





## Preface

Dear Readers,

in recent years, help networks for persons with dementia have sprung up throughout Germany. 500 such projects have been sponsored by the Federal Ministry for Senior Citizens under the federal programme 'Local Alliances for People with Dementia'. Some of them attract volunteers to get involved in rural areas. Others specifically cater to persons with a migration background who fall ill with dementia. Still others raise the awareness of professionals who interact with dementia patients on a daily basis. The local alliances for persons with dementia cover a wide array of topics because needs vary just as widely.



All of them, however, share the same premise: local impact, central importance. Whether or not counselling and support services for persons with dementia and their relatives are in place and make a difference gets determined on the ground, in the communities, by the local welfare associations, home care services or counselling centres. All across Germany, people have come to address the same set of issues and share the same mission: to match needs for assistance to the services on offer and to take up the daily questions and requests about social care options, support and assistance as well as more information about the disease. While needs profiles vary, the urgency of the need is ubiquitous.

We care for the carers. Family caregivers should get the support they need. We also care for persons living with dementia. The recent amendments in the Family Caregiver Leave Act and the Acts to Strengthen Long-term Care, have improved care options and support services. Moreover, I have made it my goal to ensure that persons with dementia can partake in social life for as long and as fully as possible. An understanding, knowledgeable and sensitive environment is helpful here – as are some good ideas. These are abundant in the local alliances for persons with dementia.

Local alliances for persons with dementia are committed and do a good job for which I want to express my deepest thanks to all of those involved. The programme is a success story. In order to ensure that the 500 local alliances can continue their engagement even after the funding period has expired, the help networks will be supported in a Federal Network from 2018 onward. The German Federal Association of Senior Citizens Organisations (BAGSO) and its national office are on hand to provide advice and assistance to all local networks.

Let these examples inspire you to set up new networks or to join an Alliance as a cooperation partner! This publication gives an overview of the main topics and illustrates the diverse nature of the activities undertaken by these local alliances. It is easier to live with dementia when you don't have to face it alone but can access help and support in the local community. An overview is provided on the website: [www.lokale-allianzen.de](http://www.lokale-allianzen.de)

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

Dr. Franziska Giffey

Federal Minister for Family, Senior Citizens, Women and Youth  
Member of the German *Bundestag*



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## Introduction

Against the backdrop of demographic change the number of people with dementia in Germany will probably double to three million by 2050. This development throws up central challenges for society. The federal pilot programme of Local Alliances is a network of regional institutions, organisations and initiatives to help tackle these tasks.

### Alliance for People with Dementia

The Alliance for People with Dementia was launched in September 2012 on the joint initiative of the Family and Health Ministries. It encompasses the action areas science and research, social responsibility, support for people with dementia and their families and the organisation of the support system. The implementation of the 150 individual measures agreed in the Agenda “Together for People with Dementia”, that was signed in 2014, is to be completed by 2018.

### Local Alliances for support in the living environment

The Local Alliances are an important component of the Agenda. By the end of 2016 500 small-scale help networks had sprung up across Germany with the goals of offering dementia sufferers and their family members’ social participation and close-at-hand support, and of raising social awareness about how to deal with dementia.

Individuals, associations, companies, educational facilities, church parishes, self-help groups, providers of support services, political circles and municipal administrations join forces in the Local Alliances. These networks offer people with dementia individual support and help in their daily lives. They ensure their social participation. Local Alliances offer a wide range of social, cultural and sports activities. Furthermore, they help people with dementia and their family members to select the right guidance and support services.

### Participation through social acceptance

People with dementia do not want to be excluded. They want to continue to be integrated into their familiar surroundings and live an active life. But they would also like to do something for others and help with daily tasks. Particularly in the early stage of dementia sufferers can still actively speak for themselves. They wish

for normality and want to be independent as possible and shape their own lives. The most important precondition for the participation of people with dementia is a change in consciousness of their fellow human beings. This includes the unbiased handling of the disease. In the case of disease onset before the standard retirement age, employers are called on to offer flexible working conditions. Dementia sufferers and their family members are still too frequently prone to feelings of shame and the fear of being excluded. Society should create an empathetic and understanding environment that meets their needs. Being diagnosed with dementia must not lead to social exclusion. The services of the Local Alliances help people with dementia to shape their daily lives together with friends and neighbours.

## Networking of existing services and initiatives

The Local Alliances draw existing structures and services together, and offer guidance to people seeking help. Multi-generational houses, local neighbourhood centres, care support centres, welfare centres, senior citizens' offices, church parishes, family doctors, hospitals, Alzheimer's societies and self-help groups are all important partners for the Local Alliances.

This publication aims to give interested individuals a general overview of the structures and work areas of Local Alliances. It provides information on diverse support opportunities. Furthermore, it gives pointers on how corresponding services can be rolled out in local communities.

Last but not least, this publication also seeks to encourage people to become active themselves: to help a neighbour who is ill or to found a Local Alliance. The 500 sites rolled out in the federal programme are intended to be just the beginning of a sustainable nationwide support network for people with dementia and their family members.

The following pages contain details of some selected projects from the ten main topics in the federal programme. They provide a good insight into the work of the Local Alliances.

## Topic Exercise, Sport and Leisure

Regular exercise, leisure activities and sport can help dementia sufferers to continue to lead an active life despite their illness. Throughout Germany the Local Alliances encompass both initiatives and also traditional sports clubs that offer special exercise and leisure options for people with dementia.

Regular exercise has positive effects not only on the body. It also helps to maintain cognitive capacity. Sports activities in particular challenge the mind as it has to remember movement sequences and rules. They trigger positive stimuli which are important particularly in the early stage of dementia in order to ensure that body and mind are sufficiently challenged.

Furthermore, taking part in joint sports and leisure activities like hiking, dancing or cycling gives people with dementia the feeling that they are still active participants in society.

### Associations extend an invitation

It is particularly important for people with dementia to be aware of the services of Local Alliances in the fields of sport, exercise and leisure. Registered sports clubs can also open up their structures and facilitate barrier-free participation in age-appropriate and dementia-friendly activities, for instance by waiving club membership.

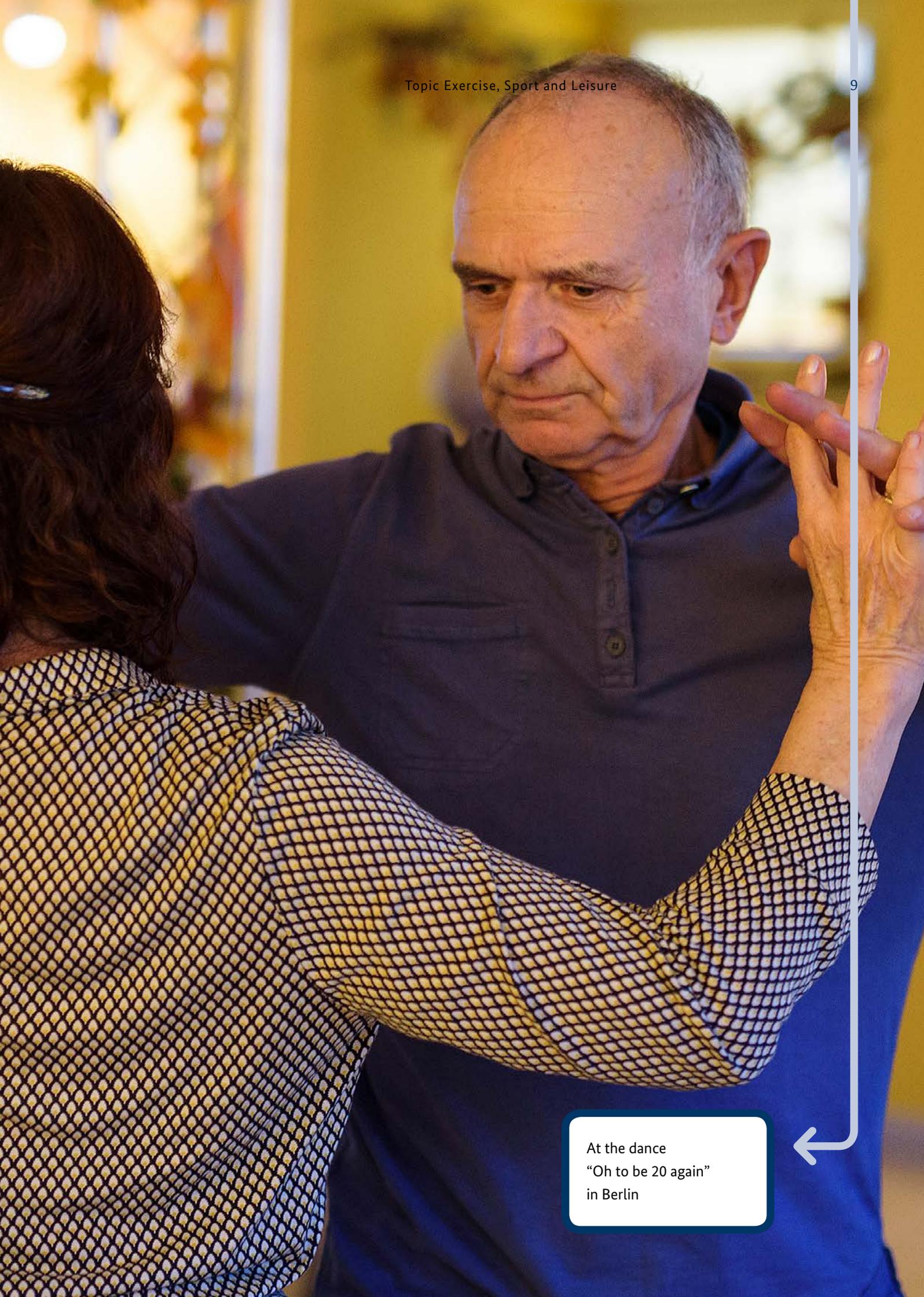
Consequently, people with dementia can not only fall back on the municipal services of Local Alliances but also enjoy support from facilities that had not been funded up to now. The goal is to further extend existing networks and, in this way, to involve civil society to a greater degree – beyond the area of sport and exercise, too.

