** The “Quality in Legal Support” research proposal also deals with the right to self-determination and the principle of necessity. Because qualitatively good support is characterised by the fact that it respects the right of self-determination of the person being cared-for, promotes perception of the right to self-determination and makes representation by the care-giver only possible if the necessity for this exists. It has been examined whether there are any structural shortcomings in legal support and recommendations for action have been drafted to remedy the shortcomings. The research proposals began at the end of 2015 and were completed in October 2017 (proposals on the principle of necessity) and November 2017 (proposals on quality). Short summaries of the two research proposals’ main findings have been published on the BMJV website.<sup>61</sup> The final reports of the two research proposals were published in the Bundesanzeiger Verlag at the beginning of 2018 and are also available on the BMJV website.
- Guide for volunteers** Among other things, the federal state of **Saxony** has published the “Betreuung und Vorsorge” (Care and prevention) and “Wegweiser für freiwillliche Betreuer” (Guide for voluntary carers) brochures by the State Ministry of Justice in Saxony. The former includes forms for a health care proxies and a living will. The publications have been placed on the Internet.<sup>62</sup> They can also be acquired at Saxony’s Ministry of Justice and the courts. Both brochures are regularly updated. Independently of this, information regarding tips for legal support as well as forms to set up a health care proxy, tips on support and the like can be called up on the aforementioned website.
- “I’ll take care of it!” brochure** The Ministry of Health and Consumer Protection in **Hamburg**, has published the “Ich Sorge vor!” (“I’ll take care of it!”) brochure. With a total circulation of about 500,000 copies, it is one of the most widely distributed publications in the city today. There is also additional brief information on the subject of health care proxies and legal support is available in German, English, French, Turkish and Russian. An official advisory office for legal support and health care proxies, as well as the Hamburg support associations, offer annual events on the subject of health care proxies. 66 events on the subject of powers of attorney for pensions are in planning for 2018.

<sup>61</sup> [www.bmjb.de/DE/Service/Fachpublikationen/Fachpublikationen\\_node.html](http://www.bmjb.de/DE/Service/Fachpublikationen/Fachpublikationen_node.html)

<sup>62</sup> [www.justiz.sachsen.de/content/formulare.htm](http://www.justiz.sachsen.de/content/formulare.htm)



The **Federal Association of Non-statutory Welfare** (BAGFW) presented the “Quality in legal support” study (Institute for Social Research and Social Policy, ISG - Dr. Dietrich Engels, on behalf of the BMJV) at its symposium in October 2017. It shows that dementia is frequently the reason for appointing caregivers, especially when appointing volunteers as external caregivers and caregiving relatives.

### “Quality in legal support” study

#### 2.3.4 Measures which restrict liberty, violence prevention

People with dementia are also still affected by measures that restrict their liberty. However, according to the 5th report by the National Association of Statutory Health Insurance Funds’ medical service (MDS) presented at the beginning of February 2018 on the quality of outpatient and inpatient care, the number of measures restricting the freedom of mobility has further decreased among the residents of homes included in the examination. There have also been improvements in regularly reviewing the need for any measures which restrict liberty - these may only be made by court order. Overall, there is thus a continuing positive trend in dealing with measures that restrict liberty, which not least points to the effectiveness of the Charter of Rights for People in Need of Long-Term Care and Assistance<sup>63</sup>, the FEM Guidelines<sup>64</sup> - initiative to avoid any measures which restrict liberty in professionally caring for the elderly and other relevant initiatives. Because the protection of patients can also be achieved by alternative measures, the Alliance’s partners want to provide more and more information on alternatives in easy language. They support greater transparency in coercive measures and draw attention to possibilities of conflict management. The aim is to further significantly reduce the number of measures which restrict liberty.

### Measures which restrict liberty

Funded by the **federal government** (BMG), the final report of the “Nonviolent Care - Prevention of Violence against Elderly Persons in Long-term Nursing Care” project, carried out by the National Association of Statutory Health Insurance Funds’ medical service (MDS) in conjunction with the University of Cologne, was published in May 2018.<sup>65</sup>

The **Centre for Quality in Care** (ZQP) continuously carries out projects on the subject of violence prevention in nursing, which are also highly relevant in the context of violence and, for example, apply to the handling of coercive measures. Information on this topic can be found in the following publications:

### Violence prevention in care

- Online portal, including an explanatory film on the prevention of violence in care<sup>66</sup>,
- ZQP “Violence prevention in care” report,
- ZQP “Effectiveness of violence prevention” study,

<sup>63</sup> [www.pflege-charta.de/de/startseite.html](http://www.pflege-charta.de/de/startseite.html)

<sup>64</sup> [www.leitlinie-fem.de/](http://www.leitlinie-fem.de/)

<sup>65</sup> [www.mds-ev.de/fileadmin/dokumente/Publikationen/SPV/Gewaltfreie\\_Pflege/090418\\_Abschlussbericht\\_Projekt\\_GfP\\_Final.pdf](http://www.mds-ev.de/fileadmin/dokumente/Publikationen/SPV/Gewaltfreie_Pflege/090418_Abschlussbericht_Projekt_GfP_Final.pdf)

<sup>66</sup> [www.pflege-gewalt.de](http://www.pflege-gewalt.de)

- Tri-state study on violence prevention by general practitioners, and in the
- “Aggressions between residents of care facilities” study, together with the Hochschule der Polizei and funded by the BMFSFJ (to be completed in 2019).

The “Guide to Dementia” online portal is regularly used to draw attention to ZQP’s range of online offers, which, among other things, use simple language to provide information on how to avoid measures which restrict liberty. Extensive information on legal issues is dealt with in detail. Aspects of the health care proxy and the living will are clearly discussed in a video on legal issues.<sup>67</sup>

#### Information on care issues

The federal state of **Rhineland-Palatinate** has organised regional conferences for geriatric care institutions, care authorities, care associations, care networks and health authorities, in which the avoidance of measures to deprive people of their liberty, especially those with dementia in care institutions, has been discussed. The problem areas in dealing with the corresponding measures have been analysed, the standard of liability in deciding for or against measures that deprive liberty has been made clear and possible alternative courses of action have been presented. To discuss cases together and find good solutions, regional meetings have been initiated in cooperation with the local care authorities, judges for guardianship, caregivers, home managers, care service managers and employees of the advisory and audit authority in accordance with the federal state’s law on forms of living and participation (LWTG).

#### Training and consulting services

A nationwide, free training and counselling programme entitled “Freiheitsentziehende Maßnahmen - Alternativen in Rheinland-Pfalz” (measures for deprivation of liberty - alternatives in Rhineland-Palatinate) has been used to raise awareness of older people in need of care, caregivers and all stakeholders involved in deciding on measures for deprivation of liberty in geriatric care. The employees of the 135 care support centres in Rhineland-Palatinate have received additional training. A brochure entitled “Es geht auch anders – Freiheitsentziehende Maßnahmen in der Pflege” (Things can be different - measures which deprive liberty in care) informs caregiving relatives, carers and nursing staff about measures on the deprivation of liberty and their consequences, and also points out alternatives and ways of allowing people in need of care more freedom of mobility and self-determination. To ensure that the use of measures which deprive liberty are dealt with more consciously, all parties involved in the process have been sensitised and informed about the alternatives. The nursing staff in the hospital are also informed on the consequences of applying measures which deprive liberty and sensitised to the topic in the “dementia in the hospital” process. Avoiding measures to deprive people of their liberty in nursing care, and especially in people with dementia, is seen as an ongoing issue. For Rhineland-Palatinate, avoiding the administration of psychotropic drugs is an area of focus needing further action in this thematic area.

<sup>67</sup> [www.wegweiser-demenz.de](http://www.wegweiser-demenz.de)



## 2.4 Information and public relations work

Increased public awareness of dementia is a primary objective of the Alliance for People with Dementia. The partners involved are therefore committed to promoting education about the disease and counteracting the taboo around it. The existing offers of information will be better networked, coordinated and expanded. Furthermore, information on diagnosis options and forms of therapy are to be improved. The annual events on World Alzheimer's Day as part of Dementia Week are important elements of public relations work.

The **federal government** (BMFSFJ) regularly updates the "Guide to Dementia" website and has extended it by several modules. In cooperation with the **German Alzheimer Society**, for example, an e-learning course has been developed which has been offered on the portal's homepage since World Alzheimer's Day 2016 and is aimed at people who look after a person suffering from dementia and are at the beginning of the care process.<sup>68</sup> The course content is also available as an interactive PDF. Among other things, the topic of dementia and hospitals was recently added to the "Guide to Dementia", a so-called "emergency button" has been placed for acute situations and a forum for specialists has been initiated for the exchange of information among professional groups involved in caring for people with dementia. In the context of Dementia Week 2017, new insightful films on everyday situations in dealing with people with dementia, as well as legal and medical aspects, have been published on the portal; the films can also be seen in Russian and Turkish. The online portal, also advertised over social media channels, regularly records high user numbers.

### Improvement and networking

### Comprehensive information in the "Guide to Dementia"



<sup>68</sup> [www.wegweiser-demenz.de](http://www.wegweiser-demenz.de)

The **federal government** (BMG) has expanded its information offering on the topic of dementia. Among other things, the “Dementia advice” brochure has been created, thus providing information on home care for people with dementia. In addition, an online guide on dementia has been developed, giving more information on the topic, answers to frequently asked questions and assistance to those affected and their relatives in living with the disease.<sup>69</sup>

#### Future Workshop on Dementia

The **federal government** (BMG) has funded a total of seven pilot projects as part of the “Dementia Workshop of the Future”: six pilot projects in the area of “Support for caregiving relatives of people with dementia” and one project in the area of “Regional Networks”. The projects’ results were presented in Berlin on 21 September 2015, World Alzheimer’s Day. The individual project results can be viewed on the Internet.<sup>70</sup> In addition, by means of general news, press releases and topic pages, the BMG regularly makes links to other dementia-related sites, including prevention, early diagnosis, care and rehabilitation.

The **German Centre for Neurodegenerative Diseases** (DZNE) supports the BMG with scientific expertise and publishes the results of the Dementia Workshop of the Future in suitable formats.

#### Dementia Campaign Week

The offers of information developed by the federal state of **Hamburg** have largely been compiled as part of the federal state’s “Living with Dementia” initiative and some, such as guidebooks or websites, are being further developed together with the organisation partners. In Hamburg, the guide has been made available both in the form of brochures and with reference to the website to all pharmacies and general practitioners, as well as to specialist practices active in dementia care. The Dementia Campaign Week, which has been in existence since 2014, is advertised throughout Hamburg. Following various formats, with and without central kick-off or information events, one day will now be organised in each of Hamburg’s seven districts alternately over the period of one week. Posters, reports in the local media and a broad distribution of the brochures with the detailed programme draw attention to the campaign week in Hamburg.

Information which has been developed and networked by 41 regional dementia networks has been made available via the regional **Rhineland-Palatinate** Dementia Campaign in Rhineland-Palatinate since 2004. Regular Dementia Network Weeks are held throughout the federal state around World Alzheimer’s Day.

A state committee for dementia in Rhineland-Palatinate was founded in 2015. This is a multi-professional exchange of information and cooperation.

<sup>69</sup> [www.bundesgesundheitsministerium.de/themen/pflege/online-ratgeber-demenz](http://www.bundesgesundheitsministerium.de/themen/pflege/online-ratgeber-demenz)

<sup>70</sup> [www.bundesgesundheitsministerium.de/themen/pflege/online-ratgeber-demenz/zukunftswerkstatt-demenz.html](http://www.bundesgesundheitsministerium.de/themen/pflege/online-ratgeber-demenz/zukunftswerkstatt-demenz.html)

With the aim of joint public relations work, the partners of the Alliance for People with Dementia have agreed to review the available information and to define the need for further information. The Alliance's organisation partners will use World Alzheimer's Day on 21 September, introduced around the globe in 1994 by Alzheimer's Disease International and the WHO, to intensify PR work for joint campaigns with comprehensive media coverage.

### Joint public relations for World Alzheimer's Day

The Alliance for People with Dementia has set up a working group to coordinate its public relations work. It held ten prep meetings between mid-2015 and the beginning of 2018, particularly for Dementia Week (that has been taking place since 2014). Included in these meetings were the selection of annual poster motifs and agreement on a common slogan. Through annual evaluations by the BMFSFJ of the activities for Dementia Week planned by the Local Alliances, activities have been continuously expanded and Dementia Week has been specifically publicised and popularised. To further promote the topic of dementia and Dementia Week 2018, the plan exists for the first time ever to make videos of the organisation partners and the BMFSFJ and BMG ambassadors available.

### Public relations working group

To the slogan of "Dementia. Focus on diversity", the **German Alzheimer Society** (DALzG), which prepared Dementia Week of and World Alzheimer's Day in the years 2015 to 2018, took the lead in materials' design in 2017.

The **Federal Association of Non-statutory Welfare** (BAGFW) is actively engaged in public relations work for World Alzheimer's Day and Dementia Week in September 2018.<sup>71</sup>

Through the associated Stiftung Deutsches Hilfswerk, the **Deutsche Fernsehlotterie** particularly supports charitable measures and projects that enable people with dementia to lead a better life. To draw attention to sponsored projects and the situation of those affected, the Deutsche Fernsehlotterie has included the topic on all its channels, for example its website, its "Du bist ein Gewinn" (You are great) online magazine, on its social media as well as when announcing the winning numbers, which is broadcast every Sunday on ARD. The topic will also be focussed on during Dementia Week.<sup>72</sup>

On the online portals of the Alliance for Dementia, the Local Alliances as well as in the Guide to Dementia, the **federal government** (BMFSFJ) regularly refers to existing offers, current publications and reports from other Alliance partners to improve the integration of offers for information.<sup>73</sup>

### Information networking

Alliance partners develop stakeholder-specific training concepts for their respective areas of responsibility and publicise them alongside existing concepts.

### Training concepts

<sup>71</sup> [www.bagfw.de/suche/detailansicht-tt-news/article/auseinandersetzung-mit-demenz-kann-hilflosigkeit-ueberwinden](http://www.bagfw.de/suche/detailansicht-tt-news/article/auseinandersetzung-mit-demenz-kann-hilflosigkeit-ueberwinden)

<sup>72</sup> [www.fernsehlotterie.de](http://www.fernsehlotterie.de), [www.fernsehlotterie.de/magazin](http://www.fernsehlotterie.de/magazin)

<sup>73</sup> [www.allianz-fuer-demenz.de](http://www.allianz-fuer-demenz.de), [www.lokale-allianzen.de](http://www.lokale-allianzen.de), [www.wegweiser-demenz.de](http://www.wegweiser-demenz.de)

**“Dementia Partner” initiative** As part of the “Dementia Partner” initiative, the **German Alzheimer Society** organises educational courses in cooperation with the **federal government** (BMG and BMFS-FJ)<sup>74</sup>. Since the initiative was launched in September 2016, more than 30,000 people have attended “Dementia Partner” courses. The aim is to significantly further increase this number.

**Course materials** To achieve the greatest possible media attention for teachers and the public, **Saxony** has published the “Understanding for People with Dementia” initiative by the **Standing Conference of the Ministers of Education and Cultural Affairs** on its own website. In addition, material for the primary sector, such as free educational software and educational games for children, has been published on the Internet.<sup>75</sup>

**Bremen** has been designing and organising a regular training programme on the subject of “people with dementia” for various professional groups in clinics since 2012.

**Guide to legal entitlements** The Alliance’s partners to have agreed to provide information about all legal claims for statutory benefits for affected persons.

With the current “Ratgeber zu rechtlichen und finanziellen Fragen” (Guide to legal and financial issues), the **German Alzheimer Society** provides information on legal claims to people with dementia and their relatives.<sup>76</sup> The “Guide to Dementia” online portal provides detailed information on rights and obligations. In advisory forums, experts give affected persons and their relatives information on individual matters. With regard to legal services, the website’s information section refers in detail to legal claims, also specifically listing further addresses or links.<sup>77</sup>

Together with the company “compass private pflegeberatung” and MEDICPROOF, the **Verband der Privaten Krankenversicherungen** (Association of Private Health Insurers) has launched an online portal to offer advice on nursing care.<sup>78</sup> There, affected persons and caregiving relatives receive answers to important questions on planning personal care. In addition, they have access to a comprehensive database with specific offers of assistance in their local areas. Using an easy-to-use search function, they can find information there on inpatient care facilities, outpatient services, day and night care facilities as well as offers for everyday support. With the help of checklists and tests, affected persons can, for example, check whether they should submit an application for long-term care benefits. As “Dementia as a special topic”, a wide range of information is available on the subject of dementia.

<sup>74</sup> [www.demenz-partner.de](http://www.demenz-partner.de)

<sup>75</sup> [www.was-hat-oma.de](http://www.was-hat-oma.de)

<sup>76</sup> [shop.deutsche-alzheimer.de/broschueren/33/ratgeber-rechtlichen-und-finanziellen-fragen](http://shop.deutsche-alzheimer.de/broschueren/33/ratgeber-rechtlichen-und-finanziellen-fragen)

<sup>77</sup> [www.wegweiser-demenz.de/informationen/rechte-und-pflichten.html](http://www.wegweiser-demenz.de/informationen/rechte-und-pflichten.html)

<sup>78</sup> [www.pflegeberatung.de](http://www.pflegeberatung.de)

### 3. Field of action III: Support for people with dementia and their families

The members of the Alliance made field of action III the focus of the interim report which was published in September 2016. For the Alliance, implementing the agreements in this field of action is a key priority in their mission's self-conception. Most elderly people, including those in need of care and assistance, want to live as long as possible in a familiar social environment. Approximately three quarters of all patients are cared for at home. Supporting, caring for and nursing people with dementia often represents a great challenge and burden for relatives, friends and neighbours. To avoid being overburdened and to maintain their quality of life, they are dependent on help tailored to their needs.

Field of action III includes the topics of counselling and support, inclusion and participation, designing the living environment as well as freedom of mobility and protection for people suffering from dementia. Effective violence prevention when caring for people with dementia and promoting the skills of caregiving relatives are particular focal points, as is the field of voluntary and civic commitment. The organisation partners have agreed on 30 agreements and 40 contributions in the agenda, of which 107 measures have already been announced.

#### Subject areas

#### 3.1 People with dementia

##### 3.1.1 Advice and support

The partners of the Alliance for People with Dementia have set themselves the goal of being able to offer people with dementia trust-building, early and continuous counselling. The sense of shame, inhibitions and ignorance of suitable offers should be reduced. The focus is on improved coordination and cooperation between counselling centres, improved service quality and individual, incoming and cross-provider counselling options, as well as improved cooperation with general practitioners.

With the second law on long-term care enhancement (PSG II), the **federal government** (BMG) has improved counselling for persons in need of care and their relatives. Fixed local contact persons have been appointed by the long-term care insurance companies for all questions relating to nursing advice and long-term care insurance. With the approval of the person in need of care but without requiring their participation, relatives may also undergo care counselling. The regional associations of the long-term care insurance funds have committed themselves to setting up an Internet comparison list with user-friendly search options of the regionally available care and support services. The information is to be regularly updated. These lists will not only include outpatient care services and nursing homes, but also, for the first time, the offers for everyday support recognised by the federal states.

