

# National Dementia Strategy 2014–2017



Schweizerische Eidgenossenschaft  
Confédération suisse  
Confederazione Svizzera  
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**Federal Office of Public Health (FOPH)**

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GDK Schweizerische Konferenz der kantonalen Gesundheitsdirektorinnen und -direktoren  
CDS Conférence suisse des directrices et directeurs cantonaux de la santé  
CDS Conferenza svizzera delle direttrici e dei direttori cantonali della sanità



# National Dementia Strategy 2014–2017

## Contents

<b>Overarching objectives and values</b>	<b>4</b>
<b>Dementia in Switzerland</b>	<b>5</b>
Dementia as a healthcare policy challenge	5
The dementia syndrome – incidence and effects	5
Care	6
Economic significance of dementia	7
<b>National Dementia Strategy 2014–2017</b>	<b>8</b>
Action areas	8
Action area 1 – «Health awareness, information and participation»	
Action area 2 – «Needs-appropriate services»	
Action area 3 – «Quality and professional skills»	
Action area 4 – «Data and knowledge transfer»	
Implementation of the National Dementia Strategy 2014–2017	13
<b>Summary of action areas – Goals and projects</b>	<b>14</b>
<b>Bibliography</b>	<b>15</b>

# Overarching objectives and values

Dementia patients and the people who accompany them in their everyday lives are at the focus of all the efforts on the part of the National Dementia Strategy 2014–2017. Care and treatment are aimed at maintaining quality of life and dignity through the preservation of physical and mental integrity, autonomy and social involvement. Individual circumstances (such as employment, marital status or migrant background) and specific needs (for example due to concomitant conditions or disabilities) are consistently taken into account.

The National Dementia Strategy 2014–2017 promotes a better understanding of dementia conditions as well as social acceptance of those affected. As a result, inhibitions and stigmatisation can be reduced and increased openness towards people suffering from dementia can be facilitated.

The National Dementia Strategy 2014–2017 wants to ensure that all people suffering from dementia have access to high-quality, low-threshold and continuous provision of integrated psychosocial, medical and nursing care services at all stages of their condition.

# Dementia in Switzerland

## Dementia as a healthcare policy challenge

In March 2012, Parliament commissioned the Federal Council with drawing up a National Dementia Strategy.<sup>1</sup> The policy mandate addresses the Confederation and the cantons and has become embedded in the National Health Policy Dialogue (Dialog Nationale Gesundheitspolitik).

Areas requiring priority action were ascertained on the basis of an expert opinion commissioned by the Federal Office of Public Health (FOPH) and the Swiss Conference of the Cantonal Ministers of Public Health (CMPH). The strategy development process also benefitted from the active involvement of representatives from patient organisations, experts from professional groups and organisations, service providers at various levels as well as staff at Confederation, cantonal and municipal levels. This approach ensured the knowledge transfer from practice and research to policy.

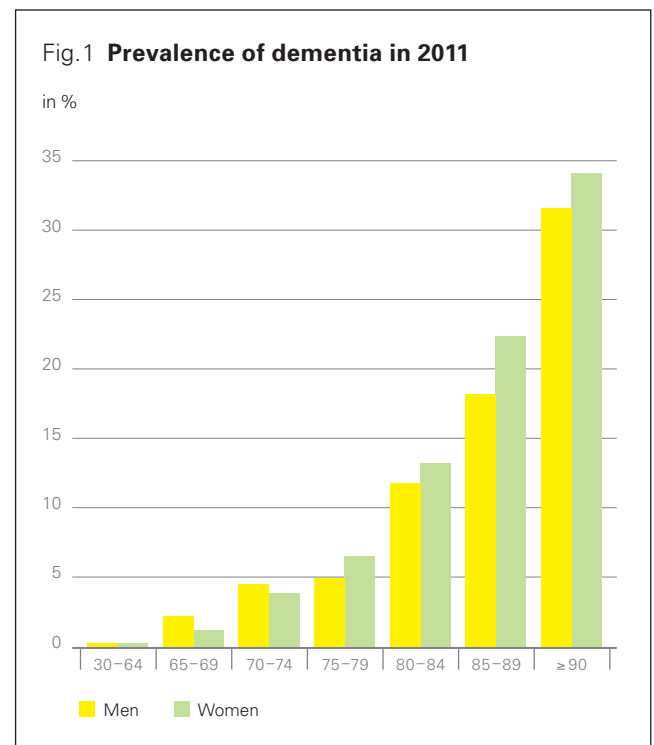
## The dementia syndrome – incidence and effects<sup>2</sup>