### Use the diverse services

The services on offer in the field of “exercise, sport and leisure” are diverse and often involve people with dementia and their family members as well as members of the public at large.



Coffee mornings as a leisure activity for dementia sufferers and their family members



At the dance  
“Oh to be 20 again”  
in Berlin



## Topic Exercise, Sport and Leisure

### ***Pia Causa Köln GmbH, North Rhine-Westphalia***

The project “We’re dancing again!” of Pia Causa GmbH is a neighbourhood and networking project in cooperation with the *Antoniter Siedlungsgesellschaft mbH* in the *Evangelischer Kirchenverband* (Protestant church association) in Cologne and the region. The initiators have put together a dance activity for tenants and people from the neighbourhood – this is how they encourage participation. In addition, they stage information events and multiplier training courses to raise awareness of the topic dementia diseases.

### ***Verein zur Förderung sozialer und kultureller Kontakte e. V. in Berlin (association to promote social and cultural contacts)***

“Oh to be 20 again” is a dance event for dementia sufferers and their family caregivers. The events start with guests being welcomed and offered a friendly cup of coffee. A musician plays well-known melodies spanning several decades and encourages the guests to get up and dance. A social worker is present at each event and offers family caregivers free-of-charge advice.

### ***Seniordienst Kümmern und So e. V. in Gifhorn, Niedersachsen, Lower Saxony (senior citizens’ service providing care etc.)***

The *Seniordienst Kümmern und So e. V.* is a recognised association that has provided low-threshold support services since 2003. One goal of the association is to train lay helpers. Together with these helpers the association now offers a new dance group for people with and without dementia. True to the motto “movement is a blessing” it taps into the positive energy of exercise. By means of regular training older people can maintain and even improve their mobility, endurance, reaction, deftness, balance and strength. Selected exercises also stimulate cognitive abilities.

Dancing at *Pia Causa* in Cologne



Sports excursion in Gifhorn

## Topic Hospital

Raising social awareness of dementia by means of counselling and education services is just as important as ensuring that dementia sufferers have access to good medical and nursing care.

However, it is by no means evident that hospitals are prepared to deal with dementia diseases or to invest in dedicated continuing training schemes for their therapeutic and nursing staff.

In the field of hospitals the Local Alliances have set themselves the goals of putting in place dementia-friendly structures in hospitals and rehabilitation centres, of raising awareness amongst hospital directors and the medical and nursing staff for the requirements of dementia sufferers, and of encouraging their ongoing development in this field. This also includes putting in place discharge management in cooperation with the local family doctors. This is the only way of ensuring that dementia patients can return to their familiar surroundings, also after being discharged from hospital, and avoiding them being placed in a care home.

The measures include, inter alia, training of hospital staff in dealing with dementia sufferers – this applies equally to doctors, nurses and other therapeutic staff, the adjustment of organisational procedures, the accessibility of infrastructures and dedicated admission and discharge management for people with dementia.

### Establish dementia-friendly support

The medical treatment of a dementia sufferer that is specifically tailored to his/her needs resulting from this illness is very important.

In particular hospitals in regions with a high average age must prepare themselves, in future, for a large number of patients with cognitive impairments and adjust their health care services correspondingly.

Continuing training can be the first step towards raising staff awareness in their interaction with dementia sufferers.

The environmental design of hospitals also takes on particular importance. For instance, the use of light and colour or a specific structural set-up of wards can have a positive impact on how patients feel.

### Networking of hospitals and counselling centres

Local Alliances that have included hospitals in their network endeavour to ensure dedicated dementia support.

They seek to build on their contacts to retirement homes, family doctors, cooperating psychiatrists, neurologists and self-help organisations and raise their awareness, too.

In the district hospital Wolgast



## Topic Hospital

### **District hospital Wolgast, Mecklenburg-Western Pomerania**

With its pilot project “Dementia-friendly hospital” the *Altersmedizinisches Zentrum Vorpommern* (Geriatric medical centre Western Pomerania – AMZ) already offers a dedicated individual treatment programme for dementia sufferers. In future, a dementia pilot is to further improve care by acting as a link between the hospital and the dementia sufferer. The pilot will stage information events and training and, in addition, develop an individual health plan for the period after a stay in hospital.

### **Alexianer Krefeld GmbH, North Rhine-Westphalia**

Elderly people in Krefeld who have mental illnesses, memory loss and orientation problems or suffer from confusion are looked after in the clinic of *Alexianer Krefeld GmbH*. The special feature: the individual support services extend beyond inpatient and partial inpatient treatment – for instance to housekeeping. The current project work involves training home helps how to interact with dementia sufferers: the focus of the work of home helps is to maintain the independence of the individuals affected and also to be made aware themselves of how to deal with dementia.

### **Oldenburg hospitals, Lower Saxony**

Caregivers, social workers, the funding bodies of educational establishments and the funding bodies of health care facilities are active in the working group “Dementia sufferers and their family members in Oldenburg hospitals”. In the course of their work one thing quickly became clear: the transition from hospital to outpatient aftercare in the region is very poor. The clear goal is, therefore, to improve discharge management. To this end, the three Oldenburg hospitals are working closely with all the stakeholders and are developing new concepts in order to make the recovery process of the individuals concerned as smooth as possible.

Individual support services of Alexianer Krefeld GmbH



Transition from inpatient to outpatient care

## Topic Municipality

Demographic change will result in an increase in the number of people who will, in future, be dependent on dedicated dementia services at their place of residence.

Dementia is taking on increasing importance in municipal communities of all sizes as a consequence of generally longer life expectancy, a different perception of dementia and a more differentiated approach to support services. Individual action concepts are needed for cities with their neighbourhoods down to rural areas.

The federal programme “Local Alliances for People with Dementia” is a response to this development as the emphasis here is on the networking of institutions in the municipal communities.

It helps if the municipality itself takes the initiative or assumes a central role, for instance by setting up a full-time position with responsibility for coordinating activities with the dementia or demography officer. This is how municipalities make a major contribution to the sustainable safeguarding of the network.

### Establish lasting municipal help networks

The initiatives of the Local Alliances promote the networking of project partners, multipliers and volunteer helpers on the ground in their municipal community.

The goal is to establish a comprehensive infrastructure that enables people with dementia, their family members and the public at large to actively confront the illness and make use of concrete offers of assistance directly at their place of residence.

The social networks of civil society are essential for municipalities as they are the forum for meeting basic needs. Overall, just under one-third of the Local Alliances have an active connection to municipal communities.

The main partners on the municipal level are: senior citizens' advisory councils, senior citizens' officers, voluntary initiatives, self-help groups / family members, hospitals, doctors, adult education centres, churches, representatives of the housing sector, associations, firms, shops, banks, care services and care support centres. The task of Local Alliances is to bring on board and coordinate all these stakeholders.

Diverse concepts for the establishment and further development of dementia-friendly municipal communities or regions, for instance on the rural district level, are now available. Mayors and district administrators lend their support in different ways to the networking activities and the development and coordination of individual counselling, relief and participation services for both dementia sufferers and their family caregivers.

## Network partners with different priorities

In future, the regional networks are to primarily offer diverse dedicated dementia services.

This may mean that various project partners turn their attention, for instance, to education projects such as, for example, the development of training concepts for volunteers or family caregivers in order to inform the public about dementia and to raise awareness about how to interact with dementia sufferers or their family members. Other Local Alliances concentrate on counselling services specifically for migrants.

The Local Alliances in the field of the municipality have set themselves the task of centrally bundling the municipal initiatives and further extending the infrastructure of the regional services. In their work and also when contacting new network partners they call for civic engagement. In principle, all initiatives of the Local Alliances are called on to network with other institutions and providers.