#### Long-term care enhancement laws

The **GKV central association** has adopted guidelines for the uniform implementation of care counselling in 2018. In addition, the legislator has made provisions for con-

tractual agreements on cooperation in counselling between the federal states, local authorities and the long-term care insurance agencies. For the first time, the regional associations of the long-term care insurance funds have been obliged to conclude federal state framework agreements with the responsible authorities of the federal states to cooperate in advisory services. This should improve cooperation between the local authorities and reduce or avoid duplication of structures from the outset. It is the task of the responsible institutions to conclude these agreements.

Based on the positive results of the DelpHi study (see 1), the **German Centre for Neurodegenerative Diseases** (DZNE) Rostock/Greifswald has applied for a pilot project to further develop care counselling according to Section 7a SGB XI. Through joint scientific projects with care support centres, the city and the administrative district of Rostock, the DZNE Rostock/Greifswald also supports the further development of the care support centres in the federal state of **Mecklenburg-Western Pomerania**. The first project phase has already been completed and further joint projects are in planning.

In **Bavaria**, wohlBEDACHT's sponsored Bavarian Counselling Centre for Rare Dementia Diseases is a point of contact for those affected and their relatives as well as for other accompanying institutions. To do this, a numerical and content-related evaluation is made of the inquiries made personally, by telephone or via the homepage. By concentrating requests for consultation, existing knowledge in the field of rare dementias is to be bundled and disseminated (for example on care offers for people with rare dementias) and existing gaps in care are to be identified.

### 3.1.2 Participation/integration

The agenda's idea of inclusion implies that people with dementia can participate in society for as long as possible. This requires a new understanding of living together with people both with and without any impairments. The organisation partners have agreed to strengthen patients' autonomy and to acknowledge their skills.

They also examine the procedures they use with regard to involving people with dementia and to adapt them where necessary. They are increasingly looking to involve dementia patients in the active design of measures.

#### Equal access to long-term care insurance benefits

With the second laws on long-term care enhancement, the **federal government** (BMG) introduced a fundamentally new definition of the need for care and a new instrument for assessment which have been in force since 1 January 2017. For the first time, all patients in need of care will have equal access to long-term care insurance benefits, irrespective of whether they are affected by physical, cognitive or psychological impairments. Personal independence is the decisive factor for the care grade, i.e. what someone can do and what he or she needs support for - regardless of whether someone suffers from dementia or any physical impairments. With new, uniform benefit entitlements for all insured persons in one care grade, the previous three care grades have been replaced by five new care grades. The new assessment instrument enables patients' impairments and existing abilities to be re-





corded more precisely. The individual care situation is thus mapped more precisely in five care grades than according to the previous legal situation. The reforms of the long-term care insurance system are undergoing a comprehensive evaluation. The aim is to gain insights into the extent to which the intended effects have occurred, particularly in the implementation of the new need-for-care concept; the various groups of persons or stakeholders (insured persons and relatives, but also nursing specialists) are included here. The evaluation should also serve to identify any possibilities for adaptation and optimisation.

The **federal government** (BMFSFJ) can also ensure that people with dementia are involved in the implementation of measures by continuously supporting the work of the **German Alzheimer Society**. Exemplary projects include the promotion of the “What can I do” handbook for people with incipient dementia and the development of the guideline on accessibility.<sup>79</sup> The participation for people with dementia in all 500 networks of the Local Alliances funded by the BMFSFJ is part of the philosophy. The “Trialogue”, by the gerontological-psychiatric centre at the Psychiatric Centre at Charité Universitätsmedizin in St. Hedwig Hospital Berlin<sup>80</sup> as well as the inter-generational meeting place in Enger/Herford administrative district<sup>81</sup> are some good examples of this.

### Exemplary projects

The partners work towards ensuring that societies and associations provide appropriately designed offers in which people with dementia can also participate.

<sup>79</sup> [www.deutsche-alzheimer.de/fileadmin/alz/broschueren/Was\\_kann\\_ich\\_tun2012\\_11.pdf](http://www.deutsche-alzheimer.de/fileadmin/alz/broschueren/Was_kann_ich_tun2012_11.pdf), [www.allianz-fuer-demenz.de/fileadmin/de.allianz-fuer-demenz/content.de/bilder/meldungen/17-05-09\\_Arbeitsgruppe\\_veroeffentlicht\\_Ratgeber/Wege\\_zu\\_mehr\\_Barrierefreiheit.pdf](http://www.allianz-fuer-demenz.de/fileadmin/de.allianz-fuer-demenz/content.de/bilder/meldungen/17-05-09_Arbeitsgruppe_veroeffentlicht_Ratgeber/Wege_zu_mehr_Barrierefreiheit.pdf)

<sup>80</sup> [www.lokale-allianzen.de/projekte/projektuebersicht/projekt/practex/show/503.html](http://www.lokale-allianzen.de/projekte/projektuebersicht/projekt/practex/show/503.html)

<sup>81</sup> [www.lokale-allianzen.de/projekte/projektuebersicht/projekt/practex/show/91.html](http://www.lokale-allianzen.de/projekte/projektuebersicht/projekt/practex/show/91.html)

**Sports and dementia** The **federal government** (BMFSFJ) and the **Robert Bosch Stiftung** support the “Was geht - Sport, Bewegung und Demenz” (What works – sports, exercise and dementia) project of Demenz Support Stuttgart. To enable inclusion to become reality, the project aims at sensitising sports clubs and other providers of exercise activities to the needs of people with dementia, developing training programmes and opening up opportunities for sports and exercise for people with dementia. Together with associations and those affected, the project is also intended to initiate the conception, testing and evaluation of new offers.<sup>82</sup>

**Participation competition** With a call for “Participation for people with dementia” and a subsequent participation competition by the Ministry of Social Affairs in 2017, the federal state of **Rhineland-Palatinate** has had some good success and made a number of different opportunities for participation visible across the region. The importance of participation for people with dementia in the midst of our society - also across generations and cultures - has been made clear in Rhineland-Palatinate and discussed in the broad-based Dementia of Rhineland-Palatinate regional committee. This process will be continued and remains a focus of action in the dementia strategy of Rhineland-Palatinate. The stakeholders in the regional dementia networks are called upon and supported by the regional dementia networks to enable the development of a wide range of participation opportunities for people with dementia. The goal is to gain access to the offers by appropriate associations in municipalities and city districts and thus at the centre of everyday life.

### 3.1.3 Structuring the home and living environment

Irrespective of the living situation, people with dementia should maintain their independence. With the help of integrated social and spatial planning and low-threshold offers of assistance, it is possible, to create constructive approaches to social participation. Particular attention should be paid to the special situation in rural areas.

Using appropriate measures, such as neighbourhood management, the Alliance’s partners improve the conditions for dementia patients in manageable welfare facilities.

**Neighbourhood points of contact** The **federal government** (BMFSFJ) funded the “Neighbourhood points of contact for older people” programme until the end of 2016. To enable participation and commitment, but also, if necessary, help, care and provide support in care, its aim was to promote the range of offers in the immediate living environment - the neighbourhood - and to establish low-threshold assistance. The programme made an important contribution to a self-determined life in old age, to reinforcing the social participation of older people and to strengthening generational cohesion. A total of around 300 projects were supported by a one-off grant from the BMFSFJ.<sup>83</sup>

<sup>82</sup> [www.sport-bewegung-demenz.de](http://www.sport-bewegung-demenz.de)

<sup>83</sup> [www.serviceportal-zuhause-im-alter.de/programme/programm-anlaufstellen-fuer-aeltere-menschen.html](http://www.serviceportal-zuhause-im-alter.de/programme/programm-anlaufstellen-fuer-aeltere-menschen.html)



The federal and state governments promote opportunities for customised housing and urban development according to the needs of dementia patients. The **federal government** (BMU) is using budget funds to promote social housing. Depending on the political priorities in the federal states, these can be principally used for barrier-free new construction and age-appropriate modernisation of existing buildings, thus also benefiting people with dementia where necessary. The promotion of social housing has been the sole responsibility of the federal states since 1 September 2006; it will be financially supplemented by use of federal compensation funds until the end of 2019. Compensation funds have been increased twice since 2016 in view of the bottlenecks on many housing markets. In 2017 and 2018, they will each amount to more than EUR1.5 bn per year. This is almost three times the amount that the federal government made available to the federal states prior to 2016. With funds from the federal and state governments, a total of around 62,000 residential units were funded in 2016. Compared to 2015, this represents an increase of around 20 percent. The construction of social rental apartments alone increased by 68 percent in 2016, when 24,550 new social rental apartments were built. Compared to the 14,653 rented apartments built in 2015, this corresponds to an increase of almost 10,000 apartments. The coalition agreement between the CDU/CSU and the SPD for the 19th legislative period provides for social housing construction to remain at least at the current level in the long term and for at least EUR 2 bn to be earmarked for social housing construction in 2020 and 2021.

### Promoting social housing

To implement this agreement, the cabinet adopted a draft law on 2 May 2018, amending the Constitution for funding social housing. This gives the federal government the opportunity to grant the federal states earmarked financial assistance for nationally significant investments in the area of social housing construction by the federal states and local authorities.

The federal and state governments' funding of urban development serves to remedy any shortcomings in urban development and support local authorities in an integrated, spatial approach to demographic, social and economic change as well as climate protection. It thus secures important and necessary investments in the urban infrastructure of cities and municipalities. An important guiding principle for the adaptation of urban districts is to place citizens' needs at the centre of any investment measures. The concerns of households with children and elderly people must be taken into account as well as the concerns of people who face special challenges due to health issues or other reasons in their freedom of mobility. In this sense, urban development funds can also be used for the barrier-free design of public spaces and buildings, as well as the residential environment in city districts. Between 1971 and 2017, the federal government provided funds totalling approximately EUR 17.7 bn for urban development. In 2018, federal funds of EUR 790 m have been earmarked for urban development programmes.

### Urban development funding

**Vario-apartments** As part of the “Zukunft Bau” (Future of construction) research initiative, the **federal government** (BMU) is encouraging the rapid construction of sustainable and affordable apartments for students and trainees, which, due to their architecture and utilisation concept, can later be converted into elderly-appropriate apartments. To prepare for “ready” barrier-free living (online at [www.readyhome.de](http://www.readyhome.de)<sup>84</sup>) or “ready-plus” barrier-free living, the concept’s implementation is defined as an eligibility criterion in accordance with the funding directive. In this way, it should be ensured that future adaptations for living in old age are prepared structurally or can be spatially realised at a later stage. Across Germany, 20 “Variowohnen” pilot projects will be funded, scientifically supported and evaluated by the BMU by the end of 2019. Research and investigation should create the basis for the further development and sustainable use of Vario apartments. After the projects’ completion, an action guideline, which can be made freely available to interested parties, is to be developed by 2020. The BMU supports the construction and accompanying scientific monitoring of 20 pilot projects in ten German federal states (Baden-Württemberg, Berlin, Brandenburg, Bremen, Hamburg, Hesse, North Rhine-Westphalia, Saxony, Saxony-Anhalt and Thuringia). The subsidised Vario apartments will be constructed both as new construction projects (70 percent of all projects) and as part of conversions (30 percent). The spectrum ranges from smaller inner-city enclosures to the complete refurbishment of a prefabricated building with more than 300 apartments. Most of the projects are already under construction. By the end of 2019, the experiences of the individual project initiators will be compiled and evaluated in various exchange formats.

**Shared apartments and day care** Inpatient care facilities also take the living habits of people with dementia into account when designing the social and living environment. In April 2016, the **Verband Deutscher Alten- und Behindertenhilfe** (German Association for Aid to the Elderly and Handicapped, VDAB) organised an entrepreneurs’ day for all nursing facilities, primarily in North Rhine-Westphalia. Workshops were held on the topic “Offering shared flats and day care for people suffering from dementia”. Since then, consultations have been continuously organised by (potential) member companies, so that numerous nursing facilities have already created special offers.

**Technical assistance systems** With the “Kommunale Beratungsstellen – Besser leben im Alter durch Technik” (Municipal advice centres - Better living in old age through technology) funding priority in 2014 and 2015, the **German federal government** (BMBF) funded the transfer of knowledge on technical assistance systems and aids for independent living in old age in 22 municipalities and regions throughout Germany. The aim was to support elderly or handicapped people in being able to live independently in their own four walls for as long as possible. For this purpose, the knowledge and consulting skills on existing, but often hardly known technical aids and assistance systems on the market was prepared and made available. After training the municipal employees appropriately, each local authority chose the appropriate approach for them. To exhibit technical aids, some locations use central points of contact for older people whereas other projects rely heavily on outreach counselling. Here,

<sup>84</sup> [www.readyhome.de](http://www.readyhome.de)

the various products such as senior citizens' telephone, fall sensors, stove cut-off or overflow protection could be tried out or rented. A national reference database has also been set up as a central tool.<sup>85</sup> This was set up during the course of the funding announcement in close cooperation with the FZI Research Centre for Technology in Karlsruhe (FZI), continuously expanded and made accessible to a wide range of users. With this database, the BMBF aims at mapping all assistance systems already available on the German market, to structure them according to practice-oriented search patterns and to provide them with information on prices and installation. With comparative information, this reference database can thus support the selection of suitable technical aids and can be accessed free of charge by anyone interested. It can serve as a basis for local authorities and regions that want to establish such an advisory service for their citizens. The measure has supported 22 projects and one research institution.<sup>86</sup> The total volume of the funding measure amounts to around EUR 4.8 m. Counselling measures have been integrated into the local senior citizens' and demographic policy. This requires networking with the relevant regional stakeholders such as town halls, public offices, care services, welfare centres, social services, health and care insurance funds, chambers, housing associations, senior citizens' representatives and senior citizens' meetings as well as representatives from industry, trade, and research and development. However, only the respective local authority or region received the grant. The 22 counselling centres in the city and rural areas have built up expertise that has been consolidated in a number of programme municipalities in established or new advisory services. Networks have developed at numerous locations and are being continued. Many consultants trained in the project are now in demand as contacts for municipalities wishing to establish similar services.

The **German Society of Geronto-Psychiatry and Psychotherapy** (DGGPP) was founded in 1992 as a medical society to improve the medical and nursing care of mentally ill elderly people and, in particular, dementia patients and their relatives. Since then, it has been involved in many projects, such as the German government's Alliance for People with Dementia, the "Charta zur Betreuung schwerstkranker und sterbender Menschen" (a care charter for the seriously ill and dying), and in the development of care concepts with the "**Aktion Psychisch Kranke**" (Mentally ill campaign, APK)" campaign. Many of its members are involved in local care structures, have co-founded self-help groups and work in old people's homes and nursing homes as doctors. Against this background, the "DGGPP seal of quality - Dementia-sensitive facility" was developed together with Alzheimer societies, the professional association for nursing care for the elderly and institutions responsible for facilities. Among other things, this seal is intended to help relatives in their decision for a suitable home. The acquisition of the seal should additionally allow homes to receive support in their work and for further development.

## Reference database

## Seal of quality

<sup>85</sup> [www.wegweiseralterundtechnik.de](http://www.wegweiseralterundtechnik.de)

<sup>86</sup> [www.technik-zum-menschen-bringen.de/foerderung/bekanntmachungen/kommunale-beratungsstellen-modul-1](http://www.technik-zum-menschen-bringen.de/foerderung/bekanntmachungen/kommunale-beratungsstellen-modul-1), [www.technik-zum-menschen-bringen.de/foerderung/bekanntmachungen/kommunale-beratungsstellen-modul-2](http://www.technik-zum-menschen-bringen.de/foerderung/bekanntmachungen/kommunale-beratungsstellen-modul-2)

Unlike the health insurance medical service's tests, applications for this seal are voluntary. There is no "perfect home"; the decisive factor for awarding the DGGPP seal of quality is rather to prove that people suffering from dementia are receiving individual and dementia-sensitive, competent care and support at the facility and that the facility is also prepared for professional development.<sup>87</sup> So far, 15 homes have been assessed, another 45 are to follow in 2018.

### 3.1.4 Freedom of mobility and protection for people with dementia

**Reduced mobility** Freedom of mobility is an important expression of self-determination. In addition, maintaining mobility for people with dementia is an effective measure to prevent falls. The use of any measures which restrict liberty, which may be justifiable for reasons of risk to themselves or others, must be regularly examined with regard to alternatives and subject to strict criteria. The organisation partners have agreed to reduce the duration and nature of such measures, to avoid as far as possible any fixations close to the body and provide information on possible interventions to avoid them.

**Fixations on the decrease** The **Federal Association of Non-statutory Welfare** (BAGFW) informs its members of the possibilities to avoid fixations close to the body. The existing framework conditions must be reviewed and the economic and human resources contractually defined between the institutions and cost units. Various studies indicate that the fixations are on the decrease (see 5th quality report of the medical service of the central organisation of Federal Association of Health Insurance Funds (MDS)).<sup>88</sup>

The **Bundesverband privater Anbieter sozialer Dienste** (Federal association of private providers of social services) regularly conducts seminars on the subject of measures which deprive liberty.

**The "Werdenfelser Weg"** By introducing the "Werdenfelser Weg" in 2012, the number of approved measures for depriving liberty (FEM) have been reduced in **Hamburg**. Judges, specially trained case guardians, legal counsellors and nursing facilities are the parties hereto. With its "Fachstelle Pflege ohne Zwang" (Care without compulsion) specialist unit, the administrative district office in Hamburg Altona, which is responsible for Hamburg's entire city area, offers legal advice and further training for citizens and institutions at the "Beratungsstelle für rechtliche Betreuung und Vorsorgevollmacht" (advice centre for legal services and health care proxies). Within the scope of a project from 2012 to 2014, introducing the "Werdenfelser Weg" enabled the approved FEMs to be significantly reduced. The result is sustainable; the reduction has continued in the years since then. An evaluation of the judicial statistics showed that the number of approved FEMs declined from 756 in 2012 to 378 in 2016. This corresponds to a decline of about 50 percent.

<sup>87</sup> [siegel.dggpp.de](http://siegel.dggpp.de)

<sup>88</sup> [www.mds-ev.de/fileadmin/dokumente/Pressemitteilungen/2018/2018\\_02\\_01/\\_5\\_PflegeQualitaetsbericht\\_des\\_MDS.pdf](http://www.mds-ev.de/fileadmin/dokumente/Pressemitteilungen/2018/2018_02_01/_5_PflegeQualitaetsbericht_des_MDS.pdf)

The **Centre for Quality in Care (ZQP)** has created an online portal based on the results of the specialist event “Care without Compulsion - Between Protection and Self-determination of People with Dementia”.<sup>89</sup> It provides permanent background information and practical recommendations for preventing and dealing with violence, including measures which deprive liberty. The target groups are people in need of care, caregiving relatives and professional carers. In addition, with financial support from the **federal government (BMFSFJ)**, the ZQP, has drawn up a report on topics relating to violence prevention in nursing care. Among other things, the document contains proposals to avoid measures to deprive liberty. It is nationally distributed via the ZQP.