Dementia is an umbrella term for various brain disorders with different causes, whereby two main categories are defined which frequently occur concurrently, namely degenerative changes in the brain, the causes of which are not fully understood to date, and vascular dementia, which is triggered by circulatory dysfunction in the brain. Alzheimer's disease is the most common type of degenerative dementia.

Dementia is defined by a memory disorder combined with at least one other disorder, such as that of speech (aphasia), movement (apraxia), recognition (agnosia) or a limited ability to plan and take action (executive function disorder) (see Monsch et al., 2012; Bassetti et al., 2011).

Approximately 110 000 people are estimated to be living with dementia in Switzerland, with some 25 000 additional individuals estimated to develop the condi-

tion annually (Bickel et al., 2002). Over the age of 65, prevalence rates rise sharply; and one in eight individuals in the 80–84 age-group is affected by dementia (see Fig. 1).<sup>3</sup>



Sources:  
Prevalence rates: Harvey et al., 1998, for the 30–64 age-group;  
Hofman et al., 1991, for 65+ age-groups;  
Federal Statistical Office (FSO), 2011a

People with dementia are mostly very elderly, and two-thirds of those affected are women. Dementia can also occur at a younger age, however, i. e. before retirement age. People with an intellectual disability such as Down's syndrome are often affected particularly early.

As dementia prevalence increases greatly with age, the number of people suffering from dementia will increase significantly in future due to the ageing population. The number of people with dementia in Switzerland is thus expected to increase to over 190 000 individuals by the year 2030, and to almost 300 000 by 2060.

<sup>1</sup> Motions 09.3509 Steiert Jean-François and 09.3510 Wehrli Reto

<sup>2</sup> The following paragraphs are based on a study on the current situation of dementia (health care services) in Switzerland (Ecoplan, 2013)

<sup>3</sup> Cf. EURODEM

The deficits associated with dementia prevent affected individuals from managing their own lives, resulting in a restriction and a need for help when it comes to everyday activities. Depending on the severity, specific resulting challenges to the healthcare system (such as targeted support services for dementia patients and the people closest to them, or palliative care in the final stage of dementia) have to be considered.