## Topic Municipality

Many municipal communities pursue the same goal



Continuing training on the topic of dementia in Plettenberg-Herscheid



### ***Gesundheits- und Pflegenetzwerk Plettenberg-Herscheid, North Rhine-Westphalia (health and care network)***

The goal of the health and care network is to further develop *Plettenberg* and *Herscheid* as dementia-friendly municipalities. To this end, training is given not only to dementia sufferers and their family members but also to taxi drivers, retailers, hairdressers and bank employees. The goal is to create a region which has a comprehensive understanding of this clinical picture and treats people with dementia accordingly.

### ***Seniorenhilfe St. Josef gmbH in Wadersloh, North Rhine-Westphalia (assistance for senior citizens)***

With a retirement home and a mobile menu service the *Seniorenhilfe St. Josef* already provides support for elderly people in the region in their daily lives. The next step is to improve and extend the networking between the services – with dementia-friendly and multi-generational living and working arrangements in Wadersloh and its districts. They aim to encourage more people to move here and counteract the depopulation of rural areas.

### **Planning for the elderly Marburg, Hesse**

The topic of planning for the elderly is particularly important for the town of Marburg. With its diverse information, action and training programme on all aspects of dementia, awareness is to be raised in the region, and the day-to-day life of dementia sufferers and their family members is to be made easier – by offering alternative living arrangements for people with dementia, an information cafe with exchange events, action days to inform the public at large or continuing training schemes for people working in the retail trade.

The *Seniorenhilfe St. Josef* provides support in everyday life



## Topic Art and Culture

Art and culture are important pillars of our society. They draw together people of all ages and enable them to experience new things. Cultural activities help people to fulfil themselves, to enter new territory and to form an opinion.

Art and cultural activities help people with dementia to enjoy a rich daily life and enable them to take part. Film showings, readings, concerts or lectures entertain them and encourage social exchange. The positive effects of cultural projects are still all too often underestimated. Their impact on the well-being, emotionality and cognitive skills of dementia sufferers has, however, been proven. Many initiatives encourage dementia sufferers and their family members to actively take part in art and cultural activities.

### Adopt a positive approach

When people with dementia get involved in art and cultural activities, for many of them this has a positive impact on their basic mood. Cultural projects in which dementia sufferers and healthy individuals from different age groups interact help to dismantle prejudices and encourage empathetic interaction with each other.

Shared activities create a feeling of closeness between the dementia sufferers, their family members and caregivers and encourages the people affected to find new courage. People retain their ability to remember old songs, pictures and texts for a long time as this part of the brain is the very last area to be affected by dementia. These positive memories of earlier interests and hobbies can then become a wonderful gift for both the dementia sufferers and their family members.

Many facilities offer different cultural activities like drama classes, dance cafes or music lessons. As regular participation stimulates memory, this makes sense from the medical perspective, too.

## Create cultural programmes

Local Alliances in the field of art and culture in particular have set themselves the specific task of creating entertainment and cultural programmes. These activities are open to people with dementia, their family members and the public at large. This takes the form for instance of cooperation with facilities or associations whose work has no specific dementia background but which nonetheless open up their join-in activities to everyone.

In various Local Alliances participants rehearse plays, visit cinemas, concerts and museums. People come together to sing, dance or take part in painting classes.



Playing music in the Berlin Drum Circle

## Topic Art and Culture

### **Art and culture in the Berlin Drum Circle, Berlin**

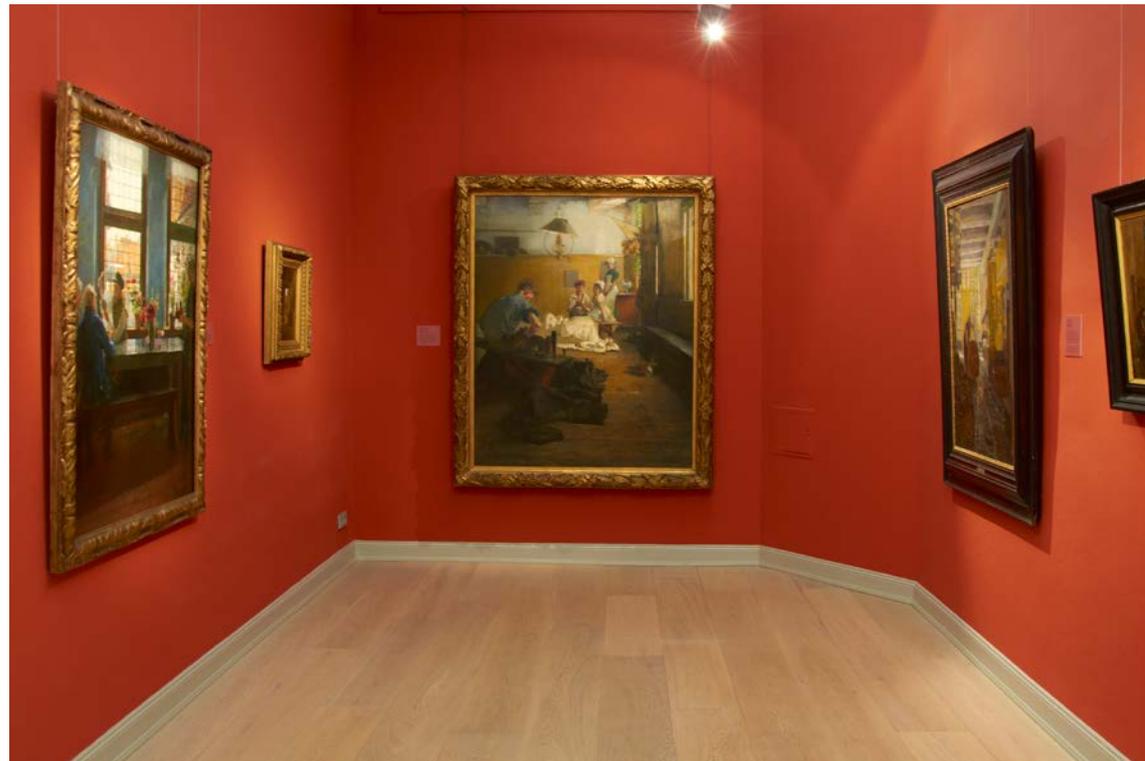
The Berlin Drum Circle taps into the positive effect of music on both the interpersonal and health-promoting levels. As part of the project “Villa Albrecht – Living arrangements and life at an advanced age”, the Drum Circle therefore extends an invitation to drumming, exercise and singing. This is a place where illness takes a back seat and enjoyment of music is centre stage. The doors of the Villa Albrecht are open to everyone. The services are intended primarily for people from the neighbourhood. A child day care centre has now also joined the partners of the Berlin project.

### ***Demenzzentrum e. V. Trier, Rhineland-Palatinate* (dementia centre)**

*The Demenzzentrum e. V. Trier* has already been active for ten years. It presents its services to the public, develops innovative support structures and so much more. With its choir project “For us it should rain red roses”, it embarks on new territory. Here people with and without dementia sing together and rehearse for a big concert in the municipal theatre in Trier. The aim of this project is to raise awareness of the topic dementia amongst as large a public as possible. It seeks to highlight the special skills that the people affected still have at their disposal.

### ***KunstImpuls Lübeck, Schleswig-Holstein* (art stimulus)**

The Lübeck museums are a network of ten museums – with a broad offering ranging from art over history to literature and natural history. With the *KunstImpuls* project the museums would like to support the self-imposed task of the Hanseatic city of enabling the elderly to enjoy independent lives as active participants in society. During a guided tour and a workshop dementia sufferers experience the Museum Behnhaus Drägerhaus as an open and safe venue – two experts speak freely and informally with the participants about the works of art on display.



Special guided tours in Lübeck museums



Group sing-alongs in the *Demenzentrum e.V.* in Trier

## Topic Migration

Against the backdrop of the major increase in in-migration in recent years, the culturally sensitive care of people with a migration background takes on increasing importance. Hospitals, counselling centres, care services, care facilities and many other providers expect to see an increase in migrants suffering from dementia in the future.

People with a migration background and dementia often suffer even more as their environment often appears to them to be “doubly alien”. Not only do their memories of their home country fade away. Their socio-cultural values acquired earlier in their country of origin also tend to resurface. The current living environment to which the migrants had successfully become acclimatised now appears increasingly alien. Another factor is that they lose the ability to speak German which they mostly learned late on in their lives.



## Removing barriers, building trust

Culturally sensitive support and care services are frequently only taken up by dementia sufferers and their family members if they can establish a relationship of trust in them. Consequently, it is important from the first contact with migrants with this illness to take into account, whenever possible, differences in origin, language, religion, traditions, customs and habits. Experience shows that the successful establishment of contact is best done through migrant organisations.

The existing Local Alliances in the field of migration are pushing for the expansion of culturally sensitive support and care in order to offer migrants more locally based assistance.

## Individual access to counselling and information

One contribution in this kind of support programme involves the intercultural training of staff in facilities that are located in a setting with a high proportion of migrants.

It makes, for instance, sense to work together with voluntary helpers on the ground who have a similar cultural background to the people with dementia and their family members. In this way language and socio-cultural communication problems can be dismantled.