## Care without compulsion

### 3.1.5 Violence

The use of violence (verbal, psychological, physical, sexual) is not in any way justifiable. Part of the care for people with dementia must therefore also be an effective prevention of violence. Violence is often an expression of excessive demands and helplessness on the part of carers or accompanying people and can also be aggravated by the patients' lack of insight. The Alliance's partners have agreed to raise awareness of the problem of using violence in care and to implement appropriate measures for its prevention and intervention.

## Preventing violence

The results of the “Potenziale und Risiken in der familialen Pflege alter Menschen” (Potentials and risks in family care for the elderly, PURFAM) study have been made available by the **federal government (BMFSFJ)**. To ensure that the measure for prevention is consistent and implemented across the board, a handbook has prepared which, in addition to background information, contains detailed instructions for using the PURFAM assessment and can be applied for primary prevention on a broad basis.

## “PURFAM” study

To prevent violence and provide assistance against violence in nursing care, municipalities and long-term care insurance funds have committed themselves to cooperate with and support points of contact for violence prevention and help with violence. In this regard, the municipal state associations and the municipalities have been informed by the **central associations of local authorities**.

The issue of violence prevention is discussed regularly in the associations affiliated to the **Federal Association of Non-statutory Welfare**. Various concepts have been developed to prevent violence. The theme of violence in nursing care is an issue in education, in many further and advanced training courses and during supervision.

<sup>89</sup> [www.pflege-gewalt.de](http://www.pflege-gewalt.de)

### 3.2 Help and support network particularly for family caregivers: supportive counselling and promoting skills

Reliable support and care for people with dementia requires an accepting basic attitude, empathy, knowledge and certain skills. Relatives of people with dementia and the personal environment, such as neighbours and friends, are particularly dependent on support. As the care and nursing situation often occurs unexpectedly, they often only have limited available time. This makes it all the more important to make information on behavioural strategies, offers of support and possibilities for funding easily accessible and to offer specific offers of assistance at low thresholds.

#### Exchanging experiences

In addition, voluntary activities, for example between the dementia patient and the dementia sponsor, must be particularly encouraged. It is also important to support local forums and networks in enabling caregivers and family members to exchange their experiences. This allows the provision of new information and promotes self-reflection.

#### Legal entitlement

The **federal government** (BMFSFJ, BMAS, BMG) is committed to further improving support and assistance for caregiving relatives. Among other things, the agenda's goal is served by the law, which came into force on 1 January 2015, to improve the reconcilability between family, care and career. It includes significant changes in the law on nursing times, the family nursing times and the 9th Social Security Statute. The existing regulations have been interlinked and further developed. NT to be able to organise care at short notice in the event of a crisis, the legal entitlement to family care time and care support allowance as a wage replacement benefit for relatives, among other things, have been recently introduced.

The federal states support the further expansion of low-threshold care offers by providing corresponding funding within the framework of their capabilities.

#### Everyday support services

In **Saxony-Anhalt**, there are now about 150 recognised offers for everyday support. This number, and thus also the variety of offers, has steadily increased in recent years. With the pilot project, the offers have a good partner in the further development of their own fields of action in the agency for the placement and development of offers for support in everyday life for people in need of care (AUiA). The aim is that people in need of care and their relatives can choose from various offers close to where they live, so that caregiving relatives and those in need of care - especially people with dementia who want to stay in their own homes as long as possible - receive support.

#### “Training carousel for dementia” project

In cooperation with the clinic of the Rhineland Regional Council in Cologne, the **German Sport University Cologne** (DSHS) carried out the “Training Carousel for Dementia Disease” project between 2014 and 2017.<sup>90</sup> In a randomised-controlled study, the effects of the training programme on the behavioural symptoms of

<sup>90</sup> [doi.org/10.1186/s13195-017-0289-z](https://doi.org/10.1186/s13195-017-0289-z)



dementia patients, the strain on carers, the use of psychotropic medication, movement behaviour, daily structure and neuroprotective mechanisms of action were investigated.



To achieve an improvement in utilisation, the federal government, federal states, local authorities and the long-term care insurance companies have agreed to provide information on additional care services and the associated offers of support.

In accordance with Section 45a SGB XI, the **federal government** (BMG) informs caregivers on the offers for support in the everyday life in the Long-Term Care Guide.

**Long-Term Care Guide**

In **Saxony**, the amended Care Services Regulation came into force in 2016, taking the provisions of the long-term care enhancement laws into account. It is essential to cut the share of the municipalities to five percent, simplify the application, completely co-finance the nursing funds using state funds as well as to consider neighbourhood helpers, who can become active as individual providers according to Section 45b SGB XI. The regulation on care offers has not yet been adapted to the long-term care enhancement laws.

**Amended Care Offers Ordinance**

To facilitate access to benefits, long-term care insurers have developed their own services for care counselling, also for special target groups such as dementia patients and their family members.

- LOGBUCH Dementia** The AOK NordWest has developed the Dementia LOGBUCH for the **GKV central association**.<sup>91</sup> The results of special advice on dementia are recorded in it. This empowers those in need of care and can be used in interface management. The LOGBUCH contains all essential information about the nursing and medical situation, as well as care management, of those affected. In an emergency or during a stay in hospital, this means that important data is also available quickly and concisely.
- Alzheimer telephone** Through the Alzheimer telephone, for example, the **German Alzheimer Society** and its member associations offer independent advice and support to relatives from a self-help perspective.<sup>92</sup> Between 5,000 and 6,000 people, mainly relatives, have received counselling every year since the Alzheimer's telephone service commenced. Turkish-speaking consultation has also been offered on the telephone one time a week since October 2017.

### 3.3 Volunteer work and civic engagement

- Meaning and tasks** The more sustainable the social network is for people with dementia, the longer it is possible for them to live in their familiar home environment. Volunteers play a central role here. They enable those affected to develop new possibilities in organising their everyday lives and often support professional employees in their work. As people suffering from dementia are treated with openness and care, their commitment can serve as a role model for society in treating people suffering from dementia in a gentle and caring manner. It is therefore an important goal of the Alliance for People with Dementia to develop a culture of recognition for voluntary and civic engagement and to motivate groups that have so far been underrepresented in social commitment.

In acknowledging the importance of a well-coordinated “mix of help”, comprising full-time nursing and care provided by family members or volunteers, the partners are working towards joint learning opportunities between active citizens and professional nurses.

- Law on the reform of the nursing professions** For this reason, the **federal government** (BMG and BMFSFJ) proclaimed the law on reforming the nursing professions in July 2017, some of which has already come into force. In Section 5, the law defines the training objective of the new nursing training courses - these also take into account the “help mix” of full-time care and nursing by relatives or volunteers. As part of the new nursing training, future nursing specialists will be enabled, among other things, to independently take on guidance, advice and support from other professional groups and volunteers into the respective nursing contexts. In addition, they will involve the social caregivers in advising, guiding and supporting people to be cared for, in dealing individually with health and illness, and in maintaining and strengthening their independent lifestyle and everyday skills. The new nursing training courses will begin on 1 Janu-

<sup>91</sup> [www.kda.de/news-detail/items/logbuch-demenz.html](http://www.kda.de/news-detail/items/logbuch-demenz.html)

<sup>92</sup> [www.deutsche-alzheimer.de/unser-service/alzheimer-telefon.html](http://www.deutsche-alzheimer.de/unser-service/alzheimer-telefon.html)



ary 2020. In implementing the new training in nursing, the **federal government** is paying particular attention to this cooperation.

The federal states are developing strategies to promote civic engagement. They support the strengthening of low-threshold care provision and civic involvement through long-term care insurance.

In **Saxony**, neighbourly help is a recognised offer for support in everyday life and serves to relieve the burden off caregiving relatives. By supporting persons in need of care, caregivers are relieved of burden and the activity and independence of those affected is maintained through targeted entertainment. Persons in need of care have the opportunity to use the relief amount of up to EUR 125 per month to employ a neighbourhood worker. They must be of full age, not live in a domestic community with the person to be cared for and may not be carers within the meaning of Section 19 SGB XI. Neighbourhood helpers may not be related in the second degree by blood or marriage to those to be looked after. They must update their knowledge and skills every three years by participating in nursing courses or in an activity recognised by the long-term care insurance companies. If the neighbourhood helper has completed a nursing course, he or she is awarded a certificate and thus recognised as a neighbourhood helper. Following the first long-term care enhancement laws, which came into force at the beginning of 2015, the federal state government in Saxony revised the regulation on the recognition and promotion of care services (Verordnung zur Anerkennung und Förderung von Betreuungsangeboten) and recorded the changes in the regulation on care services. The participation of the municipalities' in the funding was reduced from 15 to 5 percent. The share of the federal state in the funding is now 45 percent. As of 27 December 2017, 1,470 neighbourhood helpers were recognised in Saxony, and 1,552 as of 28 March 2018. Their number is to be further increased.

### Neighbourhood helpers

Outpatient and inpatient care facilities work towards gaining citizens for volunteer work. They work together with the local structures and provide their volunteers with training, guidance and support.

### Winning volunteers

In the member associations of the **Federal Association of Non-statutory Welfare**, the recruitment, cooperation and coordination of volunteers is an ongoing task at state and municipal level.

The Alliance's partners have also agreed to compile their actions in recognising civic engagement and to publish them as examples of good practice.

**Examples of good practice** The **federal government** (BMFSFJ) illustrates some examples of good practice in its “Local Alliances for People with Dementia” pilot programme. Numerous Local Alliances have developed low-threshold training concepts for volunteers. They are used as guides/godmothers or in visiting and accompanying services within the scope of neighbourhood help. The project descriptions with contact addresses can be viewed on the Internet.<sup>93</sup>

Practical projects related to care are listed in the database of the **Centre for Quality in Care** as exemplary example projects.<sup>94</sup>



**“Dementia Partner” project** The **federal government** (BMG) supports the **German Alzheimer Society’s** “Dementia Partner” project, which is also supported by the BMFSFJ. The project offers courses that enable everyone to learn about how to deal with people with dementia and how to help them in their daily lives. The “Dementia Partner” initiative ties in with the activities of the worldwide “Dementia Friends” campaign. This initiative was launched to change the image and perception of people with dementia in society as a whole. Around 30,000 dementia partners were registered in Germany in mid-2018. These include the 520 organisations, institutions and associations that have registered as course providers on the homepage.<sup>95</sup> In the fourth quarter of 2017, the BMG supported an action to increase public awareness for the initiative. Funding through the Scale Initiative will end in 2021.

<sup>93</sup> [www.lokale-allianzen.de](http://www.lokale-allianzen.de)

<sup>94</sup> [dbp.zqp.de](http://dbp.zqp.de)

<sup>95</sup> [www.demenz-partner.de](http://www.demenz-partner.de)

## 4. Field of action IV: Structuring the support and health care system

The support and care system required by people with dementia and their relatives must be tailored to the various clinical pictures, phases of the disease and the individual needs of those affected. It must reach people of all ages, origins and in all living situations, whether living alone or in the family, in the city or in rural areas.

Field of activity IV covers the areas of housing and living in the neighbourhood, rehabilitation, medical and nursing care, care in the acute hospital, the recruitment of qualified personnel and quality assurance in the inpatient and domestic areas.

### Subject areas

In the agenda, the organisation partners have agreed on 37 agreements and 53 contributions. Almost all contributions could be stored with measures. A total of 133 measures have been reported in this field of action.

### 4.1 Care structures

#### 4.1.1 Accommodation and living in neighbourhoods

Memory and orientation deteriorate during progressive dementia, making it difficult or impossible for people to stay in their familiar environment. For this reason, it is necessary to provide an environment that is as stress-free as possible and helps with orientation, as well as which offers individual forms of living and networked help structures with easy access to health facilities. The Alliance's partners support the further development of such forms of housing and the formation of networks as caring communities. The desire of most people to be able to live at home for the rest of their lives is met by outpatient assistance.

### Individual forms of living

The Multi-Generation Houses I+II (until the end of 2016) and the Multi-Generation House Federal Programme (since the beginning of 2017) action programmes funded by the **federal government** (BMFSFJ) have created a social infrastructure throughout Germany that makes a sustainable contribution to intergenerational interaction and social cohesion in the communities where the sites are located. In multi-generation houses, young and old find what they are looking for or need in their immediate vicinity: support, advice in coping with everyday life, human proximity, personal approaches, interesting opportunities to get involved and help others. The advantage of such houses lies in the flexibility and alignment which enable them to react to current requirements. The idea of bringing all generations, independent of family structures, closer together in this way has been proven to work and bears much fruit that needs maintaining. The intergenerational approach shapes the work of the multi-generation houses and is their unique selling point. This also applies to the voluntary commitment without which the houses could not implement the intergenerational approach, meaning that many offers would not be able to be implemented. Both elements will therefore continue to be part of the basic profile of every multi-generation house in the future.

### Multi-generation houses

### “Points of contact for the elderly”

The **federal government** (BMFSFJ) has also supported the “Points of Contact for Older People” programme (for details see Chapter III, 3.1.3), thus making an important contribution to an independent life in old age, to intensifying the social participation of older people and to strengthening cohesion between the generations.<sup>96</sup>

In the **federal government’s** (BMFSF) “Future Dementia Workshop” funding programme mentioned in Chapter III, 2.2 Networking, seven pilot projects in the areas of “Support for caring relatives of people with dementia” and “Regional dementia networks” were funded in the years from 2012 until 2015 with a total of around EUR 3.3 m. This was a follow-up project to evaluate and further develop pilot projects of the “Lighthouse Project Dementia” from 2008 and 2009. As a prerequisite for the dissemination of exemplary approaches, the aim of the project was to prepare the success factors for offering support and structures. Six projects evaluated pilot projects to “support the caregiving relatives of people with dementia”. The seventh project was the “DemNet-D” project. The results of the DemNet-D study were taken into account in the long-term care enhancement laws (Section 45c Para. 9 SGB XI). Since January 2017, the change in the law has made it possible for nursing care funds and private insurance companies to support regional, self-organised health networks with up to EUR 20,000 per year per district or non-county city. Including cross-sectoral provision, the funding aims at bringing together governmental, municipal and civic interests in a targeted manner.

### Measures for improving the living environment

The **federal government** (BMG) has implemented the agreed objectives in this field of action by simplifying and extending the funding opportunities for measures to improve the living environment. With the first long-term care enhancement laws (PSG I), the maximum subsidy was considerably increased from EUR 2,557 to EUR 4,000. If several patients live together, it is now possible to grant up to EUR 16,000 per measure. The improvements to benefits introduced by the Act to Reorient the Long-Term Care Insurance and PSG I have led to a significant overall increase in the use of this offer for long-term care insurance: while the long-term care insurance fund spent around EUR 103 million on this in 2011, by 2016 the corresponding expenditure item had already risen to just under EUR 341 million. The increase in expenditure exceeds the pure price effect, meaning that one can assume an increase in the number of cases. An evaluation study showed that the increase in subsidies for measures to improve the living environment was known up to EUR 4,000 per measure for 42 percent of the nursing households surveyed. It also showed that 27 percent of nursing homes have applied for measures to improve the living environment, of which 85 percent have been approved, seven percent have been rejected and eight percent are still pending a decision.<sup>97</sup>

<sup>96</sup> [www.serviceportal-zuhause-im-alter.de/programme/programm-anlaufstellen-fuer-aeltere-menschen/abschlussdokumentation.html](http://www.serviceportal-zuhause-im-alter.de/programme/programm-anlaufstellen-fuer-aeltere-menschen/abschlussdokumentation.html)

<sup>97</sup> [www.bundesgesundheitsministerium.de/fileadmin/Dateien/5\\_Publikationen/Pflege/Berichte/abschlussbericht\\_Evaluation\\_PNG\\_PSG\\_I.pdf](http://www.bundesgesundheitsministerium.de/fileadmin/Dateien/5_Publikationen/Pflege/Berichte/abschlussbericht_Evaluation_PNG_PSG_I.pdf)

## Residential communities

Outpatient residential communities for people in need of care have become an important part of care in **Berlin** since 1995. Currently, Berlin has one of the largest and most differentiated offers in Germany. In mid-June 2017, the notifications pursuant to Section 14 of the Wohn- und Teilhabegesetz (Residential and Participation Act, WTG) identified 627 shared flats with a total of 4,781 places. This development shows that Berlin's state legislation and administration do not pose any hurdles for the establishment of residential communities. The decisive influencing factors for the emergence of residential care communities are statutory regulations (according to SGB XI, SGB V and SGB XII) and the associated economic framework conditions for service providers, in addition to the desire to remain in a form of care based on domestic care. The German Bundestag sees the need to develop a concept for quality assurance in new forms of housing (Section 113b Paragraph 4 No. 6 SGB XI). The State of Berlin expressly welcomes this. In addition to this, the state of Berlin set up an "Arbeitskreis Wohngemeinschaften" (residential communities working group) in 2014 to accompany the further development of the form of residential communities and has commissioned or supported several evaluations since 2006. Furthermore, in 2018, cost bearers and providers' associations have agreed to negotiate the basis for staffing outpatient flat-sharing communities, with the aim of implementing the results of the negotiations from 1 January 2019.

With a specialist unit, **Hesse** supports initiators and project managers in setting up self-administered, ambulatory assisted living groups for people with dementia. Current residential care communities are integrated into exchange and support processes in the form of network meetings and working groups. Individual consulting appointments can also be arranged. In cooperation with representatives from municipalities, health insurance companies and housing associations, the creation of new outpatient residential communities is to be promoted.<sup>98</sup>

<sup>98</sup> [www.demenz-wg-hessen.de](http://www.demenz-wg-hessen.de)

### 4.1.2 Rehabilitation

**Entitlement** Like all other insured persons, people with dementia are legally entitled to rehabilitation services before receiving nursing care. Rehabilitation measures should maintain or improve the patients' skills. The Alliance's partners have agreed to provide suitable medical and psychosocial services within appropriately developed rehabilitation concepts.



In this context, to enable the targeted search for facilities for dementia patients with a tendency to run away, the **central association of statutory health insurers (GKV-SV)** has adopted key points for mobile indication-specific rehabilitation and expanded the central association's "Medical Rehabilitation Quality Assurance" database.

### 4.1.3 Medical and nursing care

#### Cooperation of service providers

During the course of a dementia disease, other diseases often occur that require medical and nursing care. In addition, patients increasingly lose their mobility and ability to give information, which in turn can lead to excessive demands on their relatives. In medical treatment and care, therefore, the cooperation of the various service providers is of central importance. As a result, the Alliance's partners have agreed to achieve structured cooperation between all medical, nursing and advisory institutions. At the same time, outpatient medical care is to be improved. To avoid the excessive use of psychotropic drugs, persons suffering from dementia must also be provided with medicines in accordance with their indications. Further agreements between the organisation partners are aimed at strengthening voluntary work at home and in hospice support, as well as the further development of palliative care services.