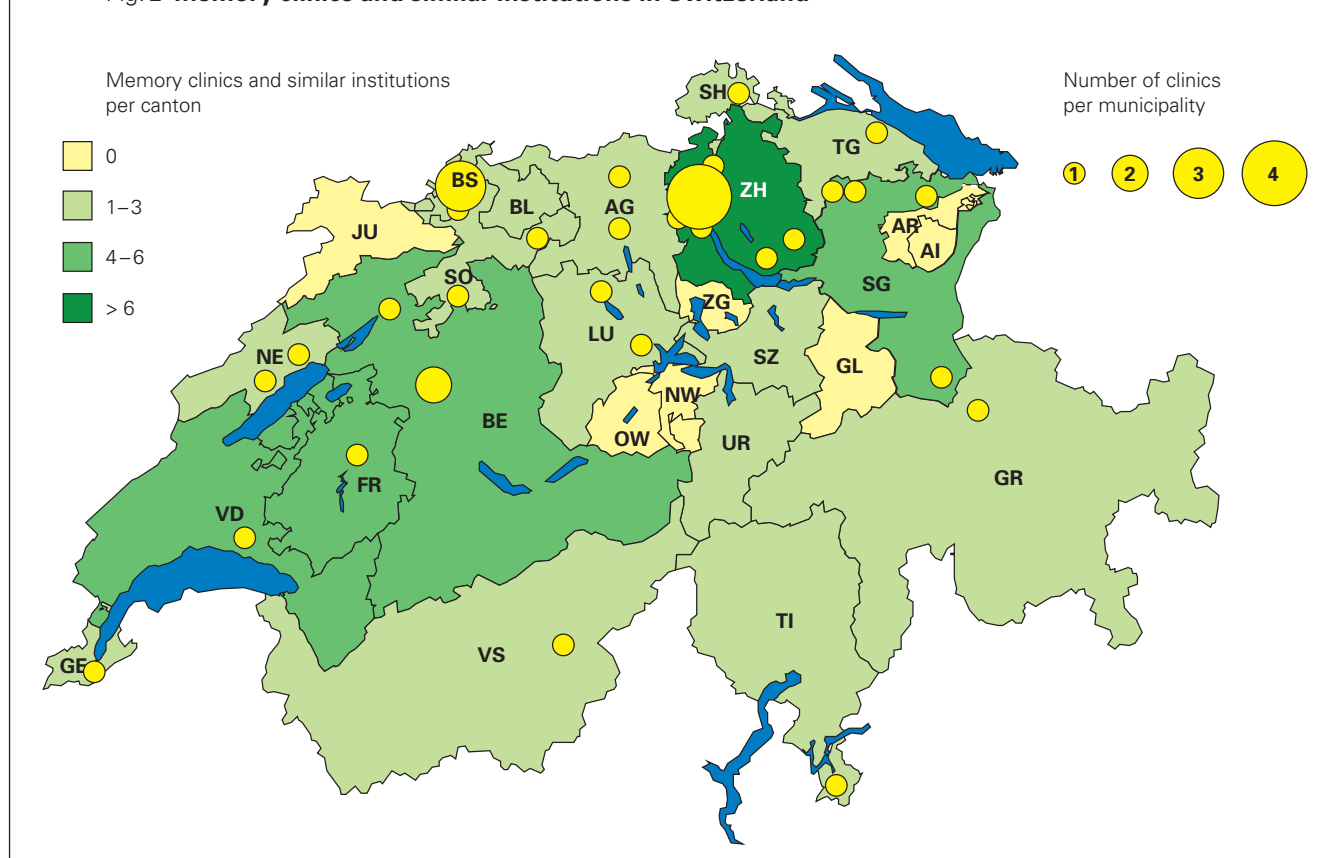
Dementia also affects the people closest to the dementia patients who provide everyday support – such as members of the family, friends or neighbours – as well as people who regularly come in contact with dementia patients in their day-to-day work. The number of individuals in Switzerland who are directly or indirectly affected is thus estimated to be around half a million.

## Care

### Diagnosis

Experts both in Switzerland and at an international level agree that early detection of the condition and dementia diagnosis make it easier for those affected to access information, advice and support as well as treatment (see WHO & ADI, 2012:8; ADI, 2011:4; Monsch et al, 2012:1246). Yet the Swiss Alzheimer's Association (ALZ) assumes that in Switzerland fewer than 50% of individuals with dementia have been diagnosed by a medical specialist. When warning signs of dementia are recognised (including any changes in terms of forgetfulness, orientation, social behaviour), the first step is usually a dementia diagnosis by a general practitioner. Differentiated diagnoses are conducted in what are currently 36 memory clinics and similar institutions (see Fig. 2).<sup>4</sup> Capacities within these insti-

Fig. 2 **Memory clinics and similar institutions in Switzerland**



<sup>4</sup> [www.alz.ch](http://www.alz.ch) and [www.swissmemoryclinics.ch](http://www.swissmemoryclinics.ch)

tutions allow some 5000 interdisciplinary diagnoses per year, which is equivalent to about one-fifth of new cases.

There are various research gaps in diagnostics. For instance, in Switzerland no data are available on the number of diagnoses made according to groups of persons, or on the form or severity of the dementia.

#### Care and nursing at home and on an out-patient basis

In Switzerland, more than 50 % of people with dementia live at home (Romero, 2011). Relatives and the people closest to them take on an important supportive role here in that they ensure everyday care, constant assistance and nursing of the person with dementia. The resulting burden is great and there is a strong desire for respite, for example through services such as day-care centres and Spitex, the home-care organisation, short stays in a care home and/or specialised information and advisory services. Yet at present, apart from a few pioneer projects, the services provided by public Spitex organisations include hardly any specific care services for people with dementia (Kopp, 2010). And the number of places available at day-care centres is also estimated to cover only 12 % of demand.