Local Alliances attract volunteers with a migration background, for instance in cooperation with mosque communities, who then assist dementia sufferers with related services in hospitals or in care homes or support them in their home environment.

*The Sozial-kulturelle Netzwerke casa e. V. (social-cultural networks casa) in Berlin wishes to provide more services for migrants*

## Topic Migration

### **Sozial-kulturelle Netzwerke casa e. V. in Berlin (social cultural networks)**

For 30 years now the Sozial-kulturelle Netzwerke casa e.V. has been actively involved in the most diverse projects in the Berlin district of Spandau. They include the dementia pilots Spandau who support people with dementia and their family members. The entire project programme is now being stepped up and extended. Migrants, too, can benefit from comprehensive support services – particularly through assistance from volunteers with a migration background. Another goal is to raise awareness amongst the public at large for this topic and to encourage the frank handling of this topic.

The Alzheimer Gesellschaft Baden-Württemberg (Alzheimer's society) has developed intercultural dementia toolkits for care facilities



### ***Miteinander e. V. in Weißwasser, Saxony (togetherness)***

The association “*Miteinander e. V.*” in Weißwasser has already been active since 2004 in promoting the integration of ethnic German resettlers, repatriates, refugees and their family members. The clear goal of the association: to consciously preserve the culture of the home countries – to consciously become familiarised with the culture of the new host country. The focus of the association is on people with dementia: their quality of life is improved through support in their daily routines, for instance when dealing with public agencies and doctors and through diverse leisure offerings.

### ***Alzheimer Gesellschaft Baden-Württemberg e. V. (Alzheimer’s society)***

The *Alzheimer Gesellschaft Baden-Württemberg e. V.* sees itself as the central point of contact for dementia. Its project “Building bridges – Intercultural dementia toolkit for care facilities” is primarily intended for institutions in the region of Heilbronn and beyond throughout the entire federal state. Each of the especially designed toolkits addresses a specific culture – for instance a toolkit for people from Turkey. The toolkits are then made available to various facilities in order to raise awareness locally for the topic of intercultural opening.

Culturally sensitive care takes on increasing importance





The Alzheimer Gesellschaft  
Schleswig-Holstein establishes  
farms as network partners

## Topic Care Services

Being diagnosed with dementia changes not only the life of the person affected but also the daily routines of supportive family members. Many families choose home-based care. Often, they are confronted with major challenges when it comes to reconciling work and the care of their family members at home.

It is, therefore, important for family members to individually weigh up: what part of the care work can they do themselves and where do they need support?

### Networking encourages a feeling of community

Besides their information and counselling offerings, the initiatives of the Local Alliances establish contact in the field of support services to public agencies and medical care centres like, for instance, care services and cultural facilities. Affected individuals and their family members are thus given diverse opportunities to deal with the illness.

Besides relieving the burden on the organisational side, psychosocial support takes on major importance when it comes to the engagement of the Local Alliances. Talking to other dementia sufferers, family members or professionals creates a forum for an exchange of information and experience, and gives dementia sufferers and their family members the feeling that they are not alone. This dialogue can be conducted in individual or group counselling sessions.

### Dedicated training schemes ensure quality

In order to maintain the quality of care, many Local Alliances offer their volunteers and full-time staff the opportunity to attend training courses and dedicated education schemes.

This not only ensures appropriate support. Beyond this, the Local Alliances contribute to a general improvement in the support landscape for people with dementia.

## Topic Care Services

### Rural district Hildesheim, Lower Saxony

The *Senioren- und Pflegestützpunkt Niedersachsen* (senior citizens and care support centre Lower Saxony – SPN) in the rural district of Hildesheim is a central counselling and networking centre for all questions to do with the topic of growing older and care. At the same time, the SPN also sees itself as the network coordinator for all stakeholders in the rural district. The current project work aims to secure family doctors as network partners in order to put in place dementia-sensitive family doctor practices. This is particularly important as these practices have often been looking after the corresponding patients for a long time – they play a crucial role.

The rural district of Hildesheim would like to promote dementia-sensitive family doctor practices



### ***Alzheimer Gesellschaft Schleswig-Holstein e.V.*** **(Alzheimer's society)**

The dementia competence centre run by the Alzheimer Gesellschaft Schleswig-Holstein e.V. is the umbrella organisation for the 13 regional Alzheimer's societies. It provides information on dementia diseases and their impact on sufferers, family members and society, and offers assisted holiday trips. Now farms in the region are to be secured as network partners in order to further extend the services offered to dementia sufferers. Farmers are recruited for the topic dementia and create biographical, meaningful and life-oriented activities. In addition, structurally weak regions can then offer activities locally.

### **Welfare and social care for the infirm and the elderly in churches in Hamburg West**

The red yarn stands for the thread running through people's lives. The project is designed for people at the onset of dementia. The goal is to avoid the social isolation that frequently occurs, which mainly results from feelings of shame and fear of making mistakes. The project tackles both sides: the people affected and the society in which they live. Care is taken to ensure that people with dementia can continue to do what they enjoy: being active members of a sports club or choir or play Skat. The awareness of people in their environment is raised in order to break down barriers.



The red yarn is the symbol for the incentive to play an active role in society

## Topic Old and Young

Dementia sufferers are particularly dependent on empathetic support and good social contacts. To prevent their social exclusion, an understanding of dementia and dementia sufferers must be established across all the generations. Furthermore, day-to-day knowledge is needed about how the people affected and their family members can be helped.

Young people, in particular, can make an important contribution to this. Often, they are spontaneous and have good ideas – a precondition for shaking up rigid thought and behavioural patterns. In future, the younger generation will have to assume responsibility in a society in which dementia will be even more present. That's why it is so important for all generations today to learn how to deal with this illness – irrespective of age, gender and origin.

In particular the interaction between very young children in child day care centres and primary schools and dementia sufferers is very enriching for both sides as the little ones see people with dementia in an unbiased manner and treat them as normal. Adults can learn from them.

### Interaction between all the generations

The Local Alliances champion the integration of people with dementia in our society. The initiatives in the area “Old and Young” pursue the goal of encouraging interaction between people from all age groups. The awareness of young people in particular is to be raised in a dialogue-oriented exchange about interacting with dementia sufferers. The realisation that the affected individuals still have potential that everyone can benefit from is particularly important here.

### Coming together in municipal meeting places

In order to strengthen a sense of belonging between people in all age groups, Local Alliances have created a forum for encounters in many municipal communities. By way of example, reference is made here to the initiatives of the multi-generational houses and child day care centres where young and old meet, learn from each other and engage in joint activities.

Meeting places of this kind are important in order to break down the fear of contact of younger generations, too, and facilitate an exchange between citizens and dementia sufferers on an equal footing.

Pupils in Aachen take part in the project “One-on-One Old and Young”



## Topic Old and Young

### ***Caritasverband für die Region Eifel e. V., North Rhine-Westphalia (Caritas association for the Eifel region)***

Pupils from the 8<sup>th</sup> grade play a social role in a nursing home in the project “One-on-One Old and Young”. What this actually means is: the young people assume a one-on-one role once or twice a month for an elderly person with dementia and learn what responsibility, an understanding for the elderly, social skills and helpfulness mean. In return for their commitment they are given a certificate and, in addition, an entry in their school record which employers and secondary schools like to see. At the present time around 20 pupils from the St. Ursula Monschau intermediate girls’ school are involved.

### ***Alzheimer Gesellschaft im Kreis Coesfeld e. V., North Rhine-Westphalia (Alzheimer’s society in the Coesfeld district)***

Since 2015 the Alzheimer Gesellschaft im Kreis Coesfeld e.V. has been working towards improving the social acceptance of people with dementia in its region. The focus of its current project work is on improving the networking of dedicated dementia services in the municipalities of Nottuln and Havixbeck – with the help of a regional dementia network in which volunteers and professional staff are brought together. In particular young people too – children and older pupils – should be familiarised with the topic of dementia.

### ***Mehrgenerationenhaus Hamburg Altona FLAKS e. V. (multi-generational house)***

A committee developed the project “Cultural hands-on projects for people with and without dementia”. Public agencies, institutions, self-help groups and people with dementia are all involved. There are plans for diverse joint activities in the field of culture like drama, making music and/or painting. Grandparents, their children and their grandchildren have fun together in artistic activities and this helps them to find new ways of interacting in daily life that is often difficult and dominated by care activities.



Doing a drama class together as a new way of interacting with people with and without dementia



Old and young together on stage

## Topic Religion and Spirituality

Religion and spirituality play an important role in many people's lives. When interacting with dementia sufferers and their family members, faith can give them strength and make them feel less alone. In their work Local Alliances with a spiritual and religious orientation foster feelings of comfort and closeness. They can give meaning to the life of people with dementia.

Often, pastors are the few people who still have access to dementia sufferers. They can take the affected individuals out of their isolation and give them access to the counselling and support offerings of the Local Alliances and the church parishes such as, for instance, discussion groups and choirs. This means that the church parishes are important partners for the Local Alliances.