The **federal government** (BMG) is further developing long-term care insurance. It will initially introduce benefit improvements to take effect in the short term, adjust the benefit amounts and launch a Long-Term Care Provident Fund (Pflege-Vorsorgefond) to create demographic reserves. On the basis of the recommendations by the expert advisory board and after prior testing, the new term “need for care” was introduced on 1 January 2017. In this way, people with dementia, in particular, should receive better and more fitting benefits.<sup>99</sup>

### Further development of long-term care insurance

In cooperation with proven experts and other stakeholders at federal level, the **Centre for Quality in Care** (ZQP) has developed a quality framework for advice in nursing which defines quality areas, quality objectives and quality criteria. The quality framework was presented by the ZQP at the beginning of 2016. Additionally, the ZQP offers a freely accessible database<sup>100</sup> with the contact information of over 4,800 non-commercial counselling offers in the context of care - especially on dementia - in Germany, as well as an overview of specialised counselling offers on the subject of violence in care.<sup>101</sup>

The **Deutsche Gesellschaft für Psychiatrie und Psychotherapie, Psychosomatik und Nervenheilkunde** (German Society for Psychiatry and Psychotherapy, Psychosomatics and Neurology, DGPPN), together with the **German Society for Neurology** (DGN) and in cooperation with the **German Alzheimer Society** (DAIzG) and the 22 other medical-scientific societies, professional associations and organisations involved in the consensus process have developed the S3 treatment guideline “Dementias”.<sup>102</sup> The DGPPN is also striving to develop a national care guideline (NV) for dementia. In addition, a guideline project (S2K) “Consent of medical measures by people with dementia” is in progress.

### Treatment guideline

Upon application, the DGPPN and the **German Society of Geronto-Psychiatry and Psychotherapy** (DGGPP) jointly award their members the certificate “Geronto-Psychiatry, Geronto-Psychotherapy and Geronto-Psychosomatics”. In view of the demographic development and the associated necessity of constantly increasing geronto-psychiatric expertise for the psychiatric-psychotherapeutic and psychosomatic care of old and often multimorbid people in need of care, awarding the certificate represents a contribution to an improvement in the quality of care, especially also of people with dementia.<sup>103</sup> To date, over 200 doctors have already been certified.

<sup>99</sup> [www.bundesgesundheitsministerium.de/fileadmin/Dateien/5\\_Publikationen/Pflege/Berichte/6\\_Pflegebericht.pdf](http://www.bundesgesundheitsministerium.de/fileadmin/Dateien/5_Publikationen/Pflege/Berichte/6_Pflegebericht.pdf)

<sup>100</sup> [www.zqp.de/beratungsdatenbank](http://www.zqp.de/beratungsdatenbank)

<sup>101</sup> [www.pflege-gewalt.de](http://www.pflege-gewalt.de)

<sup>102</sup> [www.dgn.org/images/red\\_leitlinien/LL\\_2016/PDFs\\_Download/038013\\_LL\\_Demenzen\\_2016.pdf](http://www.dgn.org/images/red_leitlinien/LL_2016/PDFs_Download/038013_LL_Demenzen_2016.pdf)

<sup>103</sup> [www.dggpp.de/zertifikat\\_DGPPN\\_DGGPP\\_neu2.htm](http://www.dggpp.de/zertifikat_DGPPN_DGGPP_neu2.htm)



### Uniform national medication plan

The statutory mandate to introduce the national medication plan in standard care has been implemented by the **National Association of Statutory Health Insurance Physicians (KBV)** since 1 October 2017. Since then, if insured persons take or use at the same time at least three drugs prescribed at the expense of the statutory health insurance funds, they are eligible to the plan's implementation. This makes it easier for people in need of care, who are dementia patients and their relatives, to take the prescribed medication correctly. The KBV's authorised workshop has also developed the concept of a prevention programme for caring relatives together with the "Wir pflegen" self-help organisation. The aim of the contract is to minimise health risks and/or restrictions as well as to prevent further health restrictions for caregiving relatives resulting from the care. The prevention programme, which complies with the guidelines, starts with the family doctor as a trusted contact for this hard-to-reach patient group. It pursues the following objectives: maintaining and promoting one's own health, avoiding morbidity and premature mortality, avoiding incapacity to work, strengthening and stabilising the care setting at home, avoiding dangerous processes and promoting the provision and networking of counselling services.

### Prevention programme for caregiving relatives

### Cooperation agreements for good care

With Section 119b SGB V, which was introduced as part of the Nursing Care and Further Development Act, inpatient nursing facilities have been given the opportunity to conclude cooperation agreements with statutory medical service providers. Upon the nursing facility's request, the Association of Statutory Health Insurance Physicians must arrange cooperation agreements to ensure adequate medical care for insured persons in need of care at the nursing facility. Participating doctors receive additional remuneration. After the Hospice and Palliative Act included corresponding provisions in the standard doctor's fee scale (EBM) as of July 2016, the evaluation report on the cooperation agreements states that considerably more cooperation agreements have been concluded than before (as of 31 March 2017: 7,888 cooperation agreements with 3,034 care facilities). Since 1 January 2014, the Act to Reorient the Long-Term Care Insurance has also required fully inpatient nursing facilities to inform the regional long-term care insurance associations of how they regulate medical, specialist and dental care, as well as drug supply.

With the **Federal Association of Statutory Health Insurance Physicians (KBV)** and the **Federal Association of Statutory Health Insurance Dentists (KZBV)**, the **Federal Association of Private Social Service Providers (bpa)** has issued a model cooperation agreement on medical and dental care for nursing facilities and doctors. The model contracts, which are intended to improve the (dental) medical care of people in need of care, have been made available to the bpa nursing facilities and are applied practically. People with dementia will then no longer have to visit perceived strange premises such as doctors' surgeries, thus avoiding any associated insecurities and difficulties with orientation.

Together with the **GKV central association**, the CBV has not only made the appropriate preparations for concluding cooperation agreements but has also successfully implemented the agreement to promote cooperative and coordinated medical and

nursing care in inpatient nursing homes (Annex 27 to the Federal Master Agreement). On the basis of these agreements, over 63,000 patients were treated by almost 2,000 doctors in inpatient care facilities in the first quarter of 2017. In total, over 7,800 cooperation agreements between doctors and nursing facilities were concluded by the end of the first quarter of 2017. The framework agreement according to Section 119b SGB V and the objectives for quality and care, rules for cooperation and tasks of the cooperation dentists agreed therein have been included in model contracts which the KZBV has made available to its members. At the 2016 Capital Congress, the CBV discussed the care situation with the federal government (BMG) and representatives of nursing care within the scope of the contracts.<sup>104</sup> By the end of 2017, over 3,700 cooperation agreements had been concluded between dentists and nursing facilities across the country. This means that around 27 percent of all inpatient nursing facilities in Germany now have a corresponding cooperation agreement.

The Federal Joint Committee adopted the first version of a directive on measures for the prevention of dental diseases among patients in need of care and people with disabilities (directive according to Section 22a SGB V) on 19 October 2017. To maintain their oral health, patients in need of care and people with disabilities have been able to take advantage of additional preventive dental services that have been considering this group of patients' special needs since 1 July 2018. A further step towards prevention has been taken with the establishment of these services in statutory health insurance (GKV central association). As there have been no needs-oriented preventive services within the GKV benefits catalogue for these people in need of nursing care up to now, this is a milestone for people in need of nursing care and people with disabilities. With the new services, the KZBV has succeeded in implementing a central component of the "oral health despite handicap and old age" dental concept in the area. The inspiration for this was provided by the "Teamwerk" pilot project in Munich for preventive dental care of patients needing care. The KZBV and the associations for statutory insurance physicians and dentists will provide a wide range of information on these new preventive GKV services.

KZBV and bpa publish the views of the dental profession and the nursing profession in their member journals to raise awareness in the other profession to their own points of view.<sup>105</sup> The bpa, the **Federal Association of Non-statutory Welfare** (BAGFW), KZBV and the Bundeszahnärztekammer (the representation of dentists in Germany, BZÄK) have also jointly published a brochure on the topic of oral health - despite age, the need for care or a disability - in which information is provided on outpatient dental services. The brochure informs patients, their relatives and the staff of outpatient care services about the new offers for dental care offers in their own four walls.<sup>106</sup> The bpa and the BAGFW have informed their members accordingly.

### Additional preventive dental services

### Public relations

<sup>104</sup> [www.hauptstadtkongress.de/index.php?id=57&id\\_programm=50](http://www.hauptstadtkongress.de/index.php?id=57&id_programm=50)

<sup>105</sup> [www.zm-online.de/archiv/2016/10/politik/kooperation-fuehrt-zum-erfolg/](http://www.zm-online.de/archiv/2016/10/politik/kooperation-fuehrt-zum-erfolg/)

<sup>106</sup> [www.bpa.de](http://www.bpa.de)

### Information for doctors and psychotherapists

Through three publications in the “Praxiswissen” series, the **National Association of Statutory Health Insurance Physicians (KBV)** provides comprehensive information for statutory health insurance physicians and statutory health insurance psychotherapists. Among other things, the KBV has published its own brochure on the subject of dementia. It has also inserted the topic of dementia into the corresponding context in its publications on accessibility and immigration.

### Offers of palliative and hospice care

A project of the Technical University of Munich, Center for Cognitive Disorders at the Clinic for Psychiatry and Psychotherapy in **Bavaria**, has the goal of issuing a brochure to help people with advanced dementia make decisions. Based on an inventory of palliative and hospice care for people with dementia in an outpatient setting and in inpatient nursing care for the elderly, a brochure has been developed which shows the possibilities and offers of palliative and hospice care and contains information on the advanced stages of dementia, the legal basis for decision-making and ethical problems, treatment options and (palliative) treatment goals. It is subsequently recorded if reading the brochure has been helpful for relatives and encourages them to play an active role in the participative decision-making process. The results are to be incorporated in the brochure’s final modification.

#### 4.1.4 Care in an acute hospital

### Problematic change of location

People with dementia who come to an acute hospital due to another illness are under increased stress due to the change of environment. The unknown environment, altered daily routines, limited opportunities to keep busy and unaccustomed activities can pose a risk for the general state of health of the person in need of care. In addition, as a result, problematic behaviour can also develop, which can result in

### Priority of outpatient treatment

the increased use of sedative drugs. Therefore, particularly for people with dementia, the principle of “outpatient is better than inpatient” and “inpatient as briefly as possible” is very important. In their agenda, the organisation partners take this into account, among other things, by agreeing that existing dementia should be recognised and taken into account as quickly as possible when a patient is admitted to hospital. To this end, staff are being trained in dealing with dementia patients and the structures for the deployment of volunteers and cooperation with full-time staff improved.

### “GHoST” study

More than eight million elderly people per annum receive inpatient treatment in Germany. According to the GHoSt study sponsored by the **Robert Bosch Stiftung (RBS)**, 40 percent of all people over 65 in need of care in general hospitals have cognitive disorders; in 2016, almost one in five were suffering from dementia.<sup>107</sup> The secondary diagnosis of dementia is often not recognised at all upon being admitted to hospital. Unable to classify the strange environment and the unknown processes, the hospital situation places an additional burden on those affected. As everyday clinical practice is often hardly adapted to people with dementia, this also poses special challenges for hospital staff. More and more acute hospitals in Germany

<sup>107</sup> [www.bosch-stiftung.de/de/publikation/general-hospital-study-ghost](http://www.bosch-stiftung.de/de/publikation/general-hospital-study-ghost)

want to change this situation. RBS supports them in the development and implementation of concepts that specifically address the needs of people with dementia in need of care in acute hospitals.

In the context of three calls for tender of the “People with dementia in acute hospitals” programme in 2012, 2014 and 2016, 17 promising hospital projects were included in the funding.<sup>108</sup> Ranging from screenings, special treatment against pain and malnutrition, optimised processes and specific further training, up to adjustments in architecture and equipment, the approaches are very diverse.

On 23 and 24 May 2017, in Saarbrücken, the **federal government** (BMFSFJ) held a conference with over 100 representatives from science and medicine on the topic of “Dementia and Hospital - Building Dementia-Friendly Structures”. Concepts on dementia-friendly structures in hospitals were discussed and concrete needs for action were identified.

## Symposium

The Local Alliances’ practical experience demonstrates that concepts for dementia-friendly structures in hospitals are of particular importance for the establishment and further development of dementia structures in Germany. As a basis for further implementations, the results of the conference were summarised and published together with the 15 Local Alliances’ existing concepts.<sup>109</sup>

In cooperation with the **German Hospital Federation** (DKG), the **German Alzheimer Society** developed and subsequently published the “Mit Demenz im Krankenhaus” (In hospital with dementia) brochure within the scope of the Alliance for People with Dementia.<sup>110</sup>

The DKG is supporting the operators of hospitals in drafting a concept to enable patients with major cognitive limitations are more rapidly identified upon admission to hospital, even in emergency situations. Depending on needs, for example, special hospital admission for senior citizens with a separate treatment area, special room design, specially trained staff or a suitable screening instrument for the prevention and early treatment of emergency patients, hospitals have meanwhile developed and introduced a series of measures.<sup>111</sup> Additionally, the hospitals have developed numerous projects, such as training programmes for nursing staff and other occupational groups in hospitals, interdisciplinary medication and polypharmacy management, support for people with dementia in operating theatres, a Delir Pocket Card and a programme to support relatives. The DKG’s topic page “Dementia” presents some examples of best practice. The DKG supports hospital operators in developing professional concepts for designing rooms in hospitals that are suitable for the needs of people with dementia, as well as for appropriate assistance, support

## Concepts in hospitals

<sup>108</sup> [www.bosch-stiftung.de/de/projekt/menschen-mit-demenz-im-akutkrankenhaus](http://www.bosch-stiftung.de/de/projekt/menschen-mit-demenz-im-akutkrankenhaus)

<sup>109</sup> [www.lokale-allianzen.de/projekte/treffen-der-lokalen-allianzen/fachkonferenzen.html](http://www.lokale-allianzen.de/projekte/treffen-der-lokalen-allianzen/fachkonferenzen.html)

<sup>110</sup> [shop.deutsche-alzheimer.de/broschueren/19/menschen-mit-demenz-im-krankenhaus](http://shop.deutsche-alzheimer.de/broschueren/19/menschen-mit-demenz-im-krankenhaus)

<sup>111</sup> [www.dkgev.de/dkg.php/cat/451/title/Demenz\\_im\\_Krankenhaus\\_-\\_Best\\_Practice\\_Beispiele](http://www.dkgev.de/dkg.php/cat/451/title/Demenz_im_Krankenhaus_-_Best_Practice_Beispiele)

and daily structuring by trained staff and volunteers. Depending on the requirements, hospitals have introduced, for example, reminder rooms, reminder suitcases, the “Safeguarding patient autonomy for people with dementia” action guideline, special wards for people suffering from dementia, support for people in need of care by so-called everyday companions, selected activity programmes for people suffering from dementia in need of care, voluntary dementia controllers or seated guards for the night.

Through the framework agreement on discharge management in the transition to care after hospital treatment, the **GKV central association**, the **National Association of Statutory Health Insurance Physicians (KBV)** and the **DKG** have also taken into account the needs of people with dementia according to Section 39 Paragraph 1a SGB V. For example, as part of the initial assessment for patients with complex care needs, such as dementia patients, the necessary care-needs following hospital treatment are identified at an early stage so that a seamless transition to outpatient care can take place without any delay. The KBV has also developed a brochure on the adequate and sensitive treatment of dementia patients.<sup>112</sup>

With eight hospitals at eleven locations, a pilot project was launched in **Rhineland-Palatinate** in 2013 to improve the quality of life and care for people suffering from dementia while staying in hospital and to support hospital staff in dealing with this group of patients. The pilot project included a range of services for counselling in dealing with people with dementia, on the communication processes in hospitals and, above all, on the admission and dismissal process. In addition, a screening procedure was examined at the time of admission in which, with the consent of people aged 70 and older in need of care, a short standard test was carried to coordinate medical and nursing care right from the start. A brochure with recommendations was developed for caregiving relatives. The findings from the model process were communicated at regional conferences. In addition, a consulting service was created for hospitals in Rhineland-Palatinate who wish to better position themselves on this topic. “Inverso” offers advisory services and multiplier training for nursing staff.<sup>113</sup>

**Care consultants** According to 45 SGB XI, the **Federal Association of Private Providers of Social Services (bpa)** has around 3,000 specially trained nursing consultants across Germany who offer transition care, individual home training sessions and care courses. The transition from stationary accommodation to domesticity is to be facilitated and the consequent care safeguarded. There are special care courses for caregiving relatives of people with dementia in need of care, in which those affected receive information about the clinical picture, tips for dealing with people in need of care and the opportunity of exchanging information with other affected relatives. The training and care courses are an important component in supporting and relieving the burden from caregiving relatives. Thus, a national network of specifically

<sup>112</sup> [www.kbv.de/html/demenz.php](http://www.kbv.de/html/demenz.php)

<sup>113</sup> [www.inverso-mainz.de/](http://www.inverso-mainz.de/)

trained nursing consultants has been established in accordance with Section 45 SGB XI. The statutory care insurance companies inform their policyholders about the services provided by these care advisors free of charge.

#### 4.1.5 Qualified personnel

Only qualified personnel can provide high-quality care that meets patients' needs. The significance of dementia must therefore already be taken into account in nurse training. In view of demographic developments, there is an increasing need to recruit qualified nursing personnel. The organisation partners have agreed that the shortage of skilled workers must be countered and the job must be made more attractive in its description. To this end, the knowledge of curative education and care for the elderly must be better interlinked and multi-professionalism promoted.

#### Dementia in training



The law on reforming the nursing professions (PflBRefG) has created a decisive foundation for a sustainable and high-quality new nursing education. By creating more and more diverse training and employment opportunities close to places of residence throughout Germany, putting an end to paying tuition fees and guaranteeing an appropriate training allowance, the **federal government** (BMFSFJ and BMG) is thus increasing the attractiveness of the nursing professions. Furthermore, there will be additional opportunities for change, deployment and promotion. Introducing a nursing course of study directly for working with people in need of care will boost the entire occupation's professionalisation. Defining

#### Reform of the care professions

reserved activities, which may only be performed by appropriately trained nursing staff, also contributes to this.

The **Federal Association of Private Providers of Social Services** (bpa) has been actively involved in the legislative process and is committed to the consideration of care for the elderly - in which particularly caring for dementia patients is also taken into account. The bpa has also played a major role in drafting the financing ordinance for the new nursing training. The bpa will accompany the further implementation of the new training for nurses and will work to ensure that the interests of elderly care - and thus of people with dementia in need of care - are also taken into account in the new training content and practical applications. Via practical assignments and the chosen focus of training, the students many select elderly care as a professional field within the framework of the training. A transitional period has been agreed

#### Accompanying nursing training



to examine the extent to which the new training will have a positive effect on the shortage of skilled workers.

Pursuant to Section 56 (4) PflBG, the **GKV central association** has played a key role in coordinating the recommendations' preparation on financing vocational training in care.