Studies into the situation of relatives providing care and nursing show the negative impact on their own quality of life: the severe strain can even lead to exhaustion and increase the carers' own risk of becoming ill (including insomnia, somatic symptoms, depression).

#### In-patient care

Hospitalisation as a result of a principal diagnosis of dementia is rare (FSO, 2011b). On the other hand, some 50 000 people with dementia are treated annually in Swiss acute care hospitals, having been admitted as a result of other diagnoses (see FSO, 2011b; Harvey et al., 1998; Hofman et al., 1991).

About two-thirds of the residents in Swiss nursing homes suffer from dementia.

The greatest challenges in the next five years are deemed to be sufficient financing for the care of dementia patients as well as sufficient nursing and care staff, as long-term in-patient nursing and care of people with dementia represents a significantly greater challenge than that of people without dementia. Wide-ranging and

seasoned professional skills are thus necessary in order to provide affected individuals with adequate assistance when it comes to everyday problems.

Challenges arising for hospitals as a result of dementia can be summarised as follows: treatment and nursing of dementia patients (e.g. cognitive impairments, orientation disorders, irritating behaviour or an urge to run away) constitute major demands on medical and nursing staff and are difficult to accommodate into hospital routines. There is also a greater risk of complications (e.g. as a result of refusal of treatment or delirium) and incorrect treatment due to problems of communication with people with dementia. The introduction of measures requiring consent can be delicate from an ethical point of view if individuals are no longer capable of giving their consent.

Dementia is the third most frequent cause of death in Switzerland today (FSO, 2010). Many people with dementia do not actually die of dementia, however, but rather with dementia. International studies show that, at the stage of advanced dementia, two-thirds of those affected die in nursing homes, whereby only a small proportion of these homes are nursing units specialised in palliative care.

#### Economic significance of dementia

In Switzerland, dementia disorders gave rise to costs of CHF 6.9 billion in 2009 (Ecoplan, 2010). Over 95 % of overall costs are care and nursing costs, the lion's share of which is spent on institutional long-term nursing and care, as well as care and nursing by the people closest to them.

The direct costs of dementia in 2009 amounted to a total CHF 3.9 billion, equivalent to 6.4 % of total healthcare cost for that year. The remaining CHF 3 billion correspond to the estimated market value of care and nursing services provided without compensation by the people closest to the dementia patients. These indirect costs are not financed.

# National Dementia Strategy 2014–2017

Based on the central idea that dementia patients and the people who accompany them in their everyday lives are the focus of the National Dementia Strategy 2014–2017, the objectives and values defined at the outset are the driving force. The overarching objective is to support those affected by dementia and promote their quality of life while consistently taking account of their individual circumstances. Throughout the course of the condition, affected individuals should have access to high-quality needs-appropriate care that is geared towards the specific target group.

Action areas, goals and projects defined in the National Dementia Strategy 2014–2017 do not claim to be a fully comprehensive discussion of the issue of dementia but reflect where priority action is needed in the central areas of dementia care. At the national level, numerous issues that have important interfaces with the issue of dementia are already being worked on and analysed in-depth. In implementing the goals and projects listed

in this chapter, it is important that synergies with these programmes and projects be used and the necessary measures coordinated accordingly in order to avoid any duplication.

## Action areas

The diverse issues to be dealt with can be assigned to four central action areas:

**Action area 1** – «Health literacy, information and participation»

**Action area 2** – «Needs-appropriate services»

**Action area 3** – «Quality and professional skills»

**Action area 4** – «Data and knowledge transfer»

## Action area 1 – «Health awareness, information and participation»

It is important to raise the population-based awareness of the needs and realities in the lives of those affected. In all stages of the condition, it is essential to promote and support or reinforce existing skills through appropriate information, as well as ensuring participation of affected individuals and the people closest to them.