The spiritual experiences often take up the life story of the people affected. In this way dementia sufferers can, amongst other things, relive their past. These activities give them strength and promote their feeling of identity.

### Extend interfaith activities

In a multicultural society it is important to include people with different socialisation backgrounds. Many of the existing initiatives make an effort to approach the affected individuals, family members and people from different cultural circles and integrate them into the community.

This applies in particular to dementia sufferers who originally come from a foreign country and bring with them a religious background that their German neighbours are not familiar with. Special knowledge about dealing with other religious communities is particularly important for the work of the Local Alliances in the field of religion and spirituality.

## More than just church services

Local Alliances in the field of religion and spirituality offer wide-ranging activities and counselling services. Besides church services, the spiritual biographical reliving of the past and information events of church parishes, the initiatives also organise neighbourhood meetings. In addition, they establish contacts to other religious representatives in order to encourage interfaith networking.

Uelsen church encourages the participation of people with dementia



## Topic Religion and Spirituality



Religion structures the daily life of many people with dementia

### **Herz-Jesu-Stift Alten- und Pflegeheim Köln GmbH, North Rhine-Westphalia (Heart of Jesus foundation retirement and care home)**

The project “Dementia + Spirituality” offers dementia sufferers and their family members support in daily life both in care facilities and in the home environment. The project participants are primarily interested in ensuring that people with dementia remain part of the community. Hence, spiritual support focuses on the importance of encounters and an instinct for inner experiences. In addition, it runs the course “Switching off – Meditative elements and exercise”. The Pilate’s sequences and muscular exercises give dementia sufferers orientation and help them relax.

### **Protestant Luther church parish Berlin-Schöneberg**

In the Protestant church parish Schöneberg, the spiritual centre looks after community members in the Berlin district who are dementia sufferers and their family members on the ecumenical and interfaith levels. Besides pastoral care the association offers spiritual and cultural activities – including church services and regular dance cafes. Numerous information events are staged in the facilities of other religions in order to open up these activities to people with a migration background, too.

### **Uelsen Church, Lower Saxony**

Preventing people with dementia from becoming lonely and isolated. This is the declared goal in the work of the Protestant reformed Uelsen Church. The church’s outreach is considerable – roughly half of the 11,235 inhabitants in the community are members. The church uses this to raise awareness of this topic and to put in place an impressive support programme. For instance lecture series are organised, cultural events like plays are staged and a shuttle service is provided. This is how the church encourages participation and, at the same time, responds to the impact of demographic change.



The project “Dementia + Spirituality” offers assistance in daily life

## Topic Living Arrangements

For many people their own house or flat is the space where they feel comfortable and safe. This is even more relevant in later life. It is especially important for people with dementia to live in their familiar surroundings despite their illness. After all, besides memory loss they are frequently confronted with spatial and temporal orientation problems and feel unsure and lost when they are in less familiar settings.

Some of the Local Alliances have set themselves the task of taking up and catering for the individual living and support wishes of dementia sufferers.

The initiatives cooperate with different network partners such as, for instance, housing associations or the providers of care facilities. By means of information, counselling and support services they create opportunities for an independent lifestyle.

### Stay independent for as long as possible

The decision about how long a person can remain at home depends on various factors. Certain physical and mental requirements must be fulfilled and the living arrangements must also meet the relevant criteria.

A suitable living environment can be created with the help of conversion work or technical aids. In addition, support from a care service makes it easier for people to stay in their familiar surroundings.

If independent living is no longer possible, there are alternatives: for instance moving into shared accommodation or a dedicated dementia care facility.

After a period of acclimatisation these new living arrangements can also become a familiar and safe environment.

## Find joint pathways to dementia-friendly living

New living arrangements are needed to meet the special requirements of people with dementia. The prerequisite is a joint initiative of all the stakeholders: municipalities, care services, family members and the people affected.

Voluntary helpers  
in Salzhausen



## Topic Living Arrangements



Specific information service on the topic of dementia in Remchingen

Music programme of the welfare and social centre in Remchingen



### **Seniorenstützpunkt Celle, Lower Saxony (senior citizen support centre)**

In the Celle region a high demand for alternative living forms has been identified. That is what prompted the *Verein Frauenräume in Celle e. V.* (association women's spaces in Celle) to suggest the founding of a flat-sharing community for people with dementia – which was finally opened in 2014. Furthermore, the *Seniorenstützpunkt Celle*, attached to the sponsoring association, offers voluntary advice on living arrangements. This responds to the wishes of many people with dementia who want to stay in their homes despite their illness.

### **Diakoniestation Remchingen e. V., Baden-Württemberg (welfare and care centre)**

In addition to general counselling services, the *Remchingen Diakoniestation* also offers a specific information service on the topic of dementia. It touches on the topic of living arrangement and care wishes, too. Many people with dementia would like to stay in their familiar surroundings. Various options for doing this are touched on in discussion rounds. Furthermore, the association provides training for tradespeople and retailers on how to interact with people suffering from dementia, in addition to offering a comprehensive music programme. Biographical work is undertaken and the group feeling strengthened.

### **Interessengemeinschaft zur Unterstützung von Alten, Kranken und Hilfsbedürftigen e. V. in Salzhausen, Lower Saxony (interest group to support the elderly, the sick and the needy)**

Already since 1986 numerous volunteers have been active in the *Interessengemeinschaft e. V.* in Salzhausen. They read to people with dementia, help in the support cafe for dementia sufferers and accompany people when they go to government offices, to name just a few of the tasks they assume. They also take into account the very specific needs of dementia sufferers in their living environment. Information events with outpatient care services, nursing homes and the providers of alternative living arrangements raise awareness and provide information on this topic.

## Topic Education

In some cases, there is still some uncertainty about dementia in society. Many people find it difficult to interact with dementia sufferers in public. Numerous individuals still feel that they are not sufficiently informed about dementia diseases. How do I interact with a dementia sufferer? Who can I alert in an emergency? Special training schemes help to answer these questions.

Most people with dementia are ashamed of the memory loss triggered by their illness and suffer from the social isolation that frequently occurs in the course of the disease. Therefore, it is important to raise awareness of and provide information for the social environment. The Local Alliances for People with Dementia have set themselves the task of informing people. They seek to attract attention to this illness, provide information about support programmes and encourage engagement.

### Training of dementia pilots

Local Alliances train volunteers as dementia pilots or companions. Individually developed curricula enable committed individuals to relieve the burden on family caregivers by home visits, to visit dementia sufferers in care facilities or to act as dementia companions for the dementia sufferers during a stay in hospital. Dementia pilots do not provide any care services. Through their presence they can take a dementia sufferer for a walk, read to, craft or chat with them. As a fixed, regular contact person and companion during a hospital stay, they give the dementia sufferer a feeling of security and contribute to their recovery.

### Information through public relations activities

The Local Alliances in the education category help to position the topic dementia in a constructive manner in society and establish it there on a permanent footing.

The ongoing networking activities of the initiatives include for instance training programmes, series of events and counselling on how to interact with dementia sufferers. Dementia doesn't just affect people with dementia themselves or the individuals in their direct environment.

For some individuals contact with people with dementia is increasingly becoming a daily occurrence. This group includes, for instance, law enforcement officers, shop assistants, taxi, bus and tram employees or public agency staff. They are the preferred target groups for courses on the right way to deal with dementia.

Local Alliances that contribute to public relations work through their training programmes help to create an enlightened and tolerant living environment.

## Create networks

Networking is one of the central tools used by the Local Alliances to achieve this goal in the field of education. In this context adult education centres are important partners of Local Alliances. By means of partnership-based links between various institutions it is possible to undertake effective educational work.

Support for people with dementia is one of the main activities of the *Arbeiter-Samariter-Bund Ortsverband Neustadt – ASB OV* (workers-Samaritans federation, local association)



## Topic Education

### **Office of the *DRK-Bildungswerk Wittlich*, Rhineland-Palatinate (German Red Cross education centre)**

The project “Timeless: Dementia campaign in the rural district of Bernkastel-Wittlich” would like to focus attention on the topics awareness raising, participation, encounters and public relations. The event series “Dementia campaign” touches on dementia and reducing the related burdens. Another dementia project is intended for the retail trade as dementia sufferers are also customers. The third project is specifically intended for people with dementia. They are invited to take part in a “singing project”. The participation of dementia sufferers in everyday life is strengthened and encounters between people with and without dementia are encouraged.

### **ASB OV Neustadt, Saxony**

The *Arbeiter-Samariter-Bund Ortsverband Neustadt/Sachsen* (workers-Samaritans federation local association Neustadt/Saxony) has already been active since 1990. With around 430 permanent members of staff it is one of the biggest employers in the region. Caring for dementia sufferers is one of its main areas of activity. Since 2014 its in-house competency centre dementia has organised various education and training programmes for professional caregivers and other interested parties. Furthermore, high-impact information events are staged in order to continue raising awareness of the topic dementia.