### Generalist education

By advocating the interests and general conditions for carers, people and clients in need of care, the **German Nursing Council (DPR)** has been actively involved in various legislative procedure. In line with the "Alliance for People with Dementia", for example, it will ensure that the examination regulations for training and the curricula for generalist training are sufficiently taken into account of the topic of dementia and the care and treatment of dementia patients. To contribute to the building of networks, it will also inform its member organisations about developments, work results and publications. The law on nursing professions introduces a new general nursing education with the vocational qualification "nursing specialist", which enables people of all ages to be cared for in all areas of care. At the same time, it still remains possible to achieve separate degrees in nursing care for the elderly and in health and paediatric care. However, trainees who see their focus in caring for elderly people or caring for children and young people can choose whether they - instead of continuing the general training - want to acquire a separate degree in geriatric care or paediatric nursing. In the third year of training, apprentices who take advantage of this right to choose can then undergo training that is specifically geared to the special needs of paediatric nursing or care for the elderly. The training then ends with the "health and paediatric nurse" vocational qualification or the "geriatric nurse" vocational qualification. The DPR points out that in the third year of training, future nursing professionals who want to devote themselves in particular to nursing care for the elderly have the opportunity to choose between general nursing training with specialisation and the vocational qualification of nursing care for the elderly. The expanded development and employment opportunities and better financing of training, especially for trainees in nursing care for the elderly, make this profession more attractive. The new law on nursing professions also regulates primary qualifying nursing training at universities (Section 37 PflBRefG). The programme should last at least three years and qualify as a nursing specialist in addition to a Bachelor's degree. The programme is intended to address new target groups and open up further career opportunities, especially in direct nursing care. The educational goals of the general nursing training are extended on the basis of scientific nursing knowledge.

### Training and examination regulations

By combining the field of learning "Care of the elderly with dementia and geronto-psychiatric conditions", provided for in the regulations for training and examination for the occupation of geriatric nurse, with other fields of learning – in the spirit of a spiral curriculum – the federal states support geriatric nursing schools in such a way that the topics of counselling (of patients and caregivers) and inclusion – particularly also in the sense of intercultural nursing – are implemented.



At the **Standing Conference of Ministers of Education and Cultural Affairs (KMK)**, the federal states coordinated their efforts and agreed on the “Examples of good practice for linking the learning area of dementia with other learning fields in nursing care for the elderly” material. The spiral curricular teaching procedure is presented as an example in this material at three nursing schools for the elderly. In a sustainable way and right from the beginning of their training, students in nursing care for the elderly should learn by linking the subject of dementia in their lessons to understand the background to problem situations and the life of dementia patients. The regulations, dated 26 November 2002, on training and examinations for the profession of geriatric nurse (AltPflAPrV) stipulates a minimum of 2,100 hours for the theoretical and practical instruction of the three-year vocational training course. Of these, the largest contingent of 720 hours relates to the learning area “Care for elderly people and situational care” (AltPflAPrV, Annex 1). The reference to dementia can be found in the “Care of dementia and geronto-psychiatrically altered elderly people” study area. Using didactic examples, it is discussed here how the learning field in spiral curricular can be linked with other learning fields within nursing care for the elderly. Some questions are, for example: How does dementia change the care process? What effects does this disease have on medical diagnostics, how can living space and living environment be designed for people suffering from dementia and what tensions can arise in the nursing relationship with those affected? To safeguard that students’ skills in nursing care for the elderly are continuous and sustainable, links connect the teaching topic of dementia with other fields of learning. The listed examples of good practice are exemplary for the spiral curricular connection between the learning field of dementia and other learning fields in nursing care for the elderly. They are intended to provide further support to teachers at nursing schools for the elderly in their teaching approach to the subject. The federal states are working towards the development and testing of appropriate qualification modules at institutes of higher education. The **Standing Conference of Ministers of Education and Cultural Affairs (KMK)** coordinates all relevant topics in the field of science and research at federal state level. To present the qualification modules within the framework of a nursing study-course, among other things, the universities have presented a detailed, exemplary and thus not final overview, which is attached to this report.

To meet the demand for skilled workers in nursing care for the elderly, the **federal government (BMFSFJ)** and the federal states and associations launched the “Training and Qualification Campaign for Nursing the Elderly” in December 2012. As a strong community initiative with a three-year term until the end of 2015, the training offensive met the challenges for the training, occupational and employment field with the aim of promoting initial, continuing and further training in geriatric care and increasing the occupational and employment field’s attractiveness through a comprehensive package of measures. While some measures were limited to the offensive’s duration, others are designed for the long term. While simultaneously and permanently reinforcing the possibility of shortening training if appropriate previous knowledge was available, the temporary reintroduction of three-year retraining support by the Federal Employment Agency for the duration

## Dementia in nursing training courses

## Qualification modules

## “Training and qualification campaign for nursing the elderly”

**“Consulting team for geriatric training course”**

of the training offensive was one of the offensive’s main objectives. This target agreement was implemented with the Act to Strengthen Vocational Education and Training in Nursing Care for the Elderly, which came into force on 19 March 2013. For starting training in nursing care for the elderly, the employment agencies and the job centres were thereafter once again able to provide three-year support to nurses for continuing vocational training for the elderly between 1 April 2013 and 31 March 2016. After an initial extension until the end of 2017, the law on nursing professions (Federal Law Gazette I 2017, 2581) allowed the possibility of an extended three-year funding for all retraining courses begun up to 31 December 2019 for training nursing staff for the elderly. For the new nursing training courses under the law on nursing professions, which will begin on 1 January 2020, the three-year funding opportunity has been permanently guaranteed. The training offensive also contributed to a considerable increase in the number of trainees in nursing care for the elderly, which has since been maintained. According to the education statistics of the Federal Statistical Office in 2016/2017, around 68,300 people were currently undergoing training as nursing staff for the elderly. This represents a new record value to date. Since commencement of the training offensive, the “Senior Care Training Advisory Team” set up by the BMFSFJ at the Federal Office of Family Affairs and Civil Society Functions (BAFzA) has been providing advice and information to nursing facilities, nursing schools for the elderly and all those interested in nursing care for the elderly across the nation with approximately 30 advisors. Nursing facilities are advised on the implementation of high-quality training and motivated to create new training places. Training associations and networks are also being organised. This continued offer now also includes the reform of the nursing professions and is supplemented by the BMFSFJ’s website.<sup>114</sup>



<sup>114</sup> [www.altenpflegeausbildung.net](http://www.altenpflegeausbildung.net)

In addition to training in nursing, the qualification of existing personnel plays an equally important role in the Alliance for People with Dementia. For the treatment of dementia patients, the **German Medical Association** (BÄK) has developed a large number of advanced training measures for physicians, which are recognised by the state medical associations and established throughout the country.

### Training activities

#### 4.1.6 Quality of care

High-quality care for people with dementia must be geared to the needs of those affected to maintain and support their independence and quality of life. In this context, the new term “need for care” has significance in terms of its function as a decisive basis for describing the group of persons who have access to services. The degree of independence of those in need of care is a new yardstick for the need for care.

On behalf of the **federal government** (BMG), expertise was developed to structure and describe nursing tasks on the basis of the new term “need for care” in 2017. This structuring and description is to be regarded as a suitable technical basis for a common understanding of care and is to be used for the adaptation and further development of technical concepts and agreements in care in the sense of maintaining and supporting independence and quality of life. Other aspects, such as staffing, employee qualification and appropriate personnel and time management are also important. The organisation partners also aim to limit bureaucracy to what is necessary and to increase the efficiency of nursing documentation.

The “structural model”, to reduce bureaucracy in nursing documentation, was developed in 2013 on behalf of the **federal government** (BMG) together with experts and practitioners. In a comprehensive practical trial, the structural model has proven its worth and was introduced throughout Germany at the beginning of 2015. The model significantly reduces the need for keeping records without compromising on quality or raising liability issues.

### Cutting down on the red tape involved in the care documentation

The project is being implemented by the care commissioner of the federal government, state secretary Karl-Josef Laumann, together with the central associations of the facility and funding agencies and the municipalities, the Health Insurance Medical Service, the auditing service of the German Association of Private Health Insurers (auditing service, PKV), the association of the caring professions and the federal states. The associations of care institutions offer training courses for non-bureaucratic care documentation for outpatient care services and inpatient care institutions and accompany the implementation on site. The goal of integrating a quarter of all nursing facilities throughout Germany was quickly achieved. After the de-bureaucratisation of nursing documentation was successfully implemented in outpatient and fully inpatient care, the structural model for day and short-term care facilities was modified, tested and then offered in training courses

for all day-care facilities. At the end of October 2017, more than 10,550 care facilities, i.e. almost every second facility in Germany, were already participating. Since November 2017, the associations responsible for nursing care for the elderly have been continuing the project at national level on their own responsibility.

## 5. Field of action overarching measures

The four fields of action described contain measures that can be assigned to coordinated contributions in specific thematic areas. In addition, the partners have carried out projects and developed strategies that pursue an overarching thematic intention and are therefore to be presented separately in this chapter.

### “Local Alliances for People with Dementia”

The **federal government** (BMFSFJ) has implemented several measures mentioned in this report whose contents could be located in several fields of action. These include the model programme “Local Alliances for People with Dementia”, in which help networks are set up in the living environment of dementia patients that help them to remain in their familiar social environment for as long as possible.

The “Guide to Dementia” central online portal, by the BMFSFJ, also offers comprehensive information on medical backgrounds and legal services, information for specialists, tips for everyday life with people with dementia and information on acute situations.<sup>115</sup> In addition, it offers regular news, advice and specialist forums and an address database for counselling and support services. A constantly updated weblog on its portal, provides tips for everyday life with patients as well on the medical and legal aspects of dementia, the e-learning module for people who are starting to care for dementia patients and a variety of video films that demonstrate the various aspects of the agenda’s agreements, in addition to brief insights into life with dementia. As an interactive online portal, the “Guide to Dementia” is also linked to the Internet portal of the Local Alliances<sup>116</sup> and the Alliance for People with Dementia.<sup>117</sup> The “Points of contact in the neighbourhood for elderly people” programme is aimed at promoting offers in the immediate living environment - the local neighbourhood - and at establishing low-threshold assistance that enables participation and commitment, but also, if necessary, help, care and support in care. With their intergenerational approach, low-threshold offerings, openness and needs-orientation, multi-generation houses are hubs in the respective social space. The **federal government’s** (BMFSFJ) funding of multi-generation houses has seamlessly continued with the federal programme for multi-generation houses, which has been running since January 2017. One of the goals it pursues is to intensify the municipal anchoring of multi-generation houses and to integrate the multi-generation houses into the long-term coordination when planning welfare facilities in municipalities.

### Multi-generation houses

<sup>115</sup> [www.wegweiser-demenz.de](http://www.wegweiser-demenz.de)

<sup>116</sup> [www.lokale-allianzen.de](http://www.lokale-allianzen.de)

<sup>117</sup> [www.allianz-fuer-demenz.de](http://www.allianz-fuer-demenz.de)

With the long-term care enhancement laws, the **federal government** (BMG) has established framework regulations for the design of a well-coordinated “help mix” comprising full-time care and care by relatives or volunteers and has thus improved existing regulations. The following regulations can be implemented by those affected:

- The services to support on-site care at home have been expanded, for example, by introducing nursing care as a new standard service in home-care assistance, by expanding day, night and short-term care services and by expanding low-threshold services to relieve the burden on everyday life.
- Agreements between the municipalities and the long-term care insurance funds should improve cooperation between the local counselling centres. To this end, it is also planned to set up an information network on the locally available support services, which can be used by the advice centres.
- Self-help groups and other groups of volunteers have been given the opportunity to participate at the district and city level in the care networks funded by the long-term care insurance system.
- If relatives care or want to care for people in need of care voluntarily, they can take part in a nursing course offered by the long-term care insurance fund free of charge. As a result of the long-term care enhancement laws, the courses are now mandatory for every long-term care insurance fund. These courses are partly offered in partnership with non-governmental welfare organisations, adult education centres, local assistance services or educational institutions. They offer practical guidance and information as well as advice and support on many different topics.
- Persons in need of care, who only receive care allowance or, who in addition to receiving care allowance, use the benefit amount of the outpatient care benefits exclusively for everyday support services are obliged in accordance with federal state law to book at-home counselling once every six months for care grades 2 and 3 and once every three months for care grades 4 and 5. This home counselling serves to ensure the quality of home care and the regular assistance and practical support of home caregivers. With the long-term care enhancement laws, the possibility of requesting these advisory visits in accordance with Section 37 Paragraph 3 SGB XI was also extended to include recipients of care services from outpatient care services to persons in need of nursing level 1. Once every half-year, they may make use of the home counselling visits. According to Section 7a SGB XI, persons in need of care and those caring for them at home are also to be provided with the information, counselling and offers of support to the care support centre responsible for them as well as to care counselling. The commissioned nursing service, the recognised counselling centre or other counselling institution within the meaning of Section 37 SGB XI must ensure that nursing staff who have specific knowledge of the symptoms of the illness and disability and the resulting need for help of the patient and have special counselling competence are deployed for a counselling visit in the domestic area.

## “Help Mix” by long-term care enhancement laws

### Information network

### Free care courses

### Counselling options

### Supporting volunteers

- The development and expansion of offers for support in everyday life and for supporting other groups of volunteers as well as other persons who are willing and voluntarily demonstrate civic commitment has been allocated particular funding. As part of the funding under Section 45c SGB XI, long-term care insurance provides EUR 25 m per calendar year to further develop care structures and care concepts, as well as to promote voluntary structures using funds of the compensation fund; this means that an annual funding volume of at least EUR 50 m can be achieved together with the partial financing of the federal states and local authorities. Among other things, this supports voluntary initiatives aimed at providing support, general care and burden relief for people in need of nursing care and their family-members, as well as caregivers who are similarly close.
- Ten cents per calendar year and per insured person are also paid in long-term care insurance to promote, establish and expand self-help groups, organisations and points of contact which have set themselves the goal of supporting people in need of care as well as their family-members and similarly close relatives.

### Bavarian dementia strategy

The Bavarian Dementia Strategy has been implemented across all departments in **Bavaria**, since 2013. Changing awareness in society when dealing with the topic of dementia and the preservation of self-determination and dignity of those affected in all phases of the disease are the key objectives. The Bavarian Dementia Strategy aims at improving the living conditions and quality of life for those affected and their relatives as well as their opportunities to participate in social life and to ensure appropriate care, nursing and medical care geared to their needs. The comprehensive objectives of the Bavarian Dementia Strategy are defined in ten fields of action, in each of which a large number of projects are carried out.<sup>118</sup>

### National Dementia Committee Rhineland-Palatinate

The Dementia Committee of **Rhineland-Palatinate** is working on a networking and participation process in Rhineland-Palatinate's dementia strategy, which was preceded by revising the approaches developed in an expert forum from 2003.<sup>119</sup> The expert forum issued recommendations in 2014, which are to be implemented together with the members of the National Dementia Committee. The aim of the dementia committee is a multi-professional and interdisciplinary exchange and participation process, which understands the care, counselling and support of people with dementia as a task for society as a whole, bundles and networks the co-operation of the various stakeholders in a targeted manner and thereby strengthens the socio-spatial support systems.

### Dementia plan for Schleswig-Holstein

The state parliament of **Schleswig-Holstein** decided in 2015 to draw up a dementia plan for Schleswig-Holstein. It will help to meet the urgent challenges in caring for dementia patients and their families and in identifying the necessary structural developments. Following the presentation of the dementia plan, it was adopted by the Schleswig-Holstein state parliament in March 2017.<sup>120</sup> With the renewal of the Dementia Competence Centre in 2017, the implementation of a large part of

<sup>118</sup> [www.leben-mit-demenz.bayern.de](http://www.leben-mit-demenz.bayern.de)

<sup>119</sup> [msagd.rlp.de/de/unsere-themen/gesundheit-und-pflege/pflege/demenzstrategie/](http://msagd.rlp.de/de/unsere-themen/gesundheit-und-pflege/pflege/demenzstrategie/)

<sup>120</sup> [www.demenzplan-sh.de/wp-content/uploads/2015/01/Bericht\\_Demenzplan-2017\\_WEB.pdf](http://www.demenzplan-sh.de/wp-content/uploads/2015/01/Bericht_Demenzplan-2017_WEB.pdf)



the dementia plan's recommendations were set forth in the catalogue of objectives and measures of the Dementia Competence Centre.<sup>121</sup> To monitor success and thus enable the dementia plan to be updated in the future, results are summarised in a monitoring procedure.

One in ten people over 65 years of age in **Saarland**, suffers from dementia. Under the scientific supervision of the iso-Institut and in a participatory process in cooperation with the Dementia Office of the State of Saarland and any interested parties, the Ministry of Social Affairs, Health, Women and Family, developed 29 specific measures during 2016 in several workshops to fill the plan's title of "Together for a dementia-friendly Saarland" with content.<sup>122</sup> The first interim balance sheet was drawn up in December 2016.<sup>123</sup> The database of the federal state's Dementia Department, which provides information on projects and offers, is regularly updated.<sup>124</sup> At the end of 2018, the second dementia plan will be drawn up in Saarland, taking into account the findings to date.

### "Together for a dementia-friendly Saarland"

With the aim of enabling people with dementia and their families to lead a good life with a new culture of help, even with dementia, **Brandenburg**, sponsored by the Alzheimer Gesellschaft Brandenburg, supports the Dementia Competence Centre as part of its care offensive.<sup>125</sup> As a service provider, the Dementia Competence Centre provides knowledge and action competence to all multipliers in the care system in the state of Brandenburg. It focuses on the four fields of action of public relations work, expanding offers of self-help offers for people with dementia and their relatives, competence development of network partners and stakeholders in standard care, as well as cooperation with science and politics. The aim is to secure the quality of life of people with dementia and their relatives by intensifying the competence of the stakeholders involved. Processes have been started in all four fields of action and/or results are already available.

### Dementia Competence Centre

In **Hamburg**, the State Initiative for Living with Dementia (LLmD) was launched by the Ministry of Health and Consumer Protection to promote the establishment of further networks and to intensify the exchange of experience and cooperation between different areas of society.<sup>126</sup> Its aim is to improve living conditions for people with dementia and their relatives. In addition to kick-off and summary events, the Hamburg stakeholders have been meeting in working groups since 2012; they have been analysing the initial situation in Hamburg, presented their fields of work, exchanged ideas and coordinated tasks since 2013. The interactive work process has resulted in various guides and other publications.