### Goal 1

**The population has a better knowledge of dementia-related diseases. It is aware of the diverse realities in the lives of those affected. Prejudices and inhibitions are reduced.**

#### *Project 1.1 Population- and community-based information and awareness-raising activities*

Information content must be adapted to the everyday lives of the various target groups and the diversity of the support services. Information must also be designed to promote solidarity and integration. Those affected are involved as stakeholders.

#### *Project 1.2 Sector-specific information materials*

Target groups who regularly come in contact with dementia patients in their day-to-day work (such as non-administrative and domestic hospital workers, employees in disabled facilities and even opticians, hairdressers, bank staff, etc.) should be made particularly aware.

Persons responsible for staff and occupational health management constitute another target group that should be made aware in the interest of early detection and timely clarification of individual support needs in the case of dementia patients of working age.

## Goal 2

**Affected persons and those closest to them have low-threshold access to a full range of information as well as to individual, appropriate counselling throughout the course of condition.**

### *Project 2.1 Individualised information and social counselling services for affected individuals*

Drawing up recommendations regarding the establishment, promotion and coordination of appropriate and comprehensive services, with due regard to any instruments aimed at preserving autonomy (new law on the protection of adults).

Implementation of these recommendations is integrated into existing services (e.g. by Pro Senectute, Pro Infirmis, Alzheimer's Association, Swiss Red Cross) with due account being taken of cantonal structures as well as interfaces with other social security schemes (e.g. entitlement to support benefits) and projects (compatibility of gainful employment with caring for relatives).

## Action area 2 – «Needs-appropriate services»

At this time, access to coordinated, flexible and easily accessible support services for the care of people with dementia is not yet ensured across the board. Collaboration across the entire care chain (e.g. through case management, outreach counselling) represents a particular challenge, as does the expansion of respite services in daily care and nursing (e.g. flexible day and night care), in order to allow people to remain in their own familiar environment for as long as possible.

The affordability of respite services and care costs (stay, care and nursing) for those affected also needs to be ensured. We should bear in mind, however, that these services must be compensated according to expenditure.

## Goal 3

**Dementia patients and the people closest to them can call on flexible, high-quality and needs-appropriate care services at every point in the care chain.**

### *Project 3.1 Establishment and expansion of regional, networked centres of competence for diagnostics*

If dementia is suspected, access to diagnostics should be promoted regardless of age, circumstances or existing conditions or disabilities.

### *Project 3.2 Promotion of coordinated services to meet individual care needs*

Preparing recommendations for developing interdisciplinary care chains that promote continuous and needs-appropriate coordination/networking of primary care services (above all in the areas of early detection, diagnostics, treatment, care and out-patient nursing).

This networking must also include crisis intervention, which serves to avoid hospitalisation of affected individuals. Services are also coordinated with information and social counselling services outside the healthcare system.

*Project 3.3 Establishment and expansion of flexible regional respite services for day and night care*

Development and expansion of regional, low-threshold and financially affordable respite services oriented to specific needs for care in the patients' familiar environment (including short-term stays, holiday beds, day and night structures, day and night services). Taking account of the potential in the area of voluntary work and involving appropriate organisations (such as Swiss Alzheimer's Association, Swiss Red Cross, Pro Senectute and Pro Infirmis).

*Project 3.4 Promotion of dementia-appropriate care in acute care hospitals*

Adapting existing infrastructures and processes (including treatment, care and nursing, room design, staff and interface management) to the increasing number of patients with dementia who are admitted to hospital because of some (other) somatic disorder. Promoting consultancy services and crisis teams to reinforce expertise and safeguard treatment quality in this area.

*Project 3.5 Promotion of dementia-appropriate care in long-term in-patient nursing and care*

Needs-appropriate adaptation of existing infrastructure (organisation, process, staff management, room design) and care processes (treatment, care and nursing) to the growing number of residents with dementia.

#### **Goal 4**

**Appropriate compensation and the financial viability of needs-appropriate services for people with dementia are guaranteed.**

*Project 4.1 Reflection and appropriate compensation of services*

Analysis of the question to what extent existing financing systems (out-patient, inpatient, long-term nursing and care) appropriately reflect and compensate the services necessary for dementia-appropriate care. The analysis also includes respite possibilities, counselling services through professional entities and care services through private persons.