### ***Bildungswerk e. V. Herne*, North Rhine-Westphalia (education centre)**

Since 2013 the *Bildungswerk e. V.* has offered a wide range of further and continuing training schemes for caregivers, some of them with the focus on dementia. It also offers training leading to a qualification as a dementia caregiver, now with the option of a focus on intercultural work. This programme is open to women and men who themselves have a migration background and would like to support people with dementia. In this way, the *Bildungswerk* would like to focus on the challenges thrown up by demographic change.



The project “Timeless: Dementia campaign in the rural district of Bernkastel-Wittlich” stages different events on the topic of dementia

Information event in Neustadt



## Pointers and Tips for Project Initiatives

### Reveal the potential of dementia sufferers and help them to become active

500 local networks in the federal programme “Local Alliances for People with Dementia” are just the start. Whether municipal communities, associations, church parishes, multi-generational houses, hospitals, doctors, cultural centres, firms, senior citizens’ offices or self-help organisations, there are no boundaries to the type of institution. It’s all about actively creating new networks and developing existing ones.

### Themenschwerpunkte

The wide-ranging services on offer up to now give dementia sufferers very diverse ways of accessing support services. This diversity is intended and takes up the different needs and interests of dementia sufferers and their family members. Previous experience has shown that priorities should be set to cater for specific target groups and regional specificities.

For instance people from other countries of origin have a special need for support. The concept of culturally sensitive care also applies to people with dementia. Other priorities are the development of networks in rural areas, more intensive cooperation with care support centres, the involvement of children and adolescents by means of multi-generational initiatives and the bringing on board of municipal communities. Numerous municipal communities already support the Local Alliances for instance through senior citizens’ service offices or demography officers. This is because ideas and activities take hold the fastest in the direct social environment of the dementia sufferers, in the action area of the municipal communities, towns and rural districts.

Draw inspiration from the diversity of the 500 networks and set up other local networks for people with dementia. Get in touch with the existing Local Alliances in your region and benefit from their experience.

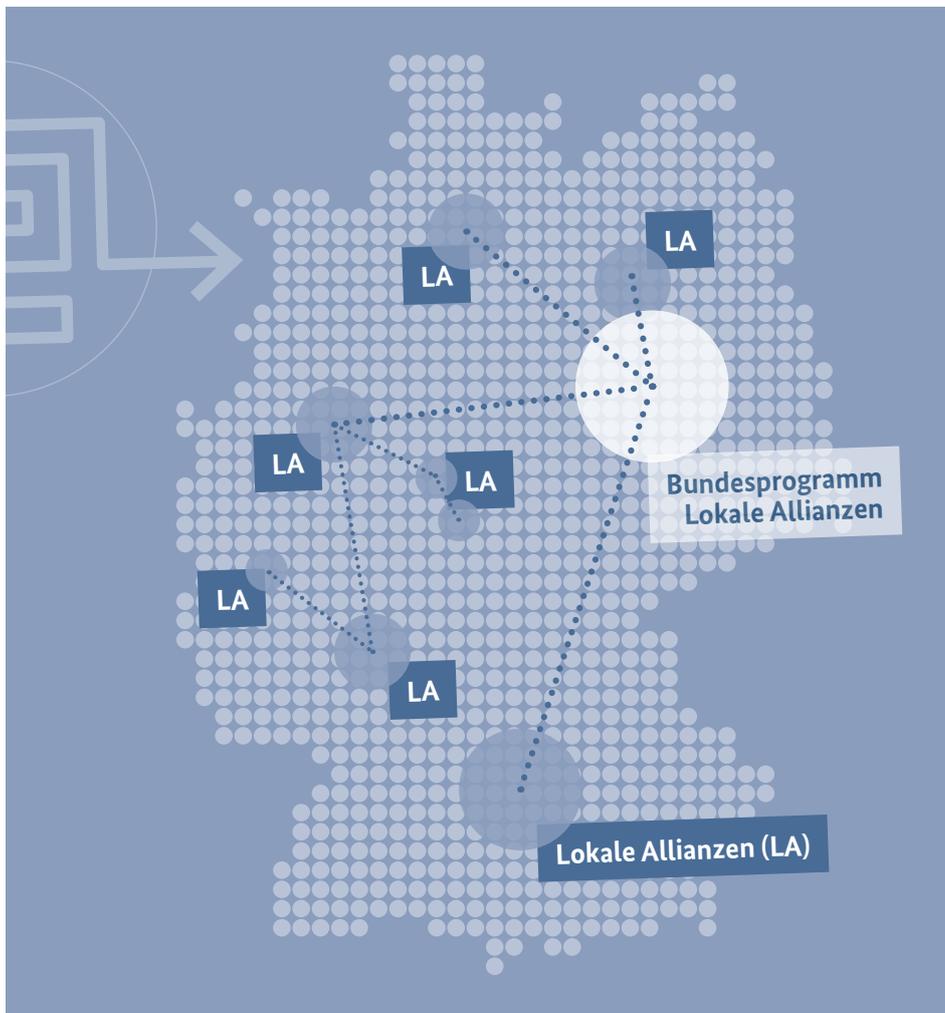
## Networked nationwide – together we are strong

### *What is a network of Local Alliances?*

- A regional form of cooperation
- A consciously selected form of cooperation
- A structured and socially recognised problem-solving strategy

### *What are the tasks of this network?*

- Improving the dementia care infrastructure
- Educating the population to ensure a tolerant living environment and extending cooperation with civil society
- Commitment to multi-professional care and support for people with dementia and their family members



## Pointers and Tips for Project Initiatives

### **... on the topic of sustainability:**

*The best network or project is worth nothing if it only functions during the project funding period. Ensuring sustainability is, therefore, a central task for all project managers. Here are some suggestions and experiences which could help you to ensure your project is sustainable.*

Plan in a timely manner! Not reflecting until the end of the project funding period about how to ensure the project work is sustainable is not likely to be crowned with success. The topic sustainability must be addressed during the project planning stage, i.e. even before the start of the project. Sustainability is also dependent on good project planning. It should always be preceded by a demand analysis: what need is there for the planned project and is there any need at all? It is important to develop realistic goals – less is often more – the achievement of which can be monitored. Participatory project planning contributes to success: key target groups are actively brought on board and involved.

If you wish to create a network, the character of the network must be clarified at the outset. Is it to be a “civil society network” or an “institutional support network”? It’s important to ensure that the benefits of participation, the time and expense involved and the degree of commitment are transparent. No matter what your project looks like, you should actively involve the municipal community. Personal contacts are important and should be nurtured. The contribution by the municipal community to the network or project in the project funding stage and after (sustainability) must be openly discussed at the beginning and must be transparent. Position your Local Alliance on several pillars and involve several cooperation partners early on.

The sustainability of a project is also determined by the degree of its visibility. Public relations work must, therefore, be ongoing. An attempt can be made, for example, to establish strategic partnerships with local media.

The funding issue is not the only question but it is an important one for the work of networks and projects – particularly from the sustainability perspective. Attempts should be made to create a *funding basis* for the network activities (e.g. membership fees, foundation fund) and to put in place *mixed financing* (e.g. basic financing (see above), project funding, sponsoring and contributions in kind from funding bodies

and project partners). Networks can also offer their own services in return for remuneration (e.g. courses or counselling services). They should always be designed in such a way that they are *viable and can be financed without special project funding*. For this existing funding options can be tapped into (e.g. Section 45 *Sozialgesetzbuch XI* [Social Code Book XI]).

*Participant and user fees* should also be introduced from the very outset.

### **New:**

Long-term care insurance funds can also fund networks for people in need of long-term care.

The *Zweites Pflegestärkungsgesetz* (Second Act to Strengthen Long-term Care – PSG II) steps up regional cooperation in supporting people in need of long-term care on the local level. Long-term care insurance funds can participate in self-organised networks for structured cooperation in care and provide funding of up to €20,000 per calendar year on the level of the districts/autonomous municipal authorities. The Act entered into force on 1 January 2017.

<https://demenznetzwerke.de/>

### **... on the need analysis:**

*Local alliances wish to create local networks and services that help people with dementia impairments and their families to remain part of the community, to make an active contribution to the community and be able to use the required support services. But what does the situation actually look like on the ground? And what is needed there? To answer this question, it is essential for a need analysis to be conducted beforehand.*

Why is no-one turning up? A few local initiatives have already had to ask themselves this very question. In many cases this is because no need analysis was done prior to designing and launching the project. A need analysis is, however, essential and the following questions can be helpful here: When and where do I start offering my services? Who needs this support? What is my “customised” offering?

## Pointers and Tips for Project Initiatives

Are there cooperation partners? Is there a need for information and how and where can I meet it? How can I reach the target groups? “Need analysis” sounds complicated and costly but it doesn’t have to be. The following methods are excellent options for conducting a need analysis without investing substantial time and money. One effective method is, for instance, desk research. This encompasses the procurement, processing and interpretation of existing data which can mainly be obtained through desk work (e.g. age data, migration levels).