### "Living with dementia" federal state initiative

<sup>121</sup> [www.demenz-sh.de/](http://www.demenz-sh.de/)

<sup>122</sup> [www.saarland.de/136770.htm](http://www.saarland.de/136770.htm)

<sup>123</sup> [www.saarland.de/218776.htm](http://www.saarland.de/218776.htm)

<sup>124</sup> [www.demenz-saarland.de](http://www.demenz-saarland.de)

<sup>125</sup> [demenz-brandenburg.de/](http://demenz-brandenburg.de/)

<sup>126</sup> [www.hamburg.de/landesinitiative-leben-mit-demenz/](http://www.hamburg.de/landesinitiative-leben-mit-demenz/)



**Dementia Atlas in Hesse**

In **Hesse**, the Dementia Atlas is an offer for those affected, caregiving relatives and those who are professionally and voluntarily committed.<sup>127</sup> In the Internet-based portal, which can be accessed throughout the federal state, you will find local offers, initiatives, services and facilities in Hesse that offer support for dementia. The Dementia Atlas in Hesse is a pilot project of the Hessian Ministry for Social Affairs and Integration and the long-term care insurance funds. It aims at creating transparency throughout Hesse regarding existing care structures for dementia patients and their relatives. The Internet portal went online on 28 November 2017 with approximately 1,000 registered offers. The activation was accompanied by a large specialist day. The portal is being constantly expanded, extended by further categories and the number of registered offers is rising. On this basis, a region where the establishment of a regional network can be supported should be identified.

**“Dementia Service”  
state initiative**

In cooperation with the state long-term care insurance funds and the private long-term care insurance, **North Rhine-Westphalia** has been gradually establishing the “Dementia Service” federal state initiative since 2004. Here, twelve dementia service centres with regional responsibility, another one for people with a migration background and, from 2018 on, another one for people with hearing impairment will perform a general advisory, innovation and networking function for dementia-related activities.<sup>128</sup>

**Dementia-friendly community**

The **central associations of local authorities** (Deutscher Landkreistag, Deutscher Städtetag, Deutscher Städte- und Gemeindebund) are committed to ensuring that local communities (towns, districts and municipalities) ensure the best possible quality in accompanying people with dementia and their relatives. Many communities promote a dementia-friendly climate in their neighbourhoods by providing targeted information and counselling services, such as signposts to the help system, maps with care and support services or other aids for orientation. In addition, the topic of dementia plays a role in policy strategy framework concepts for seniors in districts and cities, which are increasingly striving to combine challenges of demographic change, social space orientation, policy offers for seniors and care structures for the elderly with issues of nursing care and offers for people suffering from dementia and to tackle them in an integrated manner. In promoting civic engagement, many municipalities are also becoming increasingly concerned with the social and cultural participation of people with dementia. At the same time, there are further training opportunities, for example for dementia counsellors. In this context, numerous districts and cities are coordinating networks for dementia. The aim is to network and optimise existing aids for people with dementia. Impulses are also given to establish and expand new assistance, not least with a view to assistance systems that support everyday life and age-appropriate technologies. Besides this, local authorities are increasingly paying attention to the special needs of people with dementia, not only in housing counselling, but also in designing the living environment. These include local projects to support orientation out-

<sup>127</sup> [www.demenzatlas-hessen.de](http://www.demenzatlas-hessen.de)

<sup>128</sup> [www.demenz-service-nrw.de/](http://www.demenz-service-nrw.de/)

side the home as well as to secure local public transport, especially in rural areas, and to promote its use. As local support authorities, counties and cities have in recent years been focusing even more intensively on issues of local legal precaution. They support local authorities in providing information and advice on all general questions surrounding health care proxies and living wills, and in referring patients to assistance programmes that help to avoid the need for guardianship. These include, for example, the recommendations issued jointly by the Deutscher Landkreistag (German association of administrative districts) and the Deutschen Städtetag (German association of cities) on “Recommendations for the provision of other assistance”<sup>129</sup> as a new task for the local care authority, as well as the recently revised “Recommendations for care authorities in the selection of caregivers”.<sup>130</sup> In general, the central associations of local authorities see themselves as multipliers for the important topic of dementia and regularly promote the exchange between cities and districts in their association committees, in working groups, in membership circulars or events. Furthermore, the associations promote the annual “Dementia Week” and, to support the external networking of the Alliance for People with Dementia, have been involved in the relevant public relations working group for several years. Developing and providing advertising materials for municipal events and the disseminating the topic via social media play an important role here. The publication of good examples from municipal practice - for example in “Der Landkreis”, the monthly journal of the Deutscher Landkreistag - rounds off this commitment.<sup>131</sup> The districts and cities also offer their support with regard to health care, especially for people suffering from dementia. This is done primarily by networking and coordinating the population’s medical care, whereby nursing care must always be taken into account. For this reason, the **central associations of local authorities** in the working group of the federal and state governments have submitted extensive proposals in the “Sozialraumorientierte Pflege stärken durch wirkungsvolle Einbeziehung der Kommunen” (Strengthening socially oriented care through effective involvement of the municipalities) paper to strengthen the role of the municipalities in care.<sup>132</sup> In addition, central associations local authorities extensively support the implementation of the second and third long-term care enhancement laws, which has introduced the new concept of the need for care to take into account the interests of people with dementia in care insurance and social assistance.

<sup>129</sup> [www.kreise.de/\\_cms1/images/stories/publikationen/DLT\\_Bd\\_126\\_4\\_Auflage\\_6te\\_UPM\\_Ansicht.pdf](http://www.kreise.de/_cms1/images/stories/publikationen/DLT_Bd_126_4_Auflage_6te_UPM_Ansicht.pdf)

<sup>130</sup> [btdirekt.de/images/dateien\\_pdf/anforderungsprofil-fuer-betreuer-2013.pdf](http://btdirekt.de/images/dateien_pdf/anforderungsprofil-fuer-betreuer-2013.pdf)

<sup>131</sup> [www.landkreistag.de/publikationen/fachzeitschrift-qder-landkreisq.html](http://www.landkreistag.de/publikationen/fachzeitschrift-qder-landkreisq.html)

<sup>132</sup> [www.kreise.de/\\_cms1/images/stories/themen/Senioren/150223%20BV%20Konkretisierter%20Vorschlag%20Rolle%20der%20Kommunen%20in%20der%20Pflege.pdf](http://www.kreise.de/_cms1/images/stories/themen/Senioren/150223%20BV%20Konkretisierter%20Vorschlag%20Rolle%20der%20Kommunen%20in%20der%20Pflege.pdf)



## IV. Outlook

The implementation of the “Together for People with Dementia” agenda is a four-year process supported by the joint actions of the Alliance for People with Dementia and summarised in the presentation of this report according to the agreement.

The report is a concise consideration of the agenda’s important implementation steps and is a central building block for the Alliance’s further development. Many of the aforementioned measures, as well as the approximately 450 measures taken by the partners in the implementation process, will continuously improve the situation of people with dementia. In addition to the measures and projects described in this report to date, the design and cooperation partners have initiated and implemented a large number of initiatives, projects and strategies that will continue to pursue and support the objectives formulated in the agenda.

In this chapter, such measures are presented as examples and the efforts needed to continue and further develop the work of Allianz are shown.

The new training for nurses will begin on 1 January 2020. The Act on Nursing Professions takes account of the fact that the requirements for professional nursing have become more complex and the need for well-trained nursing staff is growing - also due to demographic developments. The previous training courses in health and nursing, health and paediatric nursing and geriatric care will be merged into generalist training for all areas of care. In addition, there is still the possibility of separate degrees in paediatric nursing and nursing for the elderly. The reform will adapt nursing training to the changed care structures and nursing needs and create the basis for attractive, future-oriented nursing professions. In addition, the new general training for nurses prepares students for universal employment in all general nursing fields, facilitates a change between the individual nursing areas and opens up additional opportunities for use and advancement. In the future, tuition fees will not have to be paid and sufficiently comprehensive and high-quality instruction will be ensured. An appropriate training allowance also remains enshrined in law. In addition to vocational nursing training, there will also be a course of study in nursing which qualifies students for a profession in care. The course of study will end with the award of an academic degree. The nursing course will open up new career opportunities and appeal to new target groups. In addition, it will more easily enable the improved incorporation of the constantly advancing knowledge in nursing science into nursing practice. In agreement with the **Federal Ministry of Health (BMG)** and the **Federal Ministry for Family Affairs, Senior Citizens, Women and Youth (BMFSFJ)**,

### Around 450 measures

### New training for nurses

### Vocational qualification in nursing studies

the contracting parties at federal level have been legally mandated to ensure the development and testing of a scientifically based procedure for uniform assessment of personnel requirements in nursing facilities (outpatient and inpatient) according to qualitative and quantitative standards (Section 113c SGB XI) within the framework of the second long-term care enhancement laws by 30 June 2020 (PSG II). Taking into account the concept of the need for care that has been in force since 1 January 2017, uniform standards must be determined that take particular account of qualification requirements, quantitative needs and the technical adequacy of the measures. The scientific work for this procedure is currently underway. In 2020, the personnel assessment procedure will for the first time provide a uniform nationwide instrument from which specific standards for the staffing of nursing facilities can be derived.

Future-oriented decisions have also already been made in the area of research:

#### **Cross-border coordination**

The **federal government** (BMBF) is part of the “EU Joint Programme - Neurodegenerative Disease Research” (JPND) and the “ERA-Net NEURON”. With JPND focusing on neurodegenerative diseases, the aim of both activities is to coordinate research in the neurosciences. This has already been achieved in part and is being further developed. Both JPND and NEURON have developed strategic research agendas that are coordinated with the national research agendas of the participating countries. In addition, the number of countries involved is continuously on the rise. Particularly JPND has developed from a purely European to an international initiative. Global visibility and networking are to be further expanded in the coming years.

#### **Continuation of collaborative projects**

With the funding priority “Innovative care for people with dementia”, the BMBF funds research and development projects on innovative human-technology interaction in care that support and relieve burdens from people with dementia, relatives and professional carers while going beyond the current state of the technologies developed to date. The key objective is to increase self-determination and the quality of life of all those affected. The ten collaborative projects were successfully launched in 2015 or 2016 and will run until 2018 and 2019 respectively. The projects met on 25 January 2018 to network and exchange information. The focus was on experiences and methods for the participatory development of technologies and issues regarding the evaluation of their benefits and their practical implementation. The results are to be incorporated into nursing practice after the project’s completion. To this end, in addition to the overall recovery target, the projects have also formulated organisation-specific recovery targets.

As part of the “Studies in care and nursing research for older and very elderly people” programme, the federal government (BMBF) is funding two research consortia related to dementia: “AgeWell.de” and “intersec-CM”. The two collaborative projects were successfully launched in 2017 and will be completed by 2021. The results will then be incorporated into the complex care and nursing situation of elderly and very elderly people to improve their functionality, self-determination, social participation and health-related quality of life.

Due to the great national interest in the “Barrier-free building guide” and the importance of implementing accessibility at European and international level, the guide was translated into English by the **federal government** (BMU) and published in January 2015. The updated version is expected to be available in the third quarter of 2018. The digital guide is published online.<sup>133</sup> If any technical conditions change, it is updated quarterly. Since the middle of this year, the guideline has been evaluated by those involved in construction, in particular the project managers of building authorities, commissioned planners, architects and representatives of severely disabled people. As the survey is still ongoing, detailed results are not yet available. At the same time, the digital guide is being tested in pilot projects (twelve projects from nine German states). The test phase ran until mid-2018. In addition, expert interviews are being conducted regarding the experiences made when applying the guidelines and concepts, and evidence on accessibility is being compared and analysed. The final report is expected to be available in December 2018. In the coalition agreement, the topic of accessible construction is present in connection with the “Renovation for the Elderly” KfW programme and the governing parties have agreed to consolidate and further develop the programme.<sup>134</sup>

### “Barrier-free building guide”

Further efforts and improvements are needed in the area of freedom of mobility and protection for people suffering from dementia. Measures to restrict liberty (FEM) constitute interference in human rights and must therefore be avoided. The findings of the “ReduFix” project, among other things, to avoid fixation close to the body, must be implemented. This requires economic and personnel resources for the operators of inpatient nursing facilities.

### Freedom of mobility and protection for people with dementia

The **federal government** will fund a research project with the goal of determining the possibilities for reducing pharmacological restraining measures. For this purpose, the results of the “IMPRINT” and “EPCentCare” research projects conducted at the Medical Faculty of the Martin Luther University Halle-Wittenberg (Institute for Health and Nursing Science) are being evaluated. To avoid measures which restrict liberty in old people’s and nursing homes and examined with regard to their effectiveness and safety, two variants of a guideline-based intervention programme have been implemented as part of the “IMPRINT” research project funded by the **federal government** (BMBF). In the “EPCentCare” project, which is also funded by the BMBF, a programme to promote psychosocial care in nursing homes, supposed to reduce the prescription of anti-psychotics, has been tested.

<sup>133</sup> [www.leitfadenbarrierefreiesbauen.de](http://www.leitfadenbarrierefreiesbauen.de)

<sup>134</sup> [www.bundesregierung.de/Content/DE/StatischeSeiten/Breg/koalitionsvertrag-inhaltsverzeichnis.html](http://www.bundesregierung.de/Content/DE/StatischeSeiten/Breg/koalitionsvertrag-inhaltsverzeichnis.html)

**“Dementia Competence  
Centre for M-V”**

Over the next few years, with the “Dementia Competence Centre for M-V”, the **German Alzheimer Society of Mecklenburg-Western Pomerania** will establish, analyse and maintain quality assured care structures for people with dementia. This will close any quantitative and qualitative gaps in care. To this end, a database of key players nationwide and a map of various dementia-related aids are planned. Networking is to be expanded. In addition to the structures of self-help, voluntary helpers and various initiatives on the subject of dementia, the network will also include the associations responsible for outpatient and inpatient care for the elderly, registered doctors, counsellors, social workers as well as hospitals, police and fire brigade. Professional advisory structures are to be established and expanded together with the care support centres. Exchanging experience, knowledge and information are further important building blocks. So far, a variety of measures have been initiated, organised, supported or carried out, for example the presentation of the pilot project to the municipalities, professionally active stakeholders in the context of dementia care, providers of inpatient and outpatient facilities for elderly care, self-help initiatives, experts from science, research and medicine as well as the health and long-term care insurance funds. Joining together a widely ramified dementia support network and expanding it further, also taking into account Section 45c Para. 9 SGB XI, has also been successful; events, information days, “Demenz Partner” training courses and working groups on the topic of dementia have been held. Furthermore, a data collection form for the Internet database has been developed, as have offers for dementia support, information materials have been compiled and the Internet presence expanded. The aim is that the experiences and findings from the project will be expressed in recommendations for a dementia strategy for Mecklenburg-Western Pomerania at the end of the project in 2020.

**Outlook of the  
federal government**

The Alliance’s work over the last four years for people with dementia has shown that some important successes have been achieved together. At home and abroad, the Alliance is regarded as a remarkable alliance between the federal government and civil society. In the coalition agreement, the parties supporting the federal government have agreed that people with mental illness or dementia and their relatives need good medical care and above all social connections. It continues: “Together with the federal states, all relevant stakeholders and with the involvement of people with dementia, we will continue to develop the “Together for people with dementia” agenda. The federal government will develop the Alliance for People with Dementia into a National Dementia Strategy together with all stakeholders. Taking into account national and international dementia plans and strategies and on the basis of good experience with specific agreements between various partners in Germany, new common goals are to be formulated and binding measures defined. The overarching goal of a National Dementia Strategy is to improve the quality of life and participation of people with dementia and their caregiving relatives. People with dementia should be able to stay in the midst of society as long as possible. In addition to good medical and nursing care and rehabilitation measures, competent treatment of people with dementia will also be important in the future, whether in doctors’ surgeries, hospitals or in public offices. Above all, social participation is to be further promoted by educating the population and by integrating those affected



into good network structures at local level with coordinated provision and support services.

The federal government intends to initiate the development of a National Dementia Strategy during this legislative period; the starting signal for this will be made in 2018, immediately after completion of the implementation phase of the agenda for people with dementia.





# V.

## Organisation and cooperation partners

### Organisation partners

- Aktion Demenz e. V. (Action Dementia e. V.)  
[www.aktion-demenz.de](http://www.aktion-demenz.de)
- Aktion Psychisch Kranke e. V. (Campaign for the Mentally Ill)  
[www.apk-ev.de](http://www.apk-ev.de)
- Arbeits- und Sozialministerkonferenz  
(Conference of the Ministers of Labour and Social Affairs)  
[www.mags.nrw/nordrhein-westfalen-hat-2018-den-vorsitz-der-arbeits-und-sozialministerkonferenz-asmk](http://www.mags.nrw/nordrhein-westfalen-hat-2018-den-vorsitz-der-arbeits-und-sozialministerkonferenz-asmk)
- Bundesarbeitsgemeinschaft der Freien Wohlfahrtspflege e. V.  
(Federal Association of Non-Statutory Welfare)  
[www.bagfw.de](http://www.bagfw.de)
- Bundesärztekammer (German Medical Association)  
[www.bundesaerztekammer.de](http://www.bundesaerztekammer.de)
- Bundeskanzleramt (Federal Chancellery)  
[www.bundesregierung.de/Webs/Breg/DE/Bundesregierung/Bundeskanzleramt/\\_node.html](http://www.bundesregierung.de/Webs/Breg/DE/Bundesregierung/Bundeskanzleramt/_node.html)
- Bundesministerium für Arbeit und Soziales  
(Federal Ministry of Labour and Social Affairs)  
[www.bmas.de](http://www.bmas.de)
- Bundesministerium für Bildung und Forschung  
(Federal Ministry of Education and Research)  
[www.bmbf.de](http://www.bmbf.de)
- Bundesministerium für Familie, Senioren, Frauen und Jugend  
(Federal Ministry for Family Affairs, Senior Citizens, Women and Youth)  
[www.bmfsfj.de](http://www.bmfsfj.de)
- Bundesministerium für Gesundheit (Federal Ministry of Health)  
[www.bundesgesundheitsministerium.de](http://www.bundesgesundheitsministerium.de)
- Bundesministerium des Innern, für Bau und Heimat  
(Federal Ministry of the Interior, Building and Community)  
[www.bmi.bund.de](http://www.bmi.bund.de)
- Bundesministerium der Justiz und für Verbraucherschutz (Federal Ministry of Justice and Consumer Protection)  
[www.bmjv.de](http://www.bmjv.de)