The results of this survey are to be included in the evaluation and further development of existing financing systems, taking due account on the one hand of the actual cost of providing the service, and on the other hand of the income and wealth of the affected person.

### Action area 3 – «Quality and professional skills»

The goal is to continue to guarantee reliability and quality of care services throughout the entire course of the condition. Dementia-specific professional skills in particular play a significant role in this regard and should be extended and reinforced in various occupational groups.

#### Goal 5

**The treatment, care and nursing of people with dementia are geared to ethical guidelines.**

*Project 5.1 Anchoring ethical guidelines*

Promoting the implementation of existing guidelines – while respecting individuals' rights, especially regarding the law on the protection of adults, and to avoid risk situations – in the various care structures (out-patient and in-patient). Promoting the establishment and handling of ethical guidelines for the field within the framework of organisational quality management.

#### Goal 6

**The quality of care provided to people with dementia is guaranteed throughout the course of the condition.**

*Project 6.1 Further development of recommendations in the areas of early detection, diagnostics and treatment for primary care services*

Reviewing the quality of indication criteria and assessment tools for early detection of dementia and promoting their use. Ensuring the quality of initial diagnostic interviews as well as of drug and non-drug treatment.

*Project 6.2 Promotion of interdisciplinary assessments*

Promoting the use of instruments developed on an interdisciplinary basis as part of interprofessional cooperation, and establishing appropriate framework conditions (such as standardised processes and networking). Promoting evaluation of the instruments as part of organisational quality management.

*Project 6.3 Handling of crisis situations*

Developing and implementing recommendations and guidelines for acute care hospitals (somatic and psychiatric) as well as for long-term nursing and care, whereby the provisions of the new law on the protection of adults must be taken into account in the decision processes.

### **Goal 7**

**Specialists in all relevant health and social professions have the skills necessary in their respective professional field to make quality-oriented diagnoses or situational analyses as well as to provide treatment, care and nursing for people with dementia. The skills of relatives and persons engaged in volunteer work are strengthened in line with their needs.**

- Project 7.1 Expansion of dementia-specific training and continuing and further education*  
Investigating the need in terms of jobs and fields of study – including ethical and legal aspects – and providing services corresponding to specific needs and target groups – taking into account existing modules – for all occupational groups.
- Project 7.2 Strengthening the skills of relatives and volunteers*  
Investigating the need for building up and enhancing skills, thereby also determining possible training providers.

### **Action area 4 – «Data and knowledge transfer»**

In Switzerland, there is a lack of data on the structure of care services and their uptake. At the cantonal level, such data are crucial to long-term management and care planning.

Quality of care is improved in the field and by the practitioners employed. Besides training and continuing education services, a dialogue between research and practice can also improve access to relevant research findings, thereby promoting evidence-based action.

### **Goal 8**

**As a basis for medium- and long-term care planning and management, information is available in the cantons regarding the current and future care situation for people with dementia.**

- Project 8.1 Care monitoring*  
The feasibility of setting up a monitoring system must be reviewed. Among other things, it must be established how the issue of dementia can be better reflected in existing health statistics. In case of a positive review, a monitoring system is to be defined and set up, and the data are to be updated regularly. In the system, information will be collected on dementia prevalence as well as on the supply and demand for needs-appropriate services along the entire care chain, from early detection to end of life. Based on the results, costs might also be quantified better.
- Project 8.2 Accompanying research*  
New approaches to treatment, care and nursing of people with dementia that are being launched by various service providers are increasingly being scientifically evaluated. This enables quality and reliability of care to be safeguarded and developed further.

## Goal 9

**The transfer of research findings into practice and the dialogue between researchers and users are supported with appropriate instruments.**

### *Project 9.1 Networking of research and practice*

Setting up an online platform for logging research projects on dementia and making it known in relevant places. Using appropriate instruments, such as events, to support networking of research and practice.

## **Implementation of the National Dementia Strategy 2014–2017**

The National Dementia Strategy 2014–2017 *defines a total of nine goals and 18 projects in four action areas*. Implementation of the National Dementia Strategy 2014–2017 must take account of the federalist division of tasks between levels of government – Confederation, cantons and municipalities.