Walk-through surveys are another option. In this case sites are visited from the angle of the target group in order to record environmental factors and also any existing infrastructure. Here it is helpful to bring in a key figure from the neighbourhood as an interview partner. In surveys it is also possible to collect a wealth of important information. You can gain an initial impression of the need for your initiative from standardised questionnaires and telephone interviews. In contrast, face-to-face interviews with open questions call for a bigger investment in terms of time and money. Another method: bring in the people affected as experts acting on their own behalf. Start with the sites where people with dementia and their family members are to be found (e.g. pharmacies, doctors’ practices, care support centres, self-help groups, etc.).

Based on a sound need analysis you can then customise the design of your project and networking and avoid any frustration. This need analysis should, therefore, always precede the project.



## Pointers and Tips for Project Initiatives

### ... on networking:

*Local Alliance: This is another expression for a network in a specific location or in a certain region. The programme “Local Alliances for People with Dementia” mainly encompasses what are known as civil society networks. For instance associations, churches, municipalities, cultural facilities and citizens’ projects join forces. Getting a network of this kind up and running is a big task.*

1. It is important to define common goals in a network. It is equally important to set concrete and realistic goals. Overly high but also overly vague goals generally lead to frustration and jeopardise networking.
2. If joint goals have been defined, then the next step could be to define action areas in which the network will work. Then, preferably concrete action steps and measures can and must be derived from these action areas and then agreed on.

Make binding arrangements for instance in terms of the nature and scale of involvement in the network or in terms of decisions and task allocation within the network. This may encompass agreements between the network partners but contracts with legal implications are also feasible.

To ensure your project also works smoothly from the organisational angle, it is advisable to hire an “organiser”. He/she then attends to the binding management of appointments, spaces and meetings. Institutional networks can frequently offer a paid position for this. In civil society networks this work is often done by volunteers who assume the role of the “organiser”.

But do strive in each case to actively involve the municipal community as much as possible. This can range from networking down to the active participation of municipal representatives. Support from the municipal community in the shape of the provisions of premises and other resources is another option.

And please don't forget to offer diverse types of work and event formats, to share successes and, of course, to set aside time for fun, too.

In-depth information on the setting up of networks can be accessed in the study by the Deutsches Zentrum für Neurodegenerative Erkrankungen (German Centre for Neurodegenerative Diseases – DZNE – DemNet-D).

<https://www.dzne.de/standorte/witten/projekte/demnet-d.html>

in the support programme “Future Workshop Dementia”  
of the Federal Health Ministry

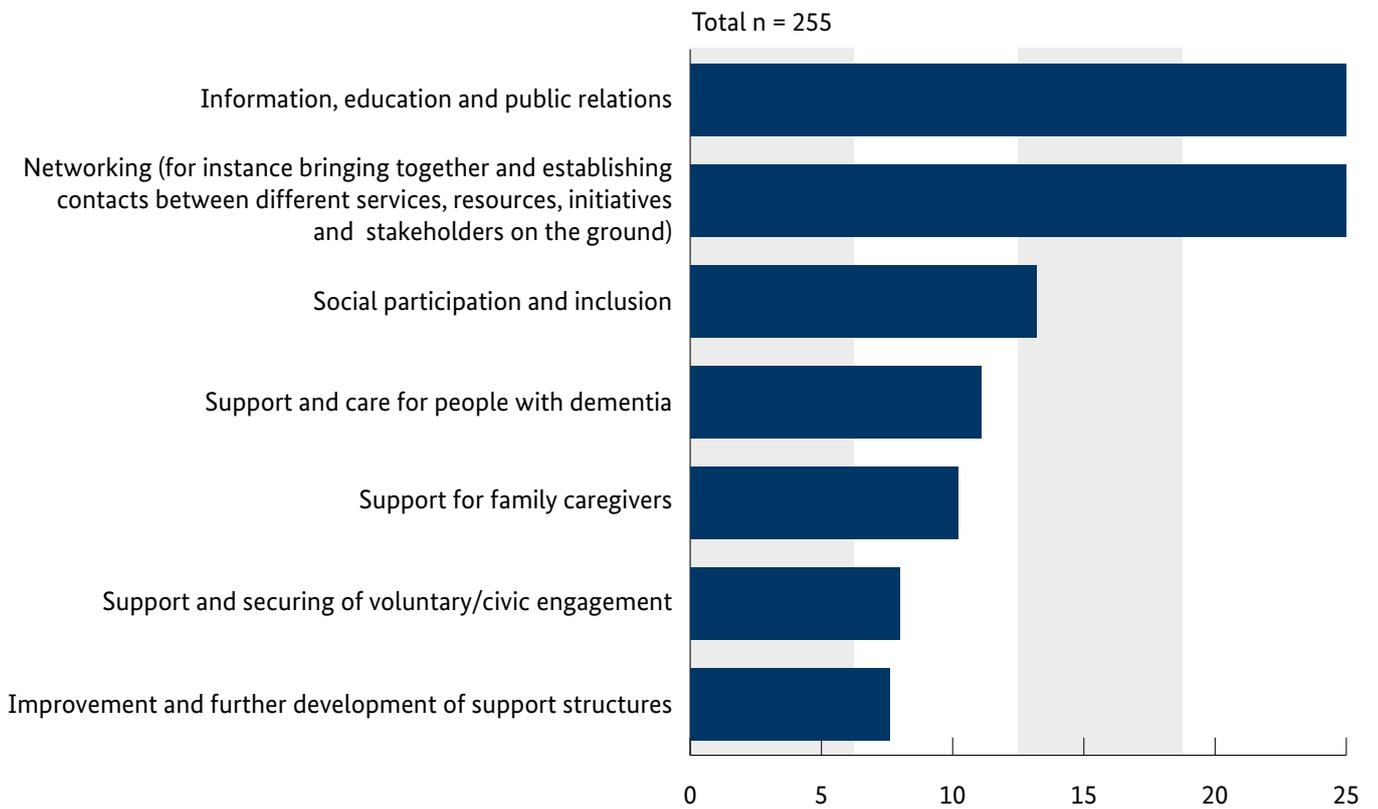
<http://www.zukunftswerkstatt-demenz.de/>

and in the dementia toolbox

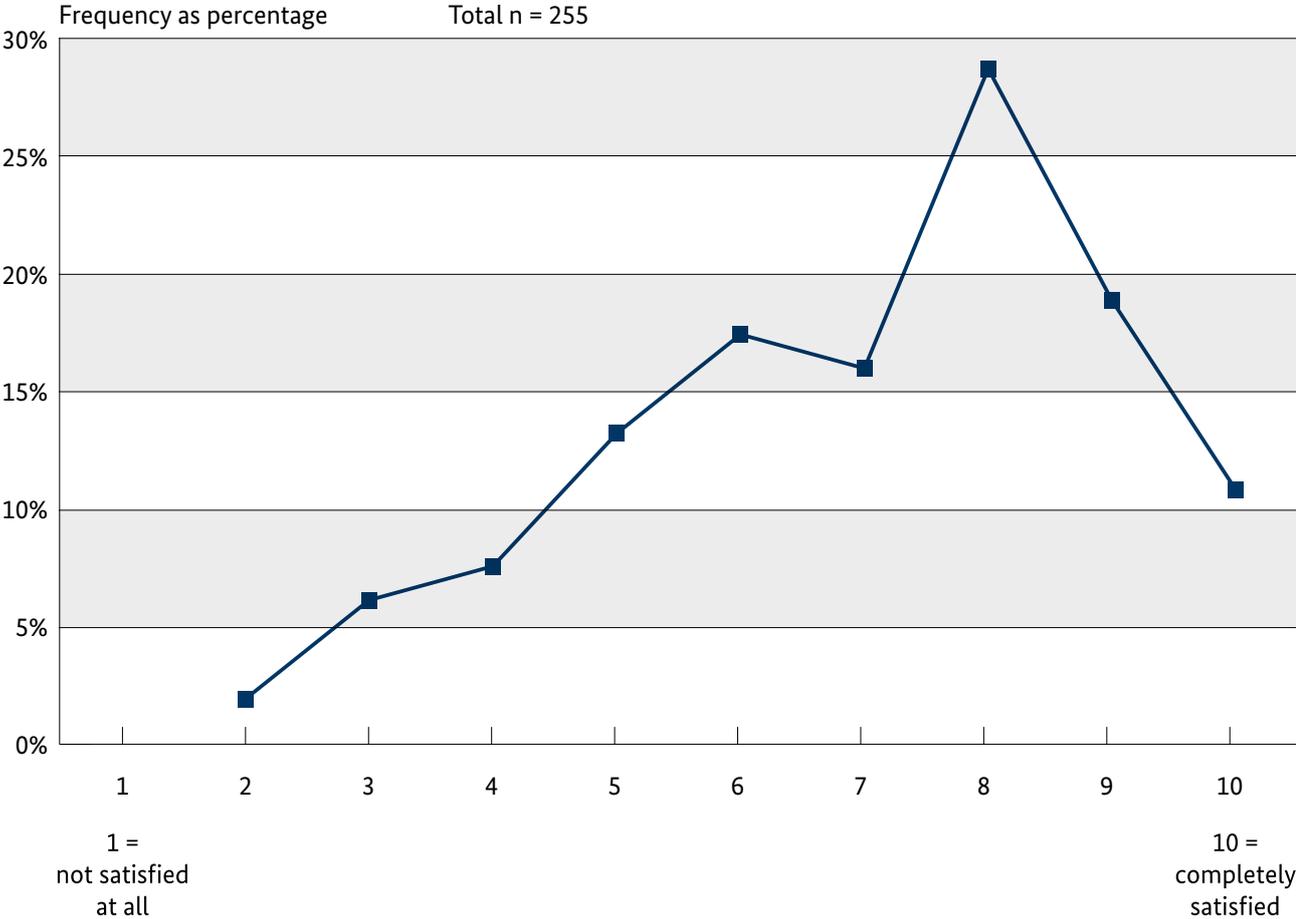
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## Project Assessments