- Bundesministerium für Umwelt, Naturschutz und nukleare Sicherheit  
(Federal Ministry for the Environment, Nature Conservation and Nuclear Safety)  
[www.bmu.de](http://www.bmu.de)
- Bundesverband privater Anbieter sozialer Dienste e. V.  
(Federal Association of Private Providers of Social Services)  
[www.bpa.de](http://www.bpa.de)
- Deutsche Alzheimer Gesellschaft e.V.  
(German Alzheimer Society - Dementia Self-Help)  
[www.deutsche-alzheimer.de](http://www.deutsche-alzheimer.de)
- Deutsche Gesellschaft für Gerontopsychiatrie und -psychotherapie e. V.  
(German Association for Gerontopsychiatry and Gerontopsychotherapy)  
[www.dggpp.de](http://www.dggpp.de)
- Deutsche Krankenhaus Gesellschaft e.V. (German Hospital Federation)  
[www.dkgev.de](http://www.dkgev.de)
- Deutscher Pflegerat e.V. (German Nursing Council)  
[www.deutscher-pflegerat.de](http://www.deutscher-pflegerat.de)
- Deutscher Verein für öffentliche und private Fürsorge e. V.  
(German Association for Public and Private Welfare)  
[www.deutscher-verein.de](http://www.deutscher-verein.de)
- Deutsches Zentrum für Neurodegenerative Erkrankungen e. V.  
(German Centre for Neurodegenerative Diseases)  
[www.dzne.de](http://www.dzne.de)
- Gesundheitsministerkonferenz  
(Conference of the Ministers Responsible for Health)  
[www.gmkonline.de](http://www.gmkonline.de)
- GKV-Spitzenverband  
(National Association of Statutory Health Insurance Funds umbrella organisation)  
[www.gkv-spitzenverband.de](http://www.gkv-spitzenverband.de)
- Kassenärztliche Bundesvereinigung  
(National Association of Statutory Health Insurance Physicians)  
[www.kbv.de](http://www.kbv.de)
- Kuratorium Deutsche Altershilfe  
(German Foundation for the Care of Older People)  
[www.kda.de](http://www.kda.de)
- Kultusministerkonferenz  
(Standing Conference of the Ministers of Education and Cultural Affairs)  
[www.kmk.org](http://www.kmk.org)
- Kommunale Spitzenverbände (Deutscher Landkreistag, Deutscher Städtetag,  
Deutscher Städte- und Gemeindebund (Central municipal associations))  
[www.landkreistag.de](http://www.landkreistag.de)  
[www.staedtetag.de](http://www.staedtetag.de)  
[www.dstgb.de](http://www.dstgb.de)

- Verband der Privaten Krankenversicherung e. V.  
(Association of German Private Health Care Insurers)  
[www.pkv.de](http://www.pkv.de)
- Verband Deutscher Alten- und Behindertenhilfe e.V.  
(German Association for the Elderly and Disabled)  
[www.vdab.de](http://www.vdab.de)

### Cooperation Partners

- Bundeszentrale für gesundheitliche Aufklärung  
(Federal Centre for Health Education)  
[www.bzga.de](http://www.bzga.de)
- Charta zur Betreuung schwerstkranker und sterbender Menschen  
(Charter for the care of seriously ill and dying people)  
[www.charta-zur-betreuung-sterbender.de](http://www.charta-zur-betreuung-sterbender.de)
- Deutsche Fernsehlotterie gGmbH (German Television Lottery)  
[www.fernsehlotterie.de](http://www.fernsehlotterie.de)
- Deutsche Gesellschaft für Pflegewissenschaft e. V.  
(German Society for Nursing Science)  
[www.dg-pflegewissenschaft.de](http://www.dg-pflegewissenschaft.de)
- Deutsche Gesellschaft für Psychiatrie und Psychotherapie, Psychosomatik und Nervenheilkunde e. V. (German Society for Psychiatry and Psychotherapy, Psychosomatics and Neurology e. V.)  
[www.dgppn.de](http://www.dgppn.de)
- Deutsche Sporthochschule Köln (German Sports University Cologne)  
[www.dshs-koeln.de](http://www.dshs-koeln.de)
- Robert Bosch Stiftung GmbH (Robert Bosch Foundation)  
[www.bosch-stiftung.de](http://www.bosch-stiftung.de)
- Sachverständigenrat zur Begutachtung der Entwicklung im Gesundheitswesen  
(German Council of Experts for the Assessment of Developments in the Health Care Sector)  
[www.svr-gesundheit.de](http://www.svr-gesundheit.de)
- Spitzenverband ZNS (Zusammenschluss der Verbände BVDN Berufsverband Deutscher Nervenärzte (Central Association of German Psychiatrists), Deutsche Gesellschaft für Neurologie e.V. (Federal Association of German Neurologists), Berufsverband Deutscher Psychiater, BVDP (Professional Association of German Psychiatrists) and Berufsverband für Kinder- und Jugendpsychiatrie, Psychosomatik und Psychotherapie in Deutschland e. V. BKJPP (Professional Association for Child and Adolescent Psychiatry and Psychotherapy))  
[www.spitzenverband-zns.org](http://www.spitzenverband-zns.org)
- Zentrum für Qualität in der Pflege (Centre for Quality in Nursing)  
[www.zqp.de](http://www.zqp.de)



## VI. Information services, links

### Information offers by the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth)

Service telephone of the BMFSFJ:

- 030 20197130 (Monday to Thursday from 9.00 to 18.00 hrs)

Publications directory:

- The current list of publications of the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth is available free of charge at [www.bmfsfj.de/bmfsfj/service/publikationen/publikationsverzeichnis/96418](http://www.bmfsfj.de/bmfsfj/service/publikationen/publikationsverzeichnis/96418) oder über

E-mail: [publikationen@bundesregierung.de](mailto:publikationen@bundesregierung.de)

Telephon: +49 (0) 30 18 272 2721

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Publication dispatch of the federal government

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Selected brochures:

- Agenda "Together for people with dementia - the fields of action" under [www.allianz-fuer-demenz.de](http://www.allianz-fuer-demenz.de)
- "Interim report on the implementation of the agenda" at [www.allianz-fuer-demenz.de/service/meldungen/zwischenbericht-zur-umsetzung-der-agenda.html](http://www.allianz-fuer-demenz.de/service/meldungen/zwischenbericht-zur-umsetzung-der-agenda.html)
- "We support people with dementia - in 500 local help networks across Germany" available at [www.bmfsfj.de/bmfsfj/service/publikationen/wir-unterstuetzen-menschen-mit-demenz/96106](http://www.bmfsfj.de/bmfsfj/service/publikationen/wir-unterstuetzen-menschen-mit-demenz/96106)

Internet pages:

- [www.allianz-fuer-demenz.de](http://www.allianz-fuer-demenz.de)  
The website offers general information about Allianz for People with Dementia and contains all publications of the working group.
- [www.wegweiser-demenz.de](http://www.wegweiser-demenz.de)  
The "Wegweiser Demenz" website provides information, refers to offers of help and networks affected persons, relatives and specialists who have to do with dementia.



- [www.lokale-allianzen.de](http://www.lokale-allianzen.de)  
The website “Local Alliance for People with Dementia” provides information on the 500 projects funded throughout Germany as part of the federal model programme of the same name.
- [www.bmfsfj.de/bmfsfj/themen/aeltere-menschen/demenz](http://www.bmfsfj.de/bmfsfj/themen/aeltere-menschen/demenz)  
The website of the Federal Ministry for Family Affairs, Senior Citizens’ and Women’s Affairs (BMFSFJ) presents priorities of senior citizens’ policy for people with dementia, their relatives and other stakeholders in this thematic area.

### **Information provided by the Federal Ministry of Health**

Citizen’s telephone number of the Federal Ministry of Health on the subject of care:

- +49 (0)30 3406066-02  
(Monday to Thursday from 10 a.m. to 8 p.m., Friday to Sunday from 10 a.m. to 6 p.m.)

Publications directory:

- The current list of publications of the Federal Ministry of Health is available at: [www.bundesgesundheitsministerium.de/service/publikationen/ministerium/details/?bmg%5Bpubid%5D=2731](http://www.bundesgesundheitsministerium.de/service/publikationen/ministerium/details/?bmg%5Bpubid%5D=2731)

Selected brochures:

- Final reports of the “Zukunftswerkstatt Demenz” funding programme are available at [www.bundesgesundheitsministerium.de/service/publikationen/pflege/details/?bmg%5Bpubid%5D=3106](http://www.bundesgesundheitsministerium.de/service/publikationen/pflege/details/?bmg%5Bpubid%5D=3106)
- Future Workshop Dementia available at [www.bundesgesundheitsministerium.de/service/publikationen/pflege/details/?bmg%5Bpubid%5D=2959](http://www.bundesgesundheitsministerium.de/service/publikationen/pflege/details/?bmg%5Bpubid%5D=2959)
- Dementia Handbook - information for caring for people with dementia at home is available at [www.bundesgesundheitsministerium.de/service/publikationen/pflege/details/?bmg%5Bpubid%5D=2929](http://www.bundesgesundheitsministerium.de/service/publikationen/pflege/details/?bmg%5Bpubid%5D=2929)
- Care Guide  
[www.service/publikationen/pflege/details/?bmg%5Bpubid%5D=13](http://www.service/publikationen/pflege/details/?bmg%5Bpubid%5D=13)
- Overview of all counselling services:  
[www.bundesgesundheitsministerium.de/service/publikationen/pflege/details/?bmg%5Bpubid%5D=2656](http://www.bundesgesundheitsministerium.de/service/publikationen/pflege/details/?bmg%5Bpubid%5D=2656)  
[www.pflegestaerkungsgesetz.de/pflege-alltag/demenz-ratgeber/](http://www.pflegestaerkungsgesetz.de/pflege-alltag/demenz-ratgeber/)
- National Health Goal - Healthy ageing is available at [www.bundesgesundheitsministerium.de/service/publikationen/praevention/details/?bmg%5Bpubid%5D=814](http://www.bundesgesundheitsministerium.de/service/publikationen/praevention/details/?bmg%5Bpubid%5D=814)

**Websites:****| [www.demenznetzwerke.de/](http://www.demenznetzwerke.de/)**

In cooperation with the Institute for Community Medicine of the University Medicine Greifswald, the Internet portal of the German Centre for Neurodegenerative Diseases serves as an Internet portal for those interested in the reconstruction and further development of dementia networks.

**Information offered by other institutions****Websites:****| [www.demografie-portal.de](http://www.demografie-portal.de)**

The website of the Federal and State Demography Portal, located at the Federal Institute for Population Research, brings together the fields of action of the federal government's demography strategy and supplements them with factual and practical knowledge.

**| [www.deutsche-alzheimer.de](http://www.deutsche-alzheimer.de)**

The website of the German Alzheimer Society provides information on the activities of the self-help organisation for relatives of dementia patients.

**| [www.demenz-partner.de](http://www.demenz-partner.de)**

The website of the German Alzheimer Society offers compact courses on dementia.

**| [www.gkv-spitzenverband.de](http://www.gkv-spitzenverband.de)**

Joint circulars on the benefit regulations for long-term care insurance at [www.gkv-spitzenverband.de/media/dokumente/pflegeversicherung/richtlinien\\_\\_vereinbarungen\\_\\_formulare/empfehlungen\\_zum\\_leistungsrecht/2018\\_02\\_16\\_GemR\\_zu\\_leistungsrechtliche\\_Vorschriften.pdf](http://www.gkv-spitzenverband.de/media/dokumente/pflegeversicherung/richtlinien__vereinbarungen__formulare/empfehlungen_zum_leistungsrecht/2018_02_16_GemR_zu_leistungsrechtliche_Vorschriften.pdf)

**A collection of links** (in the order in which they appear in the text)

- [www.iso-institut.de/download/Nationale\\_Demenzstrategien\\_Endbericht\\_BMFSFJ.pdf](http://www.iso-institut.de/download/Nationale_Demenzstrategien_Endbericht_BMFSFJ.pdf)
- [www.deutsche-alzheimer.de/fileadmin/alz/pdf/factsheets/infoblatt1\\_haeufigkeit\\_demenzerkrankungen\\_dalzg.pdf](http://www.deutsche-alzheimer.de/fileadmin/alz/pdf/factsheets/infoblatt1_haeufigkeit_demenzerkrankungen_dalzg.pdf)
- [www.kmk.org](http://www.kmk.org)
- [www.neurodegenerationresearch.eu/supported-projects](http://www.neurodegenerationresearch.eu/supported-projects)
- [www.deutsche-alzheimer.de/die-krankheit/demenz-im-juengeren-lebensalter-ratgeber-junge-demenz.html](http://www.deutsche-alzheimer.de/die-krankheit/demenz-im-juengeren-lebensalter-ratgeber-junge-demenz.html)
- [www.bmbf.de/foerderungen/bekanntmachung-1534.html](http://www.bmbf.de/foerderungen/bekanntmachung-1534.html)
- [www.dzne.de/forschung/studien/projekte-der-versorgungsforschung/insidedem/](http://www.dzne.de/forschung/studien/projekte-der-versorgungsforschung/insidedem/)
- [www.technik-zum-menschen-bringen.de/foerderung/bekanntmachungen/pflegeinnovationen-fuer-menschen-mit-demenz](http://www.technik-zum-menschen-bringen.de/foerderung/bekanntmachungen/pflegeinnovationen-fuer-menschen-mit-demenz)
- [www.gesundheitsforschung-bmbf.de/de/intersec-cm-sektorenubergreifendes-care-management-zur-unterstuetzung-kognitiv-6665.php](http://www.gesundheitsforschung-bmbf.de/de/intersec-cm-sektorenubergreifendes-care-management-zur-unterstuetzung-kognitiv-6665.php)
- [www.bmbf.de/foerderungen/bekanntmachung-1113.html](http://www.bmbf.de/foerderungen/bekanntmachung-1113.html)
- [www.dzne.de/forschung/forschungsbereiche/populationsforschung/](http://www.dzne.de/forschung/forschungsbereiche/populationsforschung/)
- [www.dzne.de/aktuelles/presse-und-oeffentlichkeitsarbeit/pressemitteilungen/presse/detail/mehr-lebensqualitaet-fuer-menschen-mit-demenz-und-angehoerige/](http://www.dzne.de/aktuelles/presse-und-oeffentlichkeitsarbeit/pressemitteilungen/presse/detail/mehr-lebensqualitaet-fuer-menschen-mit-demenz-und-angehoerige/)
- [www.designingfordementia.eu](http://www.designingfordementia.eu)
- [www.bosch-stiftung.de/sites/default/files/publications/pdf\\_import/Studie\\_Demenz\\_im\\_Akutkrankenhaus.pdf](http://www.bosch-stiftung.de/sites/default/files/publications/pdf_import/Studie_Demenz_im_Akutkrankenhaus.pdf)
- [www.bosch-stiftung.de/de/projekt/masterstudiengang-versorgung-von-menschen-mit-demenz-ma](http://www.bosch-stiftung.de/de/projekt/masterstudiengang-versorgung-von-menschen-mit-demenz-ma)
- [www.bosch-stiftung.de/de/projekt/graduierntenkolleg-menschen-mit-demenz-im-akutkrankenhaus](http://www.bosch-stiftung.de/de/projekt/graduierntenkolleg-menschen-mit-demenz-im-akutkrankenhaus)
- [www.gkv-spitzenverband.de/pflegeversicherung/forschung/modellprojekte/modellprojekte.jsp](http://www.gkv-spitzenverband.de/pflegeversicherung/forschung/modellprojekte/modellprojekte.jsp)
- [www.zqp.de](http://www.zqp.de)
- [www.hag-gesundheit.de/lebenswelt/leben-mit-demenz/dokumentationen](http://www.hag-gesundheit.de/lebenswelt/leben-mit-demenz/dokumentationen)
- [www.dzne.de](http://www.dzne.de)
- [www.demenznetzwerke.de](http://www.demenznetzwerke.de)
- [www.gkv-spitzenverband.de](http://www.gkv-spitzenverband.de)
- [www.gkv-spitzenverband.de/pflegeversicherung/forschung/forschung.jsp](http://www.gkv-spitzenverband.de/pflegeversicherung/forschung/forschung.jsp)
- [www.palliativzentrum.uk-koeln.de/forschung/arbeitshilfe-bei-demenz](http://www.palliativzentrum.uk-koeln.de/forschung/arbeitshilfe-bei-demenz)
- [www.kompetenzzentren-gia.de](http://www.kompetenzzentren-gia.de)
- [www.demenz-und-migration.de](http://www.demenz-und-migration.de)

- [www.bosch-stiftung.de/de/projekt/demigranz-bundesweite-initiative-demenz-und-migration](http://www.bosch-stiftung.de/de/projekt/demigranz-bundesweite-initiative-demenz-und-migration)
- [www.demenzfreundliche-kommunen.de](http://www.demenzfreundliche-kommunen.de)
- [www.transcript-verlag.de/978-3-8376-2996-5/im-leben-bleiben](http://www.transcript-verlag.de/978-3-8376-2996-5/im-leben-bleiben)
- [www.quartier2020-bw.de](http://www.quartier2020-bw.de)
- [www.wir-stärken-die-pflege.de](http://www.wir-stärken-die-pflege.de)
- [www.bundesgesundheitsministerium.de/themen/pflege/online-ratgeber-demenz](http://www.bundesgesundheitsministerium.de/themen/pflege/online-ratgeber-demenz)
- [www.lokale-allianzen.de](http://www.lokale-allianzen.de)
- [www.lzg-rlp.de](http://www.lzg-rlp.de)
- [www.hamburg.de/pflege](http://www.hamburg.de/pflege)
- [www.zqp.de](http://www.zqp.de)
- [www.pflege-gewalt.de](http://www.pflege-gewalt.de)
- [www.pflegeberatung.de](http://www.pflegeberatung.de)
- [www.compass-pflegeberatung.de](http://www.compass-pflegeberatung.de)
- [www.medicproof.de](http://www.medicproof.de)
- [www.leitfadenbarrierefreiesbauen.de](http://www.leitfadenbarrierefreiesbauen.de)
- [www.bmfsfj.de/bmfsfj/service/publikationen/hat-mama-demenz-/111782](http://www.bmfsfj.de/bmfsfj/service/publikationen/hat-mama-demenz-/111782)
- [www.bmfsfj.de/bmfsfj/service/publikationen/-herausforderung-demenz--fuer-menschen-mit-lernschwierigkeiten/116086](http://www.bmfsfj.de/bmfsfj/service/publikationen/-herausforderung-demenz--fuer-menschen-mit-lernschwierigkeiten/116086)
- [www.deutsche-alzheimer.de/fileadmin/alz/broschueren/Wege\\_zu\\_mehr\\_Barrierefreiheit.pdf](http://www.deutsche-alzheimer.de/fileadmin/alz/broschueren/Wege_zu_mehr_Barrierefreiheit.pdf)
- [www.kzbv.de/barrieren-abbauen.783.de.html](http://www.kzbv.de/barrieren-abbauen.783.de.html)
- [www.kzbv.de/versorgung-von-pflegebeduerftigen-menschen.912.de.html](http://www.kzbv.de/versorgung-von-pflegebeduerftigen-menschen.912.de.html)
- [www.deutscher-verein.de/de/](http://www.deutscher-verein.de/de/)
- [www.demenznetzwerke.de](http://www.demenznetzwerke.de)
- [www.bosch-stiftung.de/de/projekt/european-foundations-initiative-dementia-efid](http://www.bosch-stiftung.de/de/projekt/european-foundations-initiative-dementia-efid)
- [www.hamburg.de/demenz](http://www.hamburg.de/demenz)
- [www.hag-gesundheit.de/lebenswelt/leben-mit-demenz](http://www.hag-gesundheit.de/lebenswelt/leben-mit-demenz)
- [www.demenz-rlp.de](http://www.demenz-rlp.de)
- [www.wegweiser-demenz.de/informationen/gesetzliche-leistungen.html](http://www.wegweiser-demenz.de/informationen/gesetzliche-leistungen.html)
- [www.bmjv.de/DE/Service/Fachpublikationen/Fachpublikationen\\_node.html](http://www.bmjv.de/DE/Service/Fachpublikationen/Fachpublikationen_node.html)
- [www.justiz.sachsen.de/content/formulare.htm](http://www.justiz.sachsen.de/content/formulare.htm)
- [www.pflege-charta.de/de/startseite.html](http://www.pflege-charta.de/de/startseite.html)
- [www.leitlinie-fem.de](http://www.leitlinie-fem.de)
- [www.mds-ev.de/fileadmin/dokumente/Publikationen/SPV/Gewaltfreie\\_Pflege/090418\\_Abschlussbericht\\_Projekt\\_GfP\\_Final.pdf](http://www.mds-ev.de/fileadmin/dokumente/Publikationen/SPV/Gewaltfreie_Pflege/090418_Abschlussbericht_Projekt_GfP_Final.pdf)
- [www.pflege.gewalt.de](http://www.pflege.gewalt.de)