Most projects are initiated and specified on a decentralized basis and are financed and staffed by the stakeholders involved. As they are responsible for the overall strategy, the Confederation (FOPH) and the cantons (CMPH) take on, above all, tasks involving process and coordination responsibility (coordination committee), quality assurance support (National Dementia Strategy 2014–2017 platform) and the anchoring of the objectives of the National Dementia Strategy 2014–2017 in service provider associations (consultative body).

### [Coordination committee](#)

The coordination committee is made up of representatives of the Confederation (DHA/FOPH) and the cantons (CMPH). Apart from its coordinating role, the committee also assumes the direction of the consultative body and the National Dementia Strategy 2014–2017 platform as well as providing regular reports to the contracting authority on the status of implementation (National Health Policy Dialogue).

### [Consultative body](#)

This body consists of representatives from patient groups, professional and trade associations, service provider associations as well as educators and researchers. The consultative body is tasked with anchoring the National Dementia Strategy 2014–2017 in the associations and professional bodies.

### [National Dementia Strategy 2014–2017 platform](#)

This body comprises those offices of the Confederation, cantons and organisations which are in charge of implementing projects of the National Dementia Strategy 2014–2017. The platform is used to document, assess and valorise how implementation is progressing.

# Summary of action areas – Goals and projects

## Overarching objectives and values

### Action area 1 – Health awareness, information and participation

- Goal 1**     **The population has a better knowledge of dementia-related diseases. It is aware of the diverse realities in the lives of those affected. Prejudices and inhibitions are reduced.**  
*1.1 Population- and community-based information and awareness-raising activities*  
*2.1 Sector-specific information materials*
- Goal 2**     **Affected persons and those closest to them have low-threshold access to a full range of information as well as individual, appropriate counselling throughout the course of the condition.**  
*2.1 Individualised information and social counselling services for affected individuals*

### Action area 2 – Needs-appropriate services

- Goal 3**     **Dementia patients and the people closest to them can call on flexible, high-quality and needs-appropriate care services at every point in the care chain.**  
*3.1 Establishment and expansion of regional, networked centres of competence for diagnostics*  
*3.2 Promotion of coordinated services to meet individual care needs*  
*3.3 Establishment and expansion of flexible regional respite services for day and night care*  
*3.4 Promotion of dementia-appropriate care in acute care hospitals*  
*3.5 Promotion of dementia-appropriate care in long-term in-patient nursing and care*
- Goal 4**     **Appropriate compensation and the financial viability of needs-appropriate services for people with dementia are guaranteed.**  
*4.1 Reflection and appropriate compensation of services*

### Action area 3 – Quality and professional skills

- Goal 5**     **The treatment, care and nursing of people with dementia are geared to ethical guidelines.**  
*5.1 Anchoring ethical guidelines*
- Goal 6**     **The quality of care provided to people with dementia is guaranteed throughout the course of the condition.**  
*6.1 Further development of recommendations in the areas of early detection, diagnostics and treatment for primary care services*  
*6.2 Promotion of interdisciplinary assessments*  
*6.3 Handling of crisis situations*
- Goal 7**     **Specialists in all relevant health and social professions have the skills necessary in their respective professional field to make quality-oriented diagnoses or situational analyses as well as to provide treatment, care and nursing for people with dementia. The skills of relatives and persons engaged in volunteer work are strengthened in line with their needs.**  
*7.1 Expansion of dementia-specific training and continuing and further education*  
*7.2 Strengthening the skills of relatives and volunteers*

### Action area 4 – Data and knowledge transfer

- Goal 8**     **As a basis for medium- and long-term care planning and management, information is available in the cantons regarding the current and future care situation for people with dementia.**  
*8.1 Care monitoring*  
*8.2 Accompanying research*
- Goal 9**     **The transfer of research findings into practice and the dialogue between researchers and users are supported with appropriate instruments.**  
*9.1 Networking of research and practice*

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Further information:

FOPH, Health Policy Directorate  
National Dementia Strategy 2014–2017, CH-3003 Bern  
[demenzstrategie@bag.admin.ch](mailto:demenzstrategie@bag.admin.ch)

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