### The most frequently mentioned goals of the projects

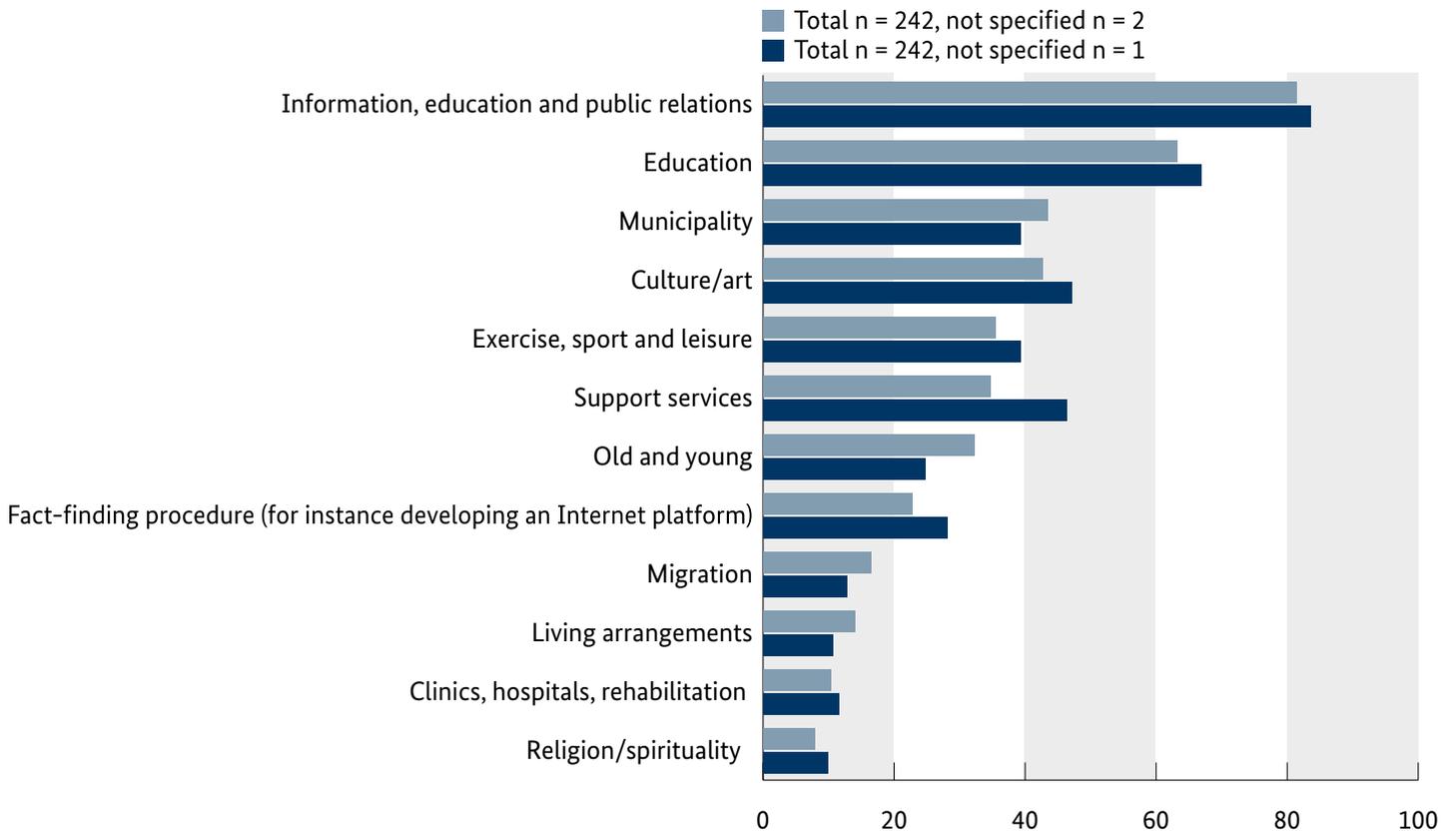


### Satisfaction with what has been achieved (up to now)

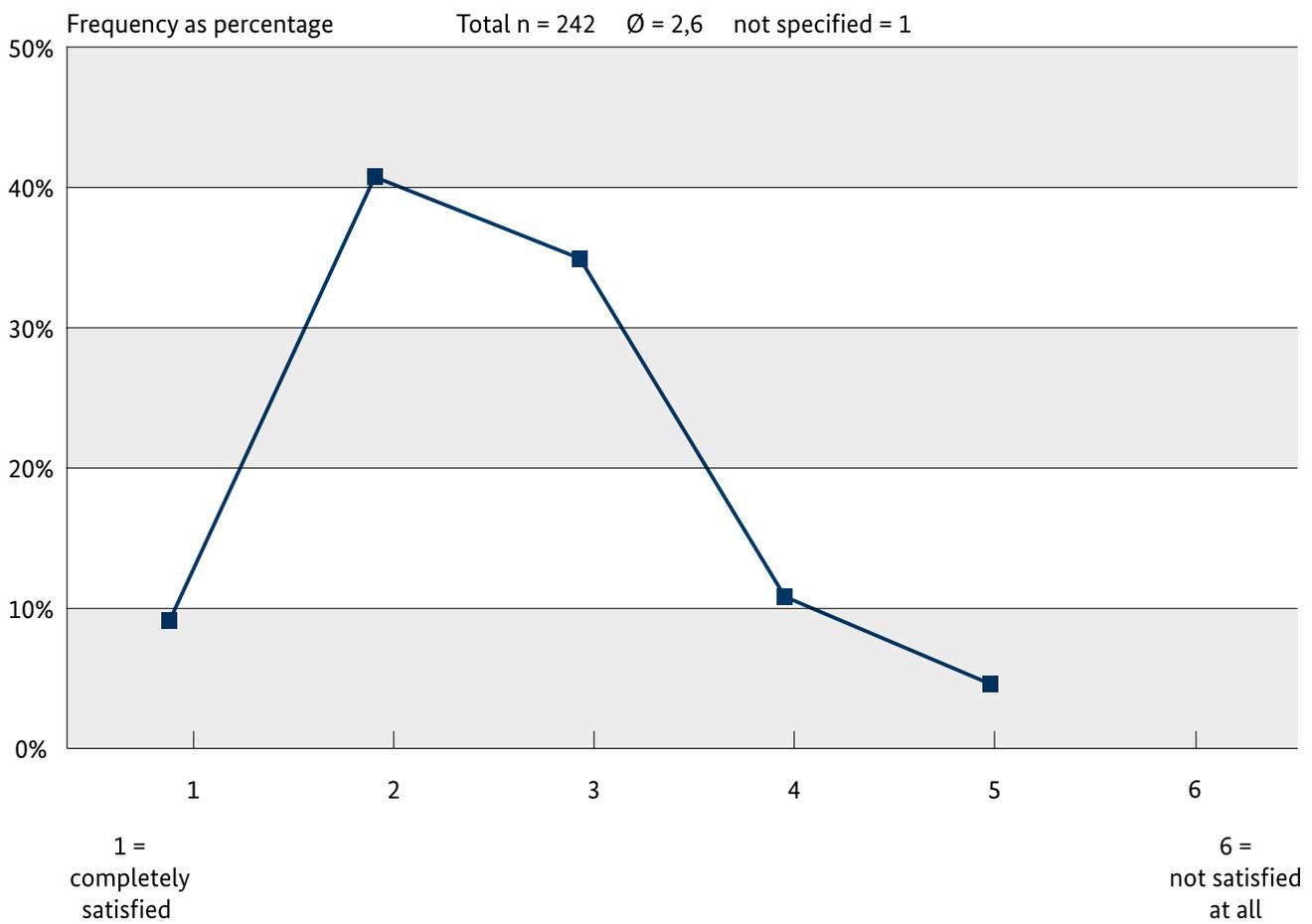


# Project Assessments

## Planned services/activities and their implementation



## Satisfaction with the response to the services/activities



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