- [www.bundesgesundheitsministerium.de/themen/pflege/online-ratgeber-demenz](http://www.bundesgesundheitsministerium.de/themen/pflege/online-ratgeber-demenz)
- [www.bundesgesundheitsministerium.de/themen/pflege/online-ratgeber-demenz/zukunftswerkstatt-demenz.html](http://www.bundesgesundheitsministerium.de/themen/pflege/online-ratgeber-demenz/zukunftswerkstatt-demenz.html)
- [www.bagfw.de/suche/detailansicht-tt-news/article/auseinandersetzung-mit-demenz-kann-hilflosigkeit-ueberwinden](http://www.bagfw.de/suche/detailansicht-tt-news/article/auseinandersetzung-mit-demenz-kann-hilflosigkeit-ueberwinden)
- [www.fernsehlotterie.de](http://www.fernsehlotterie.de)
- [www.fernsehlotterie.de/magazin](http://www.fernsehlotterie.de/magazin)
- [www.demenz-partner.de](http://www.demenz-partner.de)
- [shop.deutsche-alzheimer.de/broschueren/33/ratgeber-rechtlichen-und-finanziellen-fragen](http://shop.deutsche-alzheimer.de/broschueren/33/ratgeber-rechtlichen-und-finanziellen-fragen)
- [www.wegweiser-demenz.de/informationen/rechte-und-pflichten.html](http://www.wegweiser-demenz.de/informationen/rechte-und-pflichten.html)
- [www.pflegeberatung.de](http://www.pflegeberatung.de)
- [www.deutsche-alzheimer.de/fileadmin/alz/broschueren/Was\\_kann\\_ich\\_tun2012\\_11.pdf](http://www.deutsche-alzheimer.de/fileadmin/alz/broschueren/Was_kann_ich_tun2012_11.pdf)
- [www.allianz-fuer-demenz.de/fileadmin/de.allianz-fuer-demenz/content.de/bilder/meldungen/17-05-09\\_Arbeitsgruppe\\_veroeffentlicht\\_Ratgeber/Wege\\_zu\\_mehr\\_Barrierefreiheit.pdf](http://www.allianz-fuer-demenz.de/fileadmin/de.allianz-fuer-demenz/content.de/bilder/meldungen/17-05-09_Arbeitsgruppe_veroeffentlicht_Ratgeber/Wege_zu_mehr_Barrierefreiheit.pdf)
- [www.lokale-allianzen.de/projekte/projektuebersicht/projekt/practex/show/503.html](http://www.lokale-allianzen.de/projekte/projektuebersicht/projekt/practex/show/503.html)
- [www.lokale-allianzen.de/projekte/projektuebersicht/projekt/practex/show/91.html](http://www.lokale-allianzen.de/projekte/projektuebersicht/projekt/practex/show/91.html)
- [www.sport-bewegung-demenz.de](http://www.sport-bewegung-demenz.de)
- [www.serviceportal-zuhause-im-alter.de/programme/programm-anlaufstellen-fuer-aeltere-menschen.html](http://www.serviceportal-zuhause-im-alter.de/programme/programm-anlaufstellen-fuer-aeltere-menschen.html)
- [www.readyhome.de](http://www.readyhome.de)
- [www.wegweiseralterundtechnik.de](http://www.wegweiseralterundtechnik.de)
- [www.technik-zum-menschen-bringen.de/foerderung/bekanntmachungen/kommunale-beratungsstellen-modul-1](http://www.technik-zum-menschen-bringen.de/foerderung/bekanntmachungen/kommunale-beratungsstellen-modul-1)
- [www.technik-zum-menschen-bringen.de/foerderung/bekanntmachungen/kommunale-beratungsstellen-modul-2](http://www.technik-zum-menschen-bringen.de/foerderung/bekanntmachungen/kommunale-beratungsstellen-modul-2)
- [siegel.dggpp.de](http://siegel.dggpp.de)
- [www.mds-ev.de/fileadmin/dokumente/Pressemitteilungen/2018/2018\\_02\\_01/\\_5\\_PflegeQualitaetsbericht\\_des\\_MDS.pdf](http://www.mds-ev.de/fileadmin/dokumente/Pressemitteilungen/2018/2018_02_01/_5_PflegeQualitaetsbericht_des_MDS.pdf)
- [www.pflege-gewalt.de](http://www.pflege-gewalt.de)
- [www.doi.org/10.1186/s13195-017-0289-z](http://www.doi.org/10.1186/s13195-017-0289-z)
- [www.kda.de/news-detail/items/logbuch-demenz.html](http://www.kda.de/news-detail/items/logbuch-demenz.html)
- [www.deutsche-alzheimer.de/unsere-service/alzheimer-telefon.html](http://www.deutsche-alzheimer.de/unsere-service/alzheimer-telefon.html)
- [www.dbp.zqp.de](http://www.dbp.zqp.de)
- [www.demenz-partner.de/index.php?id=34](http://www.demenz-partner.de/index.php?id=34)

- [www.serviceportal-zuhause-im-alter.de/programme/programm-anlaufstellen-fuer-aeltere-menschen/abschlussdokumentation.html](http://www.serviceportal-zuhause-im-alter.de/programme/programm-anlaufstellen-fuer-aeltere-menschen/abschlussdokumentation.html)
- [www.bundesgesundheitsministerium.de/fileadmin/Dateien/5\\_Publikationen/Pflege/Berichte/Abschlussbericht\\_Evaluation\\_PNG\\_PSG\\_I.pdf](http://www.bundesgesundheitsministerium.de/fileadmin/Dateien/5_Publikationen/Pflege/Berichte/Abschlussbericht_Evaluation_PNG_PSG_I.pdf)
- [www.demenz-wg-hessen.de](http://www.demenz-wg-hessen.de)
- [www.bundesgesundheitsministerium.de/fileadmin/Dateien/5\\_Publikationen/Pflege/Berichte/6.Pflegebericht.pdf](http://www.bundesgesundheitsministerium.de/fileadmin/Dateien/5_Publikationen/Pflege/Berichte/6.Pflegebericht.pdf)
- [www.zqp.de/beratungsdatenbank](http://www.zqp.de/beratungsdatenbank)
- [www.dgn.org/images/red\\_leitlinien/LL\\_2016/PDFs\\_Download/038013\\_LL\\_Demenzen\\_2016.pdf](http://www.dgn.org/images/red_leitlinien/LL_2016/PDFs_Download/038013_LL_Demenzen_2016.pdf)
- [www.dggpp.de/zertifikat\\_DGPPN\\_DGGPP\\_neu2.htm](http://www.dggpp.de/zertifikat_DGPPN_DGGPP_neu2.htm)
- [www.hauptstadtkongress.de/index.php?id=57&id\\_programm=50](http://www.hauptstadtkongress.de/index.php?id=57&id_programm=50)
- [www.zm-online.de/archiv/2016/10/politik/kooperation-fuehrt-zum-erfolg/](http://www.zm-online.de/archiv/2016/10/politik/kooperation-fuehrt-zum-erfolg/)
- [www.bpa.de](http://www.bpa.de)
- [www.bosch-stiftung.de/de/publikation/general-hospital-study-ghost](http://www.bosch-stiftung.de/de/publikation/general-hospital-study-ghost)
- [www.bosch-stiftung.de/de/projekt/menschen-mit-demenz-im-akutkrankenhaus](http://www.bosch-stiftung.de/de/projekt/menschen-mit-demenz-im-akutkrankenhaus)
- [www.lokale-allianzen.de/projekte/treffen-der-lokalen-allianzen/achkonferenzen.html](http://www.lokale-allianzen.de/projekte/treffen-der-lokalen-allianzen/achkonferenzen.html)
- [shop.deutsche-alzheimer.de/broschueren/19/menschen-mit-demenz-im-krankenhaus](http://shop.deutsche-alzheimer.de/broschueren/19/menschen-mit-demenz-im-krankenhaus)
- [www.dkgev.de/dkg.php/cat/451/title/Demenz\\_im\\_Krankenhaus\\_-\\_Best\\_Practice\\_Beispiele](http://www.dkgev.de/dkg.php/cat/451/title/Demenz_im_Krankenhaus_-_Best_Practice_Beispiele)
- [www.kbv.de/html/demenz.php](http://www.kbv.de/html/demenz.php)
- [www.inverso-mainz.de](http://www.inverso-mainz.de)
- [www.altenpflegeausbildung.net](http://www.altenpflegeausbildung.net)
- [www.leben-mit-demenz.bayern.de](http://www.leben-mit-demenz.bayern.de)
- [msagd.rlp.de/de/unsere-themen/gesundheits-und-pflege/pflege/demenzstrategie/](http://msagd.rlp.de/de/unsere-themen/gesundheits-und-pflege/pflege/demenzstrategie/)
- [www.demenzplan-sh.de/wp-content/uploads/2015/01/Bericht\\_Demenzplan-2017\\_WEB.pdf](http://www.demenzplan-sh.de/wp-content/uploads/2015/01/Bericht_Demenzplan-2017_WEB.pdf)
- [www.demenz-sh.de/](http://www.demenz-sh.de/)
- [www.saarland.de/136770.htm](http://www.saarland.de/136770.htm)
- [www.saarland.de/218776.htm](http://www.saarland.de/218776.htm)
- [www.demenz-saarland.de](http://www.demenz-saarland.de)
- [demenz-brandenburg.de/](http://demenz-brandenburg.de/)
- [www.hamburg.de/landesinitiative-leben-mit-demenz/](http://www.hamburg.de/landesinitiative-leben-mit-demenz/)
- [www.demenzatlas-hessen.de](http://www.demenzatlas-hessen.de)
- [www.demenz-service-nrw.de/](http://www.demenz-service-nrw.de/)
- [www.kreise.de/\\_cms1/images/stories/publikationen/DLT\\_Bd\\_126\\_4\\_Auflage\\_6te\\_UPM\\_Ansicht.pdf](http://www.kreise.de/_cms1/images/stories/publikationen/DLT_Bd_126_4_Auflage_6te_UPM_Ansicht.pdf)

- [btdirekt.de/images/dateien\\_pdf/anforderungsprofil-fuer-betreuer-2013.pdf](http://btdirekt.de/images/dateien_pdf/anforderungsprofil-fuer-betreuer-2013.pdf)
- [www.landkreistag.de/publikationen/fachzeitschrift-qder-landkreisq.html](http://www.landkreistag.de/publikationen/fachzeitschrift-qder-landkreisq.html)
- [www.kreise.de/\\_\\_cms1/images/stories/themen/Senioren/150223%20BV%20Konkretisierter%20Vorschlag%20Rolle%20der%20Kommunen%20in%20der%20Pflege.pdf](http://www.kreise.de/__cms1/images/stories/themen/Senioren/150223%20BV%20Konkretisierter%20Vorschlag%20Rolle%20der%20Kommunen%20in%20der%20Pflege.pdf)
- [www.leitfadenbarrierefreiesbauen.de](http://www.leitfadenbarrierefreiesbauen.de)
- [www.bundesregierung.de/Content/DE/StatischeSeiten/Breg/koalitionsvertrag-inhaltsverzeichnis.html](http://www.bundesregierung.de/Content/DE/StatischeSeiten/Breg/koalitionsvertrag-inhaltsverzeichnis.html)



**List of abbreviations****A**

AGP	Work focus gerontology and care
AltPflAPrV	Training and examination regulation for geriatric nurses
AniTa	Relatives of people with dementia in (inter)action
AOK	General public health insurance company
APK	Campaign for mentally ill people
AUiA	Agency for the placement and development of offers for everyday support for people in need of care

**B**

BÄK	German Medical Association
BAFzA	Federal Office of Family Affairs and Civil Society Functions
BAGFW	Bundesarbeitsgemeinschaft der Freien Wohlfahrtspflege e.V. (Federal Association of Non-Statutory Welfare)
BAGSO	Federal Association of Senior Citizens' Organisations
BGBI	Federal Law Gazette
BMBF	Bundesministerium für Bildung und Forschung (Federal Ministry of Education and Research)
BMFSFJ	Bundesministerium für Familie, Senioren, Frauen und Jugend (Federal Ministry for Family Affairs, Senior Citizens, Women and Youth)
BMG	Bundesministerium für Gesundheit (Federal Ministry of Health)
BMJV	Bundesministerium der Justiz und für Verbraucherschutz (Federal Ministry of Justice and Consumer Protection)
BMU	Bundesministerium für Umwelt, Naturschutz, Bau und Reaktorsicherheit (Federal Ministry for the Environment, Nature Conservation and Nuclear Safety)
BMI	Bundesministerium des Innern, für Bau und Heimat (Federal Ministry of the Interior, Building and Community)
bpa	Bundesverband privater Anbieter sozialer Dienste (Federal Association of Private Providers of Social Services)
BZÄK	Bundeszahnärztekammer (German Federal Dental Chamber)
BZgA	Bundeszentrale für gesundheitliche Aufklärung (Federal Centre for Health Education)

**C**

CCG	Competence Center Health
CDU	Christlich Demokratische Union Deutschlands (Christian Democratic Union of Germany)
CSU	Christlich-Soziale Union in Bayern (Christian Social Union)

**D**

DAIzG	German Alzheimer Society
DaTraV	Datentransparenzverordnung (Data Transparency Regulation)
DCM	Dementia Care Management

DELCODE	Longitudinal Cognitive Impairment and Dementia Study
DGGPP	Deutsche Gesellschaft für Gerontopsychiatrie und –psychotherapie (German Society of Geronto-Psychiatry and Psychotherapy)
DGN	Deutsche Gesellschaft für Neurologie (German Association for Neurology)
DGPPN	Deutsche Gesellschaft für Psychiatrie und Psychotherapie, Psychosomatik und Nervenheilkunde (German Association for Psychiatry, Psychotherapy and Psychosomatics)
DIMDI	Deutsches Institut für Dokumentation und Information (German Institute of Medical Documentation and Information)
DKG	Deutsche Krankenhausgesellschaft (German Hospital Federation)
DPR	Deutscher Pflegerat (German Council of Nursing)
DSHS	Deutsche Sporthochschule Köln (German Sport University Cologne)
DZNE	Deutsches Zentrum für Neurodegenerative Erkrankungen (German Centre for Neurodegenerative Diseases)
DV	Deutscher Verein für öffentliche und private Fürsorge (German Association for Public and Private Welfare)

**E**

EBM	Standard doctor's fee scale
EFID	European Foundations' Initiative on Dementia
EU	European Union

**F**

FAU	Friedrich-Alexander-Universität Erlangen-Nürnberg
FEM	Freiheitsentziehende Maßnahmen (measures involving deprivation of liberty)
FZI	Forschungszentrum Informatik

**G**

G-BA	Gemeinsamer Bundesausschuss (Federal Joint Committee)
GKV	Statutory Health Insurance
GKV-SV	National Association of Statutory Health Insurance Funds

**H**

HAG	Hamburgische Arbeitsgemeinschaft für Gesundheitsförderung
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**I**

iiDeMM	Initiative und Information für demenzerkrankte Menschen mit Migrationshintergrund (Initiative and information for dementia patients with a migration background)
IMOA	Improving Health Monitoring in Old Age
IFOK	Institut für Organisationskommunikation GmbH
ISG	Institut für Sozialforschung und Gesellschaftspolitik
INA	Interkulturelles Netz Altenhilfe

intersec-CM cross-sectoral Care Management  
 IZPH Interdisziplinäres Zentrum für Health Technology Assessment und Public Health (Interdisciplinary Center for Health Technology Assessment and Public Health)

## J

JPND EU Joint Programme – Neurodegenerative Disease Research

## K

KBV Kassenärztliche Bundesvereinigung  
 (National Association of Statutory Health Insurance Physicians)

KDA Kuratorium Deutsche Altershilfe  
 (German Foundation for the Care of Older People)

KPflAPrV Training and examination regulation for the professions in nursing

KrPflG Krankenpflegegesetz (Act on the Professions in the Field of Nursing)

KfW Kreditanstalt für Wiederaufbau

KMK Kultusministerkonferenz  
 (Conference of the Ministers of Education and Cultural Affairs)

KZBV Kassenzahnärztliche Bundesvereinigung  
 (National Association of Statutory Health Insurance Dentists)

## L

LeDeHa Leben mit (beginnender) Demenz in Hamburg  
 (Living with Dementia in Hamburg)

LLmD Landesinitiative Leben mit Demenz in Hamburg  
 (Living with Dementia in Hamburg state initiative)

LWTG Landesgesetz über Wohnformen und Teilhabe  
 (Housing and Participation State Law)

## M

MDS Medical Service of the Central Association of Health Insurance Funds  
 (registered association)

MinD Designing for People with Dementia

## N

NAKO NAKO health study

NAR Network Aging Research

NEF Network of European Foundations

NEURON Network of European Funding for Neuroscience Research

NV National Care Guideline

## P

PAWEL Patient Safety, Economy and Quality of Life

PfADe Preventive care structures for caring relatives of people with dementia

PfIBG Nursing Profession Act

PfIBRefG Nursing Profession Reform Act

PiA Society for prevention in the age registered association.

PKV	Verband der Privaten Krankenversicherung e.V. (Association of German Private Health Care Insurers)
POCD	Postoperative cognitive dysfunction
PR	Public Relations
PSG	Long-term care insurance laws
PräSenZ	Prevention for seniors at home
PURFAM	Potentials and risks in the family-based care of old people

**R**

RAGA	Regional Working Group of Elderly and Family Counselling Centres
RBS	Robert Bosch Foundation
RKI	Robert Koch Institute

**S**

SEBKam	Cross-sectoral deployment of care workers at the interface of hospitals and outpatient care
SGB	Social Security Code
SPD	Sozialdemokratische Partei Deutschlands (Social Democratic Party of Germany)

**U**

UN	United Nations
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**V**

VDAB	Verband Deutscher Alten- und Behindertenhilfe (Association of German Assistance for the Elderly and Disabled)
VStG	Care Structure Act

**W**

WHO	World Health Organization
WTG	Wohn- und Teilhabegesetz (Housing and Participation State Law)

**Z**

ZQP	Centre for Quality in Care
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**Annexes**

KMK-Overview Research